

Engaging Consumer Stakeholders to Improve Systems of Care for Dual Eligibles

Technical Assistance Brief

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State officials develop new programs with the best intentions. They may be trying to achieve a goal set by their legislatures, or to implement a best practice demonstrated by other states or the private sector. They convene internal work groups, and toil for months, or sometimes years, to identify a model that will achieve better care, service delivery, and/or program satisfaction for beneficiaries. Then they go out into the community to convince people that this new approach is better and, if the program is not mandatory, to urge beneficiaries to sign up.

Meanwhile, beneficiaries and their advocates have spent that same period struggling to navigate the current system. And just when they have found their way through the maze of state and local programs, and created a network of providers and services that meet their needs, the state approaches them with the new model. Beneficiaries are presented with new ways to apply, new people to get to know, new phone numbers to learn, and new appeals processes. Is it any wonder that beneficiaries and advocates are frequently frustrated with the best intentions of state officials, and states are equally frustrated by the often challenging pursuit of stakeholder buy-in? This scenario creates tension between the states and their stakeholders in any new program development, but the tension increases when the state is trying something without a proven track record.

Over the past two years, the Center for Health Care Strategies (CHCS) has worked with several states that are seeking to change the scenario described above and start listening more closely to stakeholders during program development for beneficiaries who are eligible for Medicaid and Medicare. These states, which participated in *Transforming Care for Dual Eligibles*, are developing improved systems of care for dually eligible beneficiaries. In this brief, their lessons are combined with advice from Kevin Prindiville of the National Senior Citizens Law Center, an expert on dual eligible beneficiary issues who has extensive experience in stakeholder processes at the state and federal levels.

IN BRIEF

For states looking to integrate care for duals, a robust stakeholder engagement process will provide invaluable feedback for shaping programs to best meet consumer needs. To help guide states in effectively engaging consumer stakeholders, this brief outlines:

- Potential questions that should be addressed during the stakeholder engagement process;
- Benefits to integrated care approaches from the beneficiary perspective; and
- Advice from a national consumer advocacy expert on consumer engagement.

In sum, while involving consumers effectively will take extra effort and time in the short-term, doing so early on in the design planning process will result in more effective and more responsive program models in the long-run.

Anticipating Questions from Stakeholders

As states present ideas for integrating financing of care for dual eligibles, they may encounter a range of reactions from utter confusion to strong concern from consumers and their advocates. Beneficiaries in some states are automatically enrolled into Medicaid in order to cover Medicare copays and deductibles. If beneficiaries do not need long-term supports and services (LTSS), they often may not even know that Medicaid is helping to pay for their medical care. So the first questions at large public meetings of beneficiaries are typically basic:

- *What does Medicaid cover? What does Medicare cover? Why do I need to have both?*

Thus, for initial meetings, it is often helpful for states to step back and provide a very basic overview of how the current system works (and does not work), before getting into more detailed specifics of what the new proposed program is seeking to achieve.

Once the participating stakeholders are better versed in the basics, their questions will invariably become more sophisticated. The fact that the state does not have ready answers to all stakeholder questions does not mean that officials should stay in their closed-door meetings until they have everything worked out. To the contrary: knowing what questions are important to stakeholders can help shape the program, as well as the outreach and education needed for those who are not actively participating. Typical questions around specific issues that have emerged from state-stakeholder dialogue follow:

Provider

- **BASIC:** *Will patients be able to see their favorite doctor? Will they be able to use the same pharmacy? Will they be able to go to the same hospital? Will they have a choice of providers?*
- **ADVANCED:** *Will specialists be allowed to serve as primary care providers? How will continuity of care be preserved? What is the extent of overlap of the current Medicare and Medicaid provider network? Will the same care manager coordinate both long term care and medical services?*

Consumer

- **BASIC:** *Who do I call with questions? How do I make a complaint?*
- **ADVANCED:** *What protections are going to be in place for beneficiaries? Who will monitor that their legal rights are enforced?*

Financing

- **BASIC:** *What rates will be paid to providers? Will Medicare rates prevail?*
- **ADVANCED:** *How will funds be blended? How will they be spent? Will any money saved be re-invested in the program or services?*

Program Evaluation

- **BASIC:** *How will the state tell whether the program is making a difference?*
- **ADVANCED:** *Will there be a period of piloting during which an evaluation will determine if the model is to be implemented as a permanent program? Which standards will be used to monitor the implementation? What are the critical outcomes of interest (e.g. beneficiaries' experience of care, ability to live independently and meet their own goals; health status; utilization of services, etc.)?*

In working through these questions, state officials can begin to address the concerns of beneficiaries while the program design is still being considered.

Listening to Stakeholders

State officials have their own goals for integrating care for dual eligibles, but should ask stakeholders what goals they have as well. For a program to be successful, the goals of the state and consumer stakeholders should intersect. The following list of potential advantages of integrated financing emerged during a stakeholder meeting in California, and has been modified by input from stakeholder meetings in other states as well.¹ Addressing the below issues from the consumer perspective will help in clarifying the benefits of integrated care programs and distilling consumer preferences.

Assistance in navigating the system

- A single point of coordination for all Medicare and Medicaid benefits and connected providers.
- Help with navigating a very complicated system and lining up the right services in a timely manner.
- Potential for more care management, including preventive care and LTSS.

Greater flexibility in service use through blended funding

- An integrated benefit package that is greater than the sum of the funds and programs separately, and may limit cost shifting from Medicare/Medicaid.
- The most appropriate services, provided in the right, least restrictive, setting.
- Improved access to comprehensive care while reducing cost and eliminating redundancies.
- Redirection of acute care savings to LTSS; increased likelihood that people remain at home longer.
- Potential for alignment of the full spectrum of services (medical, social support, LTSS) with financial incentives.

Access to the full continuum of services, including community-based care options

- Ability to leverage all services and levels of care, including inpatient, behavioral health (BH), outpatient, preventive services, home- and community-based services (HCBS), LTSS, to deliver services to individuals that keep them at optimal health and in the best setting.
- Consumer access to the full range of social and health services.
- Wrapping LTSS around medical/behavioral services and keeping patient and family at the center thereby enhancing communication at all levels to contribute to quality outcomes for patient and family.

Person- and family-centered approach to care

- Person-centered care for the individual, i.e., consumer access to what he or she needs to stay as healthy and as independent as possible.
- A clear, shared understanding by all providers of the whole person at multiple levels, including, but not limited to, behavioral, physical, and social needs.
- Better support for family caregivers.

¹ CHCS' work in California is illustrated by this report: M. Bella, A. Lind, and S.A. Somers. *Options for Integrated Care for Duals in Medi-Cal: Themes from Interviews with Key Informants and Community Dialogues*. Center for Health Care Strategies, Inc., March 2010.

Improved health outcomes and consumer satisfaction

- A system that is efficient and preferred by consumers.
- Better health outcomes and more effective maintenance of health status.

Advice from an Advocate

At the final meeting of states participating in the national *Transforming Care for Dual Eligibles* initiative, Kevin Prindiville offered advice for those engaging stakeholders. These points are worth considering when starting any new program development.

- **Trust the process.** Stakeholders want to contribute to a good result. Go into the process with the expectation of learning valuable information, not “managing” stakeholder involvement.
- **Engage narrowly and broadly.** Stakeholders bring various levels of expertise and interest. A successful approach will find ways to broadly include all stakeholders, while more directly engaging those stakeholders with the most expertise and interest. For example, technical workgroups can serve to advise a broader stakeholder group. Stakeholders can help identify other stakeholders who offer perspectives that may be missing or who have particular depth of expertise.
- **Get input from local and state advocates.** If considering a local pilot project, it is important to have a process that engages the local community. However, statewide advocates should also be included to offer a different perspective on how a local pilot may impact or influence other parts of the state.
- **Include real beneficiaries.** The process will have much more credibility if actual dual eligibles in the community have been included. For example, dual eligible beneficiaries should be invited to participate in listening sessions at community centers. Duals should also be included on any workgroups or advisory committees that are developed. Since dual eligibles are a diverse group with heterogeneous needs, states should seek a broad range of representatives including people of different ages, different disabilities, and different health needs.
- **Share your process.** Explain your plan for stakeholder involvement from the beginning and be responsive to ideas for adjusting. Tell stakeholders what you would like from them. Acknowledge that stakeholders have expertise, experience, and relationships that will help the state develop a better model. Recognize their value and ask them for help. The more specific you can be, the more effective they can be.
- **Provide a variety of opportunities for stakeholders to participate.** Different stakeholders are able and prefer to participate in different ways. Listening sessions, workgroup meetings, public hearings, and written notice and comment periods should all be part of the process. Build in sufficient time in the planning process for stakeholders to contribute and to respond to proposals. Create a website with information about meetings, drafts of documents, etc. Create email distribution lists to notify interested parties when new information is posted. Since not all dual eligibles have computer access, states should also work with advocates to reach out to involve non-computer savvy individuals in the stakeholder process.
- **Include stakeholders from the beginning.** Waiting until a plan is developed and then trying to “sell” it can be very difficult. Instead, work to build a plan with stakeholders. Lay the options on the table and then have an open discussion. Give stakeholders a chance to address the core question, i.e., how do we build a better system for serving dual eligibles in the most appropriate setting? Then plan to continue stakeholder engagement throughout the implementation and evaluation process.

- **Share drafts of proposals and other documents.** These documents often contain the details that people care most about. Share them and provide opportunities for reaction and response before finalizing and submitting to the Centers for Medicare & Medicaid Services (CMS).
- **Be responsive to concerns raised.** If a concern is raised repeatedly, respond in some way – either by changing your approach or by explaining why the approach cannot be changed. Formal response to comments in writing is an effective way to demonstrate that concerns raised have been heard and considered. Developing a formal process for collecting concerns and then responding to them all at once, rather than individually, is best.
- **Consider evaluation from the beginning.** How the program will be evaluated has implications for program design. Stakeholders should be included in the process for developing evaluation questions and determining how evaluation results will be shared down the road.

Conclusion

Officials in innovative states embrace the benefits of stakeholder engagement and understand the contribution that a robust stakeholder process makes to the design of successful state programs. Some states, however, have limited stakeholder involvement and have had a difficult time developing a process for structured stakeholder input.

The Patient Protection and Affordable Care Act, in Section 10201(i), outlines public notice requirements for states working with CMS to obtain authority for demonstration projects through 1115 waivers. This provision creates a new opportunity for states to work with stakeholders and a new opportunity for stakeholders to better understand the often challenging rules and requirements of the federal government. This notice process will increase the transparency and involvement of stakeholders and further states' goals of providing the high-quality services and supports that individuals need.

State officials want their new programs to be well-received and successful. Likewise, stakeholders want their health care needs met through high-quality and responsive services. By starting with a shared understanding of the issues, and then working together on program design and development, the prospect for success is much greater.

Transforming Care for Dual Eligibles – Resources at www.chcs.org

Under *Transforming Care for Dual Eligibles*, the Center for Health Care Strategies (CHCS) is working with seven states -- **Colorado, Maryland, Massachusetts, Michigan, Pennsylvania, Texas, and Vermont** -- to develop and implement innovative strategies for integrating care. This national initiative, made possible by The Commonwealth Fund, is seeking to develop a range of integrated delivery models for dual eligibles that can be implemented by other states across the country. Participating states are receiving in-depth technical assistance covering program design, care models, financing mechanisms and contracting strategies and CHCS is also facilitating linkages with the Centers for Medicare & Medicaid Services to identify new avenues for Medicare-Medicaid integration.

To learn about CHCS' *Transforming Care for Dual Eligibles* initiative or to download related resources, including policy briefs, hands-on tools, and templates to help guide state integration efforts, access *Integrating Care for Dual Eligibles: An Online Toolkit* at www.chcs.org.

About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center dedicated to improving health care quality for low-income children and adults, people with chronic illnesses and disabilities, frail elders, and racially and ethnically diverse populations experiencing disparities in care. CHCS works with state and federal agencies, health plans, and providers to develop innovative programs that better serve Medicaid beneficiaries with complex and high-cost health care needs.