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Dual Eligible Demonstrations: The Beneficiary Perspective

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The [financial alignment demonstrations](#) for seniors and younger people with disabilities dually eligible for [Medicare](#) and [Medicaid](#) are joint efforts [of selected states](#) and the Centers for Medicare and Medicaid Services (CMS), designed to align benefits and financing with the goals of delivering better coordinated care and reducing costs. These three-year [demonstrations](#) are based on [authority](#) in the Affordable Care Act and were implemented beginning in July 2013.

Recent case studies describe program design and early implementation activities in three of the first states to enroll dually eligible beneficiaries in these demonstrations: [Massachusetts](#), [Ohio](#), and [Virginia](#). This issue brief provides additional information and insights about initial program activities from the perspective of beneficiaries in these three states, based on 12 individual interviews conducted in early 2015. Profiles of six beneficiaries are presented to illustrate representative program experiences, along with key findings from across all of the interviews.

Interviewees include seniors and younger people with a range of physical and mental health disabilities and chronic conditions. All live independently in the community. Some voluntarily enrolled in the demonstration, and others were automatically enrolled. They were asked to comment on how they initially heard about the demonstration, their experience with the enrollment process, whether they had help or advice when they enrolled, the needs assessment process associated with the demonstration, their access to medical and other services, their experience with care coordination, if they know who to contact should problems arise, and whether they have suggestions for improving the program.

KEY FINDINGS

Although interviewees' experiences differed, certain common themes provide insights that can help inform states and other stakeholders as the demonstrations progress and as other new programs, particularly managed care delivery systems that integrate medical care and long-term services and supports, are implemented.

- **Generally, interviewees tended to enroll in the demonstration based on information or with assistance from trusted sources.** These sources included providers, colleagues in the disability community, and service coordinators at a housing complex and a center for independent living. Interviewees put particular trust in their medical and LTSS providers with regard to whether to enroll in the

demonstration. Consequently, when providers are not familiar with the demonstration, are not participating in health plan networks, or are wary about program policies, interviewees were less inclined to participate.

- **Interviewees who opted out of the demonstrations often did so because they did not understand what the new program would mean for them or felt that the risk of disrupting established services outweighed any potential benefits.** Interviewees reported that they were afraid of change or were simply comfortable their current situation and not want to “rock the boat.” Interviewees who have longstanding relationships with personal care attendants who help them with day-to-day functioning were especially reluctant to change delivery systems if their aides are not participating in the new health plan networks. Word of mouth has a powerful impact on interviewees’ decisions about whether to participate in the demonstrations. Interviewees who heard about gaps in service or other problems that occurred in parts of the state where implementation occurred earlier were not inclined to enroll. For example, in Ohio, which had a two-part enrollment process, several people characterized the transition to Medicaid managed care, which occurred first, as “a bumpy start” and said that, as a result, they were reluctant to enroll in Medicare managed care later.
- **Interviewees’ participation in the demonstrations can be disrupted if they lose eligibility for either Medicare or Medicaid benefits.** Both of these programs have complex rules, and Medicaid eligibility must be periodically renewed. An interviewee, who continued to meet the eligibility criteria but temporarily lost Medicaid benefits due to glitches in renewal paperwork, was faced with having to re-enroll in the demonstration once Medicaid eligibility was re-established. Other interviewees were at risk of losing Social Security Disability, and consequently Medicare, benefits as a result of a return to work or medical improvement in disability status and therefore would no longer be eligible for the demonstrations even though they still may have the same underlying chronic conditions or other needs that would benefit from the care coordination offered by the demonstrations.
- **Interviewees universally embrace the concept of better-coordinated care, although initial implementation of this feature of the demonstrations was slow.** Those who received care coordination services were very positive about the program. Those who did not, particularly after they requested help, became frustrated and anxious due to the lack of communication with care coordinators because they had complex needs that must be addressed often daily. Interviewees said that health plans seemed overwhelmed by the number of new enrollees. Consequently, interviewees did not always hear from care coordinators immediately or have initial needs assessments, which are used as the basis for planning services, in a timely manner. Similarly, a broader team approach to care planning, which is a prominent feature of each demonstration, had not yet been implemented to any significant extent.
- **Although interviewees generally understood that their benefits had changed at the start of the demonstrations, many were confused about what the change meant for them.** The experience of those who did not have smooth transitions to the new programs suggests that better coordination requires improved communication among state agencies and health plans, between different departments within health plans, between former and new providers, among care coordinators if interviewees had more than

one, and within care teams. Otherwise, interviewees may have received confusing or conflicting information and assistance.

- **In some instances, health plan provider networks were not as robust as interviewees thought they would be.** Interviewees cited several reasons for this, including that some providers, particularly independent caregivers, were not always aware that they would be required to have contracts with and bill health plans; some providers were negotiating but had not yet been certified to participate in health plan networks; and some providers simply were not familiar with the new program or had not been able to get the information they needed to apply to be in plan networks.
- **Beneficiary interviews revealed a need for greater assistance and more information about how to get help with obtaining needed services and answering questions.** Although each state established an ombuds office for the demonstration, most interviewees did not know about those services or how to access them. Interviewees were more apt to know the name of their insurance plan than of the new program, and they tend to contact their health plan directly when they have questions. Early on, however, respondents indicated that health plan customer service representatives could not answer their questions or that plan representatives acted more as gatekeepers than assistors. Some interviewees reported that health plan staff did not seem to understand the nature of long-term services and supports, including the need for quick responses to problems that can have an immediate effect on beneficiaries' safety and ability to function on a daily basis.

BENEFICIARY PROFILES

Desiree, age 28, Massachusetts

Desiree lives independently and uses a power wheelchair, a service dog, and personal care services for help with activities of daily living as a result of a genetic condition. She is happy with the demonstration now that she has an assigned care coordinator but found the program very difficult to navigate initially, leading to a delay in a needed wheelchair service authorization. She believes that the demonstration could be improved to better meet the needs of people like her who work full-time.

Rob, age 65, Ohio

Rob, who has multiple chronic conditions, likes the concept of the demonstration, but has had initial difficulties with the enrollment process and getting updated information about participating providers. After initial delays in having someone assigned, he is now in regular contact with his care coordinator but has not yet received a needs assessment to begin the care planning process.

Eric, age 31, Virginia

Eric attends community college and receives regular intensive outpatient behavioral health services. He was surprised to be enrolled in the demonstration but is generally satisfied, particularly with the new dental benefit. He has only had one call from his health plan, however, and does not know who to contact with questions, such as where he should go in a psychiatric emergency.

Mary Francis, age 88, Virginia

Following a stroke, Mary Francis has difficulty walking and is prone to falls. She has multiple chronic conditions and attends an adult day health center. Mary Francis is very pleased with her care coordinator's review of her medications, help with arranging rehabilitation services, and accompanying her to a doctor's visit. However, she recently was disenrolled from the demonstration, due to a mix-up with her Medicaid renewal paperwork, and is in the process of re-enrolling with the health plan.

John, age 41, Ohio

John has quadriplegia and worried that enrolling in a health plan would disrupt his existing arrangements with the home health aides on whom he relies to help him get ready each morning. He was unable to find a health plan whose network included all of his longstanding providers, although he thinks that the plan provider networks are growing. He also experienced a delayed authorization to replace the battery in his ceiling lift, as a result of late plan payments to the vendor, placing him at risk of injury when transferring from his power wheelchair. He is interested in possibly self-directing his services once that option is fully implemented.

Sylvia, age 44, Massachusetts

Anxiety and depression made it difficult for Sylvia to make and keep physical therapy appointments following back and shoulder surgery and to arrange care for other conditions. Living alone and feeling isolated at times, she enrolled in the demonstration because she would welcome help with care coordination. Her regular doctor was able to become a participating network provider without any disruption in her care, but Sylvia does not know how to initiate the care planning process with her health plan.

DESIREE, AGE 28

MASSACHUSETTS

Desiree has a Master of Science degree in Education and Assistive Technology and has worked for Easter Seals for the past year and a half as a youth services manager. She lives with a roommate in a physically accessible apartment in downtown Boston and uses public transportation to commute to work, go to the gym, and go out with friends. She has a power wheelchair with a seat elevator, which she needs because of her short stature and brittle bones, characteristics of osteogenesis imperfecta type III, a genetic condition. Desiree does not have other medical problems. She receives routine care from her primary care doctor and sees an orthopedist and a neurosurgeon when necessary. She also receives 22 hours of personal care services each week. Desiree also has had a service dog for the past two and a half years. The dog performs tasks such as opening doors, switching on lights, and picking things up.



Desiree first heard about the demonstration from colleagues at the Center for Independent Living. She was eager to enroll when the program became available, and so, when she received a letter introducing the program, she signed up to receive services from the only plan available in her area. Her early program experiences were discouraging, however; initially, she found the program “very difficult to navigate.” For example, no one from the health plan contacted her, and a visit from a care coordinator did not occur until seven or eight months after she called to request one. It took about a year for the LTSS coordinator to respond to her request to meet.

“One thing I like about [the demonstration] is that once it’s straightened out, there’s not a lot of hoops to jump through.”

Once she connected with the care coordinators, Desiree was pleased. She received authorization for additional personal care hours. She now has an assistive technology device that helps extend her reach, and the LTSS coordinator is working with her building manager to make the kitchen in her apartment fully accessible.

Not having a specific contact at the health plan early on was particularly problematic when Desiree needed authorization to service her wheelchair. It took two weeks before the calls she made to health plan were returned. Each time Desiree spoke with plan representatives, she was told that they would give the care coordinator her message, but she was unable to contact the care coordinator directly, and her wheelchair was “pretty much out of commission” by the time she got a response. Her experience was much different once she had an established care coordinator who she could call directly. When she injured her shoulder, for example, she received immediate authorization to see her orthopedist although he is not in the plan’s network, because he already knows her medical history and seeing him was a good alternative to going to the emergency room.

Desiree recently learned that she would have a new care coordinator though she does not know the reason for the change. She would prefer not to have to start again with someone new. Also, she would rather not have so many meetings with care coordinators, particularly in-person meetings. She suggested that phone meetings

might be a good alternative, particularly for independent working enrollees who have proven ability to manage their own care.

At this point, Desiree is pleased to be enrolled in the demonstration as a dual eligible. Looking ahead, she is concerned, however, that her length of work will affect her Medicare eligibility and, in turn, her eligibility for the demonstration because if she loses Medicare coverage, she will no longer be a dual eligible. Now that she is working, she is in a transition period during which she retains Medicare but no longer receives Social Security Disability benefits. After five years of work, she can pay to receive Medicaid benefits through the buy-in program for working adults with disabilities, but once she loses Medicare coverage, she will no longer be dually eligible and so does not think she will be able to participate in the demonstration. In speaking about the program, she notes, “It really wasn’t made for working professionals. I don’t think it’s understood that there [are] working professionals who need it.”

ROB, AGE 65

OHIO

Rob lives alone, but doesn’t spend much time by himself. He helps care for his brother and his nephew, both of whom have disabilities and live nearby. He is active with his church and with a civic association that polices the neighborhood, and he advocates for many friends. Rob has degrees in business administration and music. Before he retired, he worked as an education program coordinator and as a professional musician.



Rob is grateful to be able to be so active because he has multiple health problems. He has been diagnosed with diabetes, hypertension, arthritis, and spinal stenosis. He suffers from migraines and back pain. He has had numerous surgeries including gastric bypass, knee replacements, hernia repair, and gallbladder, appendix, tumor removal. Rob’s main health care need now is prescription drugs. He takes 14 pills a day and uses a special cream for his knees. Sometimes he uses a walker, and he has trouble getting up steps but manages for now. Rob says that his mental health is sound because he stays active, travels to see family, and has a strong relationship with God.

When Rob received the first letter about the demonstration, he understood that he had to choose one of two health plans in his area for his Medicaid services. He chose his health plan because he had heard about payment problems in the past with the other plan from home health aides. Rob understood that he could voluntarily enroll in the same health plan to also receive Medicare services or remain in traditional Medicare. He contacted the health plan to ask for information. His main concern was what would happen with his coverage when he travels out-of-state. He also wanted to know whether the health plan would pay for the cream he uses for his knees because it comes from a specialty pharmacy in another state. His Medicare Part D plan now covers it but that took effort to arrange. The health plan

“When you see it on paper, it’s great. . . There are some pluses. . . [but] I want to see it fixed, or I want to see it gone.”

customer service representative could not answer his questions so he decided to keep his traditional Medicare coverage. When the letter regarding enrollment for the second phase of Ohio’s demonstration arrived, Rob was surprised to see that he had been assigned to the health plan for his Medicare coverage because he thought that he had already chosen to retain his traditional Medicare. He called the state “to opt out again” so that he retains his traditional fee-for-service Medicare coverage and is enrolled in a health plan for his Medicaid coverage.

Rob still has not received an assessment by his health plan. He said, “I was completely on my own” because his care manager did not contact him until six months after he enrolled in the demonstration. He and his care manager now communicate by phone, and he is pleased to “have a direct line with [the health plan].” Rob has contacted the health plan customer service representatives, the demonstration enrollment broker, the ombuds office, and the state insurance commission. He reports that the ombuds office was helpful, but he would not have known about those services if he had not had help from a local beneficiary advocacy group. Rob also notes that many enrollees do not have the awareness, perseverance, or time that he does to devote to getting answer to questions.

Rob has particular concerns about the provider network available through his health plan. He says the list of doctors is not up-to-date. Consequently, people go to their appointments and are told that doctors can no longer see them. Rob is under the impression that many doctors’ offices do not like the new program because they have to have new contracts, have to bill in a different way, and are not getting paid on time. He notes that these problems affect patients as well. However, Rob does think that the demonstration has potential.

ERIC, 31 VIRGINIA

Eric is a community college student who hopes to continue studying social sciences at a local university. When he is not studying, he enjoys playing laser tag and video games with friends, going to the gym, and eating Indian food at a local restaurant. He also takes care of his fish and walks his friend’s dogs. He lives by himself in an apartment.

Eric last worked in 2003. He was doing kitchen work but stopped working after he was admitted to an inpatient psychiatric hospital and diagnosed with schizoaffective disorder. He was in and out of the hospital for four years, but has not been hospitalized since 2007. He is grateful to have more stability now, to be responding well to his medication, and to have coverage for routine medical care. Eric has a regular primary care physician. He is being treated for high blood pressure.

Eric was surprised when he received the letter that introduced the demonstration and indicated that he would be enrolled in a particular health plan unless he chose another plan. He called the phone number on the letter and asked some general questions, then decided to go with the health plan to which he was assigned. Soon afterward, he received an insurance card from the plan and a call from someone at the plan who asked a number of



“I already have a case manager, so it might be redundant.”

questions. Eric was not sure why she called, and at first, he thought she was a telemarketer. She has not called since, and Eric does not have her name or contact information.

To his knowledge, Eric does not have a health plan case manager, and he has not heard any discussion about a behavioral health home, one of the features planned for Virginia's demonstration. He says these features might be a good idea for others, but Eric says that he already has an established case manager at the behavioral health organization where he goes for regular treatment.

Eric does have some questions related to his new coverage. One question is whether there is a particular hospital where he would have to go to in an emergency, for example, if he had a psychotic break. He is also unsure why a different doctor rather than his own doctor is listed as the primary care doctor on his health plan card, although he has not had problems having visits with his regular doctor covered. Basically, however, Eric is satisfied with the demonstration. He has used the extra dental benefits to have his teeth cleaned. He does not have to pay for his prescriptions or monthly lab work. His only concern at this point is whether he will be able to maintain his Social Security Disability benefits. He has just appealed a decision to discontinue these benefits, and the outcome could affect his Medicare eligibility as well.

MARY FRANCIS, AGE 88

VIRGINIA

Fifteen years ago, Mary Francis moved from Oklahoma, where she was retired after working as a cook in a restaurant, to live with her daughter, Mary, in Virginia. She had had a stroke, which left her with little muscle control in her left leg. She uses a walker and is prone to falls and bone fractures. She still has pins in one knee because of a fall. Mary Francis has had a few surgeries over the years. She has hypertension and advanced glaucoma and is followed for a heart murmur.



Mary Francis has been attending the same adult day health center for 15 years. She participates in all of the activities that are offered and says she enjoys every one of them. She is proud to have attended the center longer than anyone else. She also receives 44 hours per week of home health services, including help with dressing, preparing meals, and grocery shopping. Her granddaughter is available to provide respite care. In describing her situation, Mary Francis says, "I'm loved."

She and her daughter first heard about the demonstration at a meeting sponsored by the adult day health center. Representatives from the state as well as the participating health plans made presentations. Mary and her mother were drawn to the demonstration because of the extra benefits, such as podiatry, that were available and the promise of care coordination. They said it was also reassuring to know that they could leave the program if they did not like it. Mary chose a health plan after she determined that all of her mother's doctors were in the plan's network. In making the choice, she contacted a counselor from Virginia's state health insurance assistance program for Medicare beneficiaries. The counselor had made a presentation at the introductory session and provided her contact information.

Shortly after she enrolled, a care coordinator visited Mary Francis at home to conduct an assessment, including a review of her prescription medications. The coordinator also called to check on Mary Francis at least once a month. Mary was particularly pleased that the coordinator was available to help arrange care for her mother after she fell, had to go to the emergency room, and needed rehabilitation services. In the past, Mary said, she would have had to make all of those arrangements. She appreciated the help.

The only “glitch” that Mary Francis encountered was that she lost eligibility for the demonstration for 45 days because of an administrative error related to her Medicaid eligibility. Although her daughter submitted the Medicaid eligibility renewal paperwork before the deadline, it was not processed on time, and therefore, Mary Francis lost her dual eligibility status and was removed from the demonstration. Mary was able to re-establish her mother’s Medicaid eligibility and to re-enroll her in the demonstration with help from the social worker at the adult day health center. They are hoping to be able to continue working with the same care coordinator who already knows Mary Francis and has been so helpful, but they do not know yet whether that will be possible after the gap in coverage.

*The Care Coordinator
“was really good. . .
When she was first
assigned, she went
with me to meet
Mama’s primary care
physician just so she
could let them know
who she was and what
Services she was going
to be providing.”*

JOHN, AGE 41

OHIO

At the age of 19, John, a college freshman, lost his balance when he jumped into a local pond on a hot summer day. The accident left him with C5 quadriplegia. After his accident John was fortunate to find Creative Living, a residential community for people with high-level physical disabilities near his university. Living there allowed John to finish his undergraduate degree. He now lives independently in a condominium in the same neighborhood as his mother and two sisters and has a close relationship with his twin nephews. He likes to be outside as much as possible and vacations at state parks. Currently, he serves on the Board of Trustees for Creative Living. He volunteers in other capacities, helping organizations with IT issues and advocating on behalf of others with disabilities.



Overall, John describes himself as “fairly healthy” but must be constantly vigilant to avoid skin breakdown and other complications related to his disability. He relies on home health aides for about 12 hours each day and has nursing services several times a week. He uses a power wheelchair, a hospital bed, ceiling lift, and shower chair. His condominium has been modified with ramps and widened doors, and he has a minivan modified to accommodate his wheelchair.

John has had Medicaid and Medicare since his accident. The demonstration is his first experience with managed care. When he learned about the program from others in the disability community, he was anxious about transitioning to a new delivery system.

John chose his health plan and was distressed because he could not keep all of his providers. Some did not participate with both or either of the health plans in his area, making it difficult to select a plan.

Provider networks are improving, but John thinks that what is happening now should have happened a year earlier. He appreciates the program policy that will reimburse out-of-network providers who continue to see beneficiaries during a grace period but says that in practice, “it’s less than advertised” because some doctors are unfamiliar with the program and therefore reluctant to schedule appointments with demonstration enrollees.

Prior to the demonstration, John had a longstanding relationship with his case manager but he had to switch because his new health plan uses a different case management organization. When no one contacted him, John called the health plan to request a visit. He liked the new case manager but was distressed that she knew nothing about him. His understanding is that his previous case management records had been sent to the health plan but subsequently lost. Later, an assessor from the health plan visited him. There were no service changes in his new care plan except for a small number of more flexible hours that he can use to juggle his aides’ schedules when necessary.

After the transition to the demonstration, John was able to keep his personal care team, but he says it required a “Herculean effort.” All but one of his six personal care aides was an independent provider, and none had any knowledge about the impending program change. Under the demonstration, independent providers have to be part of the health plan network and must bill the plan for claims. Only by inquiring as if he were an independent provider himself, was John able to obtain guidance about how to complete the required paperwork. After extensive consultation with the health plan, John made a template for his independent providers and helped them all apply to the plan’s network. Another early challenge was that even after they joined the plan network, his providers were not paid for almost two months. They finally received checks just after he called attention to the situation publicly.

Delayed payments had practical consequences for John in another way when a battery for his ceiling lift had to be replaced. He called his new case manager and learned that he now needs prior authorization for a battery, but the case manager was not successful initially at getting the prior authorization from the plan. John is able to transfer on his own on occasion, but when he must do this for a prolonged period of time, both he and his aides are at risk of injury. The repairman who he knew and contacted had a contract with the health plan, but because the repair company had not been paid for prior work, they would not change the battery without prior

“I hated the idea of being transferred. I had a wonderful support team and it seemed ominous and very disruptive. . . i worried about who would get me up in the morning.”

“How do you choose between a neurologist you’ve had for 20 years and a DME provider who customized your seat you use every day?”

authorization. Finally, after several weeks, John called the customer relations representative at the plan; he received authorization the next day. John said that this story shows how much the plan's the customer relations function has improved but also illustrates a particular challenge associated with his change in coverage.

The option for self-directed care in Ohio's demonstration is a new feature that is particularly appealing to John, but he had to take the initiative to find out about it, and at this point, after talking with his case manager and another representative from the health plan, he concluded that "essentially they are still building the [self-direction] model." A major outstanding issue is whether his aides would be paid the same wage under self-direction as under the current program.

John sees potential in a system that would provide a single point of contact to coordinate all of his Medicaid and Medicare services, but he opted out of the Medicare portion of the demonstration before it became effective because his experience with his health plan so far had been challenging. Also, since his current doctor accepts Medicare but not Medicaid, he can only continue to see his doctor if he stays with traditional Medicare.

SYLVIA, 44

MASSACHUSETTS

Sylvia enjoys reading and writing and is working on a memoir. She has two adult children and lives alone. Sometimes, she feels isolated. Sylvia has worked since she was 14, most recently in the customer service field, but following back and shoulder surgery due to injuries from a car accident is not feeling well enough to go back to work. She has received some physical therapy and has a prescription for more as well as a prescription for acupuncture for pain management but has not made appointments for these services yet. She is taking anti-inflammatory medicine. Sylvia also has peptic ulcers and sees a dermatologist for skin conditions.



Sylvia has had anxiety and depression her whole life as well as prolonged grief associated with trauma in her past. She had received therapeutic counseling, but the clinic she attended shut down, and she was told that there was a two to three month wait to see a new therapist. Rather than stay on a waiting list and go through the orientation and intake process again, she relies on her primary care doctor who has prescribed medication.

Sylvia has received Social Security Disability benefits since 2001. She has had Medicare coverage for 12 years and has qualified for Medicaid off and on during that time as her income has fluctuated. The hospital helped her apply for Medicaid when she had surgery. She heard about the demonstration then and decided to enroll because she was looking for someone to help her with care coordination. However, no one from the health plan has called or visited her since she enrolled. Sylvia assumes that they are probably overbooked or backlogged. She did get a packet of information but says most of it pertained to choosing doctors. She already has a regular doctor, who was not originally part of the health plan's network, but Sylvia received care without interruption,

and her doctor is now a network provider. Sylvia also read about care teams in a brochure that she received, but she does not think she has one yet and is not sure if it is up to her or her doctor or someone else to set up the team.

Sylvia knows that she should make an appointment to see a gynecologist. She is trying to get to the acupuncturist and physical therapist and would like to attend a weight management clinic but finds it “difficult to get started.” Also, she says that sometimes appointments are scheduled too far in advance, and she forgets about them. She has a car but sometimes does not feel up to driving or does not have money for gas. She does not know if she would qualify for assistance with transportation or how to arrange those services but thinks it would help her get to some appointments.

“I feel prone to being lost in the system. . . i really want someone to work with me. I need someone to communicate and listen to me and explain what’s going on with me to doctors.”

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