Dual Eligible Demonstration Projects: Top Ten Priorities for Consumer Advocates

Background

There are approximately 9 million seniors and people with disabilities enrolled in both Medicaid and Medicare programs (“dual eligibles”). These consumers represent some of the most vulnerable populations in the United States. Because of their poorer health status, they make greater use of medical and support services and are, too often, unnecessarily admitted to hospitals or placed in nursing homes. Navigating both of these public programs is an added burden: the programs have different sets of rules and requirements that result in inadequate coordination of services and fragmented care. As a result of these challenges, the cost of dual eligibles’ care is disproportionately expensive. While they make up only 15 percent of Medicaid enrollees, they account for 39 percent of total Medicaid spending. Similarly, they represent 21 percent of Medicare enrollees, but account for 36 percent of total Medicare expenditures. This situation is both harmful to the health and independence of dual eligibles and unsustainable from a state and federal budget standpoint.

Prompted by provisions in the Affordable Care Act (ACA), fast-moving efforts are now afoot in many states to change how services are provided to dual eligibles. The stated goals are laudable: better care, delivered more cost effectively. But the risks are also great. It is critical that consumer advocates get engaged in shaping the design and implementation of these new initiatives to make the most of the opportunities and to reduce the risks.

This fact sheet provides advocates with background and guidance to help them engage in shaping these new programs to address the medical and long-term care needs of seniors and people with disabilities, and in the process, lower the overall cost.

Opportunities in the Affordable Care Act

The ACA created two new offices within the Centers for Medicare and Medicaid Services (CMS) to promote long-term systemic improvements for dual eligibles. The Center for Medicare and Medicaid Innovation (Innovation Center) was established to rapidly test, evaluate and replicate innovative models of care. The Medicare-Medicaid Coordination Office (MMCO) was created to promote policies and assist states in better integrating care specifically for dual eligibles. These offices have worked closely to launch new initiatives to help this population. For example, 15 states have planning grants to develop models of care for dual eligibles. They and 24 other states have indicated interest in testing two new payment models – the “capitated” and “managed fee-for-service” approach. These approaches are designed to help states improve quality and share in the lower costs that should result from better care coordination.
What Consumer Advocates Need to Know

The opportunities to improve care for dual eligibles arise at a time when there is urgent pressure at the state and federal levels to find Medicaid and Medicare savings. Far too many proposals for reducing spending in these programs do nothing to improve care. Rather, they seek to cut benefits, eligibility or provider rates: all dangerous options for beneficiaries. The new duals demonstration projects present an opportunity to avoid these harmful cuts by creating savings through improving and integrating medical care and support services.

But, while the opportunities are great, there are also risks. Specifically, if these projects are not well-designed and implemented:

- Access and quality may be compromised in the name of saving money.
- There may be inadequate provider capacity or buy-in, resulting in poor quality care.
- The move to managed care for this population could disrupt existing provider relationships, undermine the existing safety net, and allow large, for-profit plans to enter the market and game the system.
- New programs may not be tailored to meet the unique needs of subpopulations such as those with complex physical disabilities or with deep and persistent mental illness.

These risks are only amplified by an aggressive timeframe for implementation: demonstration programs are expected to begin enrolling people in newly integrated programs in January 2013.

Critical to mitigating these risks is the involvement of consumers and their advocates. Indeed, all states participating in the duals demonstration program are required to engage the stakeholder community – including beneficiaries, advocates, providers and plans – in the process of developing their demonstration project proposal. But, it is incumbent on advocates to take the initiative to make this engagement meaningful.

To help advocates in this work, Community Catalyst provides below 10 top priorities for shaping state duals demonstration projects. These draw on Community Catalyst’s extensive experience with the duals demonstration planning process in Massachusetts and its work with national advocacy groups both in the senior and disability communities.

1. Enrollment

Driven by a desire to achieve sufficient program scale, to generate delivery system change and to realize savings, we expect most states to propose passively enrolling dually eligible beneficiaries into integrated care systems. CMS has explicitly permitted states pursuing the demonstration projects to use this approach.

However, given the aggressive proposed timeframe for start-up and the uncertainty about the entities that will serve the duals, we recommend that advocates seek a voluntary, opt-in enrollment process in order to safeguard beneficiaries. States – on their own and through respected community-based organizations – can assist with the process of publicizing the strengths of the program and participating plans to meet reasonable enrollment goals.
Given that many states are already proposing the use of passive enrollment, it may be difficult, if not impossible, to prevail on an "opt in" approach. Therefore advocates should also be prepared to articulate safeguards that must accompany a passive enrollment approach. At a minimum, these should include:

- Require that consumers have at least 90 days to make a choice among integrated care entities.
- Require plans to contract with community-based organizations such as Aging and Disability Resource Centers (ADRCs), Independent Living Centers, chapters of the Arc, and peer support programs for people with mental illness, to educate potential enrollees about their options and to assist them in selecting delivery systems that best serve their individual needs.
- Allow enrollees to change plans at any time, without imposing a lock-in period.

2. Provider Networks

Advocates should urge that the state require delivery systems to 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 and/or disabilities. They should also ask the state to require that all providers are trained on independent living and mental health recovery approaches.

In addition, many dual eligibles have longstanding, beneficial relationships with providers that might not be in the existing network of a health plan or delivery system that participates in a duals demonstration program. To maintain continuity of care and respect these relationships, integrated systems should:

- Maintain an open network provider system in order to contract with providers that are not currently in the network.
- Offer “single-case agreements” that allow members to continue seeing their existing provider while being reimbursed by the health delivery system, without arbitrary limits on their duration.

3. Long-Term Services and Supports

Long-term services and supports (LTSS) include a broad range of assistance needed by people of all ages who have disabilities. These include services like home care, consumer directed personal assistance, peer supports, habilitation services, provision of durable medical equipment and transportation. The goal of LTSS for dual eligibles should be to promote their independence, choice, dignity, autonomy and privacy. And, to the extent possible, LTSS must emphasize community and home-based services over institutional care, ensuring compliance with the Supreme Court’s Olmstead decision. To achieve these goals, consumer advocates should urge states to require new integrated entities to:

- Conduct a comprehensive and conflict-free assessment of each beneficiary’s LTSS needs that includes an evaluation of functional status, social and vocational needs, socioeconomic factors, personal preferences, and the ability to obtain accessible services.
- Maintain current levels and breadth of LTSS until the comprehensive assessment is conducted.
- Contract with LTSS providers who have the capacity and expertise to meet member needs.
4. Coordination

Many dual eligibles see multiple providers and specialists, take numerous medications, and have trouble with multiple activities of daily living. Coordinating all of these medical and non-medical services is a monumental task for beneficiaries and their caregivers.

Consumer advocates should urge states to include the use of an interdisciplinary team to coordinate beneficiaries’ care. The beneficiary is the most important member of the team, along with his/her caregiver. And, depending on the person’s needs, this team could also include physicians, advanced practice registered nurses, social workers, pharmacists, nutritionists and specialists in durable medical equipment. The team would also appoint a care manager whose job is to help the beneficiary and caregiver navigate the system and take the steps necessary to pursue a care plan established by the team.

Equally important to the team is an LTSS coordinator who would be charged with managing a beneficiary’s LTSS needs. For enrollees without LTSS needs, the LTSS coordinator does not need to continue on the care team. However, the integrated entity must make the option of an LTSS coordinator available upon enrollee request. This approach is a critical component of the Massachusetts proposal for dual eligibles aged 21-64, which incorporated the requirement that the beneficiary’s care team includes an independent LTSS coordinator based on discussion with and input from consumer advocates. This individual will be contracted from an independent community-based organization with expertise in working with people with disabilities. The coordinator’s role is to:

- Conduct an initial assessment to determine the beneficiary’s level of need and to develop an appropriate LTSS plan in partnership with the beneficiary.
- Ensure all LTSS needs of the beneficiary are efficiently addressed and communicated to the entire care team.
- Communicate, as needed, with the beneficiary about his/her LTSS needs on an ongoing basis.

5. Benefits

Consumer advocates should insist that their state’s demonstration project include, at a minimum, all Medicare benefits to which a consumer is entitled plus all benefits offered through the Medicaid state plan as well as any services offered through a waiver program serving the same populations.

In addition, it is critical for advocates to push for additional needed benefits and services that are cost-effective and will contribute to beneficiaries’ good health, wellness and independence. For example, because of limited access to personal assistance services, Ohio advocates are advocating that the state adopt the Community First Choice Option under the ACA. Home modifications or even housing...
subsidies could be included in a benefit package to reduce expensive and unnecessary nursing home placements. Mental health peer support services can be critical to recovery for those with deep and persistent mental illness.

6. Consumer Engagement

Consumer engagement is an ongoing process from design and development, to implementation and oversight of the program; at each stage there is a role for consumer advocates.

Design and Development:
- Submit formal comments on the state’s draft proposal to convey concerns and solutions that will make the program consumer friendly.
- Push the state to hold public stakeholder meetings that are designed to solicit meaningful input from consumers on the demonstration design.
- Voice opinions during the 30-day public comment period that the state is required to hold prior to sending its proposal to CMS. Once CMS receives the proposal, CMS will open an additional 30-day comment period. Advocates should send comments to CMS as well.

Implementation and Oversight:
- Urge the state and CMS to develop a realistic timetable. An aggressive implementation timeline can compromise the sustainability of the program and quality of care beneficiaries receive.
- Monitor the procurement and contract development process. Make certain that the state and CMS choose a health plan(s) or delivery system that demonstrates the capacity and readiness to deliver a fully integrated system.
- Ensure oversight structures are in place to oversee the program, its policies, procedures and practices. These structures should be strongly rooted in consumer values such as the ability to live independently and participate in one’s own care, as well as legal rights such as the right to the least restrictive care that is practical.
- Seek meaningful consumer representation on integrated entities’ governing boards and advisory committees and push for the use of other means of soliciting member feedback such as focus groups or member meetings.
- Recommend the state contracts with an independent ombudsman to field beneficiary complaints and questions.

7. Beneficiary Protections

Consumer advocates should urge the state to guarantee a robust set of beneficiary protections that include, at a minimum:

- Beneficiaries have the freedom to choose their plan, providers and how care is delivered to them.
- Access to all Medicare and Medicaid covered services, in addition to enhanced services, and those that allow individuals to live at home and in the community.
- An easy-to-navigate appeals and grievances system.
- Easy to read, accessible program materials for beneficiaries including those with disabilities, speech and vision limitations, and limited English proficiency.
8. Financing and Payment

Getting the financing and payment right is critical to assuring integrated delivery systems have the necessary resources to provide the medical care and LTSS needed by their members, especially those of the most complex members. This is particularly true for state demonstration projects that plan to use a capitated financing mechanism. Without paying close attention to these issues, health systems are likely to receive either windfall profits or devastating losses, results that would undermine the goals of any demonstration program.

Consumer advocates should insist that:

- Financing and payment structures are transparent.
- Payments do not give providers an incentive for denying or minimizing services and care needed by beneficiaries.
- Payments incentivize care provided in community-based settings rather than institutional settings.
- Payments do not give states the opportunity to use federal financing to supplant a state’s Medicaid budget.
- Payments to any delivery system include aggregate and individual information in determining risk.
- Payments are risk adjusted to include validated measures of functional status, diagnosis and other relevant socioeconomic and cultural factors such as race, ethnicity, language and gender as well as other social determinants of health such as access to housing, transportation and education.
- States use risk-sharing mechanisms to avoid delivery systems receiving either windfall profits or devastating losses, particularly in the early years of a demonstration project.
- States set a minimum medical loss ratio limiting administrative expenses to a maximum of 15 percent.

9. Quality Measurements

Comprehensively assessing the quality of care provided by integrated entities and the outcomes achieved for beneficiaries through any demonstration project will be essential to evaluating how successful it has been at improving the lives of dual eligibles. Quality must be assessed at both the individual consumer level as well as the plan and system level. Consumer advocates’ role is to ensure that the state:

- Rigorously evaluates the demonstration projects 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 health care
  - level of involvement in their community
• ability to maintain meaningful relationships
• ability to choose among LTSS options (including home care services, personal care attendants and peer supports)

- Collects essential workforce data in order to thoroughly evaluate whether there is adequate access to attendant services.
- Assesses the quality of services and supports, including reliable clinical and quality of life measures, enrollee satisfaction, and key outcomes such as reduced preventable hospital admissions and readmissions, nursing home placements, and emergency room usage.
- Explores the use of incentive payments to providers based on meeting or exceeding quality targets for care integration improvements and developing innovative programs meet the unique needs of subpopulations within the dual eligible population.

10. Cultural Competency

Any duals demonstration project must be respectful of the beneficiary’s culture and seek to minimize barriers to care because of any lack in cultural competency. Consumer advocates should press their state to ensure that:

- Beneficiaries are guaranteed a choice of providers who speak and understand their culture and language, including those who use American Sign Language or who are blind.
- Written materials for beneficiaries are culturally sensitive and available in languages other than English.
- Customer service departments have oral interpretation services available to beneficiaries free-of-charge.

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3 Centers for Medicare and Medicaid: State Demonstrations to Integrate Care for Dual Eligible Individuals (April 2011) Retrieved: [https://www.cms.gov/medicare-medicaid-coordination/04_StateDemonstrationsToIntegrateCareforDualEligibleIndividuals.asp#TopOfPage](https://www.cms.gov/medicare-medicaid-coordination/04_StateDemonstrationsToIntegrateCareforDualEligibleIndividuals.asp#TopOfPage)
5 This is a feature of the Massachusetts duals demonstration proposal. [http://www.chcs.org/usr_doc/MassachusettsDualsDemonstrationProposal.pdf](http://www.chcs.org/usr_doc/MassachusettsDualsDemonstrationProposal.pdf)
8 The state must create the infrastructure needed to support self-direction. This includes developing a central mechanism to help consumers provide providers and ensure the adequacy of home care workers, including consumer-directed attendants.
10 Compliance with the ADA helps to ensure that health services are provided in a manner that meets the highest standards of quality care and equality with regard to administrative procedures, diagnostic procedures, treatment, communication, use of appropriate medical equipment, training of staff, and removal of architectural barriers. These concerns must be addressed in assessments in order to create individuals’ medical and LTSS service and care plans.

**Community Catalyst** is a national non-profit advocacy organization building consumer and community leadership to transform the American health care system. [www.communitycatalyst.org](http://www.communitycatalyst.org)