A revolution is about to occur in how healthcare is delivered to millions of the most vulnerable Americans: individuals dually eligible for Medicare and Medicaid. Dual eligibles suffer under our current fragmented health system. They have trouble navigating the complicated maze of multiple doctors, medications, and programs. They bounce in and out of emergency rooms and hospitals, experiencing poor care and bad outcomes. The Affordable Care Act seeks to address these problems, in part, by creating demonstration projects that would fundamentally change the way care is delivered to this population. These changes are beginning, with one demonstration project launching as this article went to print, and another to follow in the fall of 2013.

As with all revolutions, there exist great opportunities and equally great risks. Done well, these new programs will improve the lives of vulnerable older adults by keeping them out of hospitals and nursing homes, strengthening their connections to community-based services, improving their overall function, and promoting greater autonomy, dignity, and independence. Done badly, they could undermine peoples’ longstanding relationships with existing providers, reduce services and supports that allow them to remain in their communities, and decrease quality of life. Worse yet, the programs could exploit a poor and chronically ill population merely to fatten the bottom lines of powerful for-profit managed care plans.

The key to maximizing opportunity and mitigating risk is engaging dual eligibles and advocates in the design, implementation, and oversight of these demonstration projects. The Centers for Medicare & Medicaid Services (CMS) acknowledged the importance of consumer engagement when it announced the demonstration project opportunity:

*Medicare-Medicaid enrollees, their families and consumer organizations working with them ... have a central role to play in helping to design a person-centered system of care.*

*Therefore, CMS encourages and expects active and meaningful State engagement with stakeholders ... (CMS, 2011a).*

The CMS further clarified its expectations, as follows:

*State[s] can provide evidence of ongoing and meaningful stakeholder engagement during the planning phase and has incorporated such input into its proposal. This will include dates/descriptions of all meetings, workgroups, advisory committees, focus groups, etc., that were held to discuss the proposed model with relevant stakeholders. Stakeholders include, but are not limited to, beneficiaries and their families, consumer organiz-
integrations, beneficiary advocates, providers, and plans that are relevant to the proposed population and care model (CMS, 2011b).

Aside from requiring each state to include evidence of stakeholder engagement during the planning phase in its proposal, CMS required each state to publish its draft demonstration proposal for a thirty-day comment period, during which the state was expected to hold at least two public hearings to discuss the draft. After this thirty-day comment period, the state submitted a final proposal to CMS. CMS published the proposal on its website and sought public comment for an additional thirty-day period.

Varied Approaches to Engagement
States engaged stakeholders in a wide variety of ways. The state of Massachusetts held more than forty public meetings. In 2011, it issued a Request For Information to formally gather key stakeholder input and received fifty-five responses from organizations, including health plans, providers, and advocacy groups. Massachusetts also held several consumer focus groups and outreach sessions before issuing a draft project proposal (Massachusetts Executive Office of Health and Human Services, 2013a).

Led by an ad-hoc consumer coalition—Disability Advocates Advancing our Healthcare Rights—more than seventy-five consumers submitted comments to the state on the draft proposal, and dual eligible consumers made up an overwhelming majority of the eighty commenters at public hearings. Consumer advocates also contributed to the proposal process, with more than thirty groups commenting on the draft and final proposals in addition to regular meetings and communications with state policy makers.

California engaged stakeholders in ways similar to Massachusetts', but also hired an outside firm to maintain a website with information on proposal development, including redlined documents enabling stakeholders to track revisions (California Department of Health Care Services, 2013).

New York State issued a request for public input about its proposed fully capitated project and received fifty-eight sets of comments. A consumer-led coalition was formed, the Coalition to Protect the Rights of New York State’s Dually Eligible, to work together on making the demonstration more consumer-friendly. This coalition has submitted formal testimony and comments and has regularly met with state policy makers, CMS officials, and health plans to express concerns about the proposal. Once the state developed a proposed health home project for dual eligibles, it hosted nine webinars (typically with more than 750 participants), five regional meetings, a Twitter chat, and ongoing meetings with designated health homes (New York State Department of Health, 2012).

In Colorado, the Colorado Department of Health Care Policy and Financing established five ongoing workgroups—Communication, Coordination of Care, Behavioral Health, Developmental Disabilities, and Financial Strategies and Quality Medical Outcomes—that met regularly in Denver. And, the department maintained a dedicated Web page for the demonstration and a toll-free hotline for public comment.

In Washington State, consumers and consumer advocacy organizations sat on a thirty-four-member advisory group aimed at guiding the state as it shaped and implemented the demonstrations in 2012 and 2013.

Consumers Make an Impact
By taking advantage of opportunities for public input, consumers and advocates have shaped the
The design of demonstration projects in important ways. Massachusetts made a number of crucial changes to its proposal during the drafting process in response to consumer concerns and incorporated protections that improved the proposed demonstration for consumers. The biggest change between the draft proposal and the final proposal radically amended the way LTSS

---

**Top Consumer Issues**

Consumer feedback about the demonstrations varied, but centered on the following set of common issues:

- Enrollment in demonstrations should be voluntary via an opt-in process.
- Delivery systems must have robust provider networks that include a sufficient number of experienced providers able to meet the complex medical and support service needs of members with multiple medical conditions or disabilities. Delivery systems should be required to take steps allowing people to continue seeing long-standing providers, even those outside the network.
- Long-term services and supports (LTSS) needs should be assessed through a comprehensive and conflict-free assessment that includes an evaluation of functional status, social and vocational needs, socioeconomic factors, personal preferences, and the ability to obtain accessible services. And, current levels and breadth of LTSS should be maintained until the comprehensive assessment is conducted.
- An interdisciplinary team should be used to coordinate beneficiaries’ care. The team should include the beneficiary, his or her caregiver, and a set of providers specific to his or her needs, including an LTSS coordinator, if chosen by the beneficiary. There must be a clear plan for bridging the divide between primary care providers and behavioral health providers.
- In addition to the full range of Medicare and Medicaid benefits, states should include additional needed benefits and services that are cost-effective and will contribute to beneficiaries’ good health, wellness, and independence. These could include dental, vision, transportation, behavioral diversionary services, etc.
- While the demonstration project is being implemented, beneficiaries and advocates should have defined roles at both the state oversight and delivery system levels.
- Enrollees in demonstrations should be guaranteed a robust set of protections including the freedom to choose their plan, providers, way in which care is delivered, and access to an easy-to-navigate appeals and grievances system.
- There must be a payment structure that provides sufficient resources to meet the medical and support needs of beneficiaries, especially those with the most complex needs. There should be no expectation of savings in the first year of the demonstration.
- The state and CMS should rigorously evaluate demonstrations using meaningful and uniform quality measures that evaluate data on beneficiaries’ experience, including their level of confidence in taking care of themselves, managing problems, and getting better healthcare and level of involvement in their community.
- The demonstration project must have a plan to minimize barriers to care due to a lack of cultural competency. The state and CMS should guarantee dual eligibles a choice of providers who speak their language and understand their culture as well as culturally sensitive written materials.
is provided. Initially the Commonwealth placed LTSS under the managed care plans’ sole pur-view. The final proposal included, in addition to the care coordinator, a financially independent LTSS coordinator from a separate community-based organization who will determine an enrollee’s needs and arrange for LTSS benefits. The Commonwealth also added a quality metric to track LTSS services used, ensuring that any systematic or unexpected changes would be noticed, investigated, and righted.

Other important changes won by advocates include the following:

- Improved continuity-of-care protections for consumers by requiring single-case out-of-network agreements to providers (Massachusetts);
- Clarified that all benefits provided under Medicare and Medicaid will continue and added new services, such as vision, dental, and certain types of transportation (California, Massachusetts);
- Required managed care companies to have contracts with existing providers of LTSS services (Massachusetts);
- Increased emphasis on provider and staff compliance with the Americans for Disabilities Act, including specific training requirements for independent living and recovering learning philosophies (Massachusetts);
- Developed concrete plans for ongoing stakeholder engagement during implementation and operation for the state and within the managed care plan (Massachusetts);
- Delayed the launch date so all parties would be ready (California, Massachusetts, New York, Ohio, Washington);
- Significantly reduced the size of the target enrollee population (California, New York);
- Incorporated a voluntary enrollment period before beginning the auto-enrollment period (California, Illinois, Massachusetts, Ohio);
- Developed a new protocol for limiting disruptions to existing client-provider relationships (Colorado);
- Clarified and simplified the health homes’ care-coordination role (Washington); and
- Expanded eligibility for the health home (Washington).

Ongoing, Meaningful Consumer Engagement

Consumer and advocate input on the design of the demonstration projects has already proven valuable, but it cannot be confined to the design phase alone. Ongoing consumer and advocate involvement in demonstrations is essential to 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.

CMS acknowledged this when it said the following with respect to integrated care models: *Collaboration with consumer and consumer advocacy groups is critical. In order to achieve the important goals of better health and better care with lowered costs, we must continue to put our beneficiaries first. This is a time of significant change in the Medicaid program, and we should ensure beneficiaries’ voices are heard in the design, implementation, and oversight of new initiatives (CMS, 2012).*

Critical to meeting these goals is involvement at multiple levels, including the state and delivery system levels. (Dembner and Regan, 2013).

Consumer involvement at the state oversight level

Each state must have a detailed plan for consumer engagement in state-level demonstration decisions. 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 specific committee roles and responsibilities, including oversight of quality and performance, and how committee decisions will be carried out; rely on consumer advocacy organizations to help select appropriate members for oversight
committees; provide staffing; and use available federal money to support consumer participation in committees.

Massachusetts has created an Implementation Council (Massachusetts Executive Office of Health and Human Services, 2013b) for its duals demonstration whose membership is at least half consumers, family members, and guardians, and which is chaired by a dually eligible 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 meetings and provide trainings and physical accommodations as needed to council members. It is paying stipends to consumer members for attending meetings and doing preparatory work, and providing reimbursement for travel expenses. The state plans to draw on a federal grant to support the council’s work.

Before its recent decision to put its project on hold, Colorado convened a body called the Full Benefit Medicare-Medicaid Enrollees Advisory Subcommittee. Dual eligible individuals, family members, and concerned citizens accounted for half its membership, with providers such as home health, palliative care, hospice, and community center boards making up the other half. The state hosted pre-meetings prior to full subcommittee meetings as an opportunity for participants to consider issues and ask questions in advance. So-called learning labs were instituted by the Advisory Subcommittee as a forum for outside experts to talk about specific topics of interest.

States should also establish workgroups on specific topics with meaningful consumer advocate participation that meet regularly to address significant issues. California, Massachusetts, Michigan, and New York have included consumers in workgroups to help develop specific aspects of the demonstrations during the design phase, and they expect many of these workgroups to continue into the implementation phase.

States should also hold quarterly stakeholder meetings in each region of the state where the duals demonstration is implemented to solicit feedback on key issues and problems. In their Memoranda of Understanding (MOU), Illinois and Washington have committed to a regular schedule of stakeholder meetings.

**Consumer involvement within the delivery system**

Having consumer representation in the delivery systems—managed care plan, health home, etc.—that will be managing care for dual eligibles is also extremely important. Consumers can help shape delivery systems’ decisions and actions. This ongoing role can enable them to get proactive feedback from consumers, instead of only hearing about grievances or problems.

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

**Ongoing consumer and advocate involvement in demonstrations is essential to ensure quality, cost-effective, patient-centered care.**

As indicated in MOUs, California, Illinois, Massachusetts, Ohio, and Virginia are requiring each managed care plan in their duals demonstration to create at least one consumer advisory committee that has the ear of the governing board. Illinois requires plan officials to meet quarterly with the committee.

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

Delivery systems should also develop approaches for hearing directly from enrollees who aren’t necessarily engaged in advisory committees. For instance, they should hold community meetings for individual consumers and consumer advocates to share their experiences and concerns. The Commonwealth Care Alliance, one of the delivery systems planning to participate in the Massachusetts demonstration, uses this strategy for members in its Senior Care Option program that already serves dual eligibles who are at least sixty-five years old. The plan holds consumer meetings in each community they serve, conducting the meetings in the languages spoken in that community (Dembner, 2012a). Independence Care Systems, a plan likely to participate in the New York dual eligible demonstration, convenes a council of thirty member volunteers every other month to get feedback on its performance in New York’s Medicaid managed long-term-care program (Dembner, 2012b).

**States should require delivery systems to have a written plan on how they will ensure meaningful consumer engagement.**

When planning these types of meetings, delivery systems need the recruitment process to be representative of the population served (gender, race-ethnicity, socioeconomic factors), as well as medical condition, geography, and services used. Also critical to successful consumer engagement is overcoming barriers to participation such as transportation, physical accessibility, cultural competence, knowledge, and skill. It is incumbent on the delivery system to overcome these barriers through careful planning and attention to details of meetings and needs of enrollees.

Other tools could supplement—but not replace—these approaches, such as annual consumer surveys specific to dual eligibles, including measurement of outcomes and patient experiences. One such measurement is Wisconsin’s Personal Experience Outcomes Integrated Interview and Evaluation System (Center for Health Systems Research & Analysis, 2013). Results should be reported to the state and made public. Delivery systems should also conduct focus groups of consumers to complement the surveys.

**Conclusion: Success Lies in Ongoing Engagement**

The meaningful engagement of dual eligible beneficiaries and their advocates can be the “secret sauce” for the success of the dual eligible demonstration projects. Consumers and advocates have already positively influenced the design of the projects in many states, as evidenced by changes made during the proposal development process. But meaningful engagement goes beyond submitting comments on a draft proposal or attending a hearing. These projects cannot achieve their goals of “improving the quality of care Medicare-Medicaid enrollees receive by expanding access to seamless, integrated programs” (CMS, 2011a) without engaging patients and their advocates in a collaborative and ongoing way over the course of the three-year demonstration period. It will require state and federal policy makers, delivery systems, and consumers working together to achieve positive change.

Renée Markus Hodin, J.D., is director of the Voices for Better Health Project at Community Catalyst in Boston, Massachusetts. She may be contacted at rmhodin@communitycatalyst.org.
References


Acknowledgement

The author would like to acknowledge the contributions of Molly Warren, Maia Fedyszyn, and Melinda Becker to the content of this article.