

EXPERIENCES OF MEDICARE-MEDICAID ENROLLEES: FINDINGS FROM FOCUS GROUPS IN FIVE STATES

Beneficiaries who are enrolled in both Medicare and Medicaid participated in focus groups in five States. Commonly reported experiences included:

- *Challenges with coordination of benefits, including balance billing and difficulty obtaining authorization for services;*
- *Challenges with coordination of care, including communication among PCPs, psychiatrists and other specialists, long term services and supports case managers, and hospitals.*

Focus group participants who received Medicare and Medicaid through separate programs reported these problems consistently, while those with combined Medicare-Medicaid plans reported a markedly less complicated and time-consuming experience, particularly in regard to coordination of benefits.

All participants reported having access to a primary care provider, though many reported having had difficulty finding providers who accept both Medicare and Medicaid, especially when seeking specialists. When choosing among health plans (for Medicare, Medicaid or both) most participants reported that participation of their doctors in the networks was the most important consideration, and although many saw significant advantages in having a single plan that would combine their Medicare and Medicaid benefits, participation of their doctors trumped this and all other factors.

Background

Between April and August, 2011, the Medicare-Medicaid Coordination Office (MMCO) within the Centers for Medicare & Medicaid Services (CMS) sponsored 21 focus groups with Medicare-Medicaid enrollees in five States (Figure 1). MMCO was created by the Affordable Care Act to ensure that Medicare-Medicaid enrollees (often called dual eligibles) have full access to seamless, high quality health care, and to make the system as cost-effective as possible.

The objectives of the focus group were to:

- Gain insight as to how Medicare-Medicaid enrollees make enrollment decisions, including, where available, the decision to enroll in a single plan that combines Medicare and Medicaid services;
- Learn more about how enrollees experience various types of Medicare and Medicaid program combinations (e.g., combined in one health plan, divided across two health plans, divided between a health plan and fee-for-service); and
- Identify language used by Medicare-Medicaid enrollees that could improve the communication efforts of CMS, States, plans and community organizations.

Medicare-Medicaid enrollees are a diverse group. To ensure that a range of experiences would be captured, groups were conducted with specific subpopulations in three States: persons with physical disabilities in New Mexico, persons with serious mental illness in Pennsylvania and persons with developmental disabilities in Wisconsin. In Oregon, persons receiving community-based long term services and supports, and persons with other high needs were targeted. No specific conditions were targeted in the California groups. Table 1 provides more information about the characteristics of each group.

Focus group participants were invited by drawing random samples of Medicare-Medicaid enrollees who met the target characteristics for each group. Appendix A provides more detail about how participants were recruited.

Figure 1. Focus Group Sites

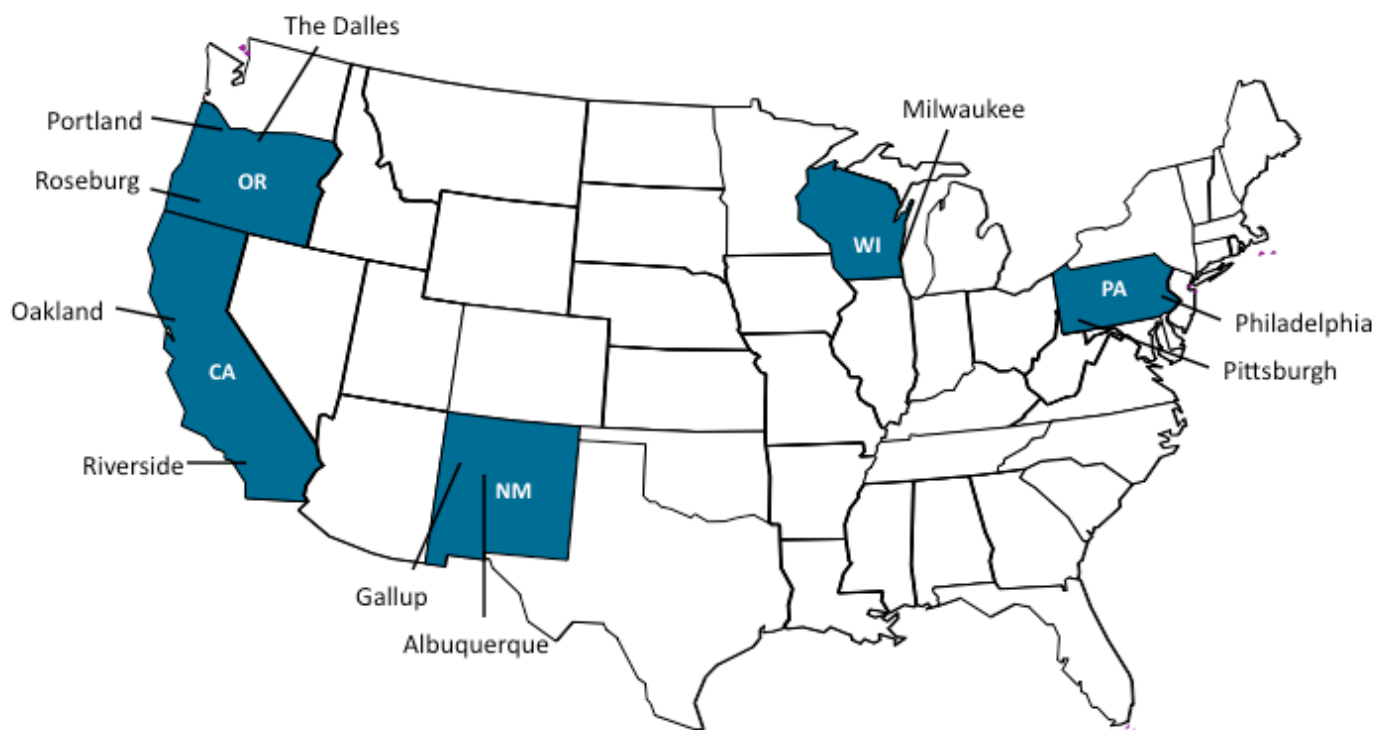


Table 1. Overview of Focus Groups with Medicare-Medicaid Enrollees

Sites	# of Groups by Age			Target Need, Condition or Disability	Target Area		Medicare and Medicaid Programs		Also noted	No. of participants
	18+	18-64	65+		Urban	Rural	Combined ¹	Separate ²		
California Oakland & Riverside		2	2	Any (no specific need targeted)	✓		✓	✓	One group with Chinese-speaking members	36
New Mexico Albuquerque & Gallup		3		Physical Disability	✓	✓	✓	✓	Majority of one group were Navajo	28
Oregon The Dalles, Portland & Roseburg	5		1	Receives LTSS (3 groups) High Need ³ (2 groups) Any (1 group)	✓	✓	✓	✓		39
Pennsylvania Philadelphia & Pittsburgh		5		Serious Mental Illness	✓		✓	✓		34
Wisconsin Milwaukee		3		Developmental Disability	✓		✓	✓		19
Total Groups 21										Total People 156

¹ Medicare and Medicaid services delivered through a single accountable organization. Combined plans all included Medicare Parts A, B and D. The range of Medicaid services in combined plans varied by State. Combined plans in New Mexico and Wisconsin included LTSS, for example, while those in other States did not.

² Medicare and Medicaid delivered through separate programs. This included persons with two unrelated health plans; persons enrolled in a health plan for one program and receiving the other through FFS, or receiving both through FFS.

³ High need was defined as having: 1) Six or more emergency department visits in 2010; a chronic mental health or substance abuse condition; or 2) any two chronic conditions. Many of the persons in the high need groups were also receiving LTSS.

Findings

1. What do Medicare-Medicaid enrollees know about the two programs?

"I believe Medicare covers the majority—and then Medical Assistance will pick up the co-pays, if I'm not mistaken."

(Female, under 65, Pennsylvania)

The degree to which participants understood the differences between Medicare and Medicaid varied widely. Some were able to describe the differences with a great deal of accuracy and specificity, including the services that each program pays for and the fact that Medicare is the first payer. Some specified that Medicare pays 80% of most visits, and Medicaid picks up the rest. Many associated Medicare with hospital coverage, and some knew that Medicaid pays for long term services and

supports. Others knew only that Medicare and Medicaid were separate programs but could not describe any differences between them. Most participants associated Medicaid with State or county social service offices, and Medicare with the Social Security office.

"Medicare will cover things as necessary to keep you alive, you know, and then I don't really know what the Medicaid covers."

(Male, under 65, Oregon)

2. How Do Medicare-Medicaid Enrollees Make Enrollment Decisions?

Sites were selected in part for the choices available to enrollees in their locales. In most areas, enrollees had access to combined plans⁴. In each State, at least one focus group consisted of Medicare-Medicaid enrollees in combined plans, and at least one group consisted of enrollees who received Medicare and Medicaid through separate service systems.

"I'd like to be on [the combined plan], but my psychiatrist won't take it, so I have to stay on straight Medicare."

(Male, under 65, with separate programs in California)

Many participants could not describe how they had chosen their Medicare and Medicaid options. Some said the arrangement had happened automatically, and others said they simply could not recall. This was reported by both Medicare-Medicaid enrollees in combined plans and those who received Medicare and Medicaid through separate systems.

Some reported having switched to their current arrangement in response to advice from someone whose opinion they valued. This was most often the person's doctor, but also mentioned were a case worker and a friend or family member. Some participants with combined

⁴ We defined "combined plans" as those that offered a combined package of Medicare and Medicaid services to enrollees. Combined plans all included Medicare Parts A, B and D. The range of Medicaid services in combined plans varied by State. Combined plans in New Mexico and Wisconsin included LTSS, for example, while those in other States did not.

plans said they had been receiving Medicaid from the plan and a care coordinator or other plan representative had informed them that they could add Medicare and have all of their benefits in one plan.

Some reported that they responded to a presentation or mail.

This included hearing a presentation at a senior center, health fair, festival or other venue, or receiving a post card, and inviting a representative to visit them in their homes.

Participants who recalled choosing combined plans

mentioned several specific reasons for having done so. These included:

- **Dental and eye care benefits** offered through combined plans that were not otherwise available if they maintained separate Medicare and Medicaid;
- **Reduced cost.** Some reported that they had joined a Medicare Advantage plan with a very low premium or no premium, and when the premium was scheduled to increase substantially, they had switched to a combined plan because it eliminated the premium;
- **Reduced “hassle” factor**, which included having a single health plan card to present to providers, elimination of balance billing, and a single number to call for service authorization or to resolve problems, regardless of payer.

“Well they can be quite overwhelming, you know. You don’t understand what they’re offering.”

(Female, under 65, with separate programs in Pennsylvania)

When asked what was most important to them in choosing a plan, most participants, regardless of whether they were in combined plans or separate systems, cited the **presence of their physician** in the network. For most participants with serious mental illness, **presence of their psychiatrist** in the network was most important. Chinese-speaking participants cited the **presence of Chinese-speaking doctors** in the network as most important.

“Medicare Advantage was OK at first, but then the monthly payment started creeping up. When I started, it was \$30 a month, but then it was going to be \$300, so that’s when I switched to the comprehensive.”

(Female, 65+, with combined plan in California)

For most participants, benefits were next in importance.

Dental and eye care benefits were mentioned in every focus group, and, as mentioned above, provided a particularly strong incentive to join combined plans. **Transportation and medication** were also mentioned by several as important. **Among persons with physical disabilities, durable medical equipment and personal care benefits** were particularly important factors.

Familiarity with a plan was also mentioned by several participants as an important factor. Some participants under 65 years of age, upon first becoming disabled and eligible for Medicaid benefits, chose the plan in which their children were enrolled. Others were in a plan for Medicaid, and upon becoming eligible for Medicare, chose to add Medicare to the same plan. For some, familiarity was a factor even if they did not like their current plan, because

staying with the plan felt safer than risking the unknowns of a new plan. Many participants expressed concern that if they switched, they might do so without understanding what they were giving up.

When asked what form information should take in order to help them make decisions, **most participants asked for written information**, with an easy-to-understand display of what is covered, what is not covered, and the cost. Chinese-speaking participants asked that materials be available in Chinese.

Several mentioned that **provider network directories** were important, but usually out of date, or misleading. Several related stories about identifying a new provider with a directory, then learning upon calling that the provider was no longer participating or was not taking new patients.

Most participants reported having **poor access to the internet** and did not favor internet-based information and tools.

Navajo participants stated a strong preference for in-person meetings on their reservation conducted in their native language.

3. How do Medicare-Medicaid enrollees experience services and benefits?

Primary Care

Most participants reported having a regular primary care practitioner (PCP). Participants were split in terms of longevity of their PCP relationships. Some reported having multi-year relationships, while others reported frequent changes in PCP. Some reported changing their PCP due to their own preference. Others reported that their regular source of care was a clinic or health center that experienced frequent turn-over among PCPs.

Navajo participants were a significant exception, with many reporting that they had difficulty accessing a regular doctor through the Indian Health Service (IHS).

"[My doctor] listened to me. He made sure that whatever concerns I had or whatever he thought it was that I needed to take care of, he took care of."

(Female, under 65, with the combined plan in Wisconsin)

While most participants reported good access to primary care, participants were split in terms of how they regarded their PCPs. Some described their PCPs as "wonderful" or "excellent." When asked what they valued in their PCPs, **most participants emphasized aspects of engagement and timely access**, including:

- Taking the time needed at appointments;
- Listening;
- Explaining things in simple language; and
- Being able to get an appointment or to talk to the PCP on the phone.

Other participants reported that they were not satisfied with their PCPs, but found it difficult to find new ones, or did not want to start over in terms of developing a relationship with a provider. The most common complaints were that PCPs did not listen, or did not take adequate time at appointments.

Hospital and Emergency Department Care

Many participants reported having had one or more hospital admissions or emergency department visits within the last year, and they described a wide range of experiences. Most reported having been admitted through the emergency department, as part of an unscheduled, urgent event, such as an accident, low blood sugar, acute pain or difficulty breathing. Some reported calling their PCPs first and being told to go to the emergency room. Others went directly to the emergency room without first calling their PCPs.

Some participants reported that their PCPs had been notified of their admission, while others said they had to tell their PCPs themselves about their admission. Many of those admitted reported that their **medication had been changed while they were in the hospital**, and they were not sure which medication to take upon discharge.

"In regards to having a problem... you have to call both numbers to get it resolved. And I was thinking, it would be just so nice if I could call one number and have it resolved."

(Female, under 65, with separate programs in California)

Participants with serious mental illness in separate Medicare and Medicaid programs reported particular difficulties when transitioning in and out of hospitals for psychiatric treatment. Participants indicated that there was little or no communication between the hospital staff and their community treatment teams. Many reported having their psychiatric medication changed while in the hospital, and being discharged with follow-up instructions that did not include their community teams. **Participants with serious mental illness who had agreed to participate in a special initiative of a combined plan reported much better communication.** Those participants had been asked to consent to electronic transfer of their information among all of their providers.

"Everything is covered. I just give them one card and I don't have to worry about co-pays, or which program pays what."

(Male, 65+ with combined plan in California)

Long Term Services and Supports (LTSS)

Most participants receiving LTSS described a parallel system that operated separately from their medical services. The person authorizing hours of "help" (personal care and homemaker services) was usually called a case manager. Most LTSS users reported that their case managers and doctors did not communicate. (Because many of the combined plans represented in the groups did not include LTSS, this was reported among both combined plan and separate program participants.)

Care Coordination

Participants identified several sources of care coordination. Participants who did not belong to combined plans more frequently reported that multiple people helped them with care coordination. Many reported having a case worker at a county or State office who addressed Medicaid eligibility issues, a worker at the Social Security office who helped them with Medicare issues and either a specific person or a department at a health plan that addressed service authorization and billing issues related to the plan. **Participants enrolled in combined plans more frequently reported the presence of care coordinators at their plans** who acted as single-point contacts when they needed help resolving problems, such as finding a new provider, getting authorization for a service, resolving a billing issue, and re-gaining Medicaid eligibility upon notice of termination.

"I was out of town, and I got sick ... so I went to a private hospital.... They just referred me back to my primary care, which is IHS. They told me any time that I need to go somewhere that I should carry a referral from IHS saying that I'm going to be out of town, that I'll be needing healthcare. That was kind of strange to me, and I said 'What are these insurance cards for?'"

(Female, under 65, in three separate programs in New Mexico)

Many participants reported that a family member (usually a spouse or grown child) or friend helped them work out problems, such as billing issues, finding a new provider, scheduling appointments and maintaining eligibility.

Many participants, in both combined plans and separate programs, noted the **importance of pharmacists in helping them with medication issues**. This included identifying changes in medication, calling PCPs with concerns about drug interactions, explaining why pills suddenly looked different (if, for example, a brand drug was being switched to a generic drug), and calling participants to remind them of upcoming refills.

Participants with serious mental illness often identified a social worker or therapist as the person they call when they need help. These were usually employees of a provider organization that provided Assertive Community Treatment teams or other community-based services.

Combined Plans v. Separate Medicare and Medicaid Programs

In general, **participants who had combined plans reported greater satisfaction with coordination of *benefits*** than those who did not. Having a single benefit card, and being able to make one call to the plan for most issues were cited as important features. Conversely, **participants accessing Medicare and Medicaid separately reported challenges related to coordination of benefits**. Most frequently cited was "getting the

run-around" when trying to solve a billing or authorization problem. Participants reported calling one organization, only to be referred to the other.

Coordination of care was less frequently mentioned as an important issue. When it was mentioned, participants usually cited lack of communication between their PCP and a specialist as the issue.

Coordination with Other Federal Programs

Several groups included one or more participants receiving services through the Veteran's Administration (VA). One group had a majority of Navajo participants accessing services through the Indian Health Service (IHS). In general, **VA participants expressed a high degree of satisfaction with their benefits, and reported no coordination problems between the VA and Medicare or Medicaid. Navajo participants reported significant coordination problems between the IHS and Medicare.** Navajo participants said they often were not certain who the primary payer was for their health services. Despite having Medicare and Medicaid coverage, participants reported that providers outside the IHS system will not see them without a referral from IHS.

4. What language do Medicare-Medicaid enrollees use?

The term “dual eligible” was not familiar to participants. When describing their dual-insurance status, participants used phrased such as “I have both;” “I get both Medicare and Medicaid;” or “I have two cards.”

“Fee-for-service” is not a familiar term. Participants often referred to the original fee-for-service program as “regular Medicare” or “straight Medicare”.

Each State has its own terminology regarding persons who play various coordination roles, though in general, **case worker** was most often associated with a county or State eligibility worker; case manager was most often associated with a key provider group, such as an Assertive Community Treatment team or long term services and supports agency, and **care coordinator** was most often associated with a health plan.

Long term services and supports were nearly universally referred to as “help” and described in terms of hours per week or per month.

People with combined care plans did not use the terms **integrated care or coordinated care**. They referred to a product name, such as “Complete Care” or “Dual Choice.” They described these plans as having “everything together.”

5. What would Medicare-Medicaid enrollees change about their care?

Common responses to this question included:

- Provide dental and eye care benefits;
- Provide better transportation benefits;
- Cover alternative treatments, such as homeopathy and herbalists;
- Eliminate duplication of testing between PCPs and specialists;
- Improve communication and coordination across providers; and
- Reduce wait times for scheduled appointments with specialists.

“[I would like] one centralized person that we would deal with that deals with everybody else, coordinating everything.”

(Female, under 65 with separate programs in Pennsylvania)

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Additional Reports

State-specific focus group reports are available for two of the States included in this brief.

California:

<http://www.dhcs.ca.gov/provgovpart/Documents/Duals/Public%20Meetings/CA%20Focus%20Group%20Findings.pdf>

Oregon:

<http://health.oregon.gov/OHA/OHPB/health-reform/docs/2011-1019-materials-med.pdf>

(Report begins on p. 66)

Appendix A. How Focus Group Participants Were Recruited

CMS and its contractors, Thomson Reuters and The Zacharias Group, worked with local partners (State agency staff, health plan staff, or both, depending on the target group) to develop and carry out the following recruitment steps:

1. A target profile was developed for each group that included service area, service delivery system (e.g., managed care or fee-for-service) and beneficiary characteristics. Having both Medicare and Medicaid benefits was required for all groups. Other characteristics varied by group. (See Table 1 for group characteristics.)
2. For each group, a State agency or health plans drew random samples from client files of between 250 and 350 persons who met the profile for that group.
3. The State agency or health plans mailed written invitations to the persons in each sample. The letters instructed interested persons to call a toll-free number if they wanted to volunteer for a group. As an incentive to participate, the letter offered a \$50 gift card to those selected. The letter also offered assistance with transportation.
4. Calls were received by the focus group moderator who asked screening questions to ensure that the caller met the group criteria and held a bona fide invitation. Callers who met the screening criteria and who stated they wanted to participate were asked for their verbal consent at that time and were told that a written consent would be completed at the group itself.
5. One week prior to the focus group date, confirmation letters were sent to participants.
6. On the day before the focus group, participants were contacted by phone to remind them of the groups and confirm any transportation arrangements required.
7. An average of 7 participants per group attended.