
A Seat at the Table: Consumer Engagement Strategies Essential to the Success of State Dual Eligible Demonstration Projects



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Introduction

New demonstration programs to improve care for people eligible for both Medicare and Medicaid (dual eligibles) are moving forward, as states receive approval from the Centers for Medicare and Medicaid Services (CMS) at the U.S. Department of Health and Human Services.¹ These demonstrations, which include capitated and managed fee-for-service models, offer an opportunity to integrate medical care and support services for millions of the most vulnerable consumers in the country. Yet there are also risks, including compromises to access and quality, and disruption of existing provider-patient relationships. Ongoing involvement of consumers and their advocates in policymaking is essential to mitigate these risks and ensure quality, cost-effective, patient-centered care. Those enrolled in these demonstrations and their families will know first-hand what they need, what is working, and what needs to be changed. They must be at the decision-making tables.

CMS has regularly consulted with national consumer advocates, has mandated consumer engagement in the state planning processes for these demonstrations and is requiring states, managed care organizations (MCOs), and health home networks to continue that engagement throughout the three years of the projects. Specifically, the CMS [“standards and conditions”²](#) for the demonstrations require that each state establish “a plan for continuing to gather and incorporate stakeholder feedback” and “a meaningful beneficiary input process.” The CMS-state memoranda of understanding ([MOU](#))³ for all four capitated demonstrations approved to date – California, Illinois, Massachusetts and Ohio – require participating MCOs to create beneficiary advisory committees that reflect the diversity of consumers and that have a channel to MCO governing boards. To enforce this provision, CMS is requiring states to withhold some funds from MCOs until they meet this and other quality standards. The MOU for Washington State’s fee-for-service health home demonstration requires each health home to establish a process for consumer input. In addition, each MOU indicates the state plans to convene a broader table of stakeholders to advise state officials.

Collaboration with consumer and consumer advocacy groups is critical... We should ensure that beneficiaries’ voices are heard in the design, implementation, and oversight of new initiatives.⁴

– Cindy Mann, Director, Center for Medicaid and CHIP Services

Unfortunately, some of the MOUs do not provide specifics about ongoing consumer engagement at the state level, and many of the demonstration proposals in states yet to obtain approval are also vague about this. In addition, only 10 states’ proposals mentioned consumer engagement in MCO governance, most often on an advisory board. None of the managed fee-for-service proposals described consumer engagement in delivery systems regardless of whether those are health homes or provider groups.

More work is needed to operationalize the intent of CMS’ directive on consumer engagement. This means requiring ongoing, meaningful consumer engagement at all stages and all levels of program development and implementation – in federal and state policymaking and oversight, in the governance and operations of MCOs and other delivery systems and in describing how individual consumers are faring. This is critical to ensure that these demonstrations improve care for consumers and achieve the goals of better health outcomes and reduced costs.

This paper details the essential elements of consumer engagement that policymakers, managed care companies and consumers should work together to put into place. CMS should take the lead by requiring a *detailed* state plan to engage consumers; then states, MCOs and other delivery systems can add elements as needed. Consumer advocates' role is to keep the pressure on to ensure this happens.

The recommendations in this paper are designed to work in parallel with other means of ensuring quality care and prompt resolution of problems, including an independent ombudsman, strong contract oversight, and a rigorous grievance and appeals process.

Top line consumer engagement strategies

- CMS requirement that each state develop meaningful consumer engagement, and CMS oversight to ensure follow-through.
- Detailed state plan for consumer engagement in formal oversight, planning and monitoring of everything from enrollment practices to provider networks to quality improvement. This includes broad consumer membership on statewide oversight councils and workgroups, requirements for MCOs and other delivery systems to implement engagement strategies, and established timetables and mechanisms for collecting feedback from individual consumers.
- Inclusion of consumers on the governing boards of MCOs or other delivery systems, or establishment of consumer advisory committees.
- State measurement of the *effectiveness* of consumer engagement as part of quality assurance and adjustment of both the engagement plan and implementation as needed. Measures might include program changes resulting from consumer engagement, the number of consumers engaged at each stage and each level, and the degree to which those involved reflect the diversity of the demonstration population.
- Federal funds made available to states for consumer engagement activities.
- Training for consumers to help them be effective in these roles.
- Stipends for consumer time and travel to participate.
- All consumer engagement conducted in a manner fully accessible to those with disabilities, and linguistically and culturally competent.
- Consumer membership on oversight or advisory committees reflects the diversity of participants in the demonstration projects.

Detailed Recommendations for Multi-Level Consumer Engagement

Engagement in policy decisions

Consumer involvement is critical because the best policies emerge when the people most directly affected are at the decision-making table.

- CMS should continue to provide regular opportunities for consumer input into the shaping of federal decisions on the demonstration initiative.
- CMS should require each state to have a more detailed plan for consumer engagement in state-level demonstration decisions.
- CMS and the states should expand the measures used to determine whether quality consumer engagement is occurring. The measures could include program changes resulting

from consumer engagement, the number of consumers engaged at each stage and each level, and the degree to which those involved reflect the diversity of the demonstration population.

Precedent: A handful of states with Medicaid managed long-term services and supports (LTSS) programs have changed contract requirements based on consumer feedback.⁵

- States should establish oversight committees that include at least 50 percent representation from consumers or consumer advocates. To ensure these committees fulfill their purposes, states should also:
 - Spell out the specific roles and responsibilities of these committees, including oversight of quality and performance, and how committee decisions will be carried out
 - Rely on consumer advocacy organizations⁶ to help select appropriate members for oversight committees
 - Provide staffing
 - Use available federal money to support consumer participation in committees

Precedent: Massachusetts created an Implementation Council⁷ for its demonstration project whose membership is at least half consumers, their family members and guardians, and which is chaired by a consumer. The council is helping shape the demonstration and will monitor implementation, including quality and access, and provide recommendations to the state. State officials staff the meetings. The state is providing trainings and physical accommodations as needed to council members. It is paying stipends to consumer members for attending meetings and doing preparatory work, and is providing reimbursement for travel expenses. The state plans to draw on a federal grant to support the council's work.

*"The ability of a strong advocacy community to identify sources of problems in the statute or in the implementation of the statute is a resource that the state needs."*⁸

— Alan Weil, Executive Director,
National Academy for State
Health Policy

Precedent: Federal law requires Community Health Centers to have boards of directors whose membership is at least 51 percent consumers.⁹

Precedent: Federal regulations authorize 50 percent federal matching funds for expenses of each state Medicaid Medical Care Advisory Committees (MCAC).¹⁰ The same regulations also require "financial arrangements, if necessary, to make possible the participation of recipient members."¹¹ Case law in several states has mandated at least 38-45 percent of the membership of MCACs be consumers.¹²

Precedent: Colorado established a state advisory committee on the demonstration project and offers a "learning lab" prior to many meetings to help consumer members deepen their understanding of issues on the agenda. The lab has enabled consumer members to participate more fully in committee discussions.¹³

- States should establish stakeholder workgroups with meaningful consumer advocate participation that meet regularly to address significant issues.

Precedent: California, Massachusetts and New York have included consumers on workgroups to help develop specific aspects of the demonstrations. States should hold quarterly stakeholder meetings in each region of the state where the demonstration project is implemented to solicit feedback on key issues and problems.

Precedent: In MOUs, Illinois and Washington have committed to a regular schedule of stakeholder meetings, although it is not clear where these meetings will be held.

Precedent: In Tennessee, the state sponsors quarterly regional stakeholder meetings for Tennessee CHOICES, its Medicaid managed LTSS program. These meetings are hosted by the Area Agencies on Aging and Disability. Advocates say these have been effective forums in the past for the state to announce changes and get feedback.¹⁴

Engagement with governance of MCOs and other delivery systems

Having consumer representation in MCOs or in fee-for-service delivery systems that will be managing care for dual eligibles is also extremely important. Consumers can help shape decisions and practices. This ongoing role can enable MCOs and other delivery systems to get pro-active suggestions from consumers, instead of only hearing about grievances or problems.

- States should require MCOs and other delivery systems to have a written plan on how they will ensure meaningful consumer engagement. That should include at least 25 percent consumer representation on any governing boards and/or establishment of regional consumer advisory committees. Issues addressed could include enrollment, network adequacy, care coordination, compliance with the Americans with Disabilities Act, and cultural and linguistic competency.

Precedent: Wisconsin requires that 25 percent of the board of each MCO in its Family Care¹⁵ managed LTSS program be members or their advocates.

Precedent: As indicated in MOUs, California, Illinois, Massachusetts and Ohio are requiring each MCO in their demonstration projects to create at least one consumer advisory committee that has the ear of the MCO governing board. Illinois is requiring MCO officials to meet with the committee quarterly.

Precedent: In Colorado's new Medicaid managed fee-for-service Accountable Care Collaborative (ACC), the state requires regional care collaborative organizations (RCCOs) to create local advisory committees with meaningful consumer membership. The requirement is included in state contracts with the RCCOs. Each local committee also sends a representative to a state-level committee that advises state officials on the whole ACC project.¹⁶

- Consumer advisory committees should meet at least quarterly, be populated by individual consumers as well as consumer advocates from all affected constituencies, and be staffed by representatives from the MCO or other delivery system.
 - MCOs or delivery systems should summarize feedback from advisory committees, share it with the state and explain how they are responding.
 - States should annually publish summaries of issues discussed at advisory committee meetings.

Direct feedback from community members

The ability to capture “on-the-ground” information directly from demonstration enrollees and their families is a third important component of assuring quality care.

- MCOs and other delivery systems should hold community meetings for individual consumers and consumer advocates to share their experiences and concerns.

Precedent: Commonwealth Care Alliance, one of the MCOs planning to participate in the Massachusetts demonstration project, uses this strategy for members in its Senior Care Option program that already serves dual eligibles who are age 65 and older. The MCO holds consumer meetings in each community they serve, conducting the meetings in the languages spoken in that community.¹⁷

Precedent: Independence Care Systems, an MCO planning to participate in the New York demonstration project, convenes a council of 30 member volunteers every other month to get feedback on its performance in NY’s Medicaid managed long-term-care program.¹⁸

- MCOs and other delivery systems should conduct yearly consumer surveys using a tool developed for duals, and should include outcomes and patient experiences, such as [Wisconsin’s Personal Experience Outcomes Integrated Interview and Evaluation System](#). Results should be reported to the state and made public. To supplement surveys, and to engage consumers unable to respond to surveys, MCOs and other delivery systems should conduct focus groups of consumers.

Precedent: In MOUs or proposals, California, Connecticut, Illinois, Massachusetts, Ohio, Rhode Island and Washington have indicated state officials plan to use surveys and focus groups in their demonstrations to gather information. However, no state has yet required MCOs or other delivery systems to use these strategies.

- States and MCOs or other delivery systems should run consumer hotlines to record and respond to problems.

Precedent: Several states, including Arizona, Massachusetts, Minnesota, New York and Texas¹⁹ run Medicaid managed care hotlines.

Conclusion

Meaningful engagement can help the dual eligible demonstration projects improve care while containing costs. Meaningful engagement goes beyond commenting on the initial proposal, attending a meeting, or reviewing information posted on the state website. Put simply, these programs cannot achieve patient-centered care without engaging patients and their advocates in a collaborative way. It will require state and federal policymakers, MCOs, delivery systems and consumers all working together to achieve positive change. Advocates can help lead the way by urging adoption of the specific approaches and requirements laid out in this paper.

¹ CMS approved proposals from Massachusetts (August 2012), Washington (October 2012), Ohio (December 2012), Illinois (February 2013), and California (April 2013).

² Medicare-Medicaid Financial Alignment Demonstrations – Standards & Conditions. January 2012.

³ Medicare-Medicaid Financial Alignment Demonstrations – Memorandum of Understanding for each state.

<http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialModelstoSupportStatesEffortsinCareCoordination.html>

⁴ Mann, Cindy. State Medicaid Director Letter on Integrated Care Models. Center for Medicaid and CHIP Services. July 10, 2012.

⁵ Lipson, Debra J. et al. [Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports](#). AAPR Public Policy Institute. July 2012.

⁶ This could include, for example, health advocacy organizations, legal services organizations, AARP and other groups representing seniors, Independent Living Centers, Recovery Learning Communities and the Arc. ,

⁷ Frequently Asked Questions About the Implementation Council. Massachusetts Dual Eligible Demonstration.

<http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/state-fed-comm/implementation-council-faq.pdf>

⁸ Staying the Course: The Essential Role of Consumer Advocates in Reforming Health Care. Robert Wood Johnson Foundation and Community Catalyst.

http://www.communitycatalyst.org/doc_store/publications/CVC_Staying_the_Course.pdf

⁹ Section 330 of the Public Health Service Act

¹⁰ 42 CFR 431.12

¹¹ 42 CFR 431.12

¹² The Advocate's Guide to the Medicaid Program. National Health Law Program. May 2011.

¹³ Interview with Elisabeth Arenales, Health Care Program Director, Colorado Center on Law and Policy.

¹⁴ Interview with consumer advocates in Tennessee. 2012.

¹⁵ 2012 Family Care Programs Contract, Article IIA. <http://www.dhs.wisconsin.gov/mltc/2012/2012Contract.htm>

¹⁶ Interview with Elisabeth Arenales, Health Care Program Director, Colorado Center on Law and Policy.

¹⁷ Dembner, Alice. Commonwealth Care Alliance's Senior Care Options Plan. Community Catalyst. 2012.

http://www.communitycatalyst.org/doc_store/publications/Commonwealth-Care-Alliance-as-model_duals.pdf

¹⁸ Dembner, Alice. Independence Care System. Community Catalyst. June 2012.

http://www.communitycatalyst.org/doc_store/publications/Commonwealth-Care-Alliance-as-model_duals.pdf.

¹⁹ Saucier, Paul et al. [The Growth of Managed Long-Term Services and Supports \(MLTSS\) Programs: A 2012 Update](#). [Truven Health Analytics and CMS](#). July 2012. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf