

What is a State Medicaid MAC/BAC?

State Medicaid programs are now required by the Centers for Medicare & Medicaid Services (CMS) to have a Beneficiary Advisory Councils (BAC) and updated Medicaid Advisory Committees (MAC). These changes come from a final rule CMS issued in 2024, which directs states to create or strengthen these groups so that Medicaid members can have a real voice in how programs are designed and run.

The BAC includes people who use Medicaid services — including individuals, families, and caregivers — to help states better understand what members need and what is working or not. Patient experience can shape policies and lead to meaningful improvements in how Medicaid services are delivered.

The updated MACs are multi-stakeholder groups including state and local community-based groups and patient advocacy organizations that represent Medicaid members, clinical providers, health plans, and other state agencies. Some members of the BAC also participate on the MAC to ensure your voices are heard.

What sort of issues will members of the MAC/BACs be expected to address?

As a MAC or BAC member, you will have the opportunity to advise the state Medicaid agency directly. Your input helps shape policies and improve how Medicaid is run.

Together with the state, MAC and BAC members help decide which topics to focus on in their quarterly or bi-monthly meetings. Examples of topics include:

- New or updated services
- How care is coordinated among different providers
- The quality of services people receive.
- The process for eligibility, enrollment, and renewals
- How the state and Medicaid plans communicate with members and providers
- Topics like cultural sensitivity, language access, health equity, and addressing disparities or bias.
- How easy or hard it is to access services.
- Any other issue that affects Medicaid care, as identified by the committee or state
- State implementation of new work and volunteering requirements

I have never done anything like this — how can I prepare?

You are not alone — many members are new to this. EveryLife is here to help you feel confident and prepared. We have created resources just for you, including:

- Access to mentors
- Training in working in diverse groups.
- Guidance on how to share your story effectively.

You can find these and more support on our [website](https://www.everylifefoundation.org) or reach out to us directly at info@everylifefoundation.org. We are here to support your voice every step of the way.

How can I make sure my voice is heard?

Your lived experience is what makes your role valuable. In addition to being prepared to share your experience and the experience of fellow advocates, to be ready for meetings you'll need to be comfortable:

- Reviewing the agenda and materials ahead of time.
- Sharing personal stories or examples that relate to the topics being discussed.
- Building relationships with other committee members, especially those who also represent beneficiaries or caregivers.
- Asking questions or asking for clarification during meetings — that's part of your role.
- Summarizing your points succinctly and leading with actionable insights.

If there's something you'd like more information or clarification on, EveryLife is ready to help! We can help provide connections to other communities and a helpful library of resource library. You can always reach out to us for support.

Are there topics I should or should not talk about?

If selected for a position on one of these councils, it's important to remember that you're acting as a trusted resource for your state's Medicaid program. You'll be expected to be:

- Informative, compelling, and concise
- Accessible, credible, and reasonable
- Ready to learn about the Medicaid services offered in your state, funding, and priorities
- Show how the problem applies to a diverse Medicaid population
- Prepared and familiar with meeting materials and relevant experience
- Remember you are the expert on your patient experience — and others may have different experiences
- Be authentic – no need to memorize information
- Respect the information and personal stories shared should be kept private and confidential to ensure a safe space for engagement

It's crucial to remember that along with access policies and program discussions, Medicaid agencies must also consider fixed budgets. Because of this, your advice may not always be reflected in the decisions made. You might disagree or these might not reflect your experience — and that's alright. Just remember to balance fact and experience with emotion, and remember that your participation is active advocacy and working to make a change.

If you are a caregiver to an adult, it is important to protect their privacy. Before applying to a MAC or BAC, talk with your family member to make sure they are comfortable with you sharing their story or experiences — they may want to join the committee themselves. When sharing, only include personal details that are necessary and meaningful for the discussion. Also, you will be asked to fill out a conflict-of-interest disclosure form — a short form to share anything in your professional or personal life that might make it hard (or even look like it might be hard) to stay objective. These disclosures are standard for advisory roles like this and help build trust in the process.

Check out this resource from Onward Living HQ for advice on sharing stories respectfully and effectively:

[Sharing Caregiving Stories While Respecting Privacy and Building Trust](#)



About the EveryLife Foundation

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.
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