



CONSUMER ENGAGEMENT IN MEDICAID ACCOUNTABLE CARE ORGANIZATIONS

A Review of Practices in Six States

AUTHORS

Kris Wiitala, Program Associate
Margaret Ann Metzger, Consultant
Ann Hwang, MD, Director

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EXECUTIVE SUMMARY

A number of states are implementing models for accountable care organizations (ACOs) within their Medicaid programs.¹ These models of care delivery are intended to improve the quality of care and health outcomes and contain health care costs. The experience of those states implementing Medicaid ACOs can provide useful insights to other states as they design their programs.

ACOs take on responsibility for providing care to a defined population of patients and are accountable for both the cost and quality of that care. The ACO model offers potential benefits for Medicaid enrollees, but risks as well. On the one hand, the ACO model, in theory, incentivizes better coordination of care and can allow for more flexibility in the types of services provided to members. In the best case scenario, an ACO would provide care that is coordinated and centered on the needs and preferences of the member. However, because ACOs face financial incentives to reduce the total cost of care, there is also potential that ACOs would focus on cost reduction at the expense of providing the level and quality of care that members need.

As states roll out Medicaid ACOs, it is critically important that the members served by these programs have a voice in their design, implementation and ongoing oversight. A strong consumer voice can help ensure that Medicaid ACOs achieve their goal of coordinated, person-centered care.

The Center for Consumer Engagement in Health Innovation at Community Catalyst reviewed the consumer engagement structures of Medicaid ACOs in six states – Colorado, Maine, Minnesota, New Jersey, Oregon and Vermont. This paper summarizes the findings from interviews with consumer advocates in each of the six states and a review of relevant documents and state websites. Our research focused on consumer participation, both at the state policymaking level related to the design, implementation and oversight of each state's ACO program, and at the ACO level.

While all of the models reviewed include some structure for consumer engagement at both the state and ACO levels, the format and effectiveness of these structures vary widely. Moreover, interviews revealed that structures for consumer engagement, such as member participation in advisory committees, stakeholder groups or governance bodies, were not sufficient on their own to drive meaningful consumer engagement. As with other efforts by Medicaid programs around the country to engage consumers in policymaking, *how* these structures are implemented makes a significant difference. For example, state policymakers and health care organization leaders can improve the efficacy of consumer engagement by: being mindful about meeting times and locations; providing adequate time in advance of meetings for consumers and consumer advocates to review materials and provide their input, ensuring that recommendations have impact; and ensuring appropriate support such as funding and training for consumers and consumer advocates. These strategies are applicable to other forms of health care delivery system reform efforts as well.

The Center for Consumer Engagement in Health Innovation believes strongly that consumers must play a critical role as states develop Medicaid ACO programs. The consumer advocates we interviewed are using their engagement activities to improve ACOs in numerous ways. They focus on the overarching issues of ensuring consumer protections and person-focused care by requiring opportunities for consumers to be heard in ACO governance and operations. They also focus on more specific and technical issues such as the impact of potential payment incentives, the availability of user-friendly enrollment and eligibility processes, full integration of behavioral health services, the availability of long-term services and supports, and improvements to cultural competency and disability sensitivity in care delivery.

Looking forward, there is a need to further assess whether strong consumer engagement structures produce meaningful consumer engagement, and in turn, whether this engagement ultimately results in better health outcomes over time. This area of research will be important to continue to advance the critically important role of consumers in delivery system reform.

INTRODUCTION

Medicaid constitutes “the single largest source of public health coverage in the U.S.”² and, as of 2015, provided health insurance coverage to more than one in five Americans.³ Medicaid plays a particularly important role in providing coverage to children, older adults, people with disabilities and low-income populations.

Medicaid enrollees often have complex medical and social needs and face particular challenges and barriers in accessing medical care. They have a higher burden of illness when compared to those with private insurance, and in particular, have higher rates of chronic conditions.⁴ Medicaid also makes up a significant percentage of state budgets: in state fiscal year 2013, Medicaid costs accounted for 19 percent of spending from state general funds.⁵ Given these budgetary impacts and the critical needs of the population served through Medicaid, the program has strong incentives to develop models of care and payment that can improve care while reducing unnecessary expenditures.

As of May 2016, nine states had implemented – and at least eight more were in the process of developing – Medicaid Accountable Care Organizations (ACOs).¹ ACOs were first developed within the Medicare program and there are now several types of ACOs in Medicare. There is no standard, nationally applicable definition of an ACO, but generally speaking, ACOs are groups of providers and/or hospitals that take on responsibility for providing care to a defined population of patients, and are accountable for both the cost and quality of that care.³ Payment methods in ACOs vary widely. Individual states are taking the initiative to develop state-specific nomenclature, definitions and requirements. The variation among states reflects each state’s health care landscape, as well as its political environment. ACO development overall remains in flux and the implementation of Medicaid ACOs varies significantly from state to state and even within a given state.

For Medicaid enrollees, ACOs bring both potential benefits and risks. The ACO model, in theory, incentivizes better coordination of care and can allow for more flexibility in the types of services that are provided to members. In the best case scenario, an ACO would provide care that is coordinated and centered on the needs and preferences of the member. For example, a patient being discharged from the hospital would have a seamless transition of care from the inpatient to the outpatient setting, with any changes to their medications reconciled and their home services resumed at discharge. Or a patient with asthma might be able to access equipment that helps prevent asthma exacerbations (an air filter or an air conditioner for example), that isn’t usually considered a covered medical supply or treatment. However, because ACOs face financial incentives to reduce the total cost of care, there is potential that ACOs will focus on cost reduction at the expense of providing the level and quality of care that members need.

Consumer engagement has been identified as an important contributor to the success of ACOs.⁶ Members served by these programs should have a voice in the design, implementation and ongoing oversight to help ensure that ACOs achieve their promise of coordinated, person-centered care.

This paper summarizes the consumer engagement structures in six states implementing Medicaid ACOs, with a goal of identifying promising practices to ensure meaningful consumer engagement. For each state, we reviewed the “on paper” requirements for consumer engagement and interviewed consumer advocates working on the ground to better understand how the statutory, regulatory and programmatic requirements translate into practice. From these interviews, we identified some of the factors that encourage and impede meaningful engagement.

APPROACH

We evaluated six states with Medicaid ACO programs: Colorado, Maine, Minnesota, New Jersey, Oregon and Vermont. These states were early adopters of the ACO model in Medicaid, and present a broad cross section of ACO models.

Chart 1: State Medicaid ACO Program Information⁷

State	ACO Program Name	Program Start Date	Number of Operational ACOs as of June 2016
Colorado	Regional Care Collaborative Organizations (RCCOs) within the Accountable Care Collaborative (ACC)	2011	7
Maine	Accountable Communities (ACs)	2014	4
Minnesota	Integrated Health Partnerships (IHPs)	2013	19
New Jersey	Accountable Care Organizations (ACOs)	2015	3
Oregon	Coordinated Care Organizations (CCOs)	2012	16
Vermont	Accountable Care Organizations (ACOs)	2014	3

For each state studied, we reviewed relevant documents such as federal waiver applications, requests for proposals, model contracts, and statutory language related to the design and implementation of that state’s ACO program, in order to identify structures and requirements for consumer engagement. We also reviewed state websites for consumer engagement requirements and opportunities and sought clarification from state officials.

We coupled our document review with semi-structured in-depth interviews with consumer advocates in each of the six states to understand the consumer engagement experience from their perspective. We selected advocacy organizations to interview based on Community Catalyst’s knowledge of the consumer health advocacy landscape in these six states. Through these interviews, we sought to better understand how the requirements for engagement translated into practice, the barriers to

engagement, and the features that enabled meaningful engagement. Interviews were conducted in May and June 2016.

In approaching our work, we defined consumer engagement as consumer participation in the design, implementation and oversight of the ACO. In this paper, we use the term “consumer advocates” to refer to individuals who are professional, paid representatives of a consumer perspective, typically working under the auspices of a non-profit consumer advocacy organization. “Consumers” refer to beneficiaries or community members who are not professional consumer representatives. References to consumer engagement include participation of either consumer advocates or consumers and, ideally, both.

OVERVIEW OF CONSUMER ENGAGEMENT STRUCTURES IN SELECTED ACO MODELS

We reviewed consumer engagement at two levels: the state level and the ACO level. State-level engagement refers to participation in the design, implementation or oversight of the state’s Medicaid ACO program, including, for example, participation in policy workgroups or steering committees. ACO-level engagement refers to participation in the governance of the ACO itself, such as serving as a member of the governing board, on a board subcommittee or on an advisory committee.

Chart 2 summarizes the consumer engagement structures at these two levels. All six states we studied engaged consumers to some degree at both the state and ACO levels, but the format and level of engagement varied greatly by state.

Chart 2: State-Level and ACO-Level Consumer Engagement Structures and Requirements

State	Requirements for State-Level Consumer Engagement	Requirements for ACO-Level Consumer Engagement
Colorado ⁸	The ACC is Colorado’s primary payment reform vehicle. RCCOs administer the ACC program by connecting members to a medical home. The ACC Program Improvement Advisory Committee (PIAC) is the primary avenue for stakeholder engagement. It is a statewide committee that provides recommendations to the Medicaid agency on areas of improvement for the ACC including ways to improve health outcomes, access, cost containment, and the client and provider experience. ⁹ The PIAC bylaws require diverse membership; each of the seven RCCOs has two representatives on the PIAC and it is a requirement that one of those two positions be a client or client advocate. ¹⁰ Public meetings must be held at least quarterly ¹¹ with meeting materials posted to the Medicaid agency website. ⁹	Each RCCO is required to have a local advisory committee to ensure the provider and member voice is part of the program. The advisory committees provide input into the performance and administration of the RCCO. The committees are required to have representation from members, families, advocates, providers, the behavioral health community and community organizations. Public meetings must be held at least quarterly with minutes posted on the RCCO website. ⁹

Chart 2: State-Level and ACO-Level Consumer Engagement Structures and Requirements (continued)

State	Requirements for State-Level Consumer Engagement	Requirements for ACO-Level Consumer Engagement
Maine	<p>As Maine Medicaid developed its AC program in 2011 and 2012, it regularly consulted with its Member Standing Committee, a group originally tasked with providing input on Maine's move to managed care, but repurposed for other health care issues, including ACs.¹² As it developed its AC program, Maine Medicaid also held regional public forums,¹³ did presentations,¹⁴ and presented at a MaineCare advisory committee that included providers and community representatives.¹⁵</p>	<p>The purpose of the AC governance structure is to provide oversight and strategic direction for the AC. The AC governance structure must ensure access to its process, decisions, and action items to all interested parties.^{14(p12)} For the first round of the program, each AC was required to include as part of its governance structure at least two members served by the AC or their caregivers.^{14(p12)} The application for the second round of the program, which began in August 2016, indicates that if the lead AC is an existing entity, then having two AC members on a separate committee constituted by the entity to advise the governing body on issues of importance will be sufficient.¹⁶</p>
Minnesota	<p>The state held public stakeholder meetings to discuss their State Innovation Model (SIM) grant application, which included IHPs.¹⁷ The Health Care Financing Task Force, which the legislature and governor created to advise them on improving access to and quality of health care, included consumer advocates,¹⁸ and provided recommendations on IHPs.¹⁹ The state also maintains a Community Advisory Task Force, which includes consumer advocates and provides guidance on the state's SIM initiative.²⁰ The SIM program holds ongoing informational events and discussions for the community that includes discussion of IHPs.²¹</p>	<p>In order to be eligible to participate in the program, each IHP must have a system for advocacy and consumer protection.²²</p>
New Jersey	<p>New Jersey used its existing Medical Assistance Advisory Council (MAAC), which holds a quarterly public meeting about Medicaid-related issues, to discuss implementation and oversight of its ACOs.²³ The Council includes Medicaid staff as well as consumers and consumer advocates appointed by the state.²⁴</p>	<p>Each ACO's governing board must include representation from at least two consumer organizations capable of advocating on behalf of consumers residing within the designated area of the ACO. One of the organizations must have extensive leadership involvement with individuals residing within the designated area of the ACO. One of the individuals representing a consumer organization must be an individual who resides within the designated area served by the ACO.²⁵ Each ACO must have a process for engaging members of the community to develop health care goals and for receiving comments with respect to its gainsharing plan.²⁶ Each ACO should make documents available to the public online where feasible.^{26 (pg.9)}</p>

Chart 2: State-Level and ACO-Level Consumer Engagement Structures and Requirements (continued)

State	Requirements for State-Level Consumer Engagement	Requirements for ACO-Level Consumer Engagement
Oregon	<p>The CCO development public process included 8 community events around the state that 1,200 people attended,²⁷ 4 workgroups that included 133 Governor-appointed members from health care sectors and communities across the state, and public testimony at monthly Oregon Health Policy Board (OHPB) meetings.²⁸ The OHPB continues to have regular, public meetings that consumers can attend. The topics for these meetings include CCO monitoring.²⁹</p>	<p>Each CCO must have a governance board that includes at least two members of the community to ensure decisions align with the community's values.³⁰ In addition to consumers on the governance board, each CCO must have a Consumer Advisory Council (CAC) that meets at least once every three months, and where consumers make up the majority of the membership.^{30(p25)} At least one member of the CAC must also serve on the governing board.^{30(p25)} There is a requirement that CAC members be surveyed annually to assess their satisfaction with the level and quality of their engagement with the functions of the CCO board.^{30(p190)}</p>
Vermont	<p>The State Innovation Model (which includes work on ACOs) workgroups and Steering Committee hold public meetings with opportunities for public comment and voting membership that includes consumers and/or consumer advocates.^{31, 32}</p>	<p>Each ACO governing board must include at least one Medicaid beneficiary and at least two consumer members who have prior personal, volunteer, or professional experience in health care advocacy.³³ Each ACO governing board must devote an allotted time at the beginning of each in-person meeting to hear comments from members of the public and must post summaries of ACO activities online.^{33(p9)} Each ACO must have a consumer advisory board with members drawn from the community served by the ACO, including patients, families and caregivers.³⁴ Members of the ACO governing board must regularly attend consumer advisory board meetings and report back to the governing board.^{33(p9)} ACOs must also gather consumer input by hosting public forums and soliciting written comments and must report to the board on all consumer input at least annually.^{33(p9)}</p>

State-level consumer engagement varied across states. In the design phase, Maine, New Jersey and Vermont used existing structures for public input on the Medicaid program to gather input on the ACO program. In the implementation phase, Maine and Oregon held public forums across the state, while Minnesota and Vermont held open, regular stakeholder meetings. Oregon, Vermont, Minnesota and New Jersey organized workgroups or councils with consumer representation in which their charge, or part of their charge, was to provide recommendations on ACO implementation. In terms of ongoing oversight, Colorado has an ACO-specific advisory committee, the PIAC, with consumer representation, and New Jersey, Vermont, and Oregon hold regular, public meetings where their ACO programs are discussed.

At the ACO level, consumer engagement requirements include consumer representation on ACO governance structures (in Maine, New Jersey, Oregon, and Vermont) and consumer advisory councils (in Colorado, Oregon, and Vermont) that provide feedback and recommendations to the governing boards.

Some states have additional unique consumer engagement structures. For example, in Oregon, each CCO's Consumer Advisory Council (CAC) is required to oversee the Community Health Needs Assessment and the development of the Community Health Improvement Plan that gives strategic guidance to the CCO governing board on how to invest its resources.^{30(p189-190)} In addition, there is a requirement that the CAC members be surveyed annually to assess their satisfaction with the level and quality of their engagement with the functions of the CCO board.^{30(p190)} The Oregon Health Authority's Transformation Center also plays a unique role when it comes to consumer engagement. The Transformation Center shares best practices among Oregon's 16 CCOs and provides support to the CACs through resources, regular meetings and funding CAC members to attend statewide conferences.³⁵

Colorado has several unique community engagement features in the ACC program. A consumer advocate currently serves as the chair of the PIAC³⁶ and was significantly involved in developing its bylaws. Colorado also has a dedicated consumer advocate on the PIAC to represent the dually eligible population – members with both Medicare and Medicaid – and a subcommittee specific to dual eligibles.³⁷ Consumer participation in this subcommittee is encouraged by creating an accessible meeting space – individuals who are able to attend in-person can receive a paid parking voucher, and individuals not able to attend in person have the option to join the meeting via phone or webinar. Having alternative methods for including consumers is important for achieving statewide representation at committee meetings. For a period of time, a state staff person took the initiative to organize educational sessions to help consumer participants feel more comfortable contributing to this subcommittee.

The consumer advocates we interviewed are using their engagement to improve the ACO models in numerous ways. They focus on the overarching issues of ensuring consumer protections and person-focused care by requiring opportunities for consumers to be heard in ACO governance and operations. They also focus on more specific and technical issues such as the impact of potential payment incentives, the availability of user-friendly enrollment and eligibility processes, full integration of behavioral health services, the availability of long-term services and supports, and improvements to cultural competency and disability sensitivity in care delivery. Consumer advocates considered the following to be among their successes:

- Pushing during the design phase to require that multiple consumers and consumer advocates serve on ACO boards and to require consumer input on each ACO's financial incentive models;
- Helping the ACO initiative achieve bipartisan political support by promoting the potential advantages of the program from multiple perspectives; and
- Encouraging ACOs to cultivate consumer advisory council members as potential board members.

Consumer engagement structures are only one aspect of consumer-centered programs in Medicaid. For example, there is also a need for strong grievance and appeals processes, as well as programs to assist consumers who have questions about or encounter difficulties with ACO programs. While not the focus of this report, in our review, we did come across states that utilized Medicaid-wide ombudsman programs for ACO-related issues. The success of these programs varies greatly depending on the scope of authority they have, the adequacy of their funding, public awareness and their degree of independence. Vermont recently passed a law, Act 113 of 2016³⁸, which includes significant ACO-related consumer protections that may serve as a model for other states. The law requires ACOs to maintain a hotline for complaints and grievances; provides members with contact

information for the Office of the Health Care Advocate, an organization in Vermont that provides consumer assistance; and requires ACOs to share complaint and grievance information with the Office of the Health Care Advocate at least twice a year.

FACTORS TO CONSIDER FOR MEANINGFUL CONSUMER ENGAGEMENT

Our review of structures for consumer engagement found that all states included some degree of consumer engagement at both the state level and the ACO level. However, as concepts of consumer engagement move into practice there can be wide variability in what happens on the ground. As one consumer advocate said of the ACOs in their state, “Some of them do a better job than others at actually trying to make the model work. I don’t know if any are doing as well as we would like. Some do the bare minimum required by law, others are putting genuine effort.”

To get a better sense of how the requirements for consumer engagement above were translated into practice, we spoke with 14 consumer advocates in the selected states. From these interviews, we identified factors that can impact consumer engagement. Our interviews illuminated the concept that when it comes to implementation, regulatory and programmatic requirements can set expectations – but are not sufficient on their own – to create meaningful engagement. The factors discussed below that can impact consumer engagement include: **funding and resource gaps, representative recruitment, bandwidth, technical nature of topics, influence, scheduling, transportation, and training.**

Funding and Resource Gaps

Considerations for funding of advocates: Consumer advocates emphasized the importance of fiscal resources and support. When it comes to the ability of consumers and consumer advocates to participate meaningfully, funding matters. With adequate funding, consumers can get necessary training and reimbursement for their time. With adequate funding, consumer advocates are able to bring more to the table, in terms of soliciting input from a broader range of consumers and sharing stories from consumers impacted by the changes being considered. While there are some models of funding from states and plans, currently philanthropy has a primary role in supporting consumer participation. For example, in one state, consumer advocates sat on a task force that had a subcommittee dedicated to making recommendations to the legislature on the state’s ACO program. With philanthropic support, these consumer advocates engaged community members for input on the kinds of recommendations that should be made and brought that information back to the task force. In another state, there was a robust stakeholder process related to mental health because a local behavioral health organization funded a convening of participants.

There are limitations to relying on philanthropic funding to support consumer engagement. Funding tends to follow the “hot issues” and many issues (including violence, education reform, substance use, etc.) compete for funding and for consumer advocates’ time and attention. Several interviewees noted that there was funding for training about health care issues after the passage of the Affordable Care Act, but that this funding is no longer available. Interviewers also raised the point that funding needs to be provided in a way that allows for long-term organizing and flexibility. It is not realistic to train people about every micro-issue related to health care reform – there needs to be a bigger picture perspective and ongoing support for training about health system transformation.

Considerations for funding of consumer participants in ACO engagement: Interviewees discussed the need for adequate funding for consumer participation to lay the groundwork for success. The consumers whose voices are most lacking are often those who have low incomes and who have many demands on their time and resources. They “must giv[e] up valuable time to join these meetings.” Stipends for participation can help offset costs related to participation such as child care or time off from work. As one consumer advocate interviewee put it “we are paid to be there and those folks are not. We might need to even the playing field by reimbursing them for their time and providing transportation vouchers. It would be a low-cost, but high-impact way to improve participation.” In one state, a foundation provided funding for transportation, gift cards, and American Sign Language interpretation support consumer engagement. However, one interviewee cautioned that when providing stipends, it is important to know whether the stipend is considered income for the purposes of public programs, so as not to jeopardize members’ ongoing eligibility for such programs.

In order to build a strong and continuing infrastructure of consumer engagement, states should recognize and fund consumer engagement as a critical component of program implementation, in the same way that technical assistance to providers is provided to facilitate model adoption.

Representative Recruitment

Interviewees highlighted the importance of recruiting consumers who are representative of program membership, rather than, in the words of one interviewee, “pseudo consumers.” In some cases, consumer advocates noted that consumer seats on stakeholder committees were filled by family members of elected officials or industry stakeholders. One interviewee noted the importance of having both consumers and consumer advocates as they each can provide a unique perspective.

Bandwidth

Consumer advocates noted the immense amount of time that was required in order to meaningfully participate in some ACO engagement opportunities. In one state, for example, there were seven workgroups that each held monthly meetings for two to three hours during the work day. Meaningful participation in a workgroup required attendance at every meeting plus advance reading to review all of the material being considered. For consumer advocates, who may be expected to cover a broad range of policy priorities in their jobs, this creates a challenging drain on their time and scarce resources. For consumers, who are generally not paid for their time and have other commitments, this amount of time can be discouraging or prohibitive to participation. Moreover, the time commitment to attend many meetings about very detailed technical issues can make participation feel intimidating or unappealing. One way to address this concern is for state agencies to coordinate their requests for consumer input so that requests are spread out over time.

Technical Nature of Topics

A frequent theme raised by interviewees was the technical, detailed nature of the topics covered in ACO-related work. One interviewee noted, “It can’t be as simple as training people around ACOs, because people won’t stick around for that. People will care about different issues at different times and need to have the flexibility for that or you lose people. This needs to be bigger level work.” Interviewees spoke about the difficulty both consumers and advocates have learning the acronyms and the policy and procedural content to get to a point where they feel comfortable speaking up in

meetings. Even then, there is the challenge that many of the issues are so technical or procedural, as to seem unrelated to real-life experiences and problems. These two factors coupled together can discourage consumers from participating. A solution is for information to be presented in simpler language, and this can be done with a commitment by ACO staff to do so. As one interviewee put it, “There needs to be a bit of a culture shift at the board meetings. It doesn’t need to be so wonky. We can challenge ourselves to speak more simply about the issues.”

Influence

A lack of perceived impact or influence can discourage consumer and consumer advocate participation. One interviewee said, “There weren’t barriers to our participation. There were barriers to our influence.” This sense of unequal power also emerged in another interviewee’s experience, in which the consumer representatives were outnumbered and routinely outvoted by all of the provider representatives. Consumer advocates in some states felt that an advisory role was sometimes not impactful. One interviewee said, “We just make recommendations. There aren’t any teeth.” In contrast, in Colorado, a consumer advocate member of the PIAC, the state-level steering committee, was selected to be a co-chair. Requiring that consumers have significant leadership roles can create confidence that the committee values consumers and their perspectives. One advocate suggested offering a “ladder of engagement” so that consumers can participate in increasingly active ways such as by moving from a consumer advisory council to a governance council or from an ACO-level consumer advisory council to a state-level consumer advisory council.

Scheduling

A number of states include consumer participation in various workgroups or committees. However, the time of day that meetings are scheduled affects which consumers are able to attend. Individuals who work during weekday business hours, for example, are unlikely to be able to attend meetings scheduled during that time. One particular challenge raised was the participation of parents with young children, given the need for child care.

Transportation

Interviewees also raised the need to reimburse or arrange for travel, particularly in large rural states. Advocates saw states’ and other organizations’ unwillingness to reimburse for travel as a lack of commitment to actually have consumers and consumer advocates participate. As one interviewee noted, “Even if they want people there, they aren’t putting resources into getting them there.” Access to transportation is particularly important to ensure that people with disabilities are able to participate meaningfully.

Training

Interviewees identified training as a key need. Consumers need time to “learn the acronyms” and prepare. The Oregon Health Authority’s Transformation Center provides funding for consumer representatives on the CACs to receive training. As mentioned earlier, in Colorado, a state employee took the initiative to support consumers who attended a PIAC subcommittee’s meetings by organizing regular educational sessions prior to meetings to help consumers be prepared to participate fully in the meetings. In another state, advocates themselves provided training, meeting with a consumer

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representative for several hours each month to get the person up to speed, so that this individual would feel comfortable serving on a statewide working group. One of the ACOs in New Jersey, the Camden Coalition, provided training for consumer board members. One advocate suggested that consumer representatives stepping down from a board or advisory committee could provide training to new representatives.

ENCOURAGING MEANINGFUL CONSUMER PARTICIPATION

For state policymakers, ACO leaders, advocates and others who are interested in encouraging meaningful consumer engagement, we highlight the following strategies:

- ✓ Be thoughtful about the time and location selected for meetings.
- ✓ Provide opportunities for consumers to offer input outside of in-person meetings.
- ✓ Accommodate consumer needs for transportation, stipends and child care.
- ✓ Engage a range of consumers who are fully representative of the ACO's Medicaid beneficiaries' demographic range.
- ✓ Ensure that consumers and consumer advocates have necessary and sufficient training.
- ✓ Provide consumer advocates with the resources to solicit broader consumer input.
- ✓ Schedule adequate time for consumers and consumer advocates to review materials and provide their input.
- ✓ Require a "critical mass" of consumers on CACs, governance, and other bodies, to ensure that their perspectives carry weight.
- ✓ Make consumers feel welcome and let them know their input is valued. This requires an effort by board/committee leaders and may involve shifting the dynamic of the board/committee meetings by, for example, making the language more inclusive and spending more time addressing issues relevant to consumers.
- ✓ Ensure consumers' contributions have impact by providing pathways to increased leadership authority in governance structures
- ✓ Track the effects of consumer inputs on outcomes.
- ✓ Ask for feedback from consumers and consumer advocates.

DISCUSSION AND CONCLUSION

States are rapidly adopting accountable care models in their Medicaid programs. These models of care delivery impact both the system's spending and the health outcomes and quality of life of the consumers served. Consumers have a critical role to play in improving the health care system. A reliable feedback loop between consumers, their caregivers and the health care delivery system is an essential element of achieving person-centered care for Medicaid enrollees, many of whom have complex care needs.

When engagement works well, consumer advocates and consumers are able to bring the voices of those impacted – positively or negatively – by the new programs to the table. These voices are an important and potent voice for change, as their stories remind everyone in the health care delivery system that their work impacts real people and that the mission is the delivery of person-centered care.

While all of the models reviewed include some structure for consumer engagement, the format and effectiveness of these structures vary widely. Moreover, beyond requiring consumer engagement, there are numerous steps that state policymakers and health care organization leaders can take to foster meaningful consumer engagement in the design, implementation and oversight of ACOs. This includes ensuring appropriate support, through adequate funding and training, so that both consumers and consumer advocates can participate meaningfully. The recommendations to ensure meaningful consumer engagement in ACOs are applicable to other forms of health care delivery system reform efforts, as well.

There is also a need for better tools to monitor and assess the effectiveness of consumer engagement, so that states can measure how successful ACOs are in engaging consumers. The Financial Alignment Demonstrations, for example, include a quality measure of whether a plan established a consumer advisory board or included consumers on their governance board, consistent with contract requirements.⁴⁰ However, additional measures are needed to assess more than whether or not an engagement structure was established. There is a need to further assess whether strong consumer engagement structures produce meaningful consumer engagement, and in turn, whether this engagement ultimately results in better health outcomes over time. These measures could look at factors such as how well the composition of an advisory board reflects the composition of the consumer population being served. These areas of research will be important for continuing to advance the critically important role of consumers in delivery system reform.

Ultimately, consumers should be the “north star” that guides the design, implementation and monitoring of the programs meant to serve them. This is especially true for vulnerable populations such as those with low-incomes or complex care needs. Consumers bring a unique and critical voice to the table that can help guide our health care system to one that can create better health for all.

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@CCEHI
healthinnovation.org

COMMUNITY CATALYST
ONE FEDERAL STREET, 5TH FLOOR
BOSTON, MA 02110
617.338.6035