



Understanding the Experiences of Dually Eligible Beneficiaries Enrolled in One Care

Report Summary

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Diane Beaver, Rachel Gringlas, Danielle Jacobs, Lauren Coy, Joe Baker

Overview

This brief report describes our research on the beneficiary experience of care coordination and access to health care services, home- and community-based services (HCBS), and social services in the Medicare-Medicaid Financial Alignment Initiative (FAI) demonstration in Massachusetts.¹ One Care is the only FAI demonstration that limits enrollment to dually eligible beneficiaries ages 21 to 64.² It was designed to serve a complex population, many with Long-Term Services and Supports (LTSS) and behavioral health (BH) needs.

The research results are based on interviews conducted from July to August 2022 with One Care members dually eligible for Medicare and full Medicaid benefits. This research was designed in collaboration with the Centers for Medicare & Medicaid Services (CMS) and Massachusetts and was informed in part by the state's Care Model Focus Initiative (CMFI), which aimed to identify action steps to ensure that the demonstration is implemented as intended. One Care is governed by a three-way contract (TWC) with CMS, Massachusetts and participating Medicare-Medicaid Plans (MMPs). Though this research was conducted under a CMS contract, the findings are not an indication of compliance (or lack thereof) with the TWC.

Methods

We asked the state to provide contact information for about 1,000 One Care beneficiaries eligible for recruitment into the study. Using this information, we randomly selected beneficiaries with diverse demographic characteristics to reflect the following sampling subgroups: those with multiple chronic conditions (MCCs), users of BH services, users of LTSS, or some combination of these. We focused on these higher risk subgroups as these individuals generally have greater care coordination needs.

Given the importance of gathering the data needed to improve health equity, we also oversampled people who were (1) from racial and ethnic minority populations, (2) Spanish-speaking and not bilingual, (3) Deaf or hard of hearing, and/or (4) blind or had low vision. The goal was to understand if these groups have distinct experiences with their One Care plan.

We then conducted 42 semi structured telephone interviews with higher-risk beneficiaries enrolled in MMPs for at least 12 months. Though most interviews were conducted in English, eight were conducted in Spanish. Participants included 13 individuals who identified as White and Hispanic, 11 as White and Non-Hispanic, 11 as Black and Non-Hispanic, six as multi-racial, and one as Asian. Thirteen beneficiaries either identified as Deaf or hard of hearing, blind or low vision, or both³.

After receiving their consent to participate, we asked beneficiaries about their experiences with: (1) their care team and the level of coordination among their providers, (2) their experiences completing health assessments and developing care plans, (3) the care they received from their MMP during an episode of

¹ Information on One Care can be found at <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Massachusetts>.

² Those who are over 65 may participate in One Care only if they were 64 years old or younger at the time of MMP enrollment. Other dually eligible beneficiaries are excluded from One Care, including those receiving services in intermediate care facilities for individuals with intellectual disabilities and those receiving services through a Section 1915(c) HCBS waiver.

³ Of these 13 beneficiaries, five identified as both blind or low vision and Deaf or hard of hearing; seven identified as blind or low vision only, and one identified as Deaf or hard of hearing only. One beneficiary who identified both as blind or low vision and Deaf or hard of hearing also only spoke Spanish.

higher health needs, (4) their expectations of their care coordinator and their care coordinator's role in their care team, (5) their social determinants of health, (6) their needs for HCBS and durable medical equipment (DME), (7) their understanding of member protections, and (8) suggestions for MMP improvements. We also asked about how the COVID-19 public health emergency (PHE) affected participants' access to services.

Results

Cross-cutting findings

After completing the field research, the study team conducted a thematic analysis of the interview notes. We analyzed participants' responses, grouping similar responses into categories, and identifying emergent themes related to care coordination and the receipt of services. The following cross-cutting results emerged during our thematic analysis of the interview notes:

- Most interviewees reported satisfaction with the access and quality of their medical care through their MMPs, and most used their MMPs to access the DME and HCBS needed to manage their health conditions.
- Interviewees generally shared positive feedback about working with health teams, especially how providers, coordinators and informal supports communicated with one another to facilitate their care. Those with a recent in-patient hospitalization were satisfied with the after-care experiences facilitated by their MMP.
- Several interviewees mentioned that they had worked with multiple MMP care coordinators, reporting that the transition to a new care coordinator had impacted their health care. Though some reported improvements after the switch, others reported disruptions in care.
- Though few recalled completing a care plan, about two-thirds of interviewees recalled their health assessments, and most shared generally positive experiences with them. Those with negative assessment experiences reported an unmet need for services.
- About half of participants reported receipt of education materials from their care coordinator, and those who did find them helpful.
- Most reported adequate access to nutritious food and transportation to health appointments, although several had unaddressed housing concerns related to stability, safety or affordability.⁴

Subgroup findings: Developing the user personas

Through our thematic analysis of the interview notes, we also observed distinct in care coordination experiences for each of the three subgroups in the sample: (1) Individuals who spoke only Spanish and

⁴ Our interview questions about needed social services centered on beneficiary access to food, housing, and transportation services, including nonemergency medical transportation (NEMT). Though the TWC does not require MMP benefits to cover all social needs identified through member Comprehensive Assessments and Individualized Care Plans, the role of an MMP care coordinator includes assisting members with identifying community resources that can satisfy these needs. Additional information about the role and responsibilities of a One Care care coordinator is in Section 2.5.4.4. of the TWC and found at: <https://www.cms.gov/medicare-medicare-coordination/medicare-and-medicare-coordination/medicare-medicare-coordination-office/financialalignmentinitiative/downloads/macontract.pdf>

were not bilingual with English, (2) Individuals who were blind or had low vision, and (3) Individuals who spoke English but did not have low vision.

Most participants in the blind or low vision and English-speaking groups reported a relationship with an MMP care coordinator, although those in the Spanish-speaking group generally reported that they did not feel connected to their MMP care coordinator. Additionally, more beneficiaries in the Spanish-speaking and blind or low vision groups reported obstacles to accessing key resources compared to those in the English-speaking group. Based on these observations, the study team developed fictitious user personas that summarize the experiences of each beneficiary subgroup:

- “Paul” personifies an individual who speaks English who represents the themes that emerged from interviews with the English-speaking group.
- “Rosa” represents a person who speaks Spanish who typifies the concepts and concerns that surfaced during interviews with the Spanish-speaking group.
- “Gwen” personifies an individual who is blind or has low vision who represents the themes that emerged from interviews with the blind or low vision group.⁵

Thus, the three user personas that follow do not represent actual people who participated in this study. Rather, the user persona content represents the key themes that came to light during our thematic analysis. We defined the demographic characteristics (gender, age and medical conditions) of each user persona by examining the most common characteristics among our subgroups.⁶

Almost three-fourths of interviewees in the sample identified as a racial or ethnic minority (which, for the purposes of this study, is classified as anything other than White, non-Hispanic). Beyond the distinct experiences of those of the Spanish-speaking group, our analysis did not reveal other significant differences in overall experiences reported by the those who identified as a racial or ethnic minority.

⁵ Though a relatively large percentage of research participants who identified as blind or low vision also identified as Deaf or hard of hearing, participants in this subgroup predominantly discussed how being blind or low vision impacted their care coordination needs and experience receiving healthcare. When asked how their hearing condition impacted their healthcare needs, participants shared their hearing loss was corrected by hearing aids and did not impact their receipt of healthcare. Thus, to accurately represent what we heard in the interviews, our “Gwen” user persona focuses on vision-related concerns and not hearing-related issues.

⁶ A majority of interviewees in the English-speaking group are Black, non-Hispanic and male. A majority of interviewees in the Spanish-speaking group are White, Hispanic and female. A majority of interviewees in the blind or low vision group are Black, non-Hispanic and female.

Fictitious user persona for beneficiaries who speak English



Paul

An English-Speaking Beneficiary*

** User personas are fictional characters that represent end user types.*

Age: 50

- Joined One Care in 2017
- Has multiple chronic conditions and uses BH services
- Lives with family
- Has 4 providers on medical team

"Everything about my conversations with [my care coordinator] is positive... She listens to what I need. She doesn't tell me what I need."

ABOUT PAUL

Paul has chronic obstructive pulmonary disease (COPD), heart disease, and an anxiety disorder. Paul doesn't feel like he's in good health, but he feels like he has a good healthcare team and is grateful for the coverage and coordination of One Care. His primary care provider (PCP) and specialists work within the same hospital system and share medical records. When Paul had a stent put in his heart, his PCP coordinated with his specialists to develop an after-care plan. Paul likes and uses telehealth regularly. He virtually meets with a therapist weekly.

Paul's care coordinator calls him quarterly to check on his health. She helped him to get a cane and nebulizer provided by the plan. She offered him HCBS to help with grocery shopping, meal preparation and cleaning, but Paul declined since his wife helps him with these things. Paul's biggest worries are financial. He would like to move due to the high crime rate in his area, but he doesn't think he can afford a different apartment. He would like help locating affordable housing so he and his wife can move to a safer neighborhood.

<h3>WHAT HE LIKES ABOUT ONE CARE</h3> <ul style="list-style-type: none">• Coordination between providers, led by PCP• Responsive care coordinator, who calls at least 4 times a year• Communication and support from care team during and after inpatient stays• Telehealth options to avoid traveling to appointments• Easy access to DME	<h3>CHALLENGES WHILE RECEIVING CARE</h3> <ul style="list-style-type: none">• Lack of a direct extension line to reach care coordinator• Limited resources for housing support
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UNFULFILLED NEEDS

Paul would like to reach his care coordinator directly when he has questions. He would also like access to a housing specialist to help him locate and secure new, affordable housing since his current neighborhood feels unsafe.

Fictitious user persona for beneficiaries who speak Spanish and are not bilingual



Rosa A Spanish-Speaking Beneficiary*

* User personas are fictional characters that represent end user types.

Age: 58

- Joined One Care in 2019
- Has multiple chronic conditions
- Lives alone, but has some family support
- Has 4 providers on medical team

"I like the attention [One Care] give(s) me, whatever I need, they help me."

ABOUT ROSA

Rosa lives alone and struggles to maintain her house and run errands on her own. Her daughter and sister stop by when they can to help or drive her to doctor's appointments. Rosa thinks she could benefit from some professional in-home support and transportation but isn't sure what's available.

Rosa has a MMP coordinator who calls twice a year to check on Rosa. While Rosa has some frustrations with the MMP, such as receiving plan notices in English and reaching English-speaking receptionists when she calls the 1-800 number, she does not bring this up with her coordinator. She overall feels very appreciative for all the MMP does for her. During one call, she asked if the plan would cover mobility devices, and the care coordinator helped her to get a cane and walker very quickly and without any co-pays. She feels this is the most comprehensive and responsive health care she has ever received.

WHAT SHE LIKES ABOUT ONE CARE

- Services and medication covered by the plan
- Communication from care team after inpatient stays
- Easy access to DME
- No co-pays at pharmacy or doctor's offices
- Care coordinator calls and checks in on her

CHALLENGES WHILE RECEIVING CARE

- Some times receiving notices from her MMP in English and not understanding the content.
- Repeating herself often with providers
- Having to wait to talk to someone at the plan who speaks Spanish or having to wait days for a call back from the plan

UNFULFILLED NEEDS

Rosa would like to easily reach Spanish-speaking personnel at her MMP and get materials in Spanish from the plan. She would like it if she had to repeat herself less with her providers. She could benefit from HCBS and NEMT, but she does not know these services are available through her MMP because her care coordinator has not brought them up with her.

Fictitious user persona for beneficiaries who are blind or have low vision



Gwen

A Blind/Low Vision Beneficiary*

* User personas are fictional characters that represent end user types.

Age: 57

- Joined One Care in 2018
- Legally blind, has multiple chronic conditions, and depression
- Lives alone, but has strong family involvement
- Has 8 providers on medical team

"[One Care] is better than the coverage I had before... I just wish they were more geared towards visually impaired people like myself."

ABOUT GWEN

Gwen experienced vision loss a few years ago after her multiple chronic health conditions worsened. Despite her highly collaborative provider team and supportive family, Gwen has found it difficult to adjust to her new life as a legally blind person due to her loss of independence. She relies upon a personal care assistant (PCA) to help her with grocery shopping, meal preparation, cleaning, and nonmedical transportation. Gwen recently moved into a new apartment, but she has trouble affording it, so her family helps her pay her rent each month.

Gwen receives a call from a MMP care coordinator at least once a month. Gwen asked the MMP to use email for correspondence so she could read notices with a screen reader. The MMP told her this could not be done. Gwen requested DME and home modifications from the MMP, but her requests were denied. She eventually received DME from the Massachusetts Commission for the Blind, and she used her savings to pay for the home modifications she needed.

WHAT SHE LIKES ABOUT ONE CARE

- High quality and comprehensive provider network
- Monthly check-ins with her care coordinator
- No co-pays at the pharmacy or her doctors' offices
- Telehealth options to avoid traveling to appointments
- Access to PCA services

CHALLENGES WHILE RECEIVING CARE

- Inability to read mail from the MMP without assistance from family or PCA
- Difficulty navigating MMP's phone system and website
- Difficulty getting approvals for DME and home modifications
- Delays in approval for PCA services
- Unreliable NEMT after a medical appointment

UNFULFILLED NEEDS

Gwen would like her One Care plan to understand what kind of accommodations she needs as a legally blind person and to pay for needed equipment and home modifications. She would also like to access a housing subsidy to help her stay in her new home long term.

Thematic Key Findings

Care coordination

- The soft skills of care coordinators resonated with interviewees. Many reported that their care coordinator sincerely cared about their needs, and they appreciated the responsiveness and outreach from their care coordinator.
- Several of those who experienced an inpatient stay since the COVID-19 PHE reported that they had either been in contact with their care coordinator during their inpatient stay or had been contacted by their care coordinator within a few days of returning home.
- Several reported that they primarily use their care coordinator for logistical coordination with the health plan (i.e., to gain access to DME or a referral to a health service) and believe that health education should be handled by their medical providers. Most beneficiaries shared that they did not use their care coordinator as a health education resource, nor did they ask their care coordinator questions about their health.
- Several interviewees from all three subgroups reported MMP care coordinator turnover. Some reported that they missed their previous coordinator, found their new coordinator to be less adept than the previous one, or had trouble contacting their new care coordinator. Others reported they had an improved experience after the change to the new care coordinator.
- About a quarter of all interviewees reported moving to a new address within the past year. About half of them had moved recently, and reported more difficulty getting in touch with their new care coordinator than their previous one.

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"[My care coordinator] makes me feel like my problems are important to her."

— Member of English-speaking group

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"[My previous CC] reached out during COVID. She called every other week. Then I switched to another person. Nowhere near. The only time I hear from my worker is when I go to the hospital. She never calls to see what I need. I have to reach out to have my worker call me."

— Member of English-speaking group

Access

- Most beneficiaries across all three subgroups reported satisfaction with their access to medical care and the medical services they received.
- Many beneficiaries used MMPs to access the DME and HCBS they needed to manage their health conditions.
- Most beneficiaries reported that their food and transportation needs were met.

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"[My care team] help me get adjusted to my new life with so many issues. They keep me from getting depressed about it, keep me going, keep me feeling positive about my life, and help me to take better care of my health."

— Member of Blind or low vision group

Challenges

While respondents reported a positive experience with their One Care plans overall, some challenges and disparities emerged. MMPs could improve the experience of their members by addressing these key challenges.

- Despite reporting highly positive MMP experiences overall, those in the Spanish-speaking group reported less communication, care coordination, HCBS and NEMT use than that reported by English-speaking participants.

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“What I don’t like is the coordination, you call on the phone about something, and you have to talk with someone else. You have to repeat yourself, and the person doesn’t know how to help.”

— Member of Spanish-speaking group

- Beneficiaries in the blind or low vision group reported more difficulty reaching their MMP and receiving educational materials on member protections than those in the other two subgroups. A few of these commented that their MMP’s automated phone system and mailed materials were inaccessible.
- Most interviewees who were blind or had low vision reported the need for DME and HCBS, but many reported difficulties accessing DME through the plan. Of these, a couple reported service denials and struggles with the appeals process due to challenges in completing the necessary paperwork.

- Many beneficiaries across all three subgroups reported housing as an unmet social need, especially citing affordability and neighborhood safety concerns. Though a few reportedly accessed community resources such as COVID-19 rental forgiveness funds or Section 8 housing vouchers, only a few reportedly discussed their housing needs with their care coordinator. Most who did ask their care coordinator for help securing affordable and safe housing said they did not receive the help they sought.

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“The plan sends me information through the mail, but I don’t always check the mail because I find it overwhelming.”

— Member of Blind or low vision group

Impact of the COVID-19 PHE

- Across all subgroups, most participants reported that during the COVID-19 PHE they continued to receive their medical services, social services, and HCBS without major disruptions, due in part to the availability of telehealth.
- Most beneficiaries did not report significant changes in the quality or frequency of care coordination services during the COVID-19 PHE.

Possible Next Steps

Based on the most significant issues raised in the interviews, we identified the following opportunities for improving care coordination and access to services for One Care members.

- **Leverage the comprehensive health assessments as an opportunity to provide targeted information about available MMP services to beneficiaries who do not speak English, as required in the TWC.** One Care plans could consider how to conduct outreach and education to

beneficiaries who do not speak English, to ensure they receive the same information with the same frequency about available benefits through their MMP as English-speakers receive.

- **Take steps to ensure MMPs communicate with members according to their preferences, as required in the TWC.** This may involve ensuring that phone systems are accessible to all callers, including voice navigation prompts, giving those who are non-English speakers or blind or have low vision direct lines to contact their care coordinators, offering the option to receive materials electronically/digitally rather than via physical mail, and approving mail-readers as medically necessary DME. MMPs may also contract with interpreter vendors or use online translation services and apps to facilitate communication with non-English speakers, even when fluent staff are not immediately available.
- **Develop procedures and training for staff for when beneficiaries move.** These trainings might include how to successfully transition care between care coordinators, initiate discussions about how to access medical teams local to the member's new address and identify updated transportation options to meet member needs.

Limitations of Qualitative Research

Due to small sample size and the nature of qualitative research, this study has the following limitations:

- Additional themes may have emerged from a broader or different sample of research participants.
- Beneficiaries who chose to participate in this study may have felt more strongly about their One Care MMP (either positively or negatively) than those who chose not to participate. The views of nonparticipants regarding care coordination or other matters may differ from those of participants.
- The demographics of study participants did not completely align with those of the broader population of MMP enrollees. The study team interviewed members from only two of One Care's three MMPs⁷, and interviewees were more likely to be Black or Hispanic/Latin(o/a/e) due to our intentional oversampling of these populations. We also interviewed a higher proportion of individuals who were Deaf or hard of hearing, and who were blind or had low vision than in the One Care population.
- Although the study team asked questions designed to elicit participants' recall of care coordination experiences, some beneficiaries may not have remembered, for example, a call from a care coordinator or receiving a care plan in the mail, even if a care coordinator had reached out to them and/or if they received a care plan. We based our findings only on beneficiaries' reported experience.
- Although the study team tried to recruit those who were Deaf or hard of hearing to learn about their care coordination experiences, we were not successful at reaching any members of the culturally Deaf community.⁸ As a result, we do not believe our results regarding how care coordination of individuals flagged as Deaf or hard of hearing in our sample reflect the needs of this community overall.

⁷ Members of UnitedHealthcare Connected (UHC) were excluded from this research study because the sample was drawn in June 2022 and UHC began operations in Massachusetts in January 2022. This meant members of UHC did not meet the criteria of continuous enrollment in their MMP for 12 months.

⁸ In the United States, the culturally Deaf community involves a group of individuals with a shared sense of identity and belonging who communicate visually using American Sign Language (ASL). Deaf culture is rich and complex, and membership does not depend on a person's level of hearing loss (medical/pathological model). Rather, it's a chosen identity that is a source of pride for many Deaf people (social/cultural model). See www.mass.gov/service-details/understanding-deaf-culture for more details of this distinction.

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