

Chapter 1:

Engaging Beneficiaries through Medical Care Advisory Committees to Inform Medicaid Policymaking

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Recommendations

- 1.1 In issuing guidance and in providing technical assistance to states on engaging beneficiaries in Medical Care Advisory committees (MCACs) under Section 42 CFR 431.12, the Centers for Medicare & Medicaid Services should address concerns raised by states related to beneficiary recruitment challenges, strategies to facilitate meaningful beneficiary engagement in Medicaid MCAC meetings, and clarify how states can provide financial arrangements to facilitate beneficiary participation.
- 1.2 In implementing requirements in 42 CFR 431.12(d)(2) that Medicaid Medical Care Advisory Committee (MCAC) membership include beneficiaries, state Medicaid agencies should include provisions in their MCAC bylaws that address diverse beneficiary recruitment and develop specific plans for implementing policies to recruit beneficiary members from across their Medicaid population, including those from historically marginalized communities.
- 1.3 In implementing requirements in 42 CFR 431.12(e) to increase the participation of beneficiary members in Medicaid Medical Care Advisory Committees (MCACs), state Medicaid agencies should develop and implement a plan to facilitate meaningful beneficiary engagement and to reduce the burden on beneficiaries in engaging in MCACs by streamlining application requirements and processes, and by addressing logistical, technological, financial, and content barriers.

Key Points

- Beneficiaries have much to offer state Medicaid programs in the development and implementation of Medicaid policies and can provide feedback to policymakers on the issues that affect their access and use of Medicaid-covered services.
- Federal rules require each state Medicaid agency to establish a Medical Care Advisory Committee (MCAC) that consists of beneficiaries or consumer group representatives, along with other stakeholders, to advise on the Medicaid program and policies (§ 1902(a)(4) of the Social Security Act, 42 CFR 431.12).
- MACPAC examined federal and state policies on beneficiary participation in MCACs and how states use beneficiary input to inform programs, policies, and operations. This work focused on how states engage groups that are often excluded from the decision making process.
- States have varied MCAC policies and implementation approaches, and the majority of state MCACs have beneficiary vacancies.
- States identified specific areas related to beneficiary inclusion in MCACs for which they need guidance and technical assistance, such as approaches for increasing beneficiary recruitment and diverse beneficiary representation, use of financial arrangements to encourage beneficiary participation, and strategies to support beneficiary engagement in discussions.
- Beneficiaries participating in MCACs generally described their experience as positive. However, they also cited challenges to participating on MCACs, such as the application and appointment process, meeting attendance requirements, and difficulty contributing to certain complex policy discussions.
- In May 2023, the Centers for Medicare & Medicaid Services released a notice of proposed rulemaking that would rename and expand the scope and use of states' MCACs; require states to make MCAC materials publicly available; and establish a beneficiary-only group consisting of Medicaid beneficiaries, their family members, and their caregivers.
- MACPAC's recommendations focus on the need for federal guidance and technical assistance to states to address beneficiary recruitment challenges, state efforts to strengthen the diversity of representation of beneficiary members, and state efforts to reduce burden on beneficiaries while participating in MCACs.

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Medicaid beneficiaries can offer state Medicaid programs their unique insight and feedback on how programs and policies are meeting their needs, challenges in accessing care, and opportunities for improvement. Policymakers can engage with beneficiaries to develop a deeper understanding of the issues that affect their access to care, co-create solutions, and anticipate potential unintended consequences of policies that would negatively affect the people served by the program. Sustained beneficiary engagement can help build trust between the community and the state Medicaid agency and promote accountability to beneficiaries (Skelton-Wilson et al. 2021). In addition, research shows that engaging people with lived experience is one strategy government officials can use to advance health equity (Allen et al. 2021, Zhu et al. 2021). However, beneficiaries are not often included in policymaking decisions that affect their coverage and health outcomes (Coburn et al. 2021).

As a way to include those with lived experience with the Medicaid program in state Medicaid agencies' policymaking process, federal rules require each state Medicaid agency to establish a Medical Care Advisory Committee (MCAC) that includes beneficiaries or consumer group representatives along with other stakeholders (§ 1902(a)(4) of the Social Security Act, 42 CFR 431.12). These rules grant states flexibility in implementing their MCACs to fit the needs of their state. As such, states have adopted varied approaches to structuring and running their MCACs. To establish more explicit expectations for including beneficiary perspectives in MCACs, in May 2023, the Centers for Medicare & Medicaid Services (CMS) proposed a rule on ensuring access to Medicaid services that also revises the MCAC regulations. This proposed rule is the first change to MCAC regulations since CMS established them in 1978. The proposed rule emphasizes beneficiary engagement and increases

transparency between the Medicaid agency and beneficiaries (CMS 2023).

Historically, little information has been reported publicly about state implementation or use of MCACs, the effectiveness of MCACs in bringing the beneficiary voice to Medicaid programs, or the experience of states or beneficiaries with MCACs. The Commission signaled that additional research should be done to learn more about current state practices for engaging beneficiaries of color, incorporating beneficiary input into program policies and operations, and promoting greater participation (MACPAC 2022a). To address gaps in knowledge about MCACs, MACPAC contracted with RTI International (RTI) to examine how states use MCACs to engage beneficiaries, particularly those from historically marginalized communities, to inform programs, policies, and operations. RTI conducted a policy scan of state statute and regulations as well as publicly available bylaws, charters, member lists, and websites for all 50 states and the District of Columbia to understand state rules for MCACs.¹ RTI analyzed MCAC membership requirements, including requirements for engaging beneficiaries from historically marginalized populations, current MCAC composition, supports offered for beneficiary participation, frequency of meetings, beneficiary recruitment practices, and policy areas in which states require MCACs' input.

Our analytic approach helped identify how each state's MCAC is established and conducted. MACPAC and RTI interviewed a CMS official from the Center for Medicaid and CHIP Services as well as state Medicaid officials, beneficiaries, and consumer group representatives who participate in the advisory committee meetings in six states.² These interviews explored the barriers to beneficiary participation as well as approaches to overcome these barriers. The majority of our research concluded before the release of the proposed rule from CMS.

The findings from the policy scan and stakeholder interviews identified several challenges with recruitment of beneficiaries, particularly those representing historically marginalized communities, and barriers to meaningful beneficiary engagement. Examples of engagement barriers include beneficiary feelings of intimidation, reacting to proposed policy versus informing the policymaking process, or inconvenient meeting times. The findings also identified potential approaches to addressing these challenges, such as

partnering with community-based organizations to recruit individuals or hosting premeeting sessions with beneficiaries to help increase their understanding of and comfort with complex policy topics.

As CMS works to finalize the rule on MCACs, the federal government and states can continue their efforts to improve beneficiary engagement. States have identified specific areas related to engaging beneficiaries in MCACs for which they need guidance and technical assistance. Beneficiaries have also cited challenges to participating on MCACs, such as the application process. Addressing challenges to beneficiary engagement in MCACs is likely to require ongoing state focus. However, our work identified steps CMS and states can now take to address challenges raised by state officials and beneficiaries. The Commission makes three recommendations to improve beneficiary engagement on MCACs:

- 1.1 In issuing guidance and in providing technical assistance to states on engaging beneficiaries in Medical Care Advisory Committees (MCACs) under Section 42 CFR 431.12, the Centers for Medicare & Medicaid Services should address concerns raised by states related to beneficiary recruitment challenges, strategies to facilitate meaningful beneficiary engagement in Medicaid MCAC meetings, and clarify how states can provide financial arrangements to facilitate beneficiary participation.
- 1.2 In implementing requirements in 42 CFR 431.12(d)(2) that Medicaid Medical Care Advisory Committee (MCAC) membership include beneficiaries, state Medicaid agencies should include provisions in their MCAC bylaws that address diverse beneficiary recruitment and develop specific plans for implementing policies to recruit beneficiary members from across their Medicaid population, including those from historically marginalized communities.
- 1.3 In implementing requirements in 42 CFR 431.12(e) to increase the participation of beneficiary members in Medicaid Medical Care Advisory Committees (MCACs), state Medicaid agencies should develop and implement a plan to facilitate meaningful beneficiary engagement and to reduce the burden on beneficiaries in engaging in MCACs by streamlining application requirements

and processes, and by addressing logistical, technological, financial, and content barriers.

This chapter begins by providing background on the importance of beneficiary engagement, challenges to beneficiary engagement, and state approaches to address these challenges. Next, we review the federal statute and regulations related to MCACs and recent proposed changes to these regulations. Then we discuss key findings about state approaches to MCAC beneficiary recruitment, meeting structure, and beneficiary engagement from the policy scan and the interviews. This section of the chapter highlights the barriers to beneficiary recruitment and engagement and examples of state strategies to address these challenges as well as how CMS plans to address certain challenges in the proposed rule. The chapter then concludes with the Commission's recommendations and its rationales.

The Importance of Beneficiary Engagement

Beneficiary engagement ensures that those being served by the health system have a voice in how policies and programs are both created and implemented, which can support states' efforts to advance health equity. The Centers for Disease Control and Prevention (CDC), which helped develop the principles of community engagement for federal health agencies, stated that the goals of community engagement are to "build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as successful projects evolve into lasting collaborations" and to engage the community in policymaking (NIH 2011, CDC 1997). Community engagement research notes that those most affected by programs and policies often have the solutions on how to improve them, which is why it is important to codevelop strategies (Agonafer et al. 2021).

Efforts to engage meaningfully with beneficiaries should be mindful of historic distrust of health care systems and other institutions and the factors that affect beneficiaries' ability to provide feedback (MACPAC 2022a). This distrust from Medicaid beneficiaries, particularly those from marginalized communities, is the product of decades-long

structural inequities (Agonafer et al. 2021).³ A 2022 U.S. Department of Health and Human Services report stated that such inequities stem from racism, ableism, and other systems of oppression and require sustained institutional changes to overcome them. This report notes individuals who experience these inequities mistrust institutions with power, such as government agencies. Trust building consists of acknowledging the systemic barriers and validates the experiences of those harmed by such systems

(Ramirez et al. 2022). Often beneficiaries are either excluded from discussions of the policies that affect their health and coverage or are asked to react to policies after decisions have been made (Coburn et al. 2021, Zhu et al. 2021). Lack of trust in government systems and programs and uncertainty about whether feedback will be taken into account may also discourage beneficiaries from sharing their views (Musa et al. 2009).

BOX 1-1. Other State Strategies to Engage Beneficiaries

State Medicaid agencies use varying methods for incorporating beneficiary input into policy and program decision making outside of Medical Care Advisory Committees (MCACs). States are required to provide public notice and offer the public the opportunity to submit comments or provide input before proposed program changes are submitted to the federal government. States can also solicit feedback from beneficiary surveys. Additional strategies for obtaining beneficiary feedback include the following:

Member-only advisory councils. Several states convene member-only advisory councils to make the engagement opportunities more accessible. In one study, states reported more robust consumer participation in beneficiary-only subcommittees compared to the committees in which other stakeholders participate (Zhu et al. 2021). For example, Pennsylvania has a beneficiary-only subcommittee that focuses on members' needs. This group is facilitated by a consumer advocacy group and meets separately from the MCAC meeting. The objective of the subcommittee is to initiate consumer-focused policy ideas and provide input on state policy initiatives. This subcommittee holds the agency accountable and elevates issues to gain greater attention (Zhu and Rowland 2020).

Tribal council consultation. State Medicaid agencies are required to consult with American Indian and Alaska Natives (AIAN) tribes and be responsive to their issues and concerns when making changes to the Medicaid program that have tribal implications (CMS 2015). Section 5006 of the American Recovery and Reinvestment Act of 2009 (P.L. 111-5) requires states to consult with tribes, designees of Indian health programs, and urban Indian organizations on matters related to Medicaid and the State Children's Health Insurance Program (CHIP) that affect the populations. States are required to consult with tribes before submitting Section 1115 waiver requests to CMS (42 CFR 431.408(b)).

Town halls. State Medicaid officials can host town hall meetings to provide beneficiaries the opportunity to share their experiences with the Medicaid program. For example, state officials in Nebraska host town hall listening sessions every six months in various locations around the state. These town halls allow for beneficiaries to directly share areas of concern as well as suggest policy and programmatic changes to improve the program.

Managed care organization (MCO) member advisory committees. Given that managed care is the predominant delivery system in Medicaid, MCOs can play a role in engaging beneficiaries and encouraging them to share their perspectives on the Medicaid program in addition to their views on the MCOs' operations. Some states require MCOs to have member advisory committees (Bailit Health 2023). For example, Oregon's Medicaid beneficiaries are enrolled in coordinated care organizations; each organization must have at least one community advisory council, and more than half of the council's voting members must include representatives of the community (ORS § 414.575). Medicaid officials can attend MCO beneficiary meetings to engage directly with beneficiaries.

Equitable engagement strategies consist of understanding the strengths that exist within communities, including members of communities that are most impacted by systemic injustices; dedicating resources to ensure engagement is done in culturally meaningful ways; providing the adequate orientation, background, or preparatory materials for effective participation; and offering supports that ensure participation for those with varied abilities and access needs (Ramirez et al. 2022).

Community engagement research highlights the importance of establishing continuous and sustained bidirectional feedback loops even if every concern cannot be addressed or recommendation made. Experts in the field of community engagement stress the need to create meaningful opportunities for input, such as engaging people as early as possible in the decision making process and being realistic with beneficiaries about timelines to help set expectations. Research also indicates that regular communication with beneficiaries about how the state uses and applies their input is particularly important to building trust and their continued engagement (Roman et al. 2023, Ramirez et al. 2022). One study of MCACs found that not all states could identify instances in which the advisory committee's recommendations affected policymaking. However, states defined success as building relationships between agency leaders and beneficiaries (Zhu et al. 2021).

Federal Statute and Requirements

Section 1902(a)(4) of the Social Security Act, as implemented in 42 CFR 431.12, requires states to have an MCAC to advise the state Medicaid agency on health and medical care services and participate in policy development and program administration. Federal regulations describe requirements for the appointment and composition of the committee members, the scope of topics for committee discussion, and the support committee members can receive from the Medicaid agency. The state Medicaid director or a higher authority in the state must appoint MCAC members on a rotating and continuous basis (42 CFR 431.12 (c)). MCACs must include (at a minimum) board-certified physicians and other health

professionals who are familiar with the medical needs of low-income population groups, Medicaid beneficiaries and members of other consumer organizations, and the director of the public welfare department or the public health department (42 CFR 431.12(d)). In addition, federal rules require states to make financial arrangements, if necessary, to support the participation of beneficiaries in MCACs and provide states flexibility in determining such arrangements (42 CFR 431.12(f)). Federal funding is available at 50 percent to cover committee expenditures (42 CFR 431.12(g)). The main purpose of MCACs is to provide a bidirectional feedback loop between the state Medicaid agency and the individuals who provide, pay for, or use Medicaid services (Davidson et al. 1984).

Proposed rule

CMS released a notice of proposed rulemaking (NPRM) in May 2023 to increase the two-way communication between state Medicaid agencies and stakeholders and to promote transparency and accountability by state Medicaid agencies to committee members.⁴ CMS's intent is to make MCAC requirements more robust to ensure all states are using these committees optimally by informing the program with the experiences of beneficiaries, their caretakers, and other stakeholders (CMS 2023).

The NPRM would add specificity to the rules for MCAC structure and operations to create more meaningful engagement opportunities for Medicaid beneficiaries. The proposed rule, if finalized, would rename MCACs to Medicaid Advisory Committees (MACs) and expand the scope of topics to be addressed by MACs.⁵ The state has discretion to identify topics the MAC will address, such as services that address health-related social needs, coordination of care, beneficiary communications from the Medicaid agency, grievances, consumer experience survey ratings, or design of a new program.

The proposed rule, if finalized, would also require that state Medicaid agencies establish a Beneficiary Advisory Group (BAG), that would meet separately from the MAC, with crossover membership with the MAC. Specifically, BAG members would constitute at least 25 percent of the MAC membership. The BAG would include Medicaid beneficiaries, their family members, and their caregivers. Other members of the

MAC would include representatives from consumer groups, clinical providers or administrators, Medicaid managed care plans, and other state agencies. The NPRM proposes minimum requirements for making information on the MAC and BAG activities publicly available. Specifically, states must post MAC and BAG membership lists, meeting schedules, meeting minutes, bylaws, recruitment processes, and an annual report on MAC activities and how the state used MAC and BAG feedback on its website. If the rule is finalized, states would have one year to implement these requirements (CMS 2023). CMS has indicated that it will issue a final rule and future guidance on meaningful beneficiary engagement and transparency, but it is unclear when this would occur.

State Implementation of MCACs

Though federal regulations require beneficiary representation on MCACs, little research has explored MCAC implementation, outcomes, and state strategies for beneficiary engagement on MCACs, particularly with those from historically marginalized communities. One study found that MCAC beneficiary engagement varies state by state; states appreciated beneficiary input in regard to identification and overcoming implementation challenges for agency programs and faced barriers when it came to authentic and sustained engagement (Zhu et al. 2021).

Our analysis also found that substantial variation exists in how states have implemented MCACs with respect to beneficiary and consumer group membership requirements and meeting participation requirements. In implementing MCACs, states experience many of the challenges with engaging beneficiaries described in community engagement research. This section highlights state approaches for MCAC beneficiary representation and recruitment, financial arrangements to encourage beneficiary participation, and beneficiary engagement, drawn from our policy scan and stakeholder interviews.

Beneficiary representation and recruitment

State rules for beneficiary representation on MCACs and approaches to recruiting beneficiaries vary. CMS defers to states on how to structure their MCAC composition and recruit beneficiaries onto their MCAC. Given this flexibility, our analysis found that each state's MCAC composition is different.

Beneficiary and consumer group membership.

In our review of publicly available information for 44 state MCACs and the District of Columbia, 38 states explicitly describe requirements for beneficiary or consumer group representation in their state policy documents. Publicly available information related to MCAC membership requirements in the remaining states was not found. Of the states that had these requirements publicly available, there was variation in committee composition and specific requirements for representation.⁶ Only 14 states explicitly require beneficiary representation (i.e., Medicaid recipients, their family members, or caregivers of Medicaid recipients) in the MCAC, and 13 of these 14 states also require consumer group representation.⁷ Twenty-three states and the District of Columbia require representation from either consumer group members or beneficiaries.⁸ Some states do not specify the number of beneficiary members, while Utah and Nebraska specify that at least 51 percent of MCAC members should be beneficiaries, beneficiary representatives, or consumer groups.

Interviewees noted that beneficiary members of MCACs may feel uncomfortable participating during meetings if they make up a small proportion of the membership relative to other types of members. In addition to consumer groups and beneficiaries, MCAC membership can include state Medicaid officials, officials from other state government agencies, health care providers, and hospital and plan representatives. State officials from two states noted that they had reconstituted their MCACs so that committee membership is weighted more equally between Medicaid beneficiaries and consumer group members relative to providers and plan representatives.

States are not federally required to have beneficiary representation from historically marginalized communities on their MCACs, but some have adopted fairly narrow, state-specific requirements. For example, Connecticut, Oregon, and Wisconsin require representation of persons with disabilities. Connecticut and Wisconsin also require representation of dually eligible beneficiaries or older adults. Minnesota requires tribal representation on its MCAC. No state requires specific beneficiary representation by race or gender. A few states have requirements for consumer group member representation. For example, Idaho requires representation from legal aid providers and clergy. Kentucky requires consumer group representation of persons reentering society after incarceration, children and youth, women, and minorities.

Diverse representation of beneficiaries can provide state Medicaid agencies with access to a broad range of perspectives on how the Medicaid program is meeting their needs and challenges with the program. As previously mentioned, meaningful engagement can help the state Medicaid agency establish trust with these communities and advance state health equity efforts by providing opportunities for beneficiaries and other MCAC members to codevelop solutions to beneficiaries' challenges. It is also a way for state Medicaid agencies to demonstrate commitment to the individuals being served, and it increases program accountability (Allen et al. 2021).

The NPRM retains current rules about beneficiary representation and does not add requirements around diverse representation. Instead, CMS encourages states to consider diverse representation as part of their member selection of Medicaid beneficiaries. The proposed rule encourages states to consider geographical diversity, tribal communities, people older than age 65, or people with disabilities. These considerations for states are consistent with CMS's strategic plan for advancing health equity for underserved populations (CMS 2023).⁹

Beneficiary member recruitment. State Medicaid agencies use different strategies to recruit beneficiaries. States advertised openings for beneficiary representation on the MCAC through announcements on their state Medicaid websites.

The policy scan found that 12 states published information on their MCAC website to actively recruit MCAC members. Our interview findings suggest that publishing information on the MCAC website alone is insufficient to recruit beneficiary members. Beneficiaries confirmed they did not learn about MCAC position openings through such a public posting. States may partner with community-based organizations to identify individuals or recruit beneficiaries directly from town halls and other public meeting forums. Another common approach is to recruit beneficiaries who serve on other state advisory committees or managed care organization beneficiary committees. Alaska, Maryland, and Utah require state Medicaid officials to contact consumer, provider, or community organizations for recommended beneficiary members. In Virginia, the state Medicaid agency works with community-based stakeholders to identify potential committee members and also sends letters to randomly selected Medicaid enrollees with information on how to apply to the committee.

States often recruit consumer group members to represent Medicaid beneficiary perspectives and to speak to issues beneficiaries experience. This strategy can be beneficial because consumer group members may be easier to recruit than beneficiaries, can represent a broader community perspective, may have more familiarity with technical Medicaid topics, and may face fewer barriers to participation. For example, one state Medicaid official stated that they rely heavily on consumer groups to gain beneficiary input. However, one consumer group member shared that although consumer group representation is important, these advocates do not necessarily provide the same perspectives as beneficiaries who have more intimate experience with the program.

The policy scan and interviews revealed little information about how MCACs recruit from historically marginalized communities. Most of the interviewed beneficiaries and consumer group representatives were unaware of MCAC efforts to recruit beneficiaries from historically marginalized communities. In Utah, the MCAC bylaws state that the MCAC should ensure that individuals from underrepresented groups, communities, or identities are aware of opportunities to participate on the MCAC.

Beneficiary recruitment challenges. State Medicaid agencies note difficulties in finding beneficiaries willing to participate in MCACs, which can lead to beneficiary vacancies. The analysis of publicly available membership lists found that the majority of states had beneficiary vacancies. Only 11 states had beneficiaries listed as part of their MCACs. One state official noted that because of challenges related to finding new beneficiary members, the same beneficiary has been a member of the MCAC for nearly two decades.

Our research shows that state educational efforts regarding MCACs is limited. Thus, beneficiaries may be unaware that their state has an advisory group that seeks their participation and input, the purpose of the MCAC, or how to apply. By increasing outreach and education about the MCAC and beneficiary opportunities to participate, states may be able to increase the number of beneficiaries choosing to participate.

State officials noted their intent and efforts to increase the number of beneficiaries on the MCACs but that doing so was difficult. Although our findings suggest that using other Medicaid-related committees to recruit members is a helpful tactic in finding beneficiaries, Medicaid officials also commented that this strategy can create challenges when multiple agencies and committees seek the same beneficiaries' input. Most state officials acknowledge that Medicaid beneficiaries, such as those who work during traditional business hours or those who are parents, have responsibilities that affect their ability to participate in MCAC meetings.

Recruiting individuals from marginalized communities requires additional effort, so some states have focused on community-based approaches to implement this tailored approach. A Nebraska state official reported that MCAC community listening sessions held in different locations around the state have been an effective tool for recruiting diverse beneficiary members. An Oregon Medicaid official described sharing recruitment information in Spanish and has offered to translate these materials into other languages to attract beneficiaries who do not speak English as their first language. Most Medicaid officials described a word-of-mouth approach in collaboration with beneficiary members from diverse communities whose terms were ending soon. Other states noted challenges with recruiting beneficiaries in general and were not yet focused on targeted recruitment of

beneficiaries from historically marginalized groups. There has been no federal guidance or technical assistance on how to recruit and retain members from historically marginalized groups.

The NPRM proposes that states develop their recruitment and appointment processes for both MAC and BAG member recruitment and appointment and publish the processes on their state websites. This information would need to be easily accessible to the public. CMS indicates that guidance about recruitment strategies is forthcoming.

State use of financial arrangements for beneficiaries

States have adopted strategies that address logistical barriers that limit beneficiary participation in MCACs. Examples of logistical barriers include the inability to take time off work and the availability and cost of transportation and childcare. Some state Medicaid agencies are beginning to host more virtual MCAC meetings to eliminate transportation barriers (Coburn et al. 2021). Other strategies to increase participation include hosting MCAC meetings outside of traditional work hours, providing food during meetings, or providing transportation to and from meetings (Allen et al. 2021).

Most states offer at least one type of financial arrangement to facilitate beneficiary participation on MCACs, but either most beneficiaries are unaware of these supports or the supports are underused. The financial support can be reimbursements for unspecified incurred expenses, per diems, or can be provided on a case-by-case basis determined by the state Medicaid agency. Among the states with published policies, travel supports was the most common. Twenty-two states offer travel expense reimbursement. All six states interviewed reimburse for beneficiary MCAC members' travel costs (which may include reimbursement of transportation and hotel expenses) to attend in-person meetings. Despite these financial arrangements for travel, some beneficiaries and consumer group members noted that individuals may experience challenges that are not addressed by available supports. For example, some beneficiaries may not be able to attend in-person meetings because they do not have a car or have limited access to alternative transportation options.

Few states offer other types of financial arrangements to support beneficiary MCAC participation. Three states offer childcare or dependent care expense reimbursement. Four states offer reimbursement for personal assistance. Vermont is unique in that it limits its per diem, reimbursement for travel and childcare expenses, and personal assistance services to MCAC members whose income does not exceed 300 percent of the federal poverty level.

Beneficiaries often cite the lack of compensation and lost income from having to take time off work as barriers to participation in MCAC meetings (Zhu and Rowland 2020). Community engagement researchers note that other experts are often compensated for providing their expertise and posit that beneficiaries, who are experts in their lived experience, should be treated similarly. Adequately compensating beneficiaries for their time and expertise demonstrates that the state Medicaid agency values their input (Roman et al. 2023, Allen et al. 2021).

Challenges in using financial arrangements. Of states providing financial arrangements, 19 states offer financial compensation; however, little information is provided on their availability or how to access them. Seven states provide financial arrangements “if needed,” and five offer reimbursements for “necessary expenses,” but no further information was provided in publicly available documentation. Oregon passed legislation in 2022 that offers certain MCAC members \$166 per day for when they are performing MCAC-related duties, such as preparing for and attending meetings (ORS § 292.495).¹⁰

Some beneficiary interviewees expressed that they do not use financial arrangements because they fear it may affect either their Medicaid eligibility or status with other entitlement programs.¹¹ During the interviews, state Medicaid officials asked for more clarification from CMS about the appropriate financial support for beneficiaries that does not affect their eligibility. States also sought more information about the appropriate forms of reimbursement, such as gift cards or checks. CMS has not indicated publicly whether it will issue further guidance about how states can offer financial support without affecting beneficiaries’ eligibility.

Efforts to support beneficiary engagement in MCAC discussions

Some states provide supports to better engage beneficiaries during MCAC meetings, but most consumer group members and beneficiaries identified this as an area for improvement. Some interviewees identified examples of helpful supports that state officials may provide, such as sharing information with committee members in advance of MCAC meetings, providing background information for agenda items, working with beneficiaries to cocreate the meeting agenda, and hosting premeeting question-and-answer sessions to help increase beneficiaries’ understanding of complex policy topics. Maryland provides staff assistance specifically for beneficiaries to review meeting materials. Some states also provide interpretation services to enable participation by beneficiaries with limited English proficiency.

States may also use subcommittees as a strategy to obtain input in specific areas that are important to beneficiaries. Twenty-three states use topic-based MCAC subcommittees or beneficiary-only subcommittees as ways to solicit beneficiary input on specific topics. Common subcommittees include, for example, special health populations, long-term services and supports, consumer-focused groups, or managed care.

State resource challenges limit additional engagement efforts. Meaningful engagement efforts to strengthen the relationship between the Medicaid agency and beneficiaries is time and labor intensive, and states face difficulty balancing this investment with other priorities. State officials agreed on the need to improve beneficiary engagement practices but acknowledged staff capacity as a key limitation to such efforts. State Medicaid officials suggested providing additional federal funding to states for the time and work state Medicaid agencies put in to organize and run MCAC meetings. State officials indicated such funding could help support state efforts to engage beneficiaries in meeting proceedings, such as preparing beneficiaries for each meeting. Under current and proposed federal MCAC rules, federal match for Medicaid administrative activities is available for expenditures related to MCAC and, in the future, MAC and BAG activities.

Beneficiary Experience Participating in MCACs

Beneficiaries participating in MCACs generally described their experience as a positive collaboration between the state Medicaid agency and MCAC members. Beneficiaries agreed that beneficiary voice on MCACs was important because it is an opportunity for policymakers to learn from the beneficiaries' lived experiences to inform current and future policies and improve program administration. At the same time, beneficiaries identified several challenges that hindered their ability to participate in MCACs. These include the application and appointment process, participation requirements, and engagement in discussions.

Application and appointment processes

In some states, the MCAC application and appointment processes, which are designed and implemented by states, can hinder new beneficiary participation. Some beneficiaries described the application to join their state's MCAC as long, complex, overly formal, and similar to a job application. Current federal regulations require appointments to an MCAC be made by either a state Medicaid director or higher state authority but does not prescribe the application process.

Challenges with completing the application.

Some state officials noted that overly complicated MCAC applications could deter potential beneficiary members, especially those with lower educational attainment and less experience with formal job applications. For example, in one state, MCAC applicants must create a profile on an online job application platform. The application requires a resume, short personal biography, and background check. Applicants must disclose potentially sensitive information, such as past bankruptcy filings or criminal charges. Although sharing this information does not automatically disqualify applicants, these questions may dissuade potential applicants. In contrast, the Nebraska MCAC application is simpler and asks applicants two open-ended questions: their affiliation

with the Nebraska Medicaid program and the reason for wanting to serve on this committee. One strategy used by state Medicaid officials is to assist potential new members with the MCAC application. This help includes previewing the application questions with potential applicants, translating the application into Spanish, and offering assistance in completing and submitting the MCAC application.

Challenges with appointment process. Some states require MCAC members be nominated and appointed by the governor. Interviewees from these states noted that this process is tedious because it requires several rounds of vetting candidates. Others noted that some beneficiaries may assume that they will not receive governor approval due to personal reasons (e.g., having a different political affiliation than the governor or a prior legal record). One consumer group member who tried to recruit more beneficiaries noted that beneficiaries who were previously incarcerated were hesitant to apply, thinking they would be disqualified, which is untrue.

MCAC participation requirements

MCAC requirements for member term length vary by state, with three years as the most common term length. Current federal rules require that after committee members complete their terms, the state will appoint a new member to ensure that membership rotates continuously. State officials indicated that it can be difficult to find beneficiaries willing to participate in a multiyear commitment. Interviewees also noted that one benefit of longer terms is gaining a deeper knowledge of the state's Medicaid program, but they acknowledged that the downside could be a lack of new voices on the MCAC, particularly from potentially diverse populations.

MCAC meeting frequency ranges from monthly to annually, though most MCACs meet quarterly. Our review found that in 44 states and the District of Columbia, MCACs have met at least once in the past two years. In addition to scheduled meetings, 18 states allow the MCAC chair, governor, state Medicaid director, or other members to schedule additional meetings as needed. Interviewees noted that increasing the frequency of meetings can strengthen

the connections between the state Medicaid agency and the MCAC members as well as provide beneficiary members greater opportunity to provide regular feedback. State officials mentioned that the transition to virtual or hybrid meetings, due to the COVID-19 pandemic, had a positive effect. Hybrid meetings had greater attendance than in-person-only meetings because they were more accessible for participants. However, some consumer group members described a lack of closeness with their peers when joining meetings only virtually.

Challenges with attending meetings. The time commitments and inconvenient meeting times can be barriers to beneficiary engagement. Across all interviewee types, most stakeholders agreed that time commitments for traveling and attending MCAC meetings can be a barrier to participation. Beneficiaries may have jobs, childcare responsibilities, or other obligations that may preclude them from joining meetings during the business day. The beneficiary experience stands in contrast to that of consumer group and other members (e.g., state agency officials, health plan representatives) who attend these meetings as part of their jobs. Some states move their MCAC meeting locations around the state, such as hosting some meetings on tribal reservations, in rural parts of the state, or in public locations such as libraries and schools, to make them accessible for diverse populations.

Engagement in MCAC discussion

Beneficiaries and other individuals, such as some consumer group members, who do not have a background in health policy may feel hesitant about participating in MCAC meetings due to the complexity and specialization of the topics. States require MCACs to discuss and provide input on a wide variety of policy topics, including program administration, covered services, quality of care, access to care, managed care, quality assurance strategies, eligibility, and enrollment. Beneficiaries tend to feel more qualified to participate in MCAC discussions on topics that directly apply to their lived experience (e.g., provider networks, covered services, and enrollment) than with other Medicaid technical topics, such as provider payments or managed care contracting. When the

latter topics are discussed, interviewees noted that beneficiaries may be less likely to speak up as they have not had experience with these issues. Given the range of topics within the purview of MCACs, it may be unrealistic to expect that beneficiary members will be able to contribute equally to them all.

Most beneficiaries interviewed reported that they received little to no orientation, training, resources, or supports to familiarize them with the MCAC or provide background information on policy topics discussed. To clarify areas in which beneficiary feedback is most needed, three states define specific areas for beneficiaries' input, such as beneficiary use of services and gaps in service, design of outreach programs, and dissemination of accessible information.

Some beneficiaries noted that they did not always receive timely responses to questions or follow-through on requested information on MCAC matters. Beneficiaries stated that they have to be persistent with the Medicaid officials to have these questions addressed and noted that not all beneficiaries feel comfortable doing this.

Uncertainty around the use of beneficiary input. Beneficiaries and consumer group members across all six study states indicated that they had experienced the Medicaid agency staff listening to their input on Medicaid policy and program topics, but some were uncertain whether their feedback led to real change. Beneficiaries indicated that they would like information from their state Medicaid programs about how their feedback leads to program improvements to demonstrate that their participation is not a pro forma activity by the state. For example, one beneficiary noted that they do not always feel like their voice has equal power compared to that of other state officials or participating providers. Another beneficiary noted that it is unclear how much authority the MCAC has to effect change and wondered if the Medicaid agency is obligated to act on their recommendations. The state's MCAC bylaws do not address this. Other beneficiary and consumer group members commented that oftentimes, MCAC meetings are solely updates from the state with little opportunity to provide input and collaboration early in the policymaking process.

Beneficiary-only subcommittees

Some state MCACs convene beneficiary-only subcommittees without the presence of other stakeholders. Beneficiaries and consumer group members described feeling intimidated or discouraged from participating if certain MCAC members, such as government officials, providers, or plan representatives, dominated the discussion. Additionally, consumer group representatives cautioned how overrepresentation of certain MCAC members in meetings compared to beneficiaries can lead to an unbalanced power dynamic and limit beneficiary participation. Beneficiary-only subcommittees can help provide a less intimidating meeting environment that is more conducive to beneficiary participation. One consumer group member stated that their state's beneficiary-only group has more representation from marginalized populations and that there is more robust participation by beneficiaries than in other state advisory groups. The NPRM would mandate each state establish a BAG consisting of beneficiaries, family members of beneficiaries, or caretakers.

Subcommittee challenges. Although beneficiary-only subcommittees may provide a less daunting environment for some members, the subcommittees may experience challenges to beneficiary engagement similar to those of MCACs generally unless steps are taken to address them. For example, beneficiaries may still feel unprepared to discuss certain topics without advanced briefings or preparation support. Depending on how the beneficiary-only subcommittee is structured, there may be an imbalanced ratio of Medicaid staff to beneficiaries, which may hamper conversation. In addition, beneficiary members may experience challenges with the time commitment associated with preparing for and attending meetings, especially if the member is expected to participate in both the subcommittee meetings and the MCAC meetings. One consumer advocate who chairs a beneficiary-only subcommittee noted the importance of ensuring that information and perspectives shared during subcommittee meetings are considered in MCAC and state Medicaid agency policy and program deliberations and acted upon. The consumer advocate noted that this has not always been the case.

Commission Recommendations

MACPAC's recommendations to improve beneficiary engagement on MCACs aim to address key challenges that emerged during our examination of state use of MCACs. The recommendations focus on the need for more federal guidance and technical assistance to states to address beneficiary recruitment challenges, efforts to strengthen the diversity of representation of beneficiary members, and efforts to reduce the burden on beneficiaries while participating in MCACs. In conjunction with ongoing work at the federal and state levels to address these challenges, these recommendations may facilitate improvements in beneficiary recruitment and participation on MCACs.

Recommendation 1.1

In issuing guidance and in providing technical assistance to states on engaging beneficiaries in Medical Care Advisory Committees (MCACs) under Section 42 CFR 431.12, the Centers for Medicare & Medicaid Services should address concerns raised by states related to beneficiary recruitment challenges, strategies to facilitate meaningful beneficiary engagement in Medicaid MCAC meetings, and clarify how states can provide financial arrangements to facilitate beneficiary participation.

Rationale

The states in our study described specific topics for which they need guidance and technical assistance from CMS to leverage the expertise and experience of beneficiary MCAC members in their program policies and operations. CMS has indicated plans to issue guidance on beneficiary recruitment and model practices for facilitating beneficiary participation in MACs and BAGs following the issuance of final rules. In issuing such guidance, CMS should ensure that it addresses the topics identified by states.

Our work highlights a number of such areas, including approaches for recruitment and retention of beneficiary members from historically marginalized groups. States experience recruitment and retention challenges for MCAC members in general, and many appear to have relatively little experience conducting outreach and

describing the need and opportunities for beneficiary participants in MCACs to certain historically marginalized communities. CMS is also well positioned to help state-to-state learning on approaches to elicit beneficiary participation during MCAC meetings. Beneficiaries indicated that it can be challenging to fully engage in MCAC discussions on certain topics, and states have noted a need for information on how to assist beneficiaries. For example, some states have adopted strategies, such as providing an orientation for new beneficiary MCAC members, facilitating premeeting briefings, collaborating on the agenda setting, and creating bidirectional feedback loops, to help beneficiaries prepare for MCACs, which may be useful for other states. In addition, there may be other areas in which guidance and technical assistance could be useful to states, such as approaches for demonstrating the ways beneficiary input has affected program policy.

In addition, states seek clarification on the rules for providing financial arrangements to help beneficiaries participating in MCACs, including, specifically, how to offer financial support without affecting beneficiaries' eligibility. State Medicaid officials indicated a need for clarification from CMS on permissible forms and amounts of financial arrangements to facilitate beneficiary participation.

At the time of publication of this report, it is unclear when the rule will be finalized or when CMS guidance on MCACs will be issued. In addition to changing the structure of MCACs, the proposed rule includes many other changes to Medicaid, which we expect will also necessitate federal guidance and technical assistance. Given the importance of beneficiary MCAC participation in lifting up the experience of beneficiaries, the Commission urges CMS to issue guidance as described above as expeditiously as possible. It is the Commission's view that the challenges states and beneficiaries experience with MCAC participation and engagement under current rules are likely to persist under the proposed restructured MACs and BAGs, if finalized. Thus, timely issuance of guidance on the topics described in this chapter is needed.

Implications

Federal spending. The Congressional Budget Office estimates this recommendation would not have a direct effect on federal Medicaid and CHIP spending. CMS would have to dedicate resources to develop the guidance and provide technical assistance to states as it indicated it would. This guidance and technical assistance will provide further clarity to the federal requirements.

States. Federal guidance could assist states with their efforts to engage beneficiaries on MCACs in a way that promotes their voice and contributes to policymaking decisions. States may be able to strengthen beneficiary participation and engagement in MCACs and benefit from the beneficiary feedback about issues related to the Medicaid program and the services it covers. This bidirectional feedback loop ensures that the program operates efficiently and as it was designed to operate.

Enrollees. When states increase meaningful engagement, beneficiaries may have a more positive experience, and they may be able to make greater contributions to the MCAC discussions. This would provide them the opportunity to have an input on policymaking.

Plans and providers. There would be no direct effect on plans and providers.

Recommendation 1.2

In implementing requirements in 42 CFR 431.12(d) (2) that Medicaid Medical Care Advisory Committee (MCAC) membership include beneficiaries, state Medicaid agencies should include provisions in their MCAC bylaws that address diverse beneficiary recruitment and develop specific plans for implementing policies to recruit beneficiary members from across their Medicaid population, including those from historically marginalized communities.

Rationale

States serve a diverse array of Medicaid beneficiaries, including those who are too often marginalized due to factors such as their race and ethnicity, age, disability, sex, gender identity, sexual orientation, and geography. The current federal regulations require state Medicaid agencies to include Medicaid beneficiaries but do not speak to their diversity. This recommendation directs states to include a diverse range of voices reflective of their Medicaid population as part of operationalizing this existing requirement. Some states will need to revise their bylaws and other policy documents to implement this recommendation. If the BAG is included in the final rule, states should also include diverse representation within this group.

Engaging beneficiaries from historically marginalized backgrounds allows them to share their unique experiences and concerns. It is the Commission's view that there should be diverse representation of Medicaid beneficiaries participating in policymaking decisions, including beneficiaries of color and individuals with disabilities, who can share their experiences with Medicaid (MACPAC 2022b). Intentional and continuous effort is required to engage people who have historically been excluded from the decision making process related to the design, implementation, and operationalization of Medicaid policies and programs.

Implications

Federal spending. The Congressional Budget Office estimates this recommendation would not have a direct effect on federal Medicaid and CHIP spending.

States. States will have to invest resources to develop strategies and policies for recruiting beneficiaries from communities that are marginalized due to factors such as their race and ethnicity, age, disability, sex, gender identity, sexual orientation, and geography. States may face resource constraints given other programmatic needs.

Enrollees. Under this recommendation, beneficiaries from historically marginalized communities may increase participation in MCACs, providing them an

avenue to share their perspectives and experiences to help improve program policy and administration.

Plans and providers. There would be no direct effect on plans and providers. State Medicaid agencies may work with plans and providers to recruit beneficiaries from diverse communities to participate in MCACs.

Recommendation 1.3

In implementing requirements in 42 CFR 431.12(e) to increase the participation of beneficiary members in Medicaid Medical Care Advisory Committees (MCACs), state Medicaid agencies should develop and implement a plan to facilitate meaningful beneficiary engagement and to reduce the burden on beneficiaries in engaging in MCACs by streamlining application requirements and processes, and by addressing logistical, technological, financial, and content barriers.

Rationale

Beneficiaries have noted challenges that can prevent their participation in MCACs. One such difficulty in some states is a burdensome application process. Application processes involving long applications or applications asking sensitive questions about issues that are unlikely to affect beneficiaries' ability to provide input and their perspective on the Medicaid program may dissuade individuals from participating. Complex applications also can hinder some beneficiaries from applying if they find the application overwhelming. In addition, application processes that require a nomination or referral from high-level state government leaders may in effect disqualify beneficiaries willing to participate. Eliminating such requirements and streamlining the application could make MCACs more accessible to and reduce the burden on the individuals willing to serve on MCACs.

Addressing logistical and other barriers may also make it more feasible for beneficiaries to participate in MCACs. Logistical barriers that hamper beneficiary participation include inconvenient meeting times, particularly for those Medicaid beneficiaries working in jobs from which it can be hard to get time off or in which taking time off results in lost income. Certain

meeting locations may be inconvenient, particularly for beneficiaries residing in rural regions or for those without reliable transportation. Other beneficiaries can face financial barriers, such as the cost of childcare or public transportation, gas, or parking associated with attending meetings. Greater state use of financial arrangements under 42 CFR 431.12(f) could help address some of these financial barriers.

Addressing the content barriers that beneficiaries experience would also assist their engagement during MCAC meetings. Medicaid beneficiaries are experts in their own experience but are not necessarily Medicaid policy or health services experts and can experience difficulty contributing to MCAC discussions. States should take steps to help beneficiaries prepare for MCAC meetings, particularly if topics are technical in nature, to ensure that beneficiary points of view are considered in those areas.

Implications

Federal spending. The Congressional Budget Office estimates this recommendation would not have a direct effect on federal Medicaid and CHIP spending.

States. States would need to dedicate resources to assessing current barriers to beneficiary participation and developing a plan for addressing them. States may face resource constraints given other programmatic needs.

Enrollees. Streamlining the MCAC application process and addressing logistical, financial, and content-related concerns for beneficiaries would reduce key barriers to their participation. By doing so, the willingness of beneficiaries to participate in MCACs could increase.

Plans and providers. There would be no direct effect on plans and providers.

Endnotes

¹ RTI conducted the policy scan in the fall of 2022. RTI was unable to find publicly available MCAC documentation for four states: Arkansas, Missouri, Tennessee, and Wyoming. RTI was unable to confirm an active committee (one that has met within the past two years) for California and New York. In the spring of 2023, California launched a Medicaid member advisory committee (DHCS 2023).

² Interviewees included state Medicaid officials, beneficiaries, and consumer group representatives from Kentucky, Maryland, Nebraska, North Carolina, Oregon, and Virginia. The state Medicaid officials identified beneficiary members and consumer group representatives on the MCACs for the interview process.

³ Marginalized communities consist of groups that are excluded from involvement in decision making processes or policies due to factors such as to race, gender identity, sexual orientation, age, physical ability, language, geography, or socioeconomic status (Pratt and Fowler 2022).

⁴ In addition to promoting beneficiary engagement, the proposed rule also includes a number of provisions designed to meet the statutory obligations to ensure that Medicaid provides access to services, such as increasing payment rate transparency and standardizing reporting (CMS 2023).

⁵ For this chapter, MACPAC staff will continue to use the term “MCAC” unless discussing the proposed rule.

⁶ The total membership requirement ranges from 9 members to 48 members, while most MCACs require between 15 and 20 members.

⁷ The 14 states that explicitly require beneficiary member representation are Alabama, Connecticut, Florida, Kentucky, Maine, Maryland, Minnesota, Mississippi, New Hampshire, North Carolina, Oregon, Pennsylvania, Vermont, and Wisconsin. Mississippi is the only state from this list that does not also explicitly require consumer group representation.

⁸ The 23 states are Alaska, Arizona, Delaware, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Louisiana, Massachusetts, Michigan, Montana, Nebraska, Nevada, North Dakota, Ohio, Oklahoma, South Dakota, Texas, Utah, Washington, and Wyoming.

⁹ In 2021, CMS announced a strategic plan to apply a health equity lens across all its programs to achieve equitable outcomes through high-quality, affordable, person-centered care (Brooks-LaSure and Tsai 2021).

¹⁰ Any member of a state board or commission, including those on MCACs, who earns less than \$50,000 per year qualifies for this per diem (ORS § 292.495). The amount is tied to the legislative per diem.

¹¹ According to the Internal Revenue Service, for any additional compensation received that is at least \$600 during one calendar year, a 1099 tax form must be completed, and the amount must be reported for tax purposes (IRS 2023).

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Commission Vote on Recommendations

In its authorizing language in the Social Security Act (42 USC 1396), Congress requires MACPAC to review Medicaid and CHIP program policies and make recommendations related to those policies to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states in its reports to Congress, which are due by March 15 and June 15 of each year. Each Commissioner must vote on each recommendation, and the votes for each recommendation must be published in the reports. The recommendations included in this report, and the corresponding voting record below, fulfill this mandate.

Per the Commission’s policies regarding conflicts of interest, the Commission’s conflict of interest committee convened prior to the vote to review and discuss whether any conflicts existed relevant to the recommendations. It determined that, under the particularly, directly, predictably, and significantly standard that governs its deliberations, no Commissioner has an interest that presents a potential or actual conflict of interest.

The Commission voted on these recommendations on December 15, 2023.

Engaging Beneficiaries through Medical Care Advisory Committees to Inform Medicaid Policymaking

- 1.1 In issuing guidance and in providing technical assistance to states on engaging beneficiaries in Medical Care Advisory Committees (MCACs) under Section 42 CFR 431.12, the Centers for Medicare & Medicaid Services should address concerns raised by states related to beneficiary recruitment challenges, strategies to facilitate meaningful beneficiary engagement in Medicaid MCAC meetings, and clarify how states can provide financial arrangements to facilitate beneficiary participation.
- 1.2 In implementing requirements in 42 CFR 431.12(d)(2) that Medicaid Medical Care Advisory Committee (MCAC) membership include beneficiaries, state Medicaid agencies should include provisions in their MCAC bylaws that address diverse beneficiary recruitment and develop specific plans for implementing policies to recruit beneficiary members from across their Medicaid population, including those from historically marginalized communities.
- 1.3 In implementing requirements in 42 CFR 431.12(e) to increase the participation of beneficiary members in Medicaid Medical Care Advisory Committees (MCACs), state Medicaid agencies should develop and implement a plan to facilitate meaningful beneficiary engagement and to reduce the burden on beneficiaries in engaging in MCACs by streamlining application requirements and processes, and by addressing logistical, technological, financial, and content barriers.

1.1-1.3 voting results	#	Commissioner
Yes	17	Allen, Bella, Bjork, Brooks, Duncan, Gerstorff, Giardino, Heaphy, Hill, Ingram, Johnson, Killingsworth, McCarthy, McFadden, Medows, Snyder, Weno