

---

September 20, 2024

## Federal Changes Provide New Opportunities to Elevate the Voices of People With Lived Medicaid Experience in Policy Decisions

By Laura Harker and Kaylin Hewitt

Few people understand the impact of Medicaid better than people enrolled in the program, but their perspectives are often underrepresented in official decision-making. New federal rules present an opportunity for state advocates working on building community power to help ensure the voices of Medicaid enrollees are centered in policy decisions.

The Centers for Medicare & Medicaid Services (CMS) finalized a rule in May 2024 that sets new standards for state agencies to better engage Medicaid enrollees and their families in the Medicaid decision-making process through implementation of Medicaid Advisory Committees (MACs) and Beneficiary Advisory Councils (BACs).<sup>1</sup> The rule provides a much-needed overhaul of previous CMS rules and guidance on Medicaid advisory groups. The previous guidance lacked specificity, leading to fragmented implementation and, in several states, a lack of diverse representation of Medicaid enrollees on these committees.<sup>2</sup>

States must launch new BACs, beneficiary-only advisory committees, by July 2025. As states create their MACs and BACs, state advocates can start now to promote transformational engagement with Medicaid enrollees and their families and caregivers, so that their experiences inform state policy decisions. Advocates can ensure people with lived experience have meaningful input in these advisory groups by sharing best practices and recommendations with the state agency; helping the state identify potential BAC members; serving on advisory groups themselves; supporting members of the BAC; and holding the state accountable in meeting requirements for the advisory councils.

---

<sup>1</sup> Centers for Medicare & Medicaid Services, Department of Health and Human Services (HHS), “Medicaid Program; Ensuring Access to Medicaid Services,” 89 Fed. Reg. 40542, May 10, 2024, <https://www.govinfo.gov/content/pkg/FR-2024-05-10/pdf/2024-08363.pdf>.

<sup>2</sup> Medicaid and CHIP Payment and Access Commission (MACPAC), “Engaging Beneficiaries through Medical Care Advisory Committees (MCACs),” September 22, 2023, [https://www.macpac.gov/wp-content/uploads/2023/09/08\\_MCAC-slides.pdf](https://www.macpac.gov/wp-content/uploads/2023/09/08_MCAC-slides.pdf).

## Changes to Advisory Groups Increase Medicaid Enrollee Participation

Federal regulations have always required states to operate a Medical Care Advisory Committee (MCAC), which is tasked with advising the Medicaid agency on health care services. Although MCACs were intended to include enrollees, there is considerable variation in whether state committees provide meaningful opportunity for enrollees to participate.

The new rule revamps the long-standing MCAC requirement in two key ways: it requires states to convene a MAC, which is the new name for the MCAC, and includes expanded requirements for the committee. The MAC will have a broader charge than the MCACs, and the regulations require a MAC to include a specified percentage of enrollee representatives from a newly formed BAC. Both the MAC and the BAC will advise and provide feedback to state Medicaid agencies regarding policy development and effective Medicaid program administration. State advocates can help shape their state's Medicaid decisions by encouraging their states to make implementation choices that elevate the voice of enrollees as the new MAC and BAC standards are implemented; considering participating in MACs themselves; and supporting enrollees who are on BACs.<sup>3</sup>

To ensure the inclusion and diversity of lived experience, the rule requires BACs to include current or past Medicaid enrollees and people with direct experience supporting them, such as family members or caregivers. The BAC will meet separately from the MAC to provide an enrollee-only venue for input. In addition, the new rule requires that 25 percent of MAC members must come from the BAC, a requirement that will be phased in over two years.

MACs must also include at least one member from each of the following: state or local consumer advocacy groups or organizations that represent or support Medicaid enrollees and their interests; clinical providers or administrators; participating managed care plans (if applicable); and other state agencies that serve Medicaid enrollees, like a mental health agency or health department (in non-voting roles).

While MCACs were limited to discussing health and medical care, the rule expands the scope of MACs and BACs to broad topics including, at minimum:

- additions and changes to Medicaid services;
- coordination of care;
- quality of services;
- eligibility, enrollment, and renewal processes;
- beneficiary and provider communications by Medicaid agency and managed care entities;
- cultural competency, language access, health equity, and disparities and biases;
- access to services; and

---

<sup>3</sup> Julia Smith and Sally Mabon, "Engaging Medicaid Members: New Requirements in the Medicaid Access Rule," State Health & Value Strategies, June 27, 2024, <https://www.shvs.org/engaging-medicaid-members-new-requirements-in-the-medicaid-access-rule/>.

- other issues impacting the provision or outcomes of health and medical services in the Medicaid program.

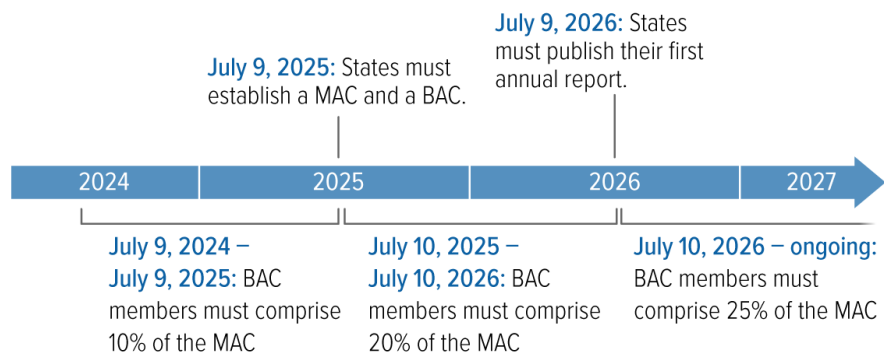
The rule includes important provisions to ensure transparency and accountability. States are required to make most MAC and BAC information public, including selection processes for, and lists of, MAC and BAC leaders and members (though BAC members can choose to remain anonymous), meeting minutes, bylaws, and annual reports. States can set term limits for MAC and BAC members, and — in a bid to increase the diversity of input — members may not serve consecutive terms. CMS also requires states to provide financial support, if necessary, to facilitate Medicaid enrollee engagement in the MAC and BAC, as discussed in more detail below.

The rule promotes equitable participation by encouraging states to rotate between in-person, hybrid, and virtual meeting formats (a telephone option must always be available) and requiring accessibility for individuals with disabilities or Limited English Proficiency. States must hold both MAC and BAC meetings at least quarterly and must devote staff resources to support the administration of both bodies.

FIGURE 1

## Timeline of New Requirements for Medicaid Advisory Groups

The new rule regarding Medicaid Advisory Committees (MACs) and Beneficiary Advisory Councils (BACs) will be phased in over time.



Source: Ensuring Access to Medicaid Services Final Rule (CMS-2442-F), May 2024

CENTER ON BUDGET AND POLICY PRIORITIES | CBPP.ORG

## Advocates Can Share Best Practices and Recommendations for States to Consider as They Establish Committees

States will need to work on setting up new BACs by the July 2025 deadline, which may include establishing completely new groups or restructuring existing beneficiary-only advisory groups to meet the new requirements. States will need to make decisions regarding their recruitment and selection process for the BAC, such as how they advertise for membership recruitment and what the application process will include. States will also have to update their existing MCACs to comply with the new regulations for the MAC (e.g., updating bylaws, planning to meet the requirement on minimum BAC membership). State advocates can share best practices and recommendations with

states as they make these decisions; CMS is also planning to share an implementation toolkit with states in the future.<sup>4</sup>

---

## Medicaid Enrollees Provide Critical Perspectives

Medicaid enrollees provide first-hand experience from their interactions with the Medicaid program, such as renewing or enrolling in coverage, scheduling appointments, and receiving care. Enrollee feedback can help identify hidden or unintended barriers to accessing care and illuminate program improvements to better meet people's needs.<sup>a</sup>

The voices of enrollees and their stories, told in their own words, are often a powerful tool to persuade decision-makers. Enrollee perspectives and storytelling add another dimension beyond statistics and data, increasing the sense of connection that decision-makers feel to the issue, and building power within communities. BACs offer a formal channel for direct communication between enrollees and state Medicaid agencies, which will help break down barriers and siloes between those in power and the people who are affected by their decisions. People with lived expertise should have a seat at the table, and this rule not only amplifies their voices, but also sets a framework to build a culture of trust and respect where these have historically been missing.

Meaningful collaboration between institutions and the communities impacted by their programs and policies can also be a powerful tool in addressing systemic inequities and structural discrimination. To avoid exacerbating or perpetuating existing inequities, states should set up their BACs to move beyond transactional interactions (e.g., only seeking input when a product is almost final) and toward transformational engagement that establishes feedback loops and forms sustainable relationships.<sup>b</sup> In recent years there has been growing awareness of the critical input that enrollees can provide, and more resources are available for states to create meaningful opportunities for input from people with lived experience.<sup>c</sup>

<sup>a</sup> Jessica Greene et al., "A Guide to Monitoring Medicaid Using Lived Experience," 100% Kids Coverage, June 2023, <https://www.cbpp.org/sites/default/files/Monitoring%20Medicaid%20Lived%20Experience%20Report.pdf>.

<sup>b</sup> State Health & Value Strategies, "Transformational Community Engagement to Advance Health Equity," January 2023, [https://www.shvs.org/wp-content/uploads/2023/03/SHVS\\_Transformational-Community-Engagement-to-Advance-Health-Equity.pdf](https://www.shvs.org/wp-content/uploads/2023/03/SHVS_Transformational-Community-Engagement-to-Advance-Health-Equity.pdf).

<sup>c</sup> See, e.g., Center for Health Care Strategies, "Community Member Engagement Resource Center," <https://www.chcs.org/resource-center/community-member-engagement-resource-center/>.

## Informing the State's Recruitment and Selection Process

Getting feedback from a diverse group of people with lived experience — e.g., by geography, race and ethnicity, and category of Medicaid membership — is valuable in better understanding how people experience Medicaid and how to make decisions that consider those different perspectives. Advocates can encourage states to do this by:

---

<sup>4</sup> The Center for Health Care Strategies is leading the "Building State Capacity for Community-Informed Policymaking Learning and Action Series" to help support states in designing and implementing the new CMS requirements. Seven states — Alaska, Arizona, Maine, Michigan, North Dakota, Oregon, and Virginia — are participating in a 14-month initiative aimed to help them establish (or strengthen) a BAC that centers Medicaid lived experience in policymaking. <https://www.chcs.org/project/building-state-capacity-for-community-informed-policymaking-learning-and-action-series-implementing-a-medicaid-member-advisory-group/>.

- offering the state ideas about outreach and communications strategies for soliciting potential committee members;
- disseminating announcements to ensure they are broadly seen by enrollees across the state; and
- providing recommendations for the Medicaid agency to consider as it sets up systems to promote language access (as required for BAC meetings in the final rule) in the recruitment and selection process, so that more people who speak languages other than English have meaningful participation.

### Participating in the Process of Structuring the Committees

The prior regulations on Medicaid advisory committees did not say anything about how often committees should meet, how they should be structured, or what information should be shared publicly. The new regulations provide minimum requirements and transparency, but still include flexibility for states on decisions such as term lengths and cadence of meetings. Advocates can provide recommendations on:

- **Meeting cadence.** Focus these recommendations on limiting the burden on BAC members who are participating in both the MAC and BAC. MACs and BACs must meet once per quarter at a minimum, and the BAC meetings need to be held separately from, and in advance of, the MAC. The regulations indicate the meeting could happen on the same day, as long as the BAC has time to debrief before the MAC meeting. As an example, Pennsylvania’s consumer subcommittee meets one day prior to the Medicaid advisory committee.
- **Length of terms.** Advocate for multi-year terms (such as two to four years). While the new regulations do not allow continuous terms for MAC and BAC members, they also do not set minimum term limits. Setting longer terms would help avoid constant turnover as terms end, mutually benefiting members and state agencies. Preparing BAC members for meetings with their state agencies is an intensive and time-consuming process. It can take multiple years for BAC members to feel comfortable engaging meaningfully in BAC meetings, even with advocates and other stakeholder groups providing them with regular technical assistance and support. Longer terms would give BAC members more time to get grounded in the issues; build relationships and trust with other members and agency staff; and feel more comfortable with sharing their experiences. Longer term lengths will also make it easier for the state agency to find and recruit potential new members.
- **List of topics covered.** Provide feedback on the list of topics the MAC and BAC will be able to cover in their work. For example, discussions about access to and quality of services can inform service delivery in the managed care system. While the new regulations include a broader set of topics for the MAC and BAC to advise on relative to the MCACs’ charge, the state has the final decision on what topics will be included.

### Giving Recommendations on How the State Provides Financial Support for BAC Members

Another best practice for ensuring people with lived experience can fully participate in groups that are soliciting their feedback is to offer financial support, both for the time people spend in these groups (some people may be losing time at work to participate in meetings) and to cover additional

expenses that participation may incur, such as transportation or child care costs. The regulations *require* the state to provide “financial support, if necessary, to facilitate Medicaid beneficiary engagement in the MAC and BAC.”<sup>5</sup> This language gives states discretion to decide how and when to reimburse or compensate members but can be a hook for ensuring that reasonable support is available.

Advocates can provide input on how the state determines when financial support is necessary and how compensation should be calculated. Types of compensation include reimbursement for expenses or direct payments.

- Examples of reimbursable expenses can include meals, child care, parking, and other transportation, like public transit or rideshare services. These payments generally are not included in income for purposes of taxes or benefit programs and tend to be relatively straightforward.
- Direct payments are valuable in allowing people to be compensated for their time and expertise, in addition to covering their expenses. Because these payments typically count as “income” for tax and benefit purposes, advocates should encourage the state to minimize the potential impact on Medicaid and SNAP eligibility and benefits for certain types of compensation provided to BAC members. Advocates can recommend the state help people understand how they could be impacted by receiving a stipend.

Aged, blind, or disabled enrollees may be able to disregard income earned from serving on an advisory committee; states that do not already have such a policy could seek a state plan amendment to ask for this authority.<sup>6</sup>

If a state decides to compensate people for their time in the form of a stipend, in addition to ensuring enrollees understand that these payments are to be counted as income, the state should offer flexible payment methods (e.g., a choice between checks or gift cards) and provide compensation promptly after the meeting.<sup>7</sup>

---

<sup>5</sup> 89 Fed. Reg. 40542, 40562 (May 10, 2024).

<sup>6</sup> Section 1902(r)(2) of the Social Security Act; 42 C.F.R. §435.601.

<sup>7</sup> Courtney Roman, Madeline Steward, and Kelly Church, “Medi-Cal Member Advisory Committee: Design Recommendations for the California Department of Health Care Services,” Centers for Health Care Strategies, July 2023, <https://www.chcf.org/wp-content/uploads/2023/06/Medi-CalMemberAdvisoryCommittee.pdf>.

---

## Resource Spotlight: North Carolina Justice Center's Member Advisory Committee (MAC) Training for Medicaid Managed Care

The North Carolina Justice Center has training resources with tips for people with lived experience on how to share their thoughts and ideas on Medicaid committees, as well as how managed care plan staff can design and run accessible and inclusive meetings. Although the resources are focused on advisory committees that are required in Medicaid managed care, many of the same principles can be applied to the MAC and BAC.

*Using Enrollee Experiences to Improve Medicaid Plans* includes guidance for people with lived experience, such as questions to reflect on their experience and ways to capture the most important points they want the staff to know. The guide also includes tips for how staff can listen with purpose, such as giving space for clarification instead of judging and practicing generous and respectful listening that goes beyond just waiting to respond.

*How to Plan and Run an Accessible and Inclusive Meeting* includes checklists of specific actions and examples that staff can use to make sure everyone can meaningfully participate. Some best practices include making sure materials are at an accessible reading level, avoid jargon, and are available in multiple formats, including formats readable by text-to-speech readers. Other best practices: co-creating group agreements at the initial meetings and promoting accessibility by using live captioning, offering live American Sign Language interpretation, and sending translated materials ahead of time. For in-person meetings, staff should ensure that the physical space also meets attendees' needs.

Source: North Carolina Justice Center, "Member Advisory Committee (MAC) Training for Medicaid Managed Care," <https://www.ncjustice.org/mac-training/#experience>

## How State Advocates Can Engage With MACs and Support BAC Participants

### Participating in the MAC

States are required to have at least one member of the MAC come from a state or local consumer advocacy organization. State advocacy organizations that are not already on the state's committee can start monitoring the state's website and communications to be aware of the opportunity to be considered for selection on the MAC. States will be required to post information on the selection and recruitment process on their website. Selections are made by the director of the Medicaid agency. Serving on the MAC provides an opportunity for advocates to build relationships with Medicaid agency staff and other stakeholders who are on the MAC. It will also allow them to receive updates directly from the agency that are useful to share with other advocates who are not on the MAC and with communities they work with. And it provides a clear avenue for bringing feedback from the advocacy community to formally make recommendations to the agency.

### Identifying Potential BAC Members

State advocacy organizations can tap into their existing networks — which can include community-based organizations, members of the groups they represent, or staff or volunteers who have lived experience (and would represent themselves in a personal capacity) — to make referrals to the state agency when they are recruiting new members for the BACs.

Furthermore, the final rule creates a separate new advisory group focused on rate setting and other matters related to home- and community-based services (HCBS). This Interested Parties Advisory Group (IPAG) may be another place to refer enrollees with HCBS experience to the state agency as it recruits members. But not all states will have a separate group for these issues; they can use their MAC and BAC to discuss HCBS payment rates so long as the state meets requirements unique to each group.

### **Providing Support to Members of the BAC**

Medicaid enrollees may face barriers to participating in the BAC. These can include lack of trust of government or the health care system; apprehension in speaking up during meetings with state agency officials who exercise power over people's benefits and eligibility; concerns that their perspectives will be seen as less important or valuable than other stakeholders who are serving in a professional capacity; uncertainty about how their feedback will be heard; and logistical issues, such as not being able to take time off from work, obtain reliable transportation or child care, or have access to accommodations they need to participate fully.<sup>8</sup> State advocates can help the agency understand and respond to these participation barriers and provide support to people who want to participate in the BAC by:

- **Increasing awareness of accessibility supports.** Help make enrollees aware of the supports and options the state Medicaid agency should be providing to facilitate their participation in the BAC and help them act if those requirements are not met.

Examples include ensuring BAC members know a required telephone dial-in option should always be available to attend meetings, and reimbursement for expenses like travel and meals is available, if the state determines members need that assistance. You can find other examples in the resource spotlight above.

Advocates can also help promote meaningful participation for BAC members with disabilities by ensuring they know what, if any, accommodations the state has made available for in-person and virtual meetings.

- **Providing policy and research support.** Provide ongoing support as BAC members develop recommendations. This could be a formal or informal role providing policy and research support on complex topics in the Medicaid program.<sup>9</sup>

State policy advocates or state and locally focused foundations can play an important role in providing objective information to BAC members. All organizations working with BAC members should be careful not to impose their agenda onto the committee and use other venues to communicate their own advocacy goals. Since many state advocates don't represent a particular industry and have a broader focus on helping improve people's health and well-being, they can be a great resource for BAC members.

---

<sup>8</sup> MACPAC, "Engaging Beneficiaries through Medical Care Advisory Committees (MCACs)," September 22, 2023, [https://www.macpac.gov/wp-content/uploads/2023/09/08\\_MCAC-slides.pdf](https://www.macpac.gov/wp-content/uploads/2023/09/08_MCAC-slides.pdf)

<sup>9</sup> Leonardo Cuello, "Beneficiary Advisory Councils: Historic Opportunity for State Medicaid Programs," Georgetown Center for Children and Families, May 13, 2024, <https://ccf.georgetown.edu/2024/05/13/beneficiary-advisory-councils-historic-opportunity-for-state-medicaid-programs/>.



Notably, providing this level of support can be time consuming and advocates should think about how involvement in supporting BAC members will fit into their existing capacity.

For example, the Pennsylvania Health Law Project — a nonprofit legal services organization — serves as a legal counsel to the members of the states’ consumer subcommittee to their Medical Assistance Advisory Committee. In this role, they brief members of the committee on health care issues, provide technical assistance, and identify and interpret legal issues.<sup>10</sup>

### **Identifying Financial Resources to Support Advocates’ Work Related to MAC and BAC**

Supporting an expanded role for people with lived expertise in Medicaid decisions is complex and can require a significant time commitment from advocates. But helping inform the structure of the committees and providing ongoing support to participants is a critical part of ensuring enrollees can meaningfully and comfortably engage and maximizes the opportunity to effectively carry their perspectives and message to policymakers.

Advocates who anticipate needing additional support to take on this work should consider reaching out to foundations interested in work that centers people with lived experience, promotes health equity, or strengthens access to Medicaid. Advocates should convey the importance of financially supporting organizations that support BAC members’ meaningful participation.

### **Advocates Can Help Hold States Accountable to New Requirements and Promote Meaningful Engagement of People With Medicaid Experience**

Federal rule changes increase transparency requirements for the Medicaid advisory groups, making it easier for advocates to hold states accountable for meeting best practices and federal requirements on an ongoing basis.

Prior to the final rule, there was no mention in MCAC regulations about transparency measures, such as publicly sharing meeting dates, outcomes of meetings, or how the state responded to recommendations from the committee. Under the new regulations, states will be required to develop and publish past meeting minutes (including a summary of the most recent BAC meeting), publish a regular meeting schedule for the MAC and BAC, and develop and publish bylaws.

The MAC will have to produce an annual report to the state on what topics they discussed and their recommendations, which must also be published on the state Medicaid agency’s website. The report also needs to include what the state has done in response to the recommendations from the MAC and BAC.

---

<sup>10</sup> Pennsylvania Health Law Project, “Our History,” <https://www.phlp.org/en/about/our-history>.

## Checklist for State Advocates: Actions to Ensure Medicaid Enrollees and Their Caregivers Can Meaningfully Participate in MACs and BACs

### Share Best Practices as Committees Are Established

#### Informing the State's Recruitment and Selection Process

- Offer ideas about outreach and communications strategies to recruit potential BAC members.
- Help disseminate announcements about the state's recruitment and selection process.
- Make recommendations on how to promote language access in the process.

#### Participating in the Process of Structuring the Committees

- Recommend a meeting cadence that limits burden on BAC members.
- Advocate for multi-year term lengths to allow BAC members more time to get comfortable with sharing their thoughts and build relationships and trust.
- Provide feedback on the list of topics that can be covered in the committees.

#### Giving Recommendations on How the State Provides Financial Support for BAC Members

- Provide input on how the state determines who needs financial support and how compensation is calculated.
- Ensure the state's method of providing financial support does not negatively impact enrollees' eligibility for Medicaid and other benefit programs.

### Participate in MAC Meetings

- Join the MAC as a representative of a state or local consumer advocacy organization.
- If not a MAC member, attend MAC meetings when they are open to non-members.



### Identify Potential BAC Members

- Refer people to the state agency's recruitment team for the BAC by using your organization's existing networks.



### Provide Support to Members of the BAC

- Help make enrollees aware of accessibility supports, including disability accommodations, they should be provided to facilitate their participation in the BAC.
- Share best practices with the state for conducting accessible meetings (e.g., making materials available in multiple formats, sending translated materials ahead of time, ensuring accessible physical spaces for in-person meetings).
- Provide policy and research support to BAC members, providing them with objective information on technical issues as they develop their own recommendations.



### Identify Financial Resources to Support Your Organization's Work Related to MAC and BAC

- Have initial conversations with funders about why advocacy organizations' work is necessary to make sure these committees are set up to meaningfully engage people with lived experience and to provide BAC members with adequate support to participate.



### Help Hold States Accountable to New Requirements

- Participate in the process of creating MAC and BAC bylaws to proactively promote transparency.
- Monitor how well the state is meeting requirements around transparency (e.g., reporting on how they are responding to MAC and BAC recommendations), accessibility, and representation on the committees.
- Raise any concerns about not meeting requirements directly with the state agency or with CMS.

MAC = Medicaid Advisory Committees; BAC = Beneficiary Advisory Councils. For more information, see Laura Harker and Kaylin Hewitt, "Federal Changes Provide New Opportunities to Elevate the Voices of People With Lived Medicaid Experience in Policy Decisions."

If the state is not meeting these transparency requirements, state advocates can raise concerns — directly with the agency or if necessary, with state and federal legislators and/or CMS — and point to these requirements as a form of accountability. Other accountability actions can include:

- Proactively influencing a culture of transparency by participating in the process of creating bylaws for the MAC and BAC.<sup>11</sup>
- Monitoring how well the state is meeting requirements, such as whether the meetings are accessible for people with disabilities and people with Limited English Proficiency and that there is adequate minimum representation of BAC members within the MAC as the requirements are phased in.
- Attending MAC meetings when they are open to non-members (for advocates who are not members of the MAC). The new regulations require at least two of the meetings each year to be open to the public.

---

<sup>11</sup> Daniel Young and Wayne Turner, “Medicaid Advisory Committees: Best Practices for Effective Stakeholder Engagement,” National Health Law Program, August 28, 2024, <https://healthlaw.org/resource/medicaid-advisory-committees-best-practices-for-effective-stakeholder-engagement/>.