Engaging Consumers in Medicaid Program Design: Strategies from the States

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Policy Points:

- As Medicaid programs grow in scale and complexity, greater consumer input may guide successful program design, but little is known about the extent to which state agencies are engaging consumers in the design and implementation of programs and policies.
- Through 50 semistructured interviews with Medicaid leaders in 14 states, we found significant variation in consumer engagement approaches, with many common facilitators, including leadership commitment, flexible strategies for recruiting and supporting consumer participation, and robust community partnerships. We provide early evidence on how state Medicaid agencies are integrating consumers' experiences and perspectives into their program design and governance.

Context: Consumer engagement early in the process of health care policymaking may improve the effectiveness of program planning and implementation, promote patient-centric care, enhance beneficiary protections, and offer opportunities to improve service delivery. As Medicaid programs grow in scale and

complexity, greater consumer input may guide successful program design, but little is known about the extent to which state agencies are currently engaging consumers in the design and implementation of programs and policies, and how this is being done.

Methods: We conducted semistructured interviews with 50 Medicaid program leaders across 14 states, employing a stratified purposive sampling method to select state Medicaid programs based on US census region, rurality, Medicaid enrollment size, total population, ACA expansion status, and Medicaid managed care penetration. Interview data were audio-recorded, professionally transcribed, and underwent iterative coding with content and thematic analyses.

Findings: First, we found variation in consumer engagement approaches, ranging from limited and largely symbolic interactions to longer-term deliberative bodies, with some states tailoring their federally mandated standing committees to engage consumers. Second, most states were motivated by pragmatic considerations, such as identifying and overcoming implementation challenges for agency programs. Third, states reported several common facilitators of successful consumer engagement efforts, including leadership commitment, flexible strategies for recruiting and supporting consumers' participation, and robust community partnerships. All states faced barriers to authentic and sustained engagement.

Conclusions: Sharing best practices across states could help strengthen programs' engagement efforts, identify opportunities for program improvement reflecting community needs, and increase participation among a population that has traditionally lacked a political voice.

Keywords: Medicaid, state health policy, consumer engagement, program design, vulnerable populations.

A BROAD BODY OF LITERATURE ARGUES THAT HEALTH CARE POL-ICYMAKING SHOULD incorporate public deliberation.[1,2] From an ethical standpoint, engagement is central to the principle of respect for persons[2] and can enhance the fairness and accountability of decision making, particularly concerning how resources are allocated.[3] Moreover, including the views of those most affected by policies is a critical component of a more equitable health policy.[4] That is, members of affected communities often know their specific needs and circumstances, thereby allowing policies to take into account knowledge that outsiders do not have.[5] In addition, research has shown tangible benefits to public engagement: policy decisions that incorporate input may better navigate

and manage value conflicts as they arise,[2] increase knowledge,[6,7] build public trust,[8] and be viewed by the public as more legitimate.[9,10,11]

Public engagement in health policy decisions is particularly important for programs that serve vulnerable communities, like those covered by Medicaid. A recent review of stakeholders' participation in health care policy found, however, very few efforts that explicitly described participation among vulnerable populations.[12] Policymaking and program design for Medicaid populations may lack meaningful engagement with enrollees[13] in part because this group typically lacks a political voice.[14] For a number of reasons, both understanding and engaging with the diverse needs of Medicaid populations are receiving more attention. First, Medicaid now constitutes the single largest source of public health insurance in the United States, covering 72 million children, older adults, people with disabilities, and low-income populations.[15] Second, alongside Medicaid expansion under the Affordable Care Act (ACA), states are increasingly pursuing their own reforms through waivers, managed care, and other population health efforts,[16] adding to the program's heterogeneity and complexity. Third, under the Trump administration, the Centers for Medicaid and Medicare Services (CMS) has advocated new priorities focused on consumer-directed health care and broader state flexibility.[17] Fourth, the ACA strengthened a number of consumer-centric processes relevant to Medicaid, such as adopting a new public comment process for Medicaid waiver applications to allow for greater transparency and public engagement.[18] The federal government now also administers a nationwide survey of adult Medicaid beneficiaries that evaluates their health care experiences.[19]

Yet there is little standardization and guidance regarding the extent to which Medicaid agencies should involve consumers in their policy and program development. Federal law currently requires that states have a medical care advisory committee (MCAC) to "advise the Medicaid agency about health and medical care services."[20] The agency director is expected to appoint "members … on a rotating and continuous basis," with at least one member being a consumer in order to provide feedback about issues such as revisions to existing policies, policy development, and methods of assessing quality and delivery of care. Without federal monitoring, enforcement, or oversight, MCACs simply represent a "floor" for consumer engagement structures and processes, with the states retaining wide latitude in deciding how to implement and monitor these efforts. Although some states have adopted new approaches

to engage consumers in policy and program design,[21,22] there has been no systematic, multistate assessment of states' consumer engagement strategies.

Reports suggest that engaging consumers early in the process of policymaking improves the effectiveness of Medicaid's program planning and implementation, promotes patient-centric care, enhances beneficiary protections, and offers opportunities to improve value in a system that increasingly must do more with less.[23,24] Recent work by Myers and colleagues, for example, found that engaging Medicaid-eligible populations in Michigan in discussions about spending priorities yielded a unique set of health care prioritization decisions. For instance, participants allocated more to mental health spending, which historically has been underfunded, and allocated less to programs outside of benefit coverage, which have received more policy attention in recent years, such as spending on healthy communities.[10] Similarly, a 2019 Community Catalyst report found that enrollees' feedback led Medicaid plans to change their outreach or communications strategies (79%), benefits packages (42%), or policies specifically related to social determinants of health (26%).[25]

We have little evidence, though, regarding how state Medicaid agencies engage consumers in their programmatic and administrative decision making. Instead, the research on Medicaid policymaking has generally focused on how states engage payers,[26,27] providers, and consumer advocacy organizations.[28] Recent studies also have tended to look at individual-level beneficiary engagement strategies[29] targeting health-promoting behaviors within Medicaid populations.[30,31,32] With the exception of some recent work on consumer input in work and community engagement requirements,[33] there has been limited research on consumer engagement in the design and implementation of Medicaid programs and policies.[13,34]

Understanding why some states engage consumers, and how they are doing so in the context of resource and time constraints, offers important lessons for Medicaid programs pursuing health systems transformation to improve the quality, value, and experience of services provided. To that end, using data collected from semistructured qualitative interviews with 50 Medicaid administrators and stakeholders in 14 states, we describe state agencies' approaches to engaging consumers in their administrative and programmatic decision making. We emphasized the motivations behind these efforts, and perceived benefits, barriers, and

facilitators to incorporating consumer voices into Medicaid's program design.

Methods

Study Design

Our goal was to recruit a diverse sample of state Medicaid programs in order to describe the scope of consumer engagement efforts across different state and administrative contexts. Accordingly, we employed a stratified purposive sampling method, selecting state Medicaid programs based on US census region, rurality, Medicaid enrollment size, total population, ACA expansion status, and Medicaid's managed care penetration. We contacted state Medicaid directors and administrators in 17 states, recruiting interview subjects in stages. Two states declined to be interviewed, and one state did not respond to multiple interview requests. Within the states, we used snowball sampling to identify and recruit additional informants who had varying roles and could explain different consumer engagement efforts across a given Medicaid agency. The Institutional Review Board at Oregon Health & Science University approved this study.

Data Collection and Analysis

From April to September 2019, three members of our research team conducted one-hour, semistructured individual ($n = 17$) and group ($n = 33$ participants in 12 group interviews) telephone interviews with Medicaid directors and other leadership (e.g., program and division directors/chiefs, program managers and coordinators, policy advisers, policy analysts, chief medical officers, medical directors, and other administrators) with relevant knowledge of consumer engagement efforts within the agency. Group interviews were conducted at the participants' request and included between two and five individuals. A total of 50 interviewees participated in 29 interviews, representing 14 state agencies.

We pilot tested the interview protocol with three former state Medicaid directors and iteratively refined it in subsequent interviews. Domains covered included: motivations and benefits of consumer

engagement; mechanisms of consumer engagement in rule making, program design, and implementation; variation of consumer engagement approaches in Medicaid populations; perceived impact and "success" of engagement efforts; and organizational/structural facilitators and barriers to consumer engagement. We asked the interviewees to share their approaches and experiences with all consumer engagement efforts, not just those they regarded as "successful." We defined consumer engagement efforts as bidirectional information exchanges between beneficiaries and Medicaid agencies to inform the design, implementation, and evaluation of state programming, rather than unidirectional outreach, marketing, and education.

We had the interview data professionally transcribed and transferred to ATLAS.ti (Version 8, ATLAS.ti Scientific Software Development) for data management and analysis. We conducted both content and thematic analyses using an inductive approach at the semantic level, focusing on capturing ideas about, perspectives of, and approaches to consumer engagement directly from the interview data.[35,36] Using an iterative process, we generated a preliminary coding schema after reviewing an initial selection of transcripts. Three research team members coded an overlapping sample of 14 transcripts, then met to discuss codes and resolve any discrepancies through consensus. We then coded the remaining transcripts independently. All of us met periodically to discuss codebook revisions and emerging themes.

Results

In this article, we describe the different consumer engagement mechanisms used, including variations of federally mandated MCACs; rationales for engagement; examples of the perceived "success" of engagement efforts and their facilitators; and the barriers encountered. Table 1 shows selected characteristics of the participating states, with counts of each state's primary "bidirectional" engagement mechanisms. Overall, the states used heterogeneous approaches to engage consumers in policy and programmatic decisions, with significant variations in the extent of engagement and use of consumer input. Two states reported limited consumer engagement efforts, citing competing priorities and scant resources. While some engagement mechanisms, like MCACs, were common, their structures and implementation varied.

Table 1. Major Consumer Engagement Mechanisms Used by State Medicaid Agencies

State	Structured, Mixed-Member Forums	Ad-hoc, Topic-Centered Meetings	Surveys	Communications Reviews	Focus Groups and Interviews	Newsletters and Email Listservs	Website and Social Media	Feedback From MCOs	Structured Consumer-Only Forums	Meetings With Advocacy Groups	Listening Sessions and Town Halls	Public Comments
A		X										
B	X	X		X	X	X	X				X	
C	X	X	X	X			X		X	X	X	
D		X		X	X		X	X	X			
E	X									X		
F	X	X			X	X		X		X	X	X
G	X	X	X	X	X		X		X	X		
H	X			X						X		
I	X	X	X			X	X			X		
J	X	X			X	X	X		X	X		
K					X			X				
L	X	X				X			X	X		
M	X	X		X					X	X		
N	X	X				X	X	X	X	X	X	

The predominant consumer engagement mechanisms reported by participating states ($n = 14$) is based on the authors' analysis of stakeholder interviews. For example, while public comment periods are federally mandated for certain policy changes, this is noted in this table only if the states explicitly cited public comments as a primary consumer engagement vehicle.

Tailoring of Medicaid Consumer Advisory Councils

Although all the states reported some form of the federally mandated Medicaid consumer advisory council (MCAC), how their agencies used the MCACs differed widely, with two states reporting few consumer members beyond the federal requirement of at least one consumer representative. For example, in one state, the MCAC was composed largely of clinicians and health care administrators, with two representatives from community advocacy organizations who were not Medicaid members themselves. These meetings were characterized as "griping" sessions, with the state working actively to repurpose this stakeholder group to facilitate more actionable steps. In addition, one state's MCAC was reported to be "symbolic" only, met twice yearly, and had no consumer members.

At the other end of the spectrum, just over half the states enhanced the consumer role in their MCACs by recruiting several consumer members to the committee or by establishing additional advisory committees made up of only Medicaid enrollees. One state had a standing subcommittee of preexpansion and postexpansion Medicaid beneficiaries who concentrated solely on identifying consumer needs and elevating them to other advisory and policymaking bodies. Another state had 30 to 35 consumer members on its main MCAC body, which met quarterly. As in many other states, this MCAC also had separate consumer advisory groups to address specific population needs like children's services and behavioral health. Yet another state reported that more than 400 enrolled individuals applied to be part of a supplementary, communications-focused, Medicaid advisory panel, with a total of 15 members chosen for a one- to two-year term. A perceived benefit of these panels was that consumer participants were more likely to develop understanding of complex Medicaid policies, thereby permitting them to contribute more relevant feedback.

Diverse Engagement Approaches

About two-thirds of states supplemented their MCACs and similar stakeholder advisory groups with additional engagement mechanisms, including standing meetings with advocacy organizations and other constituents, town halls, and focus groups. These states' leaders were more

likely to cite the importance of including consumer perspectives in Medicaid programming and reported several reasons for employing a variety of engagement efforts. First, they found that implementing a variety of approaches could more feasibly capture a mix of voices in the community. As one state Medicaid director explained, "We want every resident to have the same opportunity to provide feedback and the same weight rather than a single committee representing millions." These meetings were often devoted to a specific program. For example, one state partnered with a regional nonprofit to gather consumer experiences as part of its case management service redesign, and another state held consumer meetings as they transitioned to managed care for long-term services and supports (LTSS).

Second, those states that reported more robust consumer engagement efforts used different approaches to different-use scenarios. Table 2 shows examples of consumer engagement efforts at various stages of policy development, from early policy conception to policy design, communications about proposed changes, implementation, and review/future planning. One state supplemented a standard MCAC with short-term "collaboratives" that engaged consumers and other stakeholders in an evidence-based review of specific benefit offerings. Later these groups turned to nonemergency transportation and transgender health benefits. In states with particularly large and diverse Medicaid populations, the interviewees described consumer engagement efforts targeting specific subpopulations. One state created dedicated consumer stakeholder groups to advise on waiver programs for members with intellectual and developmental disabilities. Several others had workgroups for services for behavioral health and for children with disabilities. Three states reported developing materials specifically for non-English speakers, as well as for the visual and hearing impaired.

The states used various communication tools to recruit participants to committees, town halls, and other forums. A Medicaid deputy secretary reported developing an "extensive list of individuals for immediate contact. From that, we ask people to self-select into an advisory committee [for a particular policy]." Email communications and surveys were used to improve turnout at in-person meetings and for post-hoc program evaluations. Interviewees had mixed experiences using remote meeting options like web-based meeting platforms, but they pointed to the potential benefit of incorporating virtual meeting technologies, particularly in states with large rural populations and geographic

Table 2. States' Reported Use Scenarios for Different Consumer Engagement Mechanisms

Stage	Engagement Goals	Examples
Early Policy Conception	Proactive information gathering, including • Uncovering initial reactions to contemplated change; • Surveying beneficiary needs and priorities; • Understanding beneficiary pain points or sources of opposition; • Strategizing with beneficiaries on high-level solutions; • Reviewing RFIs and contract solicitations.	Agency holds community-based "listening sessions" to understand consumers' experiences of case management before redesign of program.
Policy Design	Obtain input on specific design features, feasibility, unforeseen consequences, barriers to implementation.	Agency recruits consumers, advocates, and other stakeholders for advisory workgroup.

Continued

Table 2. (Continued)

Stage	Engagement Goals	Examples
Member Communications About Proposed Change	Collect feedback on agency's proposed messaging and outreach: • Ensuring appropriate literacy levels; • Determining effective communication channels; • Identifying targeted audience.	Consumer communications committee previews draft of outgoing notice and provides feedback.
Real-Time Implementation	Gather time-sensitive responses to program roll-out.	Agency hosts phone conference for consumers to ask questions and provide early feedback.
Review/Future Planning	Discuss iterative input on implementation barriers and successes, needed improvements, and future program priorities.	Standing meetings between agency and advocacy groups continue to "surface" consumers' concerns.

The reported goals and examples of various consumer engagement mechanisms at different stages of the policymaking or program design process, based on the authors' analysis of stakeholder interviews.

dispersion. The states reported minimal use of social media as a way of obtaining consumers' input regarding programs or policies, citing concerns with patients' privacy and agency staffing. When used, social media were mainly a tool for outreach and Medicaid program promotion. A minority of states did report relying on public comment periods as their primary consumer engagement mechanism, although all states are federally required to hold public comment periods for certain types of proposals.

Rationales for Consumer Engagement

The states cited different reasons for implementing consumer engagement efforts. Nearly all state leaders highlighted pragmatic perceived benefits of engaging consumers, such as identifying problems more proactively; using enrollees' perspectives to improve health prevention and services; and assessing program efficacy, consumer experience, and the impact of policy or care delivery changes. Future program planning was another motivation, as one administrator stated: "When you are putting together your budget, [understanding enrollees' needs] gives you a sense of what you want to ask for in the future."

A widely shared sentiment, as one program division director put it, was the benefit of having "boots on the ground": "We can design policy all we want … but if we're not talking to the people who are directly impacted by it, we're missing nuances, potential gaps, or inadvertent issues that we wouldn't have anticipated." This rationale was driven partly by earlier adverse experiences with program implementation. One state leader recounted a Medicaid waiver rollout in which "a series of flubs [led] the community to become much more engaged" and prompted the agency to ensure "broader consumer and family involvement more formally."

Only three states explicitly linked consumer engagement with values-based motivations. Those states that did so emphasized goals like reducing health disparities and enhancing "patient-centered" program design. The respondents attributed these motivations to organizational culture and leadership at the state and agency levels. One leader of a Medicaid subagency reported that an engagement goal was to "increase awareness and concern about equity," specifically "gaps in access and achievement based on racial disparities. Could we connect with people who aren't used to working with government and learn from them?"

Figure 1. Examples of Program or Policy Changes After Consumer Input

Program Design
- Two states planned to merge all behavioral or mental health services into managed care, but retained alternatives after consumer feedback that this would disrupt care delivery for some vulnerable members.

Operations and Process
- State increased 10-day turnaround for eligibility documentation after consumers pointed out logistical flaws: "It turns out we have the shortest turnaround time in the country for beneficiaries to get their documents back to us. We're now making a change in policy."

Service Delivery
- State removed a 72-hour advance notice requirement for nonemergent transportation services after consumer input highlighted resulting barriers, for example, a parent unable to get a sick child to urgent care on short notice.

Communications
- A five-page beneficiary form regarding the appropriateness of plan assignment was revamped to be more consumer friendly. "There was a 'raise-your-hand' form ... on how an individual would notify us that we got it wrong when they were assigned [to a plan]. We started out with a form that would have confused anybody."

Figure 1 shows examples of the perceived impact of consumer engagement efforts on specific Medicaid programs and policies, based on the authors' analysis of stakeholder interviews.

Still others reported being "forced" to engage consumers through legislative mandates at the state and federal levels. Several cited the recent ACA reforms that require states to adhere to certain activities, including establishing Medicaid managed care consumer advisory panels, participating in CMS-administered patient experience surveys, and aiming toward value-based payment models compelling agencies to strengthen oversight, performance review, and evaluation efforts.

Perceived Impact of Engagement Efforts

Figure 1 shows areas of perceived impact, including examples of identified program or policy changes after consumers' input. These areas

included program redesign, such as managed care implementation, administrative operations and processes such as eligibility verification, specific covered services and service delivery, and beneficiary communications. For example, one state's Medicaid program covered only a single analog hearing aid for hearing-impaired beneficiaries, whereas targeted consumer feedback led to a benefit change to cover hearing aids as a pair.

Not all states that reported consumer engagement efforts could point to subsequent effects on policy decision making. Instead, just under half the states defined "success" as building relationships between agency leaders and Medicaid consumers. As one participant stated: "Because of ongoing dialogue … consumers show up with, 'Hey, we're glad you listened, and this is going in a lot of the ways that we wanted to see it go.'"

Perceived Facilitators of Successful Engagement Efforts

A chief facilitator of the states' consumer engagement efforts was Medicaid leadership. Five agencies highlighted leaders who attended routine meetings with consumers, responded directly to feedback provided by individual enrollees and advocacy organizations, allocated staff to gather input, and established an organizational culture that sought to understand the "lived experience" of Medicaid enrollees. As one Medicaid director remarked, "We want the person at the center of all policy … as part of our overall departmental value [to serve] the people, [not] just providers and internal stakeholders." Another state Medicaid director who attended a quarterly MCAC meeting pointed out, "I am there to receive advice, not to tell people the advice I want. … People feel that they have meaningful participation and that I'm not delegating it down to some middle manager."

Medicaid leaders highlighted a number of common factors for their perceived success in consumer engagement efforts. These included providing some minimal compensation for participation, which many states recognized often came at a cost to enrollees: "[Holding a meeting] in the middle of the day is not understanding the barriers of transportation, child care, food," a Medicaid director explained. Several agencies reported small budgets for compensating participants, particularly for those on standing committees requiring regular attendance. Some states also ensured a feedback loop by reporting (by means of public

minutes or reports) how consumers' feedback was used, invested time and staffing resources to facilitate effective interactions with consumers, and provided training for consumer participants to better understand technical language and policy complexities. Finally, those states with robust engagement efforts also pointed to the importance of aligning Medicaid agency goals with consumer expectations. A policy analyst who ran consumer advisory meetings in one state reported "one-on-one" orientations for new committee recruits to familiarize them with "CMS, the role of the council, and the work that it does."

Leveraging Relationships with Community Stakeholders

All the states reported a common facilitator for consumer engagement: a strong relationship with consumer advocacy organizations and community partners. The strength of the relationship depended on the agencies' openness to partnership, historical precedent, and the organizing power of advocacy organizations. In at least one state, collaborations changed markedly with a turnover in state leadership. The states relied on community partners to recruit consumers, fund and facilitate meetings, and support trainings. These organizations represented diverse Medicaid groups, like the disability community, women and children, those with behavioral health and substance use disorders, and people from law, academia, foundations, and interest groups. A deputy Medicaid director described these relationships: "Whenever we're building out a new effort, we tend to automatically engage the consumer-facing organizations … they're in just about every one of our advisory panels." A chief medical officer in another state reported that the agency worked "through advocacy groups to identify and recruit members" for various committees, a common occurrence in the states. Yet another Medicaid program used its long-standing relationship with a community organization to "help craft the agenda [because] they have a better understanding of the people [we] serve."

Limited State-Level Coordination with MCO Engagement Efforts

Only two states had formal mechanisms to systematically collect and utilize consumer input obtained from their contracted managed care health

plans (MCOs). Given that Medicaid's managed care plans are required to have their own consumer advisory bodies, state agencies typically delegated to these plans certain roles like issuing customer satisfaction surveys or collecting data on complaints regarding program changes. These activities varied little among the states, regardless of Medicaid managed care penetration. Only rarely did the states bring up collaborative consumer engagement efforts with MCOs. In one state that was implementing a new behavioral health home model, the agency met with MCO representatives weekly for six months to share consumers' experiences and issues with care integration, which allowed, as a Medicaid director stated, "policy [staff] to quickly come in and get feedback without reinventing the wheel." Only one state described a systematic, formalized process for channeling MCO-level input to state-level program leaders; there, consumers' concerns about a statewide policy issue—access to dental care—had arisen through an MCO community council.

Barriers and Potential Solutions to Consumer Engagement

Even though most of the states reported accelerating efforts to include consumers in Medicaid's program design, many stressed persistent barriers. Table 3 shows the commonly cited barriers and examples of strategies to address them.

The ongoing challenges were recruiting participants to engage with the agency, including incorporating a diversity of consumer voices, making consumer feedback productive and policy-relevant, and sustaining consumers' interest over time. Here, the states emphasized the tensions between engaging consumers who were already knowledgeable about Medicaid programs and policies (often members of consumer advocacy groups), and relying on the same consumer stakeholders at the expense of new voices. As a director of quality described, there is a "difference in the level of understanding and input that advocates provide [because of] being engaged in systems—or program-level thinking." By comparison, the resources needed to recruit and train individual enrollee members were more intensive. The states addressed this tension partly through engagement approaches, with different roles and expectations for different consumer groups. For instance, one state relied on community meetings to hear "the implications of how we determine eligibility and

Table 3. Key Challenges and Potential Solutions for Medicaid Consumer Engagement

Challenge	State Responses
Getting Consumers to Engage	• Using multiple mechanisms to gather input on a planned long-term services and supports (LTSS) managed-care rollout: regional town halls, an all-consumer subcommittee (per diem provided), FAQs and listening-session notes posted on website, and consumers' reviews of the evaluation plan. • Developing an agencywide engagement protocol for involving consumers. • Partnering with a community nonprofit to host a relationship-building meal with a local tribal group. • Training staff on how to relate to consumers. • Providing stipends and travel support to members of a procured advisory committee.
Overcoming Resource Constraints	• Holding telephonic "town halls" for consumers who could not attend in person. • Tapping foundations to fund consumers' participation costs, meals, and meeting facilitation. • Building consumer research into budget requests for federal programs, for example, the Delivery System Reform Incentive Payment Program (DSRIP).
Making Engagement Productive	• Using short-term workgroups regarding specific benefits to optimize consumers' interest and impact. • Using advocacy groups to identify representative consumer participants. • Implementing application and selection processes for consumers' committee membership. • Incorporating activities across different Medicaid subpopulations. • Educating new committee members on Medicaid and how to use it.

Continued

Table 3. (Continued)	
Challenge	**State Responses**
Maintaining Engagement	• Encouraging consumers to initiate policy discussions via an all-consumer MCAC subcommittee. • "Closing the loop:" sending out detailed agency responses to all public comments, ensuring that consumers see their impact. • Showing respect for consumers' input by having Medicaid director personally attend MCAC sessions.

The states reported a number of common challenges to consumers' engagement in the program and policy design. Based on the authors' analysis of stakeholder interviews, this table highlights some of the approaches that the states used to address these challenges, with examples.

deliver services." The same state used an application process to select consumer members for various policy-oriented workgroups in order to provide quarterly input on specific policies in concert with the agency's staff.

The states noted the challenges of including racially, ethnically, and linguistically diverse consumers in their engagement efforts. Despite the representation of these groups in Medicaid programs, only four states reported efforts to tailor specific outreach strategies to different cultural or linguistic needs.

The majority of states also reported scant resources devoted to consumer engagement efforts. In one state, a Medicaid program leader used his personal budget to buy food and drinks for community meetings. Three agencies with robust consumer engagement efforts leveraged relationships with local and state foundations to secure nominal budgets for training, staff time, participant compensation, and other activities. Many states, however, reported partnering with community organizations to recruit consumers, as well as to provide meeting spaces, facilitators, and transportation. Meetings with consumers were held in local churches and health centers. One state joined a community organization with "a pulse on the community" to gain feedback from Medicaid-eligible but not enrolled individuals. Transportation, in particular, was

brought up frequently as a "nontrivial barrier" to engagement. As a Medicaid program director explained, "[Members] are paying for gas, tolls, parking, and are taking time out of their day, so we want to remove as many barriers as possible."

Finally, although many states could point to the theoretical and anecdotal benefits of consumer engagement, none collected evaluation data or monitored the impact of these efforts. Moreover, no states reported formal mechanisms for sharing their experiences and learning with counterparts in other states. These barriers were brought up more often in states with fewer consumer engagement efforts. As a chief medical officer in one state explained, "We have a lot of trouble just engaging the providers … engaging the patients feels insurmountable sometimes. We don't always know the best way to go about things." Many states also wanted to understand the specific and actionable "best practices" of engaging consumers.

Discussion

Medicaid enrollees are not typically represented among the various communities of experts and bureaucrats who make program decisions, and they are often not empowered to participate in policy decisions. Including input from low-income communities in policymaking may make programs better suited to their needs and experiences. Despite little research pertaining to consumer engagement in Medicaid specifically, some evidence suggests that consumer input may improve the public's knowledge of proposed Medicaid policies, increase public engagement, and build a constituency among low-income and vulnerable populations served by Medicaid.[37] These effects could strengthen health care quality and outcomes for enrollees. Our interviews of state Medicaid agencies revealed that even though most states ensure a minimal representation of consumers on implementation and oversight committees, they vary in the degree to which they involve consumers in policy and programmatic decision making. States used a broad range of engagement approaches, ranging from limited and largely symbolic interactions to longer-term deliberative bodies in which consumers engaged in education, discussion, and recommendations about program features and policies. This spectrum of engagement approaches is consistent with past work summarizing models of engagement in health policymaking, from sporadic

consultation to ad-hoc focus groups to more consistent advisory panels and deliberative conferences.[11]

Several possible routes could enhance Medicaid agencies' ongoing efforts to include consumers in program and policy decisions. First, our findings suggest that Medicaid agencies' current consumer engagement efforts could be improved by using structured, deliberative processes to inform decision making.[38] A broader body of work has examined the effects of structured public deliberation on policymaking,[39] finding that such engagement, compared with other methods like surveys, increased consumers' knowledge of policy topics[9] and produced more valid and valuable results to incorporate into policy decisions.[6] Myers and colleagues used a public deliberation process to evaluate how low-income communities prioritized Medicaid spending in Michigan, showing that the participants advanced a set of spending priorities unique to what had been historically funded.[10] While we found examples of these deliberative processes in some states—in the form of longitudinal committees and advisory groups dedicated to consumer education, discussion, and recommendations—such deeper engagement efforts remained the exception, not the norm.

Second, although resources are critical to supporting this work, they are currently lacking in many states. Amid the gradually decreasing federal Medicaid contributions and growing enrollment, a number of state programs are facing significant budget shortfalls. Because consumer engagement efforts can be time and labor intensive, states have difficulty balancing competing priorities.[39] Some stakeholders identified a number of opportunities to maximize existing resources for consumer engagement efforts, such as strengthening relationships with community-based organizations and advocacy groups, leveraging external funders, and adopting alternative communication tools like teleconferencing.

Third, our results suggest that for many states, the benefits of consumer engagement in program design are largely still anecdotal. Those states that perceived strong benefits from their engagement efforts were most likely to describe them in operational terms, like a smoother implementation of program changes or fewer public complaints. But consistent with earlier reviews of participation efforts,[11] there was little formal evaluation of engagement methods. While there was no explicit admission that engagement activities had only limited value, some states did report little engagement activity, and virtually all the states pointed to substantial barriers and competing priorities. Accordingly, we need

better tools to monitor and assess the effects of various consumer engagement approaches, a view with which others agree.[40] Earlier research suggests several possible categories of outcome measures that are used to evaluate public input in policymaking, including engagement processes, quality of input, impact on participants' knowledge and attitudes, and impact on decision making.[6,39] Medicaid programs could also measure the downstream effects of policy changes. For instance, if the states were to adopt consumer engagement in the design of a new formulary, measures like prescription adherence (e.g., proportion of days covered) and patient satisfaction may help to assess impact of policy changes. While others have analyzed Medicaid beneficiaries' involvement in formal advisory roles and other forms of advocacy,[13,34] future research could help assess the impact of state efforts on consumer care experiences, policymaking processes, and population-level health outcomes.

Note that although nearly all the states in our study cited contractual requirements for their Medicaid MCOs to engage consumers, only two states captured input obtained through MCOs for use by agency leadership. This may represent a missed opportunity. Nationally, nearly 70% of all Medicaid beneficiaries were enrolled in comprehensive MCOs in 2017,[41] and MCOs often are among the enrollees' first and most direct contact with the Medicaid program. As managed care continues to grow, opportunities may arise to better utilize MCOs in consumer engagement efforts. For instance, MCOs often must create their own member advisory committees or include consumers on MCO governing boards. While feedback received by MCOs may largely address plan-level concerns, there is potential overlap with state-level concerns that Medicaid agencies could leverage. Moreover, as consumers engage with their Medicaid plans, and specifically their experiences with coverage, they should become more familiar with Medicaid policies and engage more at the overall program level as well. Alternatively, Medicaid agencies could consider establishing centralized entities to conduct consumer engagement, track standardized data analytics and outcomes, and avoid work redundancies at the MCO and program levels.

Finally, for many states, consumer engagement in program design and policy is an underdeveloped area of activity. Our findings reveal that some states stand out in terms of dedicated leadership, strong community partnerships, and a track record of consumer and advocacy group involvement in agency decision making. To this end, some states expressed an interest in learning from peer agencies in order to

understand how to leverage existing resources or implement new strategies in different state contexts. However, platforms for sharing knowledge are currently lacking. There may be significant opportunity for external funders and conveners, including CMS, to help support those states interested in strengthening consumer engagement efforts, by sharing agency experiences and best practices and providing technical assistance.

Our study has limitations. While our findings provide an overview of consumer engagement approaches that some states' Medicaid programs are implementing, these interviews do not represent all the views of these efforts, and our use of purposive sampling limits the generalizability of our findings. In addition, we did not interview Medicaid managed care organizations, which may have differing perspectives on consumer engagement efforts at the health plan level. We also did not interview consumer advocacy organizations or individual Medicaid beneficiaries. We are therefore unable to assess consumer perspectives of engagement efforts, for example, consumer satisfaction or quality and strength of engagement. These stakeholder groups may differ in their goals and desired outcomes, and they may have different facilitators and barriers in engaging with Medicaid agencies. Future research might include perspectives from additional stakeholders and perhaps rely on survey methods in order to capture a larger sample of states, and to identify state- or agency-level factors that predict the use of different engagement methods. Finally, as we noted earlier, this article assessed only the states' perceptions of engagement and its benefits. We also need to evaluate their impact in order to determine the effects of Medicaid beneficiary engagement on various program and policy outcomes.

Conclusions

State Medicaid programs are increasingly recognizing the importance of being able to respond more effectively to the needs of their beneficiary communities. Our findings provide some early insights into how state Medicaid agencies are integrating consumers' experiences and perspectives into their program design and governance. Future work can help strengthen the evidence regarding consumer engagement efforts and their impacts on enrollees' satisfaction, quality of care, and health outcomes. Lastly, we need to better understand and share effective

methods for engagement across states with varying resource constraints and program characteristics.

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Appendix

Medicaid Program Characteristics (n = 14)

State and Medicaid Program Characteristics	*n* (%)
Rural	8 (57.1%)
Republican state in 2016 election	5 (35.7%)
Medicaid expansion state	11 (84.6%)
Region	
West	3 (21.4%)
Midwest	3 (21.4%)
South	4 (28.6%)
Northeast	4 (28.6)
	Mean
Total population	10.4 million
Medicaid enrollment population	2.97 million
MCO Penetration	79.8%