

The Dual Eligible Population in Massachusetts: MEMBER PROFILES

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The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center committed to improving health care quality for low-income Americans. CHCS works with state and federal agencies, health plans, providers, and community-based organizations to develop innovative programs that better serve people with complex and high-cost health care needs.

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Introduction

Across the United States, over 12 million low-income seniors and individuals with disabilities receive health care coverage through both their state Medicaid program and Medicare. These dual eligible individuals often have complex care needs: Many require physical and behavioral health care, as well as long-term services and supports like home health aide and personal care services to help with getting dressed or eating meals. Because their health care coverage comes through two distinct payers — Medicaid and Medicare — it is often fragmented and uncoordinated, which can result in worse health outcomes and higher health care costs.

In Massachusetts, 312,000 of the 1.8 million people enrolled in MassHealth, the state’s Medicaid program, are dually eligible.^{1,2} Dual eligible members’ more complex care needs directly translate into more intensive, complex, and costly care than other populations. While dual eligible members make up only 18 percent of all MassHealth members, MassHealth’s spending on dual eligible members consumes over a quarter of its programmatic budget.

Recognizing the importance and challenge of coordinating care for this population, Massachusetts pioneered the development of integrated care programs that cover comprehensive Medicare and MassHealth benefits. These programs are One Care, the Program of All-Inclusive Care for the Elderly (PACE), and Senior Care Options (SCO).^{3,4} Most dual eligible individuals in Massachusetts, however, are not enrolled in integrated care programs but are instead covered by MassHealth fee-for-service (FFS). In an effort to expand enrollment in the integrated care programs, MassHealth is developing a new round of reforms known as the Duals Demonstration 2.0 with the goals of enhancing the quality of care that dual eligible individuals receive and reducing costs associated with their care.

Given the complex care needs of the dual eligible population and the dynamic state policy environment in which they receive services, the Blue Cross Blue Shield of Massachusetts Foundation partnered with Manatt Health and the Center for Health Care Strategies (CHCS) to develop an educational “primer.” The goal of the primer is to help policymakers and other interested stakeholders in Massachusetts better understand the characteristics and needs of the dual eligible population, the programs that currently serve them in Massachusetts, and upcoming reforms designed to improve care integration and quality. The primer consists of four components:

- **An issue brief**, which provides an overview of the characteristics of dual eligible members in Massachusetts and the costs associated with their care, as well as of the coverage landscape for the state’s dual eligible individuals and key objectives of the Duals Demonstration 2.0;
- **An in-depth comparative analysis** of the integrated care programs available to dual eligible members in Massachusetts;
- **A data chart pack**, which offers a detailed analysis of enrollment, demographics, and spending trends among dual eligible individuals in Massachusetts; and
- **This set of five profiles** of dual eligible members.

The goal of the member profiles is to reveal the people behind the numbers and statistics. The profiles illustrate the varied life circumstances that lead members to become dually eligible for MassHealth and Medicare. They show the challenges facing dual eligible MassHealth members and how MassHealth helps them meet those challenges.

To develop the profiles, CHCS reached out to more than 20 organizations across the Commonwealth (such as One Care and SCO plans, PACE organizations, Centers for Independent Living, Aging and Disability Resource Centers, Area Agencies on Aging, community-based groups, direct-service agencies, and advocacy organizations) to assist in identifying dual eligible individuals willing to participate. Outreach criteria were based on geography, age, and managed care or FFS program participation, among other factors, to select a group of profile subjects representing the diversity of the state’s dual eligible individuals. In-depth personal interviews were conducted between December 2019 and May 2020 with the five selected individuals and their families.

Caring for Family Through the Generations: GILDA SANTOS AND LUZIA MARQUES, NEW BEDFORD

Home, family, and community have always been important to Gilda Santos. She and her husband came to Massachusetts from Portugal in 1968, settling in New Bedford. After a few years, her parents came to join them. Gilda raised four children, including her daughter Luzia, who is now her primary caregiver. Luzia recalls that their multigenerational home was always the center of activity, with friends and family coming and going. She says, “Our house was always the one where the neighborhood kids would congregate.”



Once Gilda’s children were in school, she worked in one of the many local textile mills. She was a stitcher there for 13 years until her mother had a heart attack and Gilda left that job to care for her. Over the years, Gilda’s own health declined due to diabetes, hypertension, and angina. She had health insurance coverage through her husband’s employer until he had a stroke and was unable to return to work. Shortly afterward, in 2001, when Gilda was 59, both she and her husband qualified for MassHealth because of their health needs and low income.

When she turned 65, Gilda became eligible for Medicare as well, making her dually eligible for Medicare and Medicaid (MassHealth). During her first few years with Medicare coverage, she was enrolled in fee-for-service Medicare. At the time, her daughter Luzia worked for a home care agency, where she learned a lot about the different care options available to seniors.

Luzia says that her mother did not have any real difficulties navigating her MassHealth and Medicare coverage, perhaps because Luzia herself knew so much about the programs. Even so, she suggested that Gilda enroll in Senior Care Options (SCO), a program for MassHealth members age 65 and older. SCO provides comprehensive coverage for medical, behavioral health, and long-term care that is paid for through Medicare and MassHealth.

Luzia thought that SCO would be good for her mother because in addition to covering all MassHealth and Medicare services, it provides enrollees with a case manager and a dedicated care team. The team includes a nurse who is available if members or their caregivers have questions or need help. Luzia liked that the care managers were proactive, calling members regularly to see how they were doing and asking if they needed anything. Gilda enrolled in Senior Whole Health, a SCO plan offered in her area.

Gilda has been a member of Senior Whole Health for over 10 years now. Luzia says that it covers everything Gilda needs and that she never sees a bill. When her mother needs a service that Medicare does not cover, Luzia says that Senior Whole Health provides it without requiring her or her mother to fill out any paperwork. If Gilda were not in SCO, Medicare would deny her coverage for the service and she or Luzia would need to appeal that denial before Medicaid (MassHealth) would pay it. Instead, the Medicare-Medicaid integration in the program creates an easier and more seamless process for enrollees and their families to navigate. Gilda has no out-of-pocket costs for her care. On top of that, she receives \$100 per quarter from Senior Whole Health to pay for over-the-counter medications and health-related supplies.

When Gilda’s husband’s health declined further and he was no longer able to help with her daily needs, Gilda’s Senior Whole Health care manager arranged for a personal care attendant to help her bathe and dress a few times a week. For a while, she also participated in an adult day care program while Luzia was at work. Eventually though, Gilda stopped wanting to go to the day program. In 2015, Gilda’s husband passed away, and the family realized Gilda had dementia.

At that time, Luzia’s husband cared for Gilda while Luzia was at work. Luzia did not want to put Gilda in a nursing home, so in 2019, she took a leave of absence from her job to care for her mother. Gilda is now 78 and enrolled in Adult Foster Care. This is a MassHealth program for people age 16 and older who have a medical or mental health condition that requires supervision or physical assistance to help them live a meaningful life in a home setting.⁵

Adult Foster Care must be ordered by a physician and delivered by a qualified caregiver under the supervision of a multidisciplinary care team that includes a registered nurse and a case manager. This program allows Luzia to be her mother’s caregiver and receive a daily stipend in return for helping Gilda with self-care and preparing her meals, doing laundry, providing transportation, and so forth. Gilda’s multidisciplinary team is from the Seven Hills Foundation, a nonprofit provider of community-based services for people with disabilities. The Seven Hills Foundation also provided training to support Luzia as Gilda’s caregiver.

Not only does Gilda now have dementia, diabetes, hypertension, and angina, but she also has anxiety and depression. Luzia said that Senior Whole Health has been very supportive of her as a caregiver. The plan’s care manager receives twice-a-year updates on Gilda’s health assessment and care plan from the Seven Hills Foundation. Luzia reports that Senior Whole Health calls regularly — even more frequently since the COVID-19 pandemic began. It has also provided home health equipment, including a shower seat, handheld shower, and grab bars in the bathroom. And it has meals medically tailored for diabetes (and approved by a registered dietician and meeting evidence-based guidelines) delivered to help Luzia care for her mother at home.

Luzia says that Gilda was a great mom to her and her siblings growing up and is a loving grandmother. Luzia is grateful that she’s been able to show her mother that same love by keeping her living at home. Gilda’s SCO plan, Senior Whole Health, has provided the support she needs to help make that happen.

Setting and Surpassing His Own Care Goals: MICHAEL GEARY, BEVERLY

In Michael’s own words, he’s “been through the wringer.” When he was 24, he lost his left leg above the knee in a car accident. That didn’t stop him from working as a machinist. But at age 40, he was diagnosed with non-Hodgkin’s lymphoma, which was at a very advanced stage. As a result of the aggressive chemotherapy used to combat the cancer, Michael developed congestive heart failure.

When Michael had cancer, he needed to stop working, and he qualified for Social Security Disability Insurance, which allowed him to start receiving Medicare. Because of his low income, he also qualified for MassHealth. He needed to take 38 pills a day, mainly to treat his heart failure, and he had to manage all his care alone. During this time, his weight soared, and he spent weeks in the hospital.



In 2015, at age 52, Michael enrolled in One Care — an integrated care program for individuals 21 to 64 years old (at the time of enrollment) who are eligible for both MassHealth and Medicare. One Care covers a broad spectrum of services, including medical and behavioral health services as well as long-term services and supports, through a single health plan.

Michael chose Commonwealth Care Alliance’s (CCA) One Care plan. He’d heard that it was good at keeping people out of nursing homes, which is where he worried he would end up and didn’t want to be. Still he hesitated. He was concerned that he might lose benefits if he changed his health care coverage. He gave it a try anyway and has never regretted it.

Michael is now 56, and One Care is having a huge impact on his life by providing the care coordination and services and supports that he needs to help keep him at home. He feels that CCA has “been with me the whole time,” and it has really helped with his recovery journey.

Each One Care member receives a comprehensive health assessment soon after enrollment and then works with a care coordinator to create a plan of care based on the member’s goals. Michael’s most important care plan goal initially was to be able to get up if he fell. But he has made so much progress that his goals have expanded to include regular exercise and improved nutrition.

In 2017, Michael had gastric sleeve surgery and has lost over 150 pounds. “The CCA care coordinator really holds you accountable,” Michael says. He also recently received an Alexa — Amazon’s virtual smart assistant — from CCA, which reminds him of his daily exercise goals. “Alexa keeps me straight. She reminds me every day to get my exercise, telling me I look good, so keep on looking good!” His strength and mobility are so much improved that he’s able to do yard work, walk to the gym, and lift weights. He also recently completed a 5K race! (He walked, but he finished.) He’s proud to have come such a long way.

Michael credits CCA with being consistent, knowing his needs and routines, and supporting his health goals. Even though he has made good progress, his heart failure is severe, and he may need a heart transplant. CCA provided a motorized scooter to help him get around on days when he’s not feeling well and also set up a hospital bed in his home. CCA home-care nurses used to visit him weekly, but recently Michael moved in with his girlfriend and so now he needs less support. However, he does have 24/7 access to a nurse if he feels he needs help or medical attention.

CCA recently launched a community paramedicine program, which Michael thinks has been extremely helpful to him. It provides after-hours care by specially trained and equipped paramedics in the homes of CCA members, many of whom have multiple complex health conditions.

The program’s goal is to avoid unnecessary emergency department visits for patients who have nonemergency health issues outside the usual physician office hours. The paramedics recently assessed Michael for troubling symptoms related to his heart failure, and they determined he did need to go to the hospital for observation.

Michael’s plan is to continue to have a good attitude and keep things simple. “CCA coming to the door really helps me live my best life.” Reflecting on One Care, Michael doesn’t think that he would change anything. He’s seen firsthand how helping someone get to the grocery store, picking up prescriptions, and providing rides to medical appointments can keep the person healthy and on track.

He says, “I really struggled for a long time, so CCA means a lot to me. I’m not going to take it for granted, because I know it works.” Michael considers himself a survivor and appreciates CCA and its staff for all that they do. He says, “For people like me, coverage through One Care is a lifesaver.”

Staying Together and Staying at Home: MARGIE AND OLIVER KERR, SPRINGFIELD

Oliver and Margie Kerr met 32 years ago at a dance. Margie's gold and black outfit caught Oliver's eye. He was keen to get her phone number, but she wasn't interested. He persisted and eventually won her over. They've been together ever since.

They've worked hard throughout their lives at a variety of jobs. At one point they were both employed by a contractor to Massachusetts' Department of Developmental Services. They hit a rough patch when Oliver had a heart attack. He had to stop working and lost his health insurance. Oliver, who's now 69, began receiving Supplemental Security Disability Insurance and, after the required two-year waiting period, qualified for Medicare on the basis of his disability.



In that interim period, the couple had to make some hard choices. "We had to decide whether we wanted to make a car payment, buy food, or see the specialists we needed to see," says Oliver. Medications, in particular, were expensive and sometimes simply unaffordable. "In the end we had to borrow money from family to cover these expenses," Oliver recalled.

Margie is 77, and she too has had health issues. A bad back, caused by problems with her sciatic nerve, forced her to leave her job as an aide in a group home for people with developmental disabilities because it required too much physical labor. She then worked as a teacher's assistant and later as a security guard. She finally retired and qualified for Medicare at age 65. In addition to her sciatica, Margie has both diabetes and diverticulitis, an intestinal condition, which has required several surgeries.

Oliver had become eligible for Medicare because of a disability, and Margie qualified for Medicare when she turned 65. It wasn't until the couple spoke with a benefits counselor that they realized they could also qualify for MassHealth because they were over age 65, needed significant long-term care, and met the income eligibility requirements.

The couple heard about PACE — the Program of All-Inclusive Care for the Elderly — through neighbors in their senior living complex. PACE organizations provide a continuum of care and services at local PACE centers to people age 55 and over who need the level of care provided by a nursing facility but who want to stay in the community.

Margie enrolled in the PACE organization operated by Summit ElderCare in Springfield, and when Oliver saw the high quality of care she received, he signed up as well. When they were finally both enrolled, it was a welcome relief. "You won't find a happier person to be on PACE," Oliver says.

Oliver and Margie find it convenient to have so many services offered under one roof. Members see PACE primary care physicians on site, and certain specialty providers, such as ear, nose, and throat doctors, and podiatrists visit the facility on a regular basis. If members need other specialty medical care, PACE staff will coordinate with physicians in the community. PACE services include nutritional counseling; vision, hearing and dental care; programming for participants with Alzheimer's disease, dementia, and other cognitive impairments; and meals and social activities.

PACE also offers rehabilitation and therapy services. In fact, Oliver may have hip replacement surgery and would be able to do part of his rehab at the PACE site. "Even if I have to come every day, I'd rather be here with the people I know and trust," he says. Oliver feels that the PACE staff at Summit ElderCare make sure participants receive the

best care possible. “The people who work here like their jobs. They are enthusiastic about what they do, and that makes a big difference,” says Oliver.

Oliver and Margie like living independently and appreciate that PACE provides sufficient supports to keep people at home. Oliver serves as Margie’s primary caregiver and values the assistance he gets from PACE. Personal care workers come to their home to provide support with activities of daily living, including preparing meals and cleaning their apartment.

Nonemergency transportation has also been extremely important to the couple. Oliver and Margie rely on PACE’s shuttle service to get to the PACE center and use taxis provided by PACE to get to medical appointments. They are both enthusiastic about PACE, and they regularly try to explain the program and its benefits to others, actively encouraging their peers to join. Margie says, “It’s a godsend.”

Reflecting on a Life of Adventures:

DORIS O’CONNOR AND CHRISTINE MAGEE, MILFORD

Born in 1922, in Woonsocket, Rhode Island, Doris O’Connor is the matriarch of her close-knit family. Doris met her husband during World War II, and after dating for three years — including time he was stationed overseas — they married in 1945. During the war, Doris worked at an Air Force base in California. Afterward, the couple moved back East to be near family, and Doris had a successful career as the general manager of the local credit union in Woonsocket. She left her job following the birth of their first daughter and stayed home to take care of her family. They settled in Milford and raised three girls.

While focused on work and family, Doris and her husband were always ready for adventure. After working for many years as a machinist, Doris’ husband started a successful consulting business, which took the couple to Brazil for six months. Although the girls were adults by then, it was hard for the family to be apart. This trip spurred their interest in travel, though.

After Doris’ husband retired, the couple continued having adventures, traveling extensively to Africa, Europe, and Hawaii. Back at home, they decided to build their dream home; Doris continues to live there today, many years after her husband’s passing. Doris’ middle daughter, Christine, lives less than a mile away and serves as Doris’ health care proxy.

Doris has been on fee-for-service Medicare since she turned 65. In general, her health has been fairly good, but with age her care needs have become “somewhat challenging,” Christine says. Macular degeneration robbed Doris of her eyesight, and she has also had extensive hearing loss. The two conditions together compromised Doris’ balance and made her uneasy about walking independently. “The loss of her vision has taken a huge toll,” says Christine.

In 2016, Doris experienced excruciating back pain that sent her to the emergency room. An examination revealed that as a result of osteoporosis, she had broken four vertebrae simply by twisting the wrong way. Over time, the back injury has weakened her muscles, and now she is unable to straighten her neck. Doris uses a wheelchair to get around, but because of her neck pain, she is often more comfortable lying in bed.

Since her back injury, Doris has been in and out of nursing homes. As the cost of Doris’ care mounted, Christine saw her parents’ life savings slip away. By 2018, Doris had spent enough of her savings to be eligible for MassHealth, and Christine enrolled her mother. Doris continues to be enrolled in Medicare, which pays for things like hospital stays and doctor’s visits. And now she also is enrolled in MassHealth, which pays for long-term care like stays in a nursing home.

During her last nursing home stay, Christine recognized that her mother was not thriving. Doris was desperate to come home. Christine was advised by MassHealth to contact Tri-Valley, Inc., a home health agency that helps seniors and people with disabilities enrolled in MassHealth live independently in their homes. Tri-Valley helped equip Doris' home with safety features such as grab bars, and Christine credits Tri-Valley and MassHealth with providing Doris with a safe and comfortable return home. Doris continues to live in her own home with excellent health caregivers providing 24-hour care. The home health agency services are a comfort to her family who are happy knowing Doris is in her own home.

Doris is 98, and Christine credits Tri-Valley with keeping her mom happy and safe. She thinks the range of Medicare and MassHealth services available to Doris — even during the COVID-19 pandemic — has been “absolutely tremendous.”

Advocating for Herself and Others for High-Quality Care Management: OLIVIA RICHARD, BRIGHTON

Growing up in the foster care system, Olivia learned not to expect help from other people and to advocate for herself instead. That skill became even more important when an illness at age 27 left her partially paralyzed. Due to other care needs, Olivia was living in adult foster care at the time. But with her increased need for functional supports (such as assistance with self-care, mobility, and other instrumental activities of daily living), she ended up in a nursing facility, where she stayed for 89 days.

As a recipient of adult foster care services, Olivia was already enrolled in MassHealth, and now with a permanent disability, she also qualified for Medicare. When she left the nursing facility, she moved into her own apartment in a building for seniors and people with disabilities.



Although she received help from a personal care attendant (PCA) that was paid for by MassHealth, Olivia believed that the one hour a day that she was allocated was too little to meet her needs. She also had difficulty finding a medical equipment supplier that would take her MassHealth insurance. As a result, she had to repair her own wheelchair. “I had to learn how to weld and have resorted to using bike parts to make repairs.”

One day Olivia attended a meeting at the Boston Center for Independent Living, a Boston-based nonprofit organization that provides services to people with disabilities. There she learned about One Care, an integrated care program for individuals 21 to 64 years old (at the time of enrollment) who are eligible for both MassHealth and Medicare. One Care provides a broad spectrum of services, including medical and behavioral health services as well as long-term services and supports, through a single health plan. In 2013, she decided to enroll, joining a Medicare-Medicaid Plan offered by the Commonwealth Care Alliance (CCA).

From the outset, Olivia recalls, CCA was organized and coordinated. Still, she didn't have high expectations. All she wanted was a better wheelchair, additional PCA hours to help keep her in her home safely, and help to make her apartment a healthier place to live.

CCA assigned Olivia a care coordinator, who began by assessing her needs and developing a care plan that focused on helping Olivia to meet her goals. She says, “They seemed to know what they were doing, and I went

from having virtually nothing to having all these people and supports available to me. It was the right intervention at the right time.”

To start, her care coordinator organized a deep clean of her apartment, had the apartment treated for bedbugs, and got a hospital bed delivered. Next, Olivia’s care coordinator arranged for her to receive a power-assist wheelchair, which gives her greater independence and mobility.

Most importantly, Olivia now receives 15 hours of PCA services a week and can decide when she receives those hours. “I have some autonomy over how those hours are distributed throughout the week and have also been able to select my own PCA.” The PCA helps with meal preparation and laundry, and can run errands like picking up prescription medication from the pharmacy.

As part of her enrollment in One Care, in addition to her care coordinator, Olivia also has a long-term services (LTS) coordinator from the Boston Center for Independent Living. Her LTS coordinator helps her care coordinator navigate Olivia’s needs for long-term services and supports. Although she had worked with her LTS coordinator previously, and this person had tried hard to get Olivia the care she needed, the lack of coordination between MassHealth and Medicare before One Care made it difficult.

An example of this is when Olivia needed repairs for her wheelchair. Medicare does not cover wheelchairs or repairs to them if they are to be used outside the home, and Olivia uses hers both outside and inside the home. Medicaid will cover the wheelchair and repairs, but it is Medicare that is the primary payer for dual eligible individuals’ care and services. That means that a repair request would need to be considered by Medicare and denied — and Olivia would have to appeal that denial — before it could be approved by MassHealth.

Therefore, Medicare would routinely deny repair requests, and because the LTS coordinator had no authority over Olivia’s Medicare benefits, it was difficult to have the request considered instead by MassHealth. One Care helps to overcome this lack of coordination and better integrates the MassHealth-covered services with Medicare-covered services.

Olivia’s CCA care coordinator, who has authority over both Medicare and MassHealth benefits, is able to remove previously existing barriers. Olivia’s LTS coordinator can now arrange services — like repairs on her wheelchair — more easily. Olivia says, “Everyone seems to work well together, communication is great, and there doesn’t seem to be a hierarchy that interferes with getting the care I need.”

Olivia is now using her advocacy skills to help others. From 2012 through 2016, she was a member of One Care’s Implementation Council. The council is composed of MassHealth members with disabilities, care providers, and other stakeholders, and it helps to monitor One Care enrollees’ access to health care, track service quality, provide input to MassHealth, and promote program transparency.

Olivia was also involved in the Early Indicators Project to assess One Care’s performance by monitoring, assessing, and reporting on early indicators of eligible MassHealth members’ perceptions of and early experiences with the program. Olivia believes that the inclusion of people with lived experience in the design of programs like One Care is “incredibly important, because it means you will ask the questions that get at what’s most important to those who use the program.”

Olivia has had positive experiences with One Care, and she believes that other enrollees’ personal stories about getting services will help build enrollment in the program. “These stories are so impactful, because it means that people who were previously isolated are now getting out there. It means someone has stepped in and said your life is worth it.”

Endnotes

- 1 Mass.gov, "MassHealth Snapshot Enrollment Summary of November 2019 Caseload," available at www.mass.gov/doc/mashealth-caseload-snapshot-and-enrollment-summary-november-2019-4/download.
- 2 CMS Medicare-Medicaid Coordination Office, "People Dually Eligible for Medicare and Medicaid," March 2020, available at www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_Factsheet.pdf.
- 3 One Care is Massachusetts' capitated model demonstration under the federal Financial Alignment Initiative in which the state, the Centers for Medicare & Medicaid Services, and Medicare-Medicaid Plans enter into three-way contracts for the plans to provide comprehensive coverage for all Medicare Part A, B, and D and Medicaid services. Senior Care Options is an integrated care program in which MassHealth contracts with Medicare Advantage Dual Eligible Special Needs Plans to provide enrollees with all Medicare-covered benefits as well as MassHealth covered long-term services and supports and other wraparound benefits. PACE is a nationally available integrated care program for adults age 55 and older who need a nursing home level of care in which most participants attend adult day care programs staffed by an interdisciplinary team of health professionals. The PACE program operates in 30 states in addition to Massachusetts.
- 4 Individuals receiving both Medicare and MassHealth coverage through One Care, PACE, or SCO or MassHealth fee-for-service (FFS) are referred to as "dual eligible members" throughout the primer.
- 5 Adult Foster Care is not part of the Senior Care Options program and is not administered or managed by Senior Whole Health. However, individuals can be enrolled in Senior Care Options and Adult Foster Care at the same time.



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