

Beneficiary Experience: Early Findings from Focus Groups with Enrollees Participating in the Financial Alignment Initiative

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Executive Summary

This Issue Brief describes the results of focus groups conducted in six States as part of the Centers for Medicare & Medicaid Services Financial Alignment Initiative to test integrated care and financing models for Medicare-Medicaid enrollees. Five of these States—California, Illinois, Massachusetts, Ohio, and Virginia—are implementing a capitated model demonstration in which Medicare-Medicaid Plans (MMPs) provide coordinated benefits and access to new and flexible services through a person-centered care model. One, Washington, is implementing a managed fee-for-service model demonstration in which health homes are responsible for organizing enhanced integration of primary, acute, behavioral, and long-term services and supports across existing delivery systems for Medicare-Medicaid enrollees and for directing person-centered care for high-cost, high-risk enrollees.

Participants in the focus groups described their experiences as enrollees in these demonstrations. Specifically, focus group participants were asked to describe their overall understanding of and satisfaction with the demonstration; their experience with the assessment process, care coordination, and patient engagement; their relationship with regular providers; access to and quality of services; knowledge of beneficiary protections and rights; and impact of services on health, well-being, and quality of life. This Issue Brief highlights common themes and findings in each of these areas across the demonstrations and within subgroups, as well as some findings that were unique to specific demonstrations. This Issue Brief also includes information on the experiences of key subpopulations.

To ensure that focus group participants were enrolled in their respective demonstrations for a sufficient amount of time to be able to comment on their experiences, this Issue Brief includes the six aforementioned States, all of which had demonstration implementation dates before May 2014. In-person focus groups were conducted in each State between May 2015 and April 2016 with enrolled beneficiaries or their proxies. In some States, focus groups were conducted with only Black or only Hispanic participants to identify any unique experiences of racial, ethnic, and linguistic minorities enrolled in the demonstrations. As with any focus group data, the results presented here represent the experiences of the participants and should not be generalized to represent the experience of all individuals enrolled in the demonstration.

Focus group participants identified successes and challenges as they navigated the demonstration to obtain benefits and services. Participants identified positive changes such as greater access to a broader and more flexible range of services, including home care and home modification services. They also described improved quality of life and a more coordinated and patient-centered approach to their care. Although some Spanish speakers were not aware of the availability of Spanish-translation materials, Black and Spanish-speaking focus group participants did not identify cultural or language barriers to their care. While participants identified a number of successes, certain challenges remain that may warrant attention by the

Centers for Medicare & Medicaid Services (CMS), States, MMPs, beneficiary advocacy groups, and quality improvement organizations. These challenges include beneficiary understanding of and MMP communication about benefits, rights, and protections; issues regarding access to providers (including behavioral health providers), particularly regarding the size and scope of provider networks in the capitated model demonstration; and limited access to pharmacy, medical equipment, and supplies under the demonstrations. The groups also described concerns about the quality, reliability, and accessibility of non-emergency medical transportation. There did not appear to be a difference in experience by race or ethnicity. Although many were pleased with their care coordination experiences, stating that their care coordinator had helped them obtain needed services (e.g., home-based services and supports as well as home modifications and counseling) and that they were engaged in decisions about their care, some participants had difficulty identifying their care coordinator.

1. Introduction

The Medicare-Medicaid Coordination Office and Innovation Center at the Centers for Medicare & Medicaid Services (CMS) created the Financial Alignment Initiative to test integrated care and financing models for Medicare-Medicaid enrollees. The goal of these demonstrations is to develop person-centered care delivery models integrating medical, behavioral health, and long-term services and supports (LTSS) for Medicare-Medicaid enrollees. The expectation is that these integrated delivery models would improve the experience of beneficiaries who access Medicare- and Medicaid-covered services by aligning Medicare and Medicaid processes to address the current challenges associated with the lack of coordination of Medicare and Medicaid benefits.

Under the Financial Alignment Initiative, CMS made two financial alignment models available to States: (1) a capitated model in which health plans coordinate the full range of health care services, and (2) a managed fee-for-service model in which States are eligible to benefit financially from savings resulting from initiatives that improve quality and reduce costs. As of July 2016, 14 demonstrations are operational in 13 States. Eleven of these demonstrations, including two in New York State, use the capitated model in which MMPs provide coordinated benefits and access to new and flexible services through a person-centered care model. Two demonstrations, in Colorado and Washington, use the managed fee-for-service model in which care coordination entities are responsible for organizing enhanced integration of primary, acute, behavioral, and LTSS services across existing delivery systems for Medicare-Medicaid enrollees and for directing person-centered care for high-cost, high-risk enrollees. CMS has also partnered with Minnesota to implement an alternative administrative alignment model, building on its longstanding Minnesota Senior Health Options program.

CMS contracted with RTI to monitor demonstration implementation; evaluate the impact of the demonstrations on the experiences of beneficiaries, their families, and proxies; and monitor and evaluate the demonstrations' impact on a range of outcomes for the eligible population as a

whole and for special populations (e.g., people with mental illness and/or substance use disorders, LTSS users). To achieve these goals, the RTI evaluation team is collecting qualitative and quantitative data from States each quarter; analyzing Medicare and Medicaid enrollment and claims data as available; conducting site visits, beneficiary focus groups, and interviews; and reviewing relevant findings from any beneficiary surveys conducted by federal agencies or other entities.

This Issue Brief describes the experiences of beneficiaries who are enrolled in these demonstrations, with a specific focus on how the financial alignment of Medicare and Medicaid benefits might influence these experiences. It covers several domains including beneficiaries' overall understanding and satisfaction with the demonstration; assessment, care coordination, and patient engagement; relationship with regular providers; access to and quality of services; knowledge of beneficiary protections and rights; and impact of services on health, well-being, and quality of life. It also includes information on the experiences of key subpopulations.

Start dates varied for each of the demonstrations, which are at different stages of implementation. To ensure that potential focus group participants were enrolled in their respective demonstrations for a sufficient amount of time to comment on their experiences, this Issue Brief includes only those six demonstrations with implementation dates before May 1, 2014. **Table 1** provides an overview of the demonstrations that are discussed here. Further details on the early implementation experience of these and other demonstrations can be found in the *Report on Early Implementation of Demonstrations under the Financial Alignment Initiative*.¹ Focus groups for these six demonstrations were conducted from June 2015 through April 2016. Focus groups in the remaining demonstrations were completed in late spring and early summer 2016. Results for all focus groups conducted from June 2016 through August 2016 will be included in forthcoming State-specific annual reports.

¹ Chepaitis, A., Greene, A. M., Hoover, S., et al.: Report on Early Implementation of the Demonstrations under the Financial Alignment Initiative. Contract No. HHSM500201000021i TO #3. Waltham, MA. RTI International, October 15, 2015. <https://innovation.cms.gov/Files/reports/fai-implementationrpt.pdf>.

Table 1.
Overview of Demonstrations Included in This Issue Brief

State ^{1,2}	Demonstration Name	Implementation Date	Eligible Population and Geographic Areas	Type of Model
California	Cal MediConnect	April 1, 2014	Aged 21 or older, in 7 counties in southern California and around the Bay Area	Capitated
Illinois	Medicare-Medicaid Alignment Initiative	March 1, 2014	Aged 21 or older, in 21 counties in Greater Chicago and Central Illinois	Capitated
Massachusetts	One Care	October 1, 2013	Aged 21–64 ¹ in 9 of 14 counties in Massachusetts ²	Capitated
Ohio	MyCare Ohio	May 1, 2014	Aged 18 or older, in 29 counties (7 regions of 3–5 counties each, including major urban centers)	Capitated
Virginia	Commonwealth Coordinated Care	April 1, 2014	Aged 21 or older, in 104 localities: Central Virginia, Tidewater Northern Virginia, Roanoke, and Western/Charlottesville	Capitated
Washington	Washington Health Homes MFFS Demonstration	July 1, 2013	All ages, statewide except for 2 counties (Snohomish and King)	MFFS

MFFS = managed fee for service.

¹ The Massachusetts demonstration targets adults aged 21–64 at the time of enrollment, and allows people to remain in their Medicare-Medicaid Plan when they turn 65 as long as they maintain demonstration eligibility.

² Includes 8 full counties and 1 partial county.

2. Methods

2.1 Eligibility Criteria and Recruitment

To recruit enrollees for participation in the focus groups, the RTI evaluation team worked with the States to obtain lists of Medicare and Medicaid enrollees who met the following criteria for inclusion:

- Are age 18 or older
- Meet the minimum length of continuous enrollment for their specific State (see *Table 2*)
- Are not deaf
- Are not in a nursing facility or intermediate care facility for people with intellectual or developmental disabilities
- Reside in certain geographic regions or areas of their State
- Whose primary language is English or Spanish
- Use long-term services and supports (LTSS) and/or behavioral health services

The States provided lists of beneficiaries who met these inclusion criteria. To ensure participants had enough experience in the demonstration to be able to actively participate in the focus groups, where possible, participants needed to be enrolled in the demonstration for at least 9 months. Because some States did not have sufficient numbers of enrollees with at least 9 months of experience in the demonstration from which to recruit for eight focus groups, the time enrolled was relaxed to be at least 6 months in several States. *Table 2* summarizes the minimum enrollment length eligibility criteria for each demonstration included in this Issue Brief.

Table 2.
Length of Enrollment Criteria for Focus Group Recruiting, by State

State	Minimum Length of Enrollment (Months)
California	6
Illinois	9
Massachusetts	9–12
Ohio	9
Virginia	9
Washington	6

The RTI evaluation team included The Henne Group, which recruited for, planned, and conducted all focus groups for the evaluation. As part of recruitment, letters were sent to enrollees from the lists generated by the States containing information about the purpose of the focus groups, the incentive for participation in the focus groups, and the contact information for signing up to participate. The RTI evaluation team also made phone calls to enrollees and used a recruitment screener to recruit participants and verify information about their enrollment, LTSS needs, and health plan enrollment or receipt of health home services (for the Washington demonstration enrollees). Participants with behavioral health needs were identified either through the screener or information provided by the State as part of the recruitment list. If enrollees were eligible for the focus groups and agreed to participate, the RTI evaluation team assigned them to the focus groups based on criteria such as behavioral health needs, LTSS use, race/ethnicity, health plans, and gender to achieve a mix of participants, to the extent possible.

The RTI evaluation team conducted some focus groups with only Black or only Hispanic participants to identify any unique experiences of racial, ethnic, and linguistic minorities enrolled in the demonstrations. In all States, at least two focus groups were conducted with only Black participants, except for Washington and Massachusetts, where recruitment lists of eligible beneficiaries were not sufficiently large enough to recruit two groups of Black participants. In California, Illinois, Massachusetts, and Washington, at least one focus group was conducted in Spanish for Spanish-speaking Hispanic enrollees. Spanish-speaking Hispanic enrollees were identified using data provided by the States. For these enrollees, all recruitment materials (including the letter and screener) were translated into Spanish.

Table 3 describes the total number of focus groups conducted, the total number of focus groups conducted in Spanish, and the total number of participants in each State’s focus groups. Across the six States represented in this Issue Brief, a total of 44 focus groups were conducted with 228 participants. Most focus group participants with low English proficiency were Spanish speakers. Six of the 44 focus groups were conducted with exclusively Spanish-speaking Hispanic enrollees or their proxies. However, English-proficient native speakers of other languages such as Mandarin also participated, including proxies representing their non-English-speaking relatives.

**Table 3.
Total Number of Focus Groups and of Participants, by State**

State	Total Focus Groups Conducted (#)	Focus Groups Conducted in Spanish (#)	Participants (#)
California	8	1 ^a	27
Illinois	8	1 ^b	46
Massachusetts	7	2	41
Ohio	8	0	47
Virginia	7	0 ^c	27
Washington	6	2	40
Total	44	6	228

^a The RTI evaluation team recruited for 2 Spanish-speaking focus groups in California, but 1 was canceled because recruits failed to show up for the focus group.

^b The RTI evaluation team also conducted 1 focus group of English-speaking Hispanic enrollees in Illinois.

^c The RTI evaluation team attempted to recruit two focus groups of Hispanic enrollees in Virginia but because of the limited number of Hispanics on the recruitment list, was unable to recruit enough participants to fill the groups.

2.2 Moderating the Focus Groups

For each focus group, the RTI evaluation team made arrangements for an accessible location and accommodated beneficiaries’ special needs. Before a focus group began, participants were provided with an informed consent form that explained the purpose of the group, how they were selected for the groups, the length of time the group was expected to last, and a description that the risk for participating in the group is minimal. The form also summarized their rights as research participants, stated that information shared would be kept confidential, and asked participants not to discuss anything they heard in the group with individuals outside the group. Permission was obtained to record the discussion. Each participant signed a consent form before the start of the group. The moderator reviewed the consent language to ensure that all participants understood the focus group process and their rights as participants.

A trained moderator from the Henne Group, part of the RTI evaluation team, used a guide developed by the evaluation team to facilitate discussions with and among focus group participants about their experiences as enrollees of the demonstrations or, in some cases, as family members caring for enrollees (i.e., proxies). A Spanish-speaking moderator conducted the Spanish-language focus groups using a translated moderator guide. At the end of the focus

groups, participants received \$50 gift cards as tokens of appreciation. Focus groups were audio recorded, and the tapes were transcribed for use in analyses. Transcripts for Spanish-speaking focus groups were translated into English.

A total of 228 enrollees or their proxies participated in the focus groups. **Table 4** provides descriptive information about the participants' sociodemographic characteristics, health services use, and chronic conditions. The majority of participants were female (66.1 percent), not employed (93.0 percent), and in need of assistance with their activities of daily living (61.7 percent). Approximately half were aged 65 or older; Black; and had a high school diploma, General Educational Development, or less (51.7 percent, 50.4 percent, and 49.6 percent, respectively). The majority of participants reported more than one chronic condition.

Table 4.
Focus Group Participants' Sociodemographic Characteristics, Health Services Use, and Chronic Conditions

Sociodemographic Characteristic	N	%
Type of participant		
Beneficiary	194	84.3
Proxy	34	14.8
Gender		
Male	76	33.0
Female	152	66.1
Age		
18–64	109	47.4
65 or older	119	51.7
Race/ethnicity		
White	64	27.8
Black	116	50.4
Asian	6	2.6
Multiracial	6	2.6
North American Indian or Alaska Native	1	0.4
Hispanic	34	14.8
No response	1	0.4
Education		
High school diploma, GED, or less	114	49.6
Some college	86	37.4
College graduate	28	12.2
Employment status		
Employed part time	13	5.7
Employed full time	1	0.4
Not employed	214	93.0

(continued)

Table 4. (continued)
Focus Group Participants' Sociodemographic Characteristics, Health Services Use, and Chronic Conditions

Sociodemographic Characteristic	N	%
Help with ADLs		
Needs help	142	61.7
Does not need help	86	37.4
MH services ¹		
Uses MH services	41	17.8
Does not use MH services	109	47.4
Number of visits with primary care provider in last 6 months		
2–6 times	81	35.2
7–12 times	65	28.3
More than 12 times	82	35.7
Chronic conditions ²		
Other cardiovascular disease, such as heart disease, hypertension, or high blood pressure	146	63.5
Osteoarthritis, osteoporosis, or hip fracture	116	50.4
Depression or anxiety	107	46.5
Diabetes	82	35.7
COPD or chronic bronchitis	46	20.0
Stroke	32	13.9
Cancer of any type	30	13.0
Serious mental illness, including bipolar disorder or schizophrenia	30	13.0
Spinal cord injury	24	10.4
Neurological conditions like Parkinson's disease or multiple sclerosis	17	7.4
Traumatic brain injury	12	5.2
Other conditions	82	35.7

ADLs = activities of daily living; COPD = chronic obstructive pulmonary disease; GED = General Educational Development; MH = mental health.

¹ The count for MH services use does not sum to the total number of beneficiaries because this was not a screener question for early focus groups in Massachusetts, Virginia, and Washington. The data are therefore missing for participants in those focus groups. The percentage is based on the number of participants responding to the question.

² The percentage of chronic conditions exceeds 100 percent because participants could indicate more than one chronic condition.

2.3 Analysis

After each set of focus groups was conducted, the RTI evaluation team analyzed focus group data. Specifically, State evaluation teams reviewed their notes and the transcripts to identify key themes and sub-themes, which were categorized into the domains within the focus group moderator guide. State evaluation teams also looked for key differences across participant subgroups to identify how these themes may vary across these groups—or to highlight

similarities. State evaluation teams selected quotes to illustrate and provide a range of perspectives on the themes. The RTI evaluation team used these analyses to identify common themes and similarities across States, as well as findings that are unique to a specific State. As is the case for all focus groups, feedback from the participants is based on their own experiences and should not be generalized to the entire enrollee population.

3. Findings

Throughout these sections, differences between the demonstrations with capitated models and the Washington managed fee-for-service (MFFS) demonstration are identified where relevant. For more information about the design of the Washington MFFS demonstration, please refer to *Measurement, Monitoring, and Evaluation of the Financial Alignment Initiative for Medicare-Medicaid Enrollees: Preliminary Findings from the Washington MFFS Demonstration*.²

3.1 Overall Understanding and Satisfaction with the Demonstration

Highlights

- Overall, participants' satisfaction with the demonstration varied by State and across focus groups, and was influenced by their experience with the benefits and services they used as well as ease of access and cost.
- Some participants observed that under the demonstration it became easier to navigate the system to obtain needed services, and the cost of these services had decreased.
- Participants' awareness of the ability to opt out of the demonstrations or change plans throughout the year varied. Some were aware of this option, but others believed they needed to wait for the next enrollment period to make a change.
- Participants were confused by changes in enrollment and coverage without their knowledge or consent. They also had complaints about the limitations of the provider networks.
- Across all of the focus groups, participants reported that the written materials they received were often dense, difficult to understand, and presented an overwhelming amount of material.
- Some participants with limited English proficiency were unaware that translated materials were available.

3.1.1 Beneficiary Understanding of the Demonstration

Under the Financial Alignment Initiative, dually eligible beneficiaries were faced with changes to their health plans or health care services. For beneficiaries in a capitated model demonstration, enrollment in an MMP may have been their first experience with managed care. For beneficiaries

² Available at <https://innovation.cms.gov/Files/reports/fai-wa-prelimppone.pdf>

in an MFFS model demonstration, although services continued to be provided through the traditional fee-for-service (FFS) Medicare and Medicaid programs, beneficiaries were enrolled into new care coordination entities (e.g., health homes in the Washington MFFS demonstration) designed to coordinate services within the existing delivery systems. Because dually eligible beneficiaries are a particularly vulnerable population, States, MMPs, and other care entities operating under the Financial Alignment Initiative made it a priority to provide targeted outreach intended to ensure that beneficiaries understood changes occurring under the demonstration. Beneficiaries were mailed notices from States before enrollment in capitated model demonstrations. The notices included information on the opportunity to opt out of the demonstration. Beneficiaries were also given informational letters and booklets from the State or from their plans or care coordinators after enrollment. Similarly, Washington mailed information to beneficiaries regarding the health home program and indicated that beneficiaries could opt out of receiving health home services. The focus groups examined how well beneficiaries enrolled in the capitated demonstration models understood changes to their health plans and services and what resources beneficiaries used to obtain information about their benefits.

The focus group participants varied widely in understanding of the demonstrations. Some focus group participants enrolled in capitated model demonstrations exhibited a strong understanding of how their health plans had changed and were aware that Medicare and Medicaid coverage had been integrated under their new health plans.

The fact that they're combined between the Medi-Cal [California's Medicaid] and the Medicare, that facilitates things. Because before you had to look at the Medi-Cal portion, then you had to do the Medicare portion, and it made it more difficult... [now] we're under one umbrella. (*Proxy for Hispanic female, long-term services and supports [LTSS], California*)

It's called [plan name redacted], so it's dual. It's connecting Medicare and Medicaid.... (*Black female, LTSS, Ohio*)

Well, they changed it here in Massachusetts. So now—before it was MassHealth [Massachusetts Medicaid], and then you had your Medicare. Now they changed it to [plan name redacted]. It's One Care. It's a mesh between the two. (*White female, LTSS, Massachusetts*)

Some participants in capitated model demonstrations attributed their awareness of the demonstrations to communication with health plan representatives, care coordinators, or materials the plans mailed. In contrast, many participants reported confusion and dissatisfaction about changes in enrollment or coverage occurring without their knowledge or consent. This issue was frequently discussed alongside complaints about changes to covered services or limitations to plans' provider networks. Often, beneficiaries were at the point of receiving care services when they realized that they had been enrolled into a new health plan.

I'm very confused to what I have. All I know is... it's connected with [MMP name] somehow. And I remember running across Cal MediConnect [name of the California

demonstration], but I don't know what it was about. I feel as though I'm being switched. (*White female, LTSS, California*)

Before I was seen on [MMP name], I was seen by a different doctor, and I couldn't even see that doctor that day because they wasn't taking [MMP name]. (*Black female, LTSS, Illinois*)

Most participants in capitated model demonstrations recalled receiving informational materials from their health plans; however, the majority of participants reported that materials were too dense and difficult to understand, and many reported not reading these materials at all.

It [member handbook for One Care] wasn't easy to understand. I had more questions than anything.... They have to break down the words a bit more where people understand what they mean, instead of going to a dictionary to find out what it means or to a medical book. (*Black female, behavioral health [BH], Massachusetts*)

It's like "you really expect me to read all this?" (*Proxy for Black female, LTSS, Virginia*)

But if you read everything that they send you for each of the plans, you would never really get a chance to make a choice. So what I did was I just kind of read as much of each plan as I could, and the one that covered the most of the things that I needed covered—that's how I chose. Because they send you books that look like this [implying the book is thick], and there's no way you're going to get through all of that. (*Black female, LTSS, Ohio*)

For participants with limited English proficiency (LEP), access to information in their own language was also an issue. One of the demonstration's key goals is to ensure that enrolled beneficiaries have access to multilingual resources, and although in California, the State mandates exist to issue materials in threshold languages,³ availability of materials in participants' native languages was an important issue in other States as well. In some cases, participants were not aware that States are obligated to provide materials in most commonly spoken languages, and they were not aware that they could request these materials if they were not provided. For example, a Hispanic participant in Illinois conveyed confusion about the plan selection process and about the rules and timing for switching plans because the materials were not translated.

There were some announcements saying: "You have to pick a plan and an insurance." But they... didn't send anything in Spanish so I kind of ignored them... until somebody told me: "You know what? Because you didn't pick a medical insurance one has been picked for you..." (*Hispanic male, LTSS, Illinois*)

³ Threshold languages are those that are spoken at a high proportional rate within a geographic region of California. A full definition can be found at [https://govt.westlaw.com/calregs/Document/IF1694720DF4A11E4A54FF22613B56E19?viewType=FullText&originationContext=documenttoc&transitionType=CategoryPageItem&contextData=\(sc.Default\)](https://govt.westlaw.com/calregs/Document/IF1694720DF4A11E4A54FF22613B56E19?viewType=FullText&originationContext=documenttoc&transitionType=CategoryPageItem&contextData=(sc.Default)).

Others recalled receiving translated materials, but they echoed some of the English-speaking participants' experiences described previously—that the materials the plans sent provided an overwhelming amount of information.

Yes, they send books and all of that about the plan [in Spanish]... but the books are so big. (*Hispanic male, LTSS, Massachusetts*)

In some States, there is a greater need for access to information in multiple languages. For example, a Hispanic participant from Illinois, in response to a moderator request for suggestions to improve the Illinois demonstration for Hispanics, suggested better communication for Spanish-speaking enrollees.

Something like an information center, a phone number where we could call to get general information. (*Hispanic male, LTSS, Illinois*)

3.1.2 Participant Satisfaction with the Demonstration

As a demonstration that seeks to integrate financing and services through a person-centered model that aligns benefits across programs, feedback from participants regarding their satisfaction with the demonstration is an important indicator of whether barriers and unmet needs are being addressed. Participants had mixed reactions as to whether they were satisfied overall with the demonstration, and levels of satisfaction varied by State and within focus groups. Participants considered many factors when expressing their overall satisfaction with the demonstration. Satisfaction was influenced by participants' experience with the benefits and services they received as part of the demonstration, which was the case in California, Illinois, Massachusetts, and Washington where experiences were positive; or whether medical care and services were easy to access and cost less, which was described in Ohio and Virginia as well as Massachusetts.

I've had different insurance in the past. But when I came across Cal MediConnect that was my lifesaver... I ran across [the MMP], which I am so blessed to come [across], which connected both [Medicare and Medi-Cal]. (*Hispanic female, LTSS, California*)

I feel satisfied because I don't have to struggle for anything; just talk to my doctor and the problem gets solved. (*Hispanic male, LTSS, Illinois*)

I needed a home aide, I got one. I need[ed] meals, I got them. I get my same doctor. Anything I ask for, I get it. I needed a wheelchair, I got one of them. I got a shower bench, [the care coordinator] got it. I have no trouble with her. (*Black male, LTSS, Ohio*)

Some participants indicated that the health care that they receive has become easier to navigate and less expensive, thereby improving their access to care and quality of life, as well as their satisfaction with the demonstration.

The system has changed. It's easier. ... What I will say is health care has gotten cheaper. At least we can go to the doctor now. You know what I'm saying? But in the all-around,

you could still be a little bit better, but it has gotten really better. (*Black male, LTSS, Virginia*)

Before I got [MMP], I would have to choose in between paying my mortgage or getting my glasses, buying groceries or paying for my medication. I now don't have to make those choices. (*Black female, LTSS, Illinois*)

Some participants were not as satisfied with the demonstration, pointing to difficulties with finding a provider or specialist who contracted with the participant's plan, or services and benefits that were not covered. Some participants also felt that the demonstration was more difficult to navigate than their previous insurance. Further discussion of issues relating to access and quality of services—specifically provider networks, LTSS providers, transportation, and other benefits—can be found in **Section 3.4**.

It got a lot of difficulties to do stuff because some specialists, they don't take my insurance. Before, like I said, I was in halfway. I've got one leg done, and I even got appointment with [specialist's name redacted]. She called me about appointment. I said, "Do you take this [plan name] insurance?" She said, "Oh, yeah, unfortunately not." So what can I do? (*White male, LTSS, Illinois*)

My mom used to get Ensure. But when the switchover came, they stopped giving her Ensure... they sent me a letter and stated that she practically had to be like too thin or something like that in order for her to get Ensure. Although the doctor and even a neurologist had wrote a letter stating that my mom needed it... But once the switchover came, they would not give it to her, and that was something that I started having to buy. (*Proxy for Black female, LTSS, Ohio*)

3.2 Assessment, Care Coordination, and Patient Engagement

Highlights

- Participants described mixed experiences with the assessment process; some indicated that assessments occurred regularly, whereas others indicated that assessments occurred only as needs arose.
- Participants expressed positive experiences related to goal setting. Many were actively involved in the process and engaged with their care team and their physicians.
- Frequency of contact with care coordinators varied, but participants described these encounters as positive overall.
- Among those with limited English proficiency, linguistic access was available for care coordination services when needed.
- Participants had difficulty differentiating care coordinators from other individuals who provide assistance (case managers, other MMP team members).
- Many participants reported that their care coordinators improved coordination across providers and improved their access to needed services, but some noted lack of follow-up, heavy caseloads, and high turnover among care coordinators.

3.2.1 Assessment

All Financial Alignment Initiative demonstrations require that some form of risk assessment be conducted within specified time frames, and the format and frequency of these assessments usually vary across the demonstrations and by the level of risk or care need.⁴ Participants' recall and experience with the health assessment process reflected this variation. In California and Massachusetts, some participants remembered the assessment process, whereas others did not, and in some cases, it was not clear whether participants were confusing their risk assessment visit with other types of visits. In California, those who did recall the assessment process remembered completing a paper survey or talking with someone over the phone, and very few reported an in-person assessment. The focus group participants in Illinois did not describe a formal assessment, but most said that someone from their MMP had visited or called to assess their needs, and that they had help from care coordinators when any needs arose. In Ohio, participant discussion of needs assessment centered on whether participants were working with physicians and/or case managers on health-related goals.

I did get a call from [plan name redacted]... We had a little survey that we had to fill out at the beginning of the year, and we did it telephonically. And there was one that they sent to us as well to fill out, but I didn't send it in because I'm a little busy with all these things I have to do. But they called on the phone and I was on the phone and we went through like 40 questions or something like that. A long survey about [my mother's] health ... [It was] right after the year began, we got it, and I thought that was good because it's a good baseline where we are. (*Proxy for Hispanic female, LTSS, California*)

My social worker came and assessed me March 3rd, and she did ask me what was the goals I'm trying to reach. I wanted to walk and maintain better more independence of myself. (*Black male, LTSS, Ohio*)

A majority of focus group participants in Washington said their care coordinators assessed their needs on an ongoing basis, and Virginia participants were more likely to remember assessments if they were done regularly.

She comes once a month. She asks me, "Who's doing what for you and what do you need and can I get some information for you?" Basically, if I didn't have her, I'd really be lost. I'm lost right now. But if I didn't have her, I wouldn't have what I have right now. (*Hispanic female, LTSS, Washington*)

She [case manager] calls me every month to check and see what's changed. And like I said, that's something new that they're doing, but it's really good. (*Black male, LTSS, Virginia*)

Participants raised other issues about the assessment process. Some participants in California felt that the health risk assessment was a perfunctory process and not a meaningful conversation

⁴ Additional information on risk assessments is available within the Three-Way Contract for each State, which can be found at: <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsInCareCoordination.html>

about their unmet needs. Participants from other States raised issues with follow-through, mentioning that they did not receive the services or equipment discussed during their assessment.

They called me, yeah. Nobody came to the house. Well, at the time, I guess it wasn't—there wasn't anything I needed. She just called and like going through a list or at random or something and let me know that I have a nurse I can call. (*White female, LTSS, California*)

The first year, they did the full assessment, everybody came. They made their salary that day, but they just didn't do anything for me, [and the services and equipment they talked about never happened]. It was so discouraging that I didn't even fill out the survey... They came the second year, and that time everything I needed was done within the year, and we even have another plan so for this year they were very good... They followed through with everything. (*Black female, LTSS, Massachusetts*)

Goal setting is an important component of the demonstration and can begin at the initial assessment. Participant feedback regarding experiences with goal setting was mixed. Some participants were aware of and expressed positive experiences with goal setting, and they described participating in setting goals and getting help achieving their goals. Some participants in Illinois, Massachusetts, and Washington identified goal setting as a key part of their interaction with their care coordinators. Participants in each demonstration region in Washington reported positive experiences with health home care coordinators helping to identify their needs, discuss service options, and set personal goals.

My care coordinator and I, we do set goals every 2 months. Well, we go over the goals we set the previous time, and then we'll see if I've achieved any of those... we have continuing goals... and then we have goals of things I need to do, like see an oral surgeon. (*Black male, LTSS/BH, Illinois*)

When she was there 2 weeks ago, she [told me the goals I shared with her] when I first met her. Number one was to try to lose some weight. Number two to keep up with my water aerobics and definitely get my health in a better shape than it was. But she [does] ask me what [is] my goal every time she comes and how far I've progressed and how my medicines have changed. (*Black female, LTSS, Virginia*)

It was [the plan that started the conversation about my goals not my doctor]... I needed weight loss because I need to have a knee replacement... That was my goal. (*Black female, LTSS, Massachusetts*)

I've taken pills for my diabetes. Now I don't take anything because my diabetes is in control. (*Black female, LTSS, Washington*)

In contrast, some participants reported that no one on their care team had asked about their goals. In California, very few participants reported setting personal or care goals with their care coordinator.

I don't get no personal attention like you all get. The calls, I don't get that. (*Black female, LTSS, Illinois*)

I'm supposed to lose weight. Nobody helps me do it. (*Black female, LTSS, Virginia*)

Truthfully, that's something that has to be yourself. They'll go as far as mental evaluations and seeing if you need any mental help and stuff, but not put up goals or nothing like that. You have to—you got to do everything yourself when it comes to stuff like that. (*Hispanic male, LTSS, Illinois*)

In some cases, focus group participants expressed confusion or frustration with the goal-setting process. For example, some Ohio participants said that their care teams had not asked them about their health-related goals and were not working with them to achieve such goals.

How do you get a goal? Because I've asked the doctor, "Can you hook me up with a nutritionist?" Because I need a good nutritionist now... I tell them I got goals and it's like they're pushing me right to the side. That's why I'm looking for me a new team. (*Black female, LTSS, Ohio*)

3.2.2 Care Coordination

After assessing enrollees' needs, care coordinators are responsible for helping enrollees navigate the health care system, including managing enrollees' Medicare and Medicaid benefits and facilitating access to social services to achieve their goals. As with the assessment process, the method and frequency of follow-up for care coordination varies across the demonstrations and by the need of the individual. The RTI evaluation team asked focus group participants about their experiences with care coordinators and their satisfaction with the assistance they received. The RTI evaluation team also asked participants whether their providers seemed to work together as a team to help participants get the services they needed.

Most focus group participants said that they had care coordinators or have had contact with them. In States with capitated demonstrations, some participants understood that their care coordinators worked for MMPs and that their role is to help enrollees access services to meet enrollees' needs. In California, where some MMPs delegate care coordination to provider groups and other MMPs employ their care coordinators, participants in these focus groups provided no evidence to suggest that these different arrangements had an impact on care coordination activities. In Washington, many participants thought of their care coordinators as case managers who helped them set and achieve their goals. A small number of participants were aware of care coordinators' broad responsibility to coordinate across delivery systems. Finally, some participants in each State said that they were unaware of care coordination until the focus groups.

She seems very helpful and very much interested in my care. And we've set goals and things like that for exercising and improving my weight loss and my physical health and things like that. (*White male, LTSS, Washington*)

I have one person in charge of all of [the people helping me]. Even if I have 15 people calling me, [my care coordinator] she is the only one [in charge]. (*Hispanic female, LTSS, Massachusetts*)

I just don't know who [my mother's] care manager is because nobody has ever informed me about that... (*Proxy for Hispanic female, LTSS, California*)

In every State, some participants had trouble differentiating among the roles of various people who assist them, which might include care coordinators working for MMPs, case managers for home and community-based services (HCBS) and BH services. In Washington, participants had a particularly difficult time distinguishing their care coordinators because those services are provided by organizations that also provide HCBS or BH case management, primary care, or other community services. In Massachusetts, some participants said they had trouble differentiating among the roles of different MMP team members, and between their MMP team members and independent living and LTSS coordinators.⁵ In California and Virginia, participants described many different care providers who assist them.

I have a nurse that comes every 3 months to see me. And so that's pretty good. Well, besides that, there's two caseworkers. It's three [altogether]... [They visit] separately. (*White male, LTSS, California*)

I thought it was one lady that was the case manager. ... Then [I've] got another guy and another lady from a different location. And then this other one, she said she was one of the managers. (*Proxy for Black female, LTSS, Virginia*)

[They don't know me] because it's different people. You don't have the same one and you have three different people coming out. They've got the paper in front of them about what [the last person] did, but they don't know me. (*Black female, LTSS, Massachusetts*)

Although many participants had difficulty identifying their care coordinator, they described receiving contact information from a variety of individuals. In Ohio, participants generally knew who their care coordinators were and how to contact them; in one focus group, nearly half of the participants said they had refrigerator magnets with their care coordinators' contact information. In Massachusetts, some participants said they had contact information but were confused after being visited by multiple MMP staff and providers. For example, one participant reported having eight business cards at home on the refrigerator, whereas another reported having more than a dozen business cards.

I know there are two ladies that come to visit me. I think my case manager? (*Black female, BH, Massachusetts*)

⁵ Independent living and LTSS coordinators work with demonstration enrollees in Massachusetts to find resources and services in their communities that support wellness, independence, and recovery goals. They are not employed by the MM; they are a service provided by independent community organizations.

I sometimes call “eenie, meenie, miney, moe” for someone and they tell me, “No, this is not me, that is my co-worker but I will let her know.” (*Hispanic male, BH, Massachusetts*)

Within each State, participants who were able to identify their care coordinators said that the frequency of contacts and level of engagement with their care coordinators varied. Some participants reported that their care coordinators visited or called monthly, whereas others reported quarterly visits. Some participants said they call their care coordinators as needs arose between regular contacts. Others said that their care coordinators were not in regular contact, and they had difficulty reaching them by telephone. Still others reported they had not received care coordination services and had advocated for themselves or family members.

[My] case manager visits me every 3 months. Whatever I need, she helps me get it. And it wasn’t like that before, so that’s something new. (*Black female, LTSS/BH, Illinois*)

[S]he’s calling me, I would say, once a month and meeting with me every 3 months... Very helpful, and she’s not going to rest till I get what I need. (*White male, LTSS, Illinois*)

She comes every month to know how much she is weighing, if she’s walking, what she’s eating—because she also has diabetes—and how her health is, if she has been to the emergency room... (*Proxy for Hispanic female, LTSS, Washington*)

[Plan name redacted] sends a care manager out. I’ve had four case managers in almost 2 years. They don’t keep their jobs. Something’s going on with [plan name redacted], as far as the case managers’ positions. (*Black female, LTSS, Virginia*)

No, there is not [a care coordinator]. It’s me. I’m the point person...there’s nobody who’s really contacted [her] to say, “If you have a problem with this”—which I think the case manager should be [the point person], because they say that there’s case management. Well, who are they? (*Proxy for Hispanic female, LTSS, California*)

I just heard about [the option to have a care coordinator] right now [in this focus group]. (*Hispanic male, LTSS, Massachusetts*)

In California (where MMPs may or may not assign a care coordinator based on need and risk level) and Virginia (which, like all of the demonstration States, allows enrollees to decline care coordination services), some participants with behavioral health conditions said they were not using care coordinators because they received this service from behavioral health providers, whereas others seemed to prefer limited engagement.

The nurses at [the community behavioral health center] come out to my house and they talk to me about my goals... Like depression, stress, if I’m ever going through it or whatever, they talk to me and they keep me with meds... And I have a psychiatrist there, and there’s nurses there, care workers. They come out to us. They give us our medication. They speak with us. (*Black male, BH, California*)

Mine don't pretty much bother me, because they know if I have a problem, I call them. They pretty much leave me alone. (*Black female, BH, Virginia*)

I don't involve my caseworker with a lot of stuff unless it's something like I can't get my medicine. My case manager calls me on a daily basis just to check on me. But sometimes... I just don't want her in my business. (*Black male, BH, Virginia*)

Among participants who used care coordination, many said that the care coordination services had been helpful, and some stated that they were very pleased with these services. This was a common theme across all the States. Many said their care coordinators had helped them obtain services they needed and helped them navigate the complexities of the health care system. Participants also mentioned that their care coordinators provided information, helped resolve problems, and facilitated communication among providers. Some said their care coordinators helped them set and achieve goals, particularly in Washington, where participants described achieving health and quality of life goals, such as losing weight, reducing blood sugar levels, and overcoming social isolation.

My doctor would help me too but [the MMP] is more proactive... when I told my case manager about my eyes, she came up with a name like that... It's just that [my care coordinator] is more accessible. (*Black female, BH, Massachusetts*)

I was going to the emergency room three or four times a week for little things. Since I started working with [my care coordinator] over the last 2 years, I've been to the [emergency room] once in 2 years. (*White female, BH, Washington*)

[My mother's care coordinator] has been a godsend because she has fought for everything. When I don't get an answer from the doctor's office, she's on the phone with them. (*Proxy for Hispanic female, LTSS, California*)

[My care coordinator is] excellent... because she explains things to me; she gives me peace of mind. (*Hispanic male, LTSS/BH, Massachusetts*)

If you have a problem with falling, they pay for the unit for you to have a pendant at home so you can get help. Before, if you were having a problem, I had to try to get that for myself. (*White female, LTSS, Washington*)

Anytime I have a question, I can call anybody... I have people that genuinely care and they are trying to help me, and you can sense that. (*White female, LTSS, Massachusetts*)

Participants with LEP echoed the importance of the care coordinator and discussed the importance of linguistic access to care coordination (i.e., bilingual care coordinators or a care coordinator accompanied by a translator). Generally, Hispanic participants in Massachusetts and Washington said that linguistic access has been available for care coordination when needed. Some participants reported that their care coordinators were bilingual, whereas others said their care coordinators brought translators to home visits. However, one participant said that even when translators are available, language could still be a barrier.

I like that the plan asks if you are bilingual, American, [or] someone who just speaks only Spanish. (*Hispanic female, LTSS/BH, Massachusetts*)

I feel better having someone who speaks Spanish. But if there was no one it would also be OK to have someone with a translator. (*Hispanic female, LTSS, Washington*)

I'll differ from the others, because when I was taking care of my father, for me language wasn't a barrier... But now I feel English is a barrier, because my sister is the one in charge and needs interpreters, I think that the coordination has decreased a little. We've lost a little because of the lack of communication... sometimes the staff, without being interpreters, passes the message on. It's like it has decreased, we've lost the coordination we've always had. (*Proxy for Hispanic male, LTSS, Washington*)

Several focus group participants spoke of cultural preferences and the need for care coordinators to receive training to be sensitive to these preferences. For example, two participants in Washington said some Hispanics are averse to discussing certain medical procedures and end-of-life planning. One participant said her care coordinator helped her prepare advance directives, which was important because her husband did not share her preferences.

I believe that we are not culturally prepared to talk about things like... medical procedures that many of us won't accept like being fed through tubes or resuscitation, if you want to be kept alive with machines on certain situations... Culturally we don't accept these practices, we don't want to take those decisions, don't even want to talk about it. And so I think that this is a barrier that [care coordinators] encounter, because they don't know how to help us in those cases, they don't know how to get in. (*Proxy for Hispanic male, LTSS, Washington*)

My husband, he doesn't believe in donating his organs or getting... things like blood transfusions or anything like that. So it makes things difficult... Because of [my care coordinator], I have this document—I don't remember how it's called—which states that I do agree to have blood transfusions and am willing to get resuscitated, because if it were up to my husband, he would probably not have any of those things. (*Hispanic female, LTSS, Washington*)

In each State, at least some participants were dissatisfied with the services they received after contacting their care coordinator. One source of dissatisfaction was the lack of follow-up to address the participants' needs. Participants in Illinois, Massachusetts, and Ohio raised concerns about turnover among care coordinators. A few participants in Massachusetts felt that their care coordinators were overloaded and juggling large caseloads, at least at that point in the demonstration, which they felt affected the care coordinator's ability to be effective connecting them to services they needed.

I asked for a humidifier. She said she'd try to work it out... I haven't heard nothing. (*Black female, LTSS, Illinois*)

The coordinator doesn't call us. We don't get no call... the only way we get the diabetic shoes and the incontinence supplies, we started getting them because I called [the supervisor]. (*Proxy for Black female, LTSS, Illinois*)

Well, [I've had] three case managers in 6 months, so it's a revolving door because they said they keep changing the program. (*Black female, LTSS, Ohio*)

I've had three care coordinators and now I'm on my fourth. My care coordinator just called and said, "Yeah, I got a promotion, so it will be someone else." And it's a lot of turnover going on with them... so I don't like it. (*Black male, LTSS/BH, Illinois*)

They need to hire more people so one person doesn't get 95 people. That's not fair saying "I can't get to you because of my workload." That's not my fault. I need you. (*Black female, BH, Massachusetts*)

Communication and coordination between doctors, hospitals, and other providers are important components of care coordination. In Virginia, most participants said their providers seemed to be informed about all of the services they utilize. Many participants in Illinois and some in Washington mentioned that their primary care providers (PCPs) and specialists were affiliated with the same hospital-based health system, so they all used the same electronic health record system. However, some participants in those States, whose providers were not in the same systems, said their regular providers did not always receive test results or notices of admissions and discharges.

In my case... everything is recorded in the computer system and they can go back... and they try to relate everything so that it's beneficial for me. (*Black female, LTSS, Illinois*)

All the doctors that I go to are with [the same health system], and so they're all hooked up together. They know who does what. (*White female, LTSS, Washington*)

When I go see my doctors, I [take] all my MRIs, all that kind of stuff, I have all my blood tests. Because a lot of times I'll be saying, "Well, I've had this done, this done," and they're like, "Well, I don't see that. Can I see your paper?" I come in with this giant notebook of all my blood tests. (*White female, LTSS, Washington*)

Several participants reported that their providers and/or care coordinators worked as a team. In some cases, participants reported relying primarily on their PCP to help coordinate their care.

If I have a problem, when I ask them for things for the house or for myself, they get together and all my doctors talk to each other. (*Black female, LTSS/BH, Ohio*)

Yes, I feel they are [working] as a team, especially my doctors and therapist, I feel they are all helping me work. Were it not for them, there are times when I would be worse off. (*Hispanic male, BH, Massachusetts*)

In some focus groups, participants who were hospitalized or visited the emergency room described effective communication and coordination among providers about the event. In

Illinois, most participants who had been admitted to a hospital or had an emergency room visit said that their regular providers had been informed. Some participants in Ohio and Washington reported similar experiences. A few participants mentioned receiving assistance from care coordinators with care transitions.

My mother's nurse practitioner went and visited her while she was in the hospital. (*Proxy for Black female, LTSS, Ohio*)

And it's also set up if I get admitted to the hospital, [my care coordinator] gets an email... If I'm admitted to any hospital in the State, he gets an email and he messages me. (*White male, LTSS, Washington*)

And when I got ready to get discharged... we worked it out to where I only had to wait about 30 minutes for a ride... She was a really good care coordinator. (*Black male, LTSS/BH, Illinois*)

Other participants reported that their providers did not seem to communicate well with each other, and a few participants reported that their PCPs were not aware of emergency room visits or other care and services or benefits, such as medications or in-home services, the participants were receiving.

3.2.3 Patient Engagement

One of the care coordinator's key responsibilities is ensuring that enrollees are involved in their own care and obtain person-centered care planning. With increased care coordination through their MMPs or health homes, beneficiaries may experience changes in how they are engaged in their care and care decisions. Another area explored during focus groups was participants' engagement in their care since being enrolled in the demonstration. In particular, participants were asked about their role in making care decisions, whether they feel that they are part of a care team, and whether they work with care coordinators to set personal care goals.

Participants reported mixed experiences regarding involvement in their care decisions or (if proxies) in planning for their family members' care. Although some of these experiences related to goal setting (discussed in **Section 3.2.1**), the discussions also addressed topics of support and broad engagement with the care team. Some participants felt that they or (if proxies) their family members were well cared for and supported by a larger care team.

I feel like I'm part of a team. I have a good relationship with my doctors. My doctor tells me what he won't and what he will do. (*Black female, BH, Virginia*)

I feel they are [helping me] as part of a team, especially my doctors and therapists. Were it not for them, there are times when I would be worse off. (*Hispanic male, BH, Massachusetts*)

Regardless of whether participants felt like they were part of a care team, most participants recognized the importance of engagement with their care team. Some participants felt the need to

advocate for themselves within their care team. Some enrollees and proxies identified themselves as advocates who make sure that they or their family members' voices, goals, and preferences are heard and considered. Many considered themselves in charge of their own care. This included being able to change providers, change their health plans, or reject medical advice that they disagree with. However, some participants were not aware of their right to change their health plans or services (further discussed in *Section 3.5*).

So [there are] a lot [of services or benefits] out there that people just don't know about. I found them myself through research. ... I can get it done. (*Black male, LTSS, Virginia*)

You need to take control. You need to ask questions, be proactive, open a line of communication between your doctor and your specialists... I'm going to Seattle for the surgery. Every doctor that's involved knows I'm going, whether or not they want to know or not. (*White female, LTSS, Washington*)

If I say that I feel that this is what's wrong, [my doctor] always says right off, "No, that's not." So I just don't do what she says. (*White female, LTSS, Washington*)

I ain't going to let her [the care manager] rest. I call my doctor, he make my referral. When they don't call me back, I call them. I call them, I call their supervisor. Somebody's going to tell me what's going on. That's how I am. (*Black female, LTSS, Ohio*)

Well, as I mentioned since the beginning: the team that works for me, it works for me... I can always look for other options and change these people for other ones who do the same job. (*Hispanic male, LTSS, Illinois*)

The focus on patient engagement is a key feature in the Washington Health Homes MFFS demonstration; care coordinators focus on engaging enrollees to set health action goals and increase self-management skills to achieve optimal physical and cognitive functioning. However, many participants had not thought of calling their care coordinators when they needed help resolving problems, either because they thought of themselves as self-advocates or relied on other resources, or because they thought of their care coordinators only in terms of setting goals.

I would call different organizations, and probably that is because I worked in mental health for so many years. (*White female, BH, Washington*)

I would call [my care coordinator] if I needed help with something, but I don't think she would be very necessary because I have so many different layers of help for different things that I think she would be one of the later people I would try. (*White male, BH, Washington*)

Many participants said they were also engaged with their doctors, and some were actively modifying behaviors and managing their own health. In Washington, most participants said they had found doctors who listen, offer choices, and include them in decision-making, but some

participants raised issues they had with current or former providers who were not as engaged with the participant.

I've been seeing my primary doctor for the last few months. Prior to that, I went through three doctors. Not one of them did I like or understood me until I went to [my current PCP], and she listened and she understood. (*White female, LTSS, Washington*)

A couple other doctors I had never listened. They just told me what was wrong. They never listened to the symptoms. They never listened to what I thought was wrong. (*White female, LTSS, Washington*)

3.3 Role of Regular Providers

A key goal of the demonstrations is to integrate services provided to Medicare-Medicaid enrollees and to streamline their health experience. Along with the care coordinator, PCPs and other providers often play a pivotal role in service coordination and integration in the demonstrations. In the Washington MFFS demonstration, the State has leveraged its health homes to provide intensive care coordination and to serve as a bridge to integrate care across existing health delivery systems. In the capitated demonstrations, care coordination models vary but are often designed to include PCPs in the composition of interdisciplinary care teams, which are responsible for developing and implementing beneficiary service plans. This section describes participants' experience and relationships with regular providers, including satisfaction and the role of their providers in integrating care, as well as the degree of communication participants experience among their providers.

Highlights

- Most participants described positive experiences with their regular providers, and in capitated model demonstrations, provider participation influenced their selection of MMPs.
- Participants with limited English proficiency valued language-concordant providers, which influenced their selection of and satisfaction with demonstration health care providers.

Generally, many participants across the demonstration States included in this Issue Brief expressed satisfaction with their regular providers, and some reported long-standing relationships, especially with their PCPs. Several participants reported that a key consideration in choosing to participate in the demonstrations and in selecting their MMP included the ability to keep their same doctor. Many participants who liked their doctors reported that their doctor listened to them, provided valuable information, and treated them respectfully.

I'm very comfortable with [my doctor]. He's compassionate. He doesn't leave me hanging with questions that I ask. He answers everything. And we got a straight-on type of relationship, where if there's something wrong, he knows to tell me exactly what it is

and don't pitter-patter around the bush trying to say it's a little bit of—we don't go through that. So I'll stay with him [until I die]. (*Black male, LTSS, California*)

I am very happy with my doctor... She gives me great information, the health care, on how to take care of myself. She just breaks it down plainly to say, "There's not that much we can do for you, you have to do this for yourself." I love to hear that. You're not going to throw me some medication for every little thing, you're going to tell me how to take care of my health. (*Black female, BH, Massachusetts*)

When I take my mom over there [to see her provider], I come [home] happy. Really happy... Because, like, I see how the people treat my mom... they treat my mom like... with respect." (*Proxy for Hispanic female, LTSS, Illinois*)

My mom was able to keep the same doctor when we switched over. Because one of the things I did was ask the doctor which one of [the plans] to choose, because I wanted to make sure [my mom] kept the same doctor. And that's part of the reason why I chose [the MMP], because that was one of the ones that my mother ['s doctor] took. (*Proxy for Black female, LTSS, Ohio*)

Often, participants who reported having an attentive and communicative provider also reported greater involvement in their care decisions.

I have wanted to [go] off medicines because I take so many of them. My doctor listens to what I say and she gives me options and she really hears them. She throws out, "We can do this, this and this, and which one would you prefer?" She has to be listening to me to be able to come up with the options. (*White female, LTSS, Washington*)

My doctor, he listens. And I've had many issues with lots of specialists and people just trying to tell you, "This is what you need to do" ... So my doctor... I'll tell him what's going on. He'll ask me why do I think that's going on... "What do you think about this?" So he absolutely listens to me. That is so important to me. (*Black male, LTSS/BH, Illinois*)

Several participants reported that even when they vocalized their preferences or concerns, their providers were not sufficiently responsive to their input. Some participants reported that their providers often used complex or confusing medical language. As a result, some of these participants suggested that they were less likely to feel engaged in their care.

He doesn't listen to me... So I told them before, "I prefer a holistic method. Why do we have to keep taking these pharmaceuticals and deal with these pharmaceutical-based doctors that want to write these prescriptions?" ... Dr. [name] told me, "I agree. But they're not going to pay me to let you go to the health food store." (*Black female, LTSS, Ohio*)

When she explains stuff, I don't understand it. She uses the big terms instead of [language that is] more to my level for me to understand. (*Black female, BH, Virginia*)

Focus group participants who spoke English as a second language provided consistent evidence that linguistic access is a key consideration in selecting, maintaining, and being satisfied with their health care providers. Participants from States like California and Massachusetts spoke more often of having access to language-concordant providers than beneficiaries in other States.

The [clinic] asked me [about choosing a doctor] and I said that if he spoke Spanish it was all okay ... set me up with him. [And this doctor was assigned to me.] (*Hispanic male, BH, Massachusetts*)

[Speaking the same language] can help us understand each other. When I see [my doctor] I go there to talk, to chat, to ask for information regarding my health, about what should I do, what is right and what is not. (*Hispanic female, LTSS, California*)

We can communicate better [in Spanish] because I don't speak English. That is why I switched to that clinic. I used to go to [elsewhere] but it was in English, so I switched [providers] because there was more communication in Spanish. (*Hispanic female, BH, Massachusetts*)

From the participants' perspectives, some MMPs attempt to hire or contract with bilingual staff. The MMPs also provide interpreting services. Some focus group participants in California and Massachusetts reported having bilingual providers, whereas participants in Washington reported that they interacted with their providers via translators who were provided by programs outside of the health home. Sometimes, however, even when translation was provided, language appeared to be a barrier without the one-to-one communication with a provider.

I go [to the Federally Qualified Health Center] because they give us interpreters every time... that's why I changed from the clinic where I was before, because I had to pay for an interpreter all the time, they wouldn't give me one. And so I didn't want to be at that clinic, so I came here [to the FQHC], and here they did give me an interpreter. (*Hispanic male, LTSS, Washington*)

I feel better having someone who speaks Spanish. But if there was no one it would also be OK to have someone with a translator. (*Hispanic female, LTSS, Washington*)

Because a basic command of English is often insufficient for understanding complex materials related to plan enrollment, health benefits, and understanding discussions with providers, linguistic access was important for all of the participants in the Spanish-language focus groups, even for those who could communicate in English.

[My PCP visits are] always in Spanish and when I need someone they get me an interpreter. And because I've been going to the doctor for many years, I now understand a lot of English. I find it hard to speak the language, but I speak... I use both enough and I almost always ask for an interpreter, even if I understand but... But the language is sometimes a huge impediment; it's hard on us. (*Hispanic female, LTSS, Washington*)

3.4 Access to and Quality of Services

Focus group participants provided feedback on their experiences in accessing and utilizing services covered by the demonstrations. In States with capitated demonstrations, plans are required to provide adequate access to the full range of covered services through their provider networks. These covered services generally include medical, behavioral health, pharmacy, and LTSS. Specifications of covered benefits and requirements for network adequacy are set forth in the three-way contract among CMS, the States, and the MMPs. In Washington, which has an MFFS demonstration, the existing delivery system remains unchanged, but health homes provide enhanced care coordination to improve integration of care for Medicare-Medicaid enrollees. In addition to sufficiency of provider networks and ease of access to covered services, this section includes findings related to participants' perceptions on the quality of services.

Highlights

- Feedback was mixed regarding the size and scope of provider networks established by MMPs in the capitated model demonstrations, with limited choice of providers in some areas (particularly for behavioral health specialists, psychiatrists, pain specialists, etc.) and some participants noting frequent provider turnover.
- For some participants, care coordination increased access to new or flexible services, including home-based services and supports, home modifications, and counseling.
- In some cases, participants reported restricted access to medication and other medical equipment and supplies.
- Participants described inconsistent quality and reliability of non-emergency medical transportation, including late or missed pick-up, unsafe driving habits and inaccessible vehicles.

3.4.1 Provider Networks

Focus group participants provided mixed feedback on the overall adequacy of the size and scope of the provider networks established by the MMPs. Feedback differed within most focus groups, with some participants reporting the same or increased access to providers and others reporting more limited access to providers under the demonstrations. Depending on the demonstration State, some enrollees participating in the focus groups were previously served through FFS systems; others received all or part of their services through managed care. Some participants expressed overall satisfaction with the provider network available under the demonstration, including access to specialists.

It is an exceptionally good plan ... [under the demonstration] I have not had any problems getting an orthopedist, cardiologist, and therapist. (*Hispanic female, BH, Massachusetts*)

I feel like they saved my life... I'm a 10-year survivor of cancer. I have diabetes, high blood pressure, and a heart condition. There's always somebody to take care of me. I

have a heart doctor, I have a diabetic specialist, and I have the cancer specialist. (*Black female, LTSS, Ohio*)

I like the insurance I have now better than the old one. The old one, you were told which doctor you went to. And with this one, if I can find a good one, you're allowed to go, so I like it better now. (*White male, BH, Virginia*)

Several participants in Illinois, Massachusetts, Ohio, Virginia, and Washington reported more limited provider choices than what they had experienced before enrolling in the demonstration. These participants reported difficulties accessing certain types of specialists (e.g., pain specialists, psychiatrists, behavioral health providers, dentists) and long waits for appointments. Some participants in California noted long waits for service authorizations. In Massachusetts, a few participants mentioned being put on a waitlist for services because there are not enough of certain types of providers in the network.

There are some good doctors who are not under [my plan], and there are others who are under [my plan] and are not good. (*Hispanic male, LTSS/BH, Massachusetts*)

Right now, I'm search[ing] for a pain specialist... I'm under the plan... [but] a lot of [providers are] not taking the Medicaid part ... I'm in constant pain every day with my back and with my knee. (*Black female, BH, Virginia*)

I'm not satisfied. ... Because before we integrated, we could do a lot more things... My PCP would send us and there would be no problem. But now that we're integrated, like he was saying, certain doctors don't take you. (*Proxy for Black female, LTSS, Illinois*)

I went to see my doctor and he didn't want to see me. I tell him, "Why?" ... [He said] "Because you changed insurance that is not ours anymore." (*Hispanic male, LTSS, California*)

Some participants in the Washington MFFS demonstration also raised issues regarding access to specialty medical care, behavioral health, and dental services. Participants attributed their access issues to Medicare and Medicaid reimbursement rates and limited numbers of providers in their towns, rather than changes under the Washington demonstration, which is based on improving care coordination within the existing FFS delivery system and thus does not directly affect provider access. Some Washington participants said their care coordinators helped them find providers, whereas a few said they traveled to Seattle to access specialty care.

In general, our experience with Medicare is that you have a very limited choice. (*White male, LTSS, Washington*)

That I'm aware of, there aren't a lot of psychologists, psychiatrists in town that take Medicare and Medicaid. Mainly if a person is on Medicare and Medicaid, they have to go through the public mental health providers. (*White male, BH, Washington*)

There's only two diabetes doctors in town... when I got rid of the one, I had heard bad stuff about the other one. So that's why I said I'll just go to Seattle. Even though it takes a day trip, I'm going over there. (*White male, chronic conditions, Washington*)

As in Washington, participants in Illinois, Massachusetts, and Virginia reported limited choices of or access to behavioral health professionals.

They have mental services, but they give you the runaround with having to go and get the service... There's not enough information to inform someone of the services for a suicidal person. (*Black female, LTSS, Illinois*)

I am waiting to see a psychiatrist and since they have a lot of patients [they don't give me an appointment]. They first have to see those who are in crisis. (*Hispanic female, BH, Massachusetts*)

I'm kind of not satisfied, because I get attached to these [psychiatrists] and then they're just gone. (*Black male, BH, Virginia*)

In contrast, focus group participants in California—where these services are coordinated by the MMPs but continue to be provided by well-established county-based agencies—reported satisfaction with care they obtained from community BH service providers

I was in a program like that that really helped me...I suffered depression, anxiety, but there they have psychologists, therapists, everything, meals. That really gave me a hope... Activities when I was in a wheelchair. So they helped me so much, [having] the psychologists on site. It just completely gave me that boost and help. (*Hispanic female, LTSS, California*)

I have MAPS [Members Assertive Positive Solutions]]. They work with me ... they meet with me to talk to me. They set me up with my psychologist. And sometimes they take me places, like to go see a ballgame or to the movies or something. (*White male, BH, California*)

3.4.2 Access to New or Flexible Benefits

Because of differences in State policy and health care delivery systems, States developed different approaches to designing the demonstrations, and beneficiaries in different States may not have had access to the same set of benefits before—or after—enrolling in the demonstrations. All of the States with capitated model demonstrations, however, offer some new or flexible benefits as part of the demonstrations.

Several participants, noted that since they enrolled in the demonstration, they had increased access to new or flexible services. Access to these services was often facilitated through care coordination services, described more fully above.

I think the insurance I have now ha[s] more to offer than my previous insurance. By me being a diabetic, I can get my glasses, dental. I think what I have now is better. (*Black female, BH, Virginia*)

[One Care] provided me everything for the bathroom, the railings, the shower, the chair for bathing... Another thing was therapy. They sent me home therapy... I can now walk. (*Hispanic male, LTSS, Massachusetts*)

Participants discussed other examples of new or flexible benefits, including contact lenses, specialized wheelchairs, homemaker services, home modifications, nonmedical transportation, in-home behavioral health supports, nutrition classes, and weight loss counseling. A few participants in California and Ohio, reported that discretionary funds were used to provide household furniture and appliances.

They helped me with a bed... And they helped me with a washer and dryer. (*Black female, LTSS, California*)

So my microwave [broke], they bought me a new microwave... Microwave, maid service, a mattress. They bought me a new bed. (*Black female, LTSS, California*)

[My mom] got her bed, she got that wheelchair... I like what I got. I'm not going to change it for the world. (*Proxy for Black female, LTSS, Ohio*)

That's what they're for. I didn't have a stove. My case manager got me a stove. (*Black male, LTSS, Ohio*)

3.4.3 Quality of Transportation and In-Home Services

Several participants reported issues related to the quality of and access to transportation and in-home services. Participants were asked about their experiences with transportation services within the demonstration. Although problems with transportation vendors may have existed prior to the demonstrations, the quality and reliability of the services provided by MMPs' transportation vendors was a consistent theme reported in all States with capitated model demonstrations. Although a few participants reported positive experiences, most participants using transportation services expressed some level of dissatisfaction with them. Examples of complaints included lack of timeliness, errors in pick-up or drop-off locations, no-shows, drivers with unsafe driving habits, and inaccessible vehicles. Even though participants in Ohio described problems with the quality of the transportation services in that State, several noted that many of the problems had subsequently been resolved.

[The transportation service was] late. They just dropped me off. They were late picking me up. It got to the point that my daughter, when she was at work, I would call her and tell her. She would leave work to come to get me. So it began to be a problem. So we just cut transportation out. (*Black female, LTSS, Ohio*)

I had same-day surgery. I'm sitting waiting for them to come pick me up. I sat there 4 hours waiting on them that day. (*Black female, LTSS, Illinois*)

When you call for them, they might get there on time. Then again, they might not. They might not even show up. (*Proxy for Black male, LTSS, Virginia*)

Sometimes I'd have to sit for an hour or 2 and wait. They didn't come on time, pick me back up, and take me home. Or I'd have a crazy driver that's hitting all the potholes, and I'm hurting. And I always called and told whoever that these things happened. And then they'd send me a van that I couldn't [get in], that had a stepstool to get up into it, and I can't do that. I can't step up on—I'd have to cancel my appointment. (*White female, LTSS, California*)

Several participants reported that although transportation was an important benefit, they tried not to rely on the transportation provided by their MMPs, but instead sought out other means of transportation whenever possible because of poor quality and bad experiences with the service.

Focus group participants also reported issues with the quality and reliability of in-home caregivers providing homemaker or personal care services. This theme was expressed by participants in each of the States in which the RTI evaluation team conducted focus groups.

Sometimes you get this caregiver, they don't want to do anything. All they want to do is sit and [talk] on their phone and you got to tell them what to do ... But it's hard to get somebody to really come in and do for you. (*Black female, LTSS, Virginia*)

I would wave a wand and have an agency, home health care agency, who was absolutely 100 percent reliable. They have back-ups, they can guarantee you someone will be there, don't worry, mark it off your list.... (*Proxy for White female, LTSS, Ohio*)

I fired my [home health aide]. She was coming in and cleaning, and then I started noticing things were missing. (*White female, LTSS/BH, Massachusetts*)

3.4.4 Access to Pharmacy, Medical Equipment, and Supplies

Although most participants noted lack of a copayment on medications as a significant benefit of the demonstration, many of them reported restricted access to medication and other medical equipment and supplies since enrolling in the demonstrations. The theme was common in several of the States where focus groups were held. In some cases, participants reported that they could not access previously covered medications and supplies at all; in other cases, participants reported new and lengthy authorization processes. Because of these access barriers, participants reported disruptions in receiving prescription medications, over-the-counter medications and supplies, and medical equipment such as canes and walkers. A few participants reported issues with medical equipment repair or replacement.

Now I have [MMP]... Now I pay nothing. No copay or nothing. I love that. (*White male, LTSS/BH, Illinois*)

And also my copays have dropped down to nothing, so I'm spending about \$400 or \$500 less per year to get the same care that I was getting before, so it's been a big savings for me. (*White female, LTSS/BH, Massachusetts*)

So I go to my doctor, and he prescribes the pain patches for me... I can't get the patches because I need preauthorization. The preauthorization has been stuck in somebody's computer or somebody's desk somewhere in oblivion while I'm still in pain and I have no patches... I went through this with my nausea medication just a few months ago... So now I've got to go through all of this red tape and all this headache. (*Black female, LTSS/BH, Ohio*)

Everything worked [before we switched to an MMP]... When [my mother's incontinence supplies] came, I called again and made another order. I made the order for the next month and they always agreed to send them. And now they don't accept anything because this new insurance doesn't cover her [supplies]. And now she's the one... that has to pay... They don't cover anything anymore. (*Proxy for Hispanic female, LTSS, California*)

3.5 Beneficiary Protections and Rights

Each demonstration under the Financial Alignment Initiative includes rights and protections developed by CMS and the States to protect beneficiaries and supplement existing Medicare and Medicaid provisions. Most demonstration States created Ombudsman programs specifically for the demonstration populations. Staff of Ombudsman programs advocate on behalf of individual enrollees and provide an independent source of information about the demonstration. CMS and the States incorporated additional beneficiary protections into the design of the demonstrations, including provisions related to passive enrollment, continuity of care, access to services, and grievances and appeals. In the focus groups, we explored participants' awareness of these protections and their experience with them.

Highlights

- Awareness of the Ombudsman program was low, although participants who used it had positive experiences.
- Beneficiaries lacked awareness of their protections, mainly due to the complexity of the information provided upon enrollment.

Awareness of demonstration Ombudsman programs was low among focus group participants in most States, with Ohio being the notable exception where participants were more knowledgeable about the program.

Ombuds... What [does] this word mean? (*White male, LTSS/BH, Illinois*)

No, never. I haven't heard of [the Ombudsman program]. (*Black male, BH, California*)

No, I have no idea of anybody else to go to [for help]. (*Proxy for Black female, LTSS, Virginia*)

Few participants reported using the Ombudsman program, except for some participants in Ohio and California, who said they had called the Ombudsman's office for help and expressed satisfaction with the Ombudsman's intervention.

I had to call the Ombudsman when it came to my lift chair. Then [the case manager] [got] on his job every time. So Ombudsman is constantly calling me all the time. [The ombuds office] called me today to ... [check] on that chair. (*Female, LTSS/BH, Ohio*)

I was having a little problem with my [personal care attendant] getting her check... And I'm calling the number that you're supposed to—that person is supposed to help you, and not getting anywhere. So I called that Ombudsman... the check came 2 days later. (*Black male, LTSS, California*)

In the majority of States, participants indicated that they were not fully informed about beneficiary protections under the demonstrations. This was partially due to the complexity of the materials. As discussed in **Section 3.1**, many participants found the health plans' member handbooks to be too dense and difficult to understand. Participants in Illinois and Ohio were poorly informed about when they could change their health plan enrollment, and they believed they could not disenroll or change plans throughout the year. Some participants in Massachusetts reported that they had not received written notices when benefits were denied or not provided, so they did not have information on how to request reconsideration or file an appeal.

They give you 90 days to [choose an MMP]... and then you [are] stuck for 1 year because you can't switch [MMPs]. You have to wait. (*Proxy for Hispanic female, LTSS, Illinois*)

Yeah [you can change health plans], but it's like every 6 months or something. (*Black female, LTSS, Ohio*)

When I had surgery, I was supposed to have a nurse come out to my house, help me out because I can't lift my daughter, so I needed help with just regular stuff. I couldn't lift anything over 10 pounds, five or 10 pounds after my surgery. [When asked if she received anything in writing about how to file a grievance or appeal] I got no letter in the mail. I just got a phone call. (*Hispanic female, LTSS/BH, Massachusetts*)

Last year I had left knee surgery, and I did speak to a managed care person. I don't remember her name. But she sent someone out, a nurse. They came to my house, took all my information trying to get me prepared for the surgery, said someone would come out and help me with the showering or doing a few things. Then I got a call back right before surgery saying I'm not old enough. [I received a phone call] just saying I was not going to be able to have those services. (*Black female, BH, Massachusetts*)

3.6 Impact of Services on Health, Well-Being, and Quality of Life

A key goal of the Financial Alignment Initiative is to improve beneficiaries' quality of life by providing integrated care to Medicare-Medicaid enrollees. The focus groups examined

participants' perceptions about the demonstrations' impact on their physical and mental health and overall quality of life. Specifically, participants were asked if they obtained any new services since joining their MMP, whether they could do things that they could not do previously, whether they feel their health has changed, and whether their quality of life has changed. Many of the focus group participants in some of the States reported that their quality of life improved, but in other States, participants' responses were mixed.

Highlights

- Participants indicated that the demonstration had a positive impact on their quality of life. Most attributed this to greater access to services and achieving health-related goals.
- Negative impacts were mostly attributed to lack of access to previously available medications or supplies.

Participants who reported a positive impact on their quality of life credited the demonstration in general and specific features of the demonstration (e.g., care coordination, improved benefits) as making a positive difference in their physical and mental health and overall quality of life.

If I had to put a number on the whole Medicaid/Medicare insurance, as far as making [my] quality of life better, I would have to give it a 10. Because it has evolved so much now that it's enough even in the medical stance and getting you [out of] the house and helping you not to sit in the house wasting away. ... When I was no longer able to walk, I had to depend on the Muscular Dystrophy Foundation to help me get a lot of my stuff. Now Medicaid helps me get it or Medicare helps me get it. You have somebody to talk to now. They call you, like I say, once a month, make sure everything's all right, make sure the quality of life is still there, if there's [anything] they can do to help. (*Black male, LTSS, Virginia*)

I was shut in my house for years. My windows were drawn. I didn't have company. I just was mentally depressed, and my house was horrible—not dirty, but just like hoarders. ... Well, I'm completely off my psych medications, and I was on a lot of them for many years. I go outside. I interact with my neighbors. I go to church. My cholesterol is down to normal. It was dangerously high for many years. (*Hispanic female, LTSS/BH, Washington*)

The quality of my life? Now that, because of [BH service provider] and the rest of that, much better. They make me feel like Superman. They make me feel like a superhero. Really, I have never felt so good about myself. I thought I was going to go to hell. I really did. I thought I was going to hell in a handbasket. Now I've never felt holier in my whole life. They make me feel like Superman, they really do. (*White male, BH, California*)

I also see myself functioning better... This new coverage was able to give me things... that I couldn't get before... I can relax now knowing that [One Care] offered something to us that we definitely need. Not only that we want but we need. (*Black female, BH, Massachusetts*)

Since with insurance, a lot of things happened to me—because I used to be a hoarder. I didn't go outside. I stayed in the house 3 years straight until the workers started coming out. My primary doctor got her buddies, and they was coming by my house... They worked with me to start coming out in AA [Alcoholics Anonymous] and NA [Narcotics Anonymous] meetings. *(Black female, LTSS, Ohio)*

In cases where participants worked with a care coordinator to set goals and monitor progress toward these goals, participants reported changes in their behavior and health management that improved quality of life. These changes included weight loss, tobacco cessation, increased social activity, and improved functionality.

I was so sick until I couldn't spend any time with [my grandkids] at one point in time. When I got myself together, like I said, I'm doing way better than I was doing back then and all. I can do a lot of things now that I wasn't able to do. *(Black female, BH, Virginia)*

Oh, with my doctor's help, insurance help, as a team, this weight loss has changed my life. I do suffer from depression and the disc degenerative disease and a little bit of breathing. It's not completely over. But I'm better than I was. *(Hispanic female, LTSS, California)*

Actually, I had a goal where I use the walker when I walk... My goal is to walk around the house at least twice a day and I met that goal. My next goal is to be able to go from the living room to the bathroom and back. I met that goal also. *(White female, LTSS, Washington)*

However, some participants in a few States indicated that the demonstrations had no impact or a negative impact on their quality of life. Several participants reported that their health and health care services remained unchanged. For example, in Massachusetts, some participants expressed that their quality of life decreased because they did not have access to the medical supplies they needed. Participants in the California focus group also had mixed opinions about the demonstration.

[A participant who no longer has access to lidocaine patches described the experience with the demonstration as]: Stressful mentally. Physically, you don't have the same quality of life. If I had patches if right now, I would be able to move better, I'm afraid to move because it's going to hurt. *(Black female, Massachusetts)*

Well, for right now, I think that—it's like I told them. I said I think that my health, on one level, is about the same, but my mobility is really just not there. *(Black female, LTSS, California)*

I feel like I'm starting all over from scratch at the bottom in the meantime. We've had issues all along the way, just fighting for everything that she needs. *(Proxy for Hispanic female, LTSS, California)*

I would say we're just thankful that [my grandfather's health] stayed the same. *(Proxy for Asian male, LTSS, Virginia)*

4. Conclusions and Limitations

4.1 Conclusions

CMS created the Financial Alignment Initiative with the expectation that integrated delivery models would provide greater access and increased flexibility of services for enrollees by addressing the lack of cohesion beneficiaries face with standalone Medicare and Medicaid benefits. By aligning services through a single MMP or health home (in Washington), the Financial Alignment Initiative aims to improve beneficiaries' experience and access to and utilization of services and to achieve improved health outcomes. The design and implementation of these demonstrations reflects the States' considerable effort to develop beneficiary protections and care coordination services that are intended to support these goals.

The purpose of these focus groups was to hear directly from Medicare-Medicaid enrollees about their experiences with the services and care they are receiving under the demonstration. As is the case with qualitative research, participants were recruited to represent a mix of subpopulations, including racial and ethnic minorities, long-term services and supports users, and beneficiaries with behavioral health needs. Thus, results are not necessarily generalizable to the population of enrollees participating in the demonstration, although they are sufficient to reveal several key themes that emerged from participants' experiences in the first 6 to 12 months of enrollment.

Several similarities emerged across the States represented in this Issue Brief. The themes highlight important successes and challenges that impact beneficiaries' experiences within the demonstration.

4.1.1 Successes within the Demonstrations

Improved access and benefits, lower costs, and greater satisfaction. Some participants described overall satisfaction with the benefits they received through the demonstrations, highlighting easier access to services and increased care coordination. Most participants noted the lack of a copayment on medications as a significant benefit of the demonstration.

Positive experiences and engagement with goal setting. For some participants, goal setting was a key component of their interactions with their care coordinators, who put a plan in place to help participants achieve these goals. Participants recognized that through goal setting they were active members in their care team, and a number of participants discussed positive changes in their lives as an outcome of these goal setting activities.

Streamlined services through care coordinators. Most participants described their encounters with their care coordinators as positive, describing situations where the care coordinator had helped them obtain needed services and navigate complexities, remove barriers, and solve problems. They also described how care coordinators facilitated communication among providers.

Increased access to new or flexible services. Some participants noted that since they enrolled in the demonstration, they had access to new or flexible services, often facilitated through care coordination. Participants discussed examples of new or flexible benefits, including dental care, contact lenses, specialized wheelchairs, homemaker services, home modifications, nonmedical transportation, in-home behavioral health supports, nutrition classes, and weight loss counseling. In some states, discretionary funds were used to provide household furniture and appliances.

Maintaining long-standing relationships with PCPs. Participants valued their relationships with their PCPs, many of which were long-standing. Several participants noted that the ability to maintain this relationship with their PCP was a key consideration in choosing to participate in the demonstrations and in selecting their MMP.

Availability of bilingual providers and interpreter services. Focus group participants who spoke English as a second language provided consistent evidence that linguistic access was a key consideration in selecting, maintaining, and being satisfied with their health care providers. Some participants noted that their MMPs attempt to hire or contract with bilingual staff.

Positive impact on quality of life. Many participants credited the demonstration in general and specific features of the demonstration (e.g., care coordination, improved benefits, goal setting) as making a positive difference in their physical and mental health and overall quality of life. Most attributed this to greater access to services and achieving health-related goals through behavior change and health management.

No evidence of differences in experiences across subpopulations. Participant experiences were similar across racial and ethnic groups and there were no obvious problems that were particular to one group over another.

4.1.2 Challenges within the Demonstrations

In some cases, comments from focus group participants suggest challenges where States and, as appropriate, MMPs might consider follow-up as they continue to improve program operations and beneficiary experience. It should be noted that none of these areas were any more or less pronounced among the Black or Spanish-speaking participants. These focus areas include the following:

Demonstration materials. Participants were asked about the demonstration materials they received and the information it provided. Their overall responses indicate that participants' understanding of the demonstrations varied, and many noted that the written materials they received were often overwhelming, dense, and difficult to understand. Others were confused about changes in their coverage occurring without their knowledge or consent. Since the time these focus groups were conducted, CMS has made significant efforts to revise the national model notices to make them more readable and user-friendly, which may address some of the challenges focus group participants experienced. States might want to re-examine written

materials and processes for notifying beneficiaries about program changes, updates, or other important information that could affect access to care.

Streamlined care coordination activities. The focus group discussions also revealed that participants had difficulty differentiating care coordinators from other individuals who provide assistance (case managers, other MMP team members) and often did not understand their role. As a result, some participants were not clear about who to contact when they had problems or issues with their care. MMPs and care coordinators may need to provide additional information and reminders about care coordinators' responsibilities and how they can best help beneficiaries to address their needs.

Participants were actively involved in goal setting and were engaged with their care team and their physicians, in many cases describing a strong, positive impact on their quality of life. Most participants reported contact with their care coordinators; however, the frequency of the contact varied. Some participants also described a lack of follow-up with services needs identified during the assessment and high turnover among the care coordinators. States, MMPs, and QIOs may be particularly interested in investigating the turnover rate among care coordinators because this could potentially affect access to and utilization of needed services.

Robust provider networks and continued State and MMP provider outreach to encourage contracting. Participants had mixed experiences with access to care, with some participants describing increased access to new or flexible services including home-based services and supports, home modifications, and counseling, which had positive impacts on their quality of life. In the capitated model demonstrations, many participants reported that provider participation was a factor in their selection of MMPs; however, some described waitlists; a limited choice of specialists, such as behavioral health, psychiatrists, and pain specialists; and high turnover of Medicaid providers. As States continue to implement the demonstrations, attention should be given to the adequacy of the MMP provider networks, particularly for specialists, and States may consider additional outreach to remind beneficiaries to check plan networks for their providers before choosing.

Monitoring access to specific services. In some cases, participants reported restricted access to medication and other medical equipment and supplies. They reported problems accessing medications that had been helpful to them before the demonstration, or they cited new and lengthy authorization processes that disrupted their access to these items. As States continue to work with plans regarding covered medications and supplies, care coordinators may need to develop transition plans with beneficiaries to keep them informed of any changes and ensure that their needs are met.

The quality and reliability of non-emergency medical transportation was the most common issue participants raised. This included descriptions of late or missed pickups, unsafe driving habits, and inaccessible vehicles. Some States and MMPs have already taken action to change vendors to address this issue; however, focus group findings indicate that transportation vendors' quality

and reliability should be monitored closely, and expectations of these vendors should be clear and enforced.

Increased education about beneficiary protections and resources available, especially the Ombudsman program and resources for those with limited English proficiency. Although participants who used the Ombudsman program had positive experiences, there was a low level of awareness of the program overall. As a result, more education and greater emphasis in the notification materials about the Ombudsman program and its role may be warranted. There was also a lack of awareness of beneficiary protections, continuity of care provisions, and the ability to change plans at any time (in the capitated model demonstrations), mainly because of the complexity of the information provided upon enrollment. As mentioned earlier, CMS is already developing new materials to address this complexity. Until these materials become available, States and MMPs may consider additional efforts to disseminate information about the process for filing complaints and appeals and may instruct care coordinators to provide contact information for the Ombudsman program and remind beneficiaries of their ability to change plans at any time.

Awareness of language-concordant materials. For participants with limited English proficiency, having language-concordant materials and providers was highly valued, although in some instances, participants indicated that they were not aware of or did not have access to these resources. States and MMPs may want to consider additional outreach to provide information about these resources and inform care coordinators about their availability.

As evidenced by the highlights presented in this Issue Brief and the successes and challenges discussed above, these findings can be taken together to identify aspects of the demonstration that, from the participant perspective, appear to work well and to illustrate areas that may warrant attention from CMS, the States, MMPs, QIOs, and beneficiary advocates.

5. Next Steps

It is important to continue to monitor beneficiary experience within the demonstration. The evaluation will continue to conduct focus groups in Financial Alignment Initiative States. Focus group protocols will be tailored as needed to include questions and probes that ask participants about emerging issues. Results from these focus groups will appear in the State-specific annual reports. The evaluation will also continue to monitor the beneficiary experience through site visit interviews with States, plans, and other stakeholders, and during quarterly monitoring calls with the States.