

**Medicare's New Prescription Drug Benefit:
The Voices of People Dually Covered by Medicare
and Medicaid**

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Introduction

This focus group report was undertaken to gather the voices of “dual eligibles” on the new Medicare prescription drug law. Today, an estimated 6.4 million low-income people, including seniors and younger people with permanent disabilities, have coverage under Medicare and Medicaid. Medicare helps pay for basic health care services, like physician and hospital care, while Medicaid fills in Medicare’s gaps, and covers services and supplies that not covered by Medicare, such as prescription drugs. These people, sometimes called “dual eligibles” because both programs cover them, tend to rely heavily on medications to maintain their health and quality of life. As a result, assuring a smooth transition from Medicaid to Medicare coverage is a key implementation challenge for this population.

Beginning January 1, 2006, dual eligibles, like all other people on Medicare, will be eligible to receive drug coverage under new private, Medicare prescription drug plans. On the same date that their drug coverage shifts to Medicare, Medicaid will stop paying for their prescription drugs. Dual eligibles are expected to select and enroll in a private Medicare drug plan. If they do not sign up on their own, they may be auto-enrolled in a plan that provides drug coverage in their area. Given the importance of pharmaceuticals to dual eligibles, a smooth transition from Medicaid to Medicare plans poses numerous challenges. These low-income individuals will need to find a plan in their area that covers their drugs, then sign up for coverage under that plan, and learn how to use the plan to avoid disruptions in their care.

As the details of how dual eligibles will move from Medicaid to Medicare prescription drug coverage are being worked out, these focus groups provide some insights into the beneficiary perspective. This focus group report highlights the kinds of questions, uncertainties, and reactions that dual eligibles have when asked about the impending changes in their drug coverage.

Background on the Focus Groups

We conducted five focus groups between September and November 2004 with different groups of dual eligibles. The chart below outlines the groups and locations. The sites and participants were selected to capture a wide range of perspectives based on differing characteristics and health conditions.

Date	Location	Participants
9/28/04	Baltimore, MD	Dual Eligibles with Physical Disabilities (e.g., blindness, diabetes, neurological disease, paralysis due to stroke)
9/29	Los Angeles, LA	Dual Eligibles with HIV/AIDS
10/4	Tulsa, OK	Dual Eligibles Who are Low-Income Seniors
10/5	Tampa, FL	Dual Eligibles Who are Low-Income Seniors
11/9/04	Verona, NJ	Dual Eligibles with Mental Health Needs (e.g., post traumatic stress disorder, severe depression, schizophrenia)

To qualify for the focus groups, individuals needed to be certain about their sources of health coverage (Medicaid and Medicare) and to know that it is Medicaid that currently covers their medications. In addition, only dual eligibles that took two or more prescription medications regularly could qualify for the focus groups. As a result of the selection criteria, the dual eligibles that participated in the focus groups were likely better informed and more experienced health care consumers than many of their peers and may have more at stake in the transition given their high reliance on prescription drugs. These knowledgeable consumers were recruited intentionally to ensure participants could give thoughtful consideration to the changes that will soon be occurring in their prescription drug coverage.

Background on the Medicare Modernization Act

Creation of a Prescription Drug Benefit in Medicare

The new Medicare prescription drug law creates a “Part D” to the Medicare program to provide prescription drugs to Medicare beneficiaries. The new Part D program will rely on private plans to deliver the prescription drug benefit. Within some ground rules set up by the federal government, the private plans will have the flexibility to design the prescription drug coverage that they will provide, including to some extent which drugs they will cover.

Dual Eligibles Move from Medicaid to Medicare Drug Coverage

The new drug law also includes fundamental changes in the prescription drug coverage of people with both Medicare and Medicaid coverage. Currently, dual eligibles get their prescriptions filled through their state Medicaid programs. Although the rules vary from state-to-state, Medicaid programs generally cover all necessary medications for dual eligibles. In recognition of their limited incomes and often complicated health status, Medicaid programs generally require little or no-copayments of seniors and people with disabilities.

Under the new Medicare law, dual eligibles’ prescription drug coverage will be provided through Medicare and they will no longer have Medicaid prescription drug coverage on January 1, 2006. They are to obtain their coverage by enrolling in one of the new Medicare drug plans for their medications. Once enrolled, they will qualify for special assistance with the cost of paying their premiums and meeting their cost-sharing obligations. Specifically, they will be fully subsidized for the cost of enrolling in an average or low-cost Medicare drug plan. In the first year of the new Medicare drug benefit, they can expect to pay \$1 to \$5 when they fill a prescription. In later years, their co-payment obligations will increase with inflation.

Like other Medicare beneficiaries, dual eligibles will start getting detailed information about the plans available to them in October of 2005. About a month later, they can begin to sign up with a Medicare drug plan. If they do not sign up for a drug plan on their own, they will eventually be automatically enrolled in a low or

average cost plan on a random basis. Once assigned to a plan, dual eligibles can decide to switch plans or drop out of the Medicare drug benefit altogether.

At the time the focus groups were conducted, many details were missing about how this automatic enrollment process would work. In proposed regulations implementing the new Medicare law, the federal government said it still needed to decide whether states or the federal government should be responsible for this task. It also said that it would not begin automatically enrolling dual eligibles in plans until May of 2006, some five months after their Medicaid drug coverage ends. Since this would mean that dual eligibles could end up with no drug coverage for several months, it is likely that this decision will be reconsidered and an effort will be made to get dual eligibles into Medicare drug plans before their Medicaid drug coverage ends on January 1, 2006.

Characteristics of Dual Eligibles

Currently, Medicaid plays a key role in filling in gaps in Medicare coverage for millions of low-income seniors and people with disabilities who are enrolled in both Medicaid and Medicare. Since seniors and people with disabilities generally must have income well below the poverty line and minimal assets to qualify for Medicaid, the 6.4 million dual eligibles are much poorer than other Medicare beneficiaries. They also are far more likely to have serious health conditions such as diabetes, high blood pressure, and dementia. More than 1.5 million dual eligibles are nursing home residents. A small, but critical, minority of dual eligibles has serious mental health issues and is at considerable risk of hospitalization if they miss their medications. Similarly, some 55,000 dual eligibles, are HIV positive and risk the prospect of developing resistance to their medications if they experience disruptions in access.

Results in Brief

As noted above, to qualify for the focus groups, individuals needed to be certain about their sources of health coverage (Medicaid and Medicare); to know that it is Medicaid that currently covers their medications; and to use two or more prescription medications regularly. That these dual eligibles who are relatively sophisticated consumers find the impending changes to their prescription drug coverage to be confusing and upsetting offers a cautionary note for program implementers. In sum, they are surprised to hear that Medicaid will no longer be covering their medications as of January 2006 and have many questions about the new Medicare plans they will be choosing from and the costs associated with these plans. Most are pleased with their current Medicaid prescription drug coverage and say it is working well, so they worry that they will be worse off under Medicare. A detailed review of the focus group participants' comments on these and other issues follows:

The focus group participants were asked 1) to provide information on their current use of medications and their existing knowledge of the Medicare Modernization Act; 2) to react to specific information about how the Medicare law would work for dual eligibles; and 3) to help identify the best ways for the government and Medicare drug plans to communicate with dual eligibles. The participants' responses in each of these areas are summarized below.

I. Current Environment

Most focus group participants are very satisfied with their Medicaid drug coverage

When asked to rate their current Medicaid prescription drug coverage, most give it a positive mark of “8” or better on a 1-to-10 scale. They appreciate that Medicaid makes their medications affordable. Many say they would be unable to pay for their medications without this coverage. The majority reports they can get all the medications they need under the program. The few that have faced problems have usually been able to overcome them with help from their doctors. Since they are generally very satisfied with their current coverage, they tend to react negatively to the prospect of any changes in their Medicaid drug coverage. In every focus group, the adage “if it ain’t broke don’t fix it” was employed by a number of participants to describe their feelings about the prospect of changes to their drug coverage.

“God Bless America and thank God for Medicare and Medicaid”

– Low-income senior in Florida

Most focus group participants have positive feelings about Medicare.

Most dual eligibles in the focus groups express positive feelings about Medicare. “I’ve actually no complaints with it,” comments an individual with HIV/AIDS from Los Angeles. They appreciate Medicare coverage for the access to services it provides them as well as Medicaid for picking up many of the fees and services not covered by Medicare. However, a few know that expenses can be high under Medicare for those who do not also have Medicaid.

Medications can be the difference between life and death.

“They keep me alive” is how an individual from Baltimore with a physical disability explains the role of medications in his life. Most dual eligibles stress that their prescription medications are important for their health and quality of life. For many, if they miss even a few days of their medications they put their life at risk. “[Without medications] I wouldn’t be able to walk,” says a low-income senior from Tampa. “I get very, very bad seizures when I don’t take it,” a Baltimore woman with a physical disability explains. “[I] have asthma and [a problem with] my lungs and I have to have medication to breathe,” says a low-income senior from Tulsa. “Well, being a diabetic of

“[Without my medication] I’d be six feet under.”

– Individual with a physical disability from Baltimore

course you'd go into a coma probably if you didn't have your medication," explains a low-income senior from Tampa.

Individuals with HIV/AIDS in Los Angeles explain that they must maintain a strict drug regimen to keep their virus in check. Doing without even one of their medications can start them in a downward spiral. As one man with HIV/AIDS in Los Angeles explains:

“[Without medications] you could start a whole cycle of the quality of life issue. Whereas we may be healthy, we're healthier than we would be because we're on medications consistently. You know it could start a whole cycle of getting ill... [I]f we start missing medications, one medication out of a regimen or two is enough to start a cycle of that, just start a downward spiral. You know it's not necessarily that we would get sick and the virus would come back and we die. But it could start a whole downward spiral there.”

“I find that if I don't take my medicines ... I'm hospital material.”

– Individual with Mental Health Needs from New Jersey

In the focus groups, for nearly all of the dual eligibles with mental health needs, medication is the only path to being a functioning member of society. Many say that prescription drugs allow them to complete daily tasks, maintain self-sufficiency, and for some, to work part-time. Without consistent and appropriate medications, hospitalization (which many have already experienced), homelessness, or death could ensue. “All I know is medication for me is a life and death issue. We're talking severe problems without it,” explains an individual with mental health needs from New Jersey.

Living on fixed incomes means any new cost is problematic.

One point consistently expressed across the focus groups is that dual eligibles live on fixed incomes – usually social security checks – which leave little room for new health care costs. The participants are concerned that under the new Medicare drug plan they will have to pay higher copayments. About half of participants say they currently pay no copayment for their medications while the other half says they pay between \$2.00 and \$7.00 per prescription.

The prospect of new or higher co-payments raises concerns because the participants generally have no extra money to put to their medications. They already live beyond their budgets and often rely on their adult children to help them financially each month. Others say they do without food or other items to afford all their bills. Most assert that it is important that policymakers in Washington making decisions about the new Medicare drug plan take into consideration the limited financial means of dual eligibles. As an individual with HIV/AIDS from Los Angeles says, “[A rise in co-pay] could mean the difference between paying a light bill or buying medicine to me. I mean \$700 or \$800 dollars month is what most people get.”

Focus group participants are confused by what they are hearing about Medicare in the media.

"It's very confusing. I threw all that stuff away."

– Low-income Senior from Tampa

Many focus group participants say that the media is already putting out information about changes to Medicare, but they are uncertain as to how it relates to them. This was most apparent in Tampa, FL, where low-income seniors in the focus group tell about being barraged with information about Medicare discount cards and other Medicare information. "Yeah it's just so confusing. You get it in the mail. You see it on TV," explains a low-income senior from Tampa. Some other participants indicate that they disregard information that is sent to them about Medicare prescription drug changes because they secure medications through Medicaid. "I got some literature on it, but I didn't read it because I'm getting both [Medicaid and Medicare] and I don't want to change," says an individual from Baltimore who has a physical disability. (In fact, the Medicare drug discount cards are not available to people enrolled in Medicaid, but dual eligibles will be subject to changes in their drug coverage when the full Medicare drug benefit becomes available on January 1, 2006. The focus group participants' knowledge of and reactions to these changes are discussed in the next section.)

Most of these dual eligibles have good relationships with their doctors and pharmacists.

"My doctor is just like a friend to me," explains a low-income senior from Tampa. Most other dual eligibles in the focus groups make similar comments. "My doctor [is] different. He'll fight for you," says an individual with a physical disability from Baltimore. Many say they have turned to their doctors in the past when they faced problems obtaining a medication they needed. A number tell stories about their doctor arguing on their behalf to have a medication covered. In addition, many say their doctors have provided free samples when they could not obtain a medication. "There's one medication the insurance wouldn't cover," explains an individual with a physical disability from Baltimore, "I had the doctor [call] again. The doctor called and told them 'Yes, that's the medication he needs [that] he's got to have.'" Many feel their doctors are on their side and will advocate for them in terms of prescription medication.

Many dual eligibles in the focus groups also say they have good relationships with their pharmacists. While this feeling is not as strongly expressed as with doctors, many say they turn to their local pharmacists for information and help regarding prescription medications. One participant explains why individuals with HIV/AIDS tend to have such strong relationships with both their doctor and their pharmacist: "The [drug] combinations are complex. Most of us don't really, can't figure it ourselves, which is why we trust our doctors. You know, we really rely on pharmacists [too]."

Two exceptions to these positive feelings toward pharmacists emerged. In the Tampa focus group with low-income seniors, a few participants say they do not have strong relationships with their pharmacists and do not often seek their advice. Some blame “chain pharmacies” for replacing local, neighborhood pharmacies. “They used to take better care of you, now it’s a business situation,” observes a low-income senior from Tampa. The other negative sentiment came from a few of the participants with mental health needs in New Jersey. Because of low incomes, they express frustration that different pharmacies charge different amounts for prescriptions. In this case, it is the larger chain pharmacies that offer lower prices, compared to a neighborhood drug store.

Many of these dual eligibles have found ways to get around problems they have encountered with their medications.

Many participants in the focus groups describe situations in which they had been persistent and resourceful about getting medications that they need. “I’ll do whatever it takes,” comments an individual with HIV/AIDS from Los Angeles. Many tell stories of overcoming obstacles to their prescription medications before enrolling in Medicaid. This includes obtaining free samples from doctors, contacting pharmaceutical companies for discounted medications, enrolling in local and state pharmacy assistance programs, and enlisting their doctors to help them get coverage for a particular medication. Since enrolling in Medicaid, however, most say they have not faced these kinds of problems and so are grateful.

However, the strategies dual eligibles say they used to overcome barriers do not always work. “For some reason it was a year or so ago and I couldn’t get them to give [my medication] to me and it was the pill that controls the arrhythmia or the rhythm of the heart and all of a sudden I went into fibrillation or something like that. I had to go the emergency room,” explains a low-income senior from Tampa. Others tell of skipping medications when they were not enrolled in Medicaid and could not afford to pay on their own. Some of the dual eligibles with mental health needs mention times when they could not get medications resulting in serious withdrawal symptoms or an inability to function at work. Many have also had to be hospitalized in the past when they went without medications.

Many focus group participants feel health insurance information is difficult to understand.

In the focus groups, many dual eligibles say they feel that most health insurance information is too complicated for them to understand. They say that they “need to be a lawyer” to understand the Medicare information they currently receive in the mail. Most admit they do not read their Medicare rulebook unless they face a specific problem. “That’s one that I stuck in the bottom drawer and look at it when I have to,” comments an individual with a

physical disability from Baltimore. They say most health insurance information they see is too technical and in words they do not understand. Whether from Medicare, Medicaid, or private insurance plans, dual eligibles feel that incoherent written materials are a chronic problem of the health industry.

“[The written materials are] going to be pamphlets of information that are so confusing that at my worst I can’t even keep a paragraph in my head let alone a sentence. How am I going to read a 10-page document and then decide for myself?”

– Individual with Mental Health Needs from New Jersey

Many of the participants worry about their ability to sort through the information they will be receiving regarding the changes in their prescription drug coverage. Of note, they are most worried about their less-informed friends who are also dual eligibles and the vulnerable elderly when it comes to reading these materials and making informed choices. “I think this is good for people [who are] capable of making the decision, but there are some people that are so ill that their minds are not sharp enough to do that,” says a low-income senior from Tulsa.

The dual eligibles with mental health needs in the New Jersey focus group underscore the sentiment that health insurance materials are very difficult to comprehend. Further, they note that mental disabilities can sometimes impair someone’s cognitive ability to absorb and understand materials. A number say that they need brief, simple communications about changes to their health care benefits as well as plenty of time to absorb the information before having to act upon it.

II. Reactions to Specific Medicare Changes

An important purpose of these focus groups was to hear reactions from dual eligibles about how specific elements of the new Medicare drug law could affect them. This conversation occurred midway through each focus group and the changes were presented one-by-one so that participants could weigh each individually. Since Medicare is still making decisions about how prescription drug coverage will work for dual eligibles, some of the ideas tested may not be implemented as they were described. However, by seeking dual eligibles’ concerns, information gaps, advice about implementation, and thoughts about communication around specific types of changes, the results of these focus groups can help to highlight ways to smooth the transition in coverage for dual eligibles.

Few expect changes to their prescription drug coverage.

Few of the dual eligibles in the focus groups understand that their prescription drug coverage will change as of January 1, 2006. “This is the first time hearing [about] it,” says an individual with a physical disability from Baltimore. While some know that a law has passed enabling Medicare to cover prescription medications, most feel this law will not affect them. “It doesn’t apply to me because my [medications] are taken care of with both Medicare and Medicaid,” explains a low-income senior from Tampa. Indeed, even after being told about the pending changes to their drug coverage, a few

“‘I’m very happy with my [prescription drug] program, so why change?’”

– Low-income Senior from Tampa

actively resist the information. For example, some of the Maryland participants argued that they would not be affected by the pending changes because they are part of Medicaid waivers, although the law provides no exemption for Medicaid waiver participants.

The exception was among New Jersey participants with mental health needs who are very well-informed. They recognize and identify with the term “dual eligibles” and some already know about the upcoming changes to their prescription drug coverage. This is because many are well-connected to advocacy organizations and networks of dual eligibles. Also, a few had already received a letter from the New Jersey Secretary of Human Services advising them about pending changes. However, since most of these dual eligibles are very satisfied with existing coverage, initial reactions to change in prescription drug coverage are overwhelmingly negative.

“The fact that [my drug coverage] seems like it is working okay already... Just the fact that they’re changing it, that’s already sounds suspicious.”

– Individual with HIV/AIDS from Los Angeles

When learning their drug coverage will change, many react negatively

When told they will be moving from Medicaid to Medicare drug coverage, most question why their prescription drug coverage must change. Since they are very satisfied with their current drug coverage under Medicaid, their initial reactions are negative. They want to know who wants them to change and why. Many simply try to deny that changes will occur or hope that they will be unaffected by Medicare changes because they have Medicaid. As an individual with HIV/AIDS from Los Angeles puts it, “I don’t really have enough information to know one way or another [if this new Medicare plan will work for me]. But my initial thinking, especially since I’m pretty content with something and they’re tinkering with it.... My instinct is that it’s going to not be as good as what is being replaced.”

“I feel angry...and scared that someone is going to tell me what to take...and maybe I have some [paranoia], but I’m scared that they are just not going to give me the medicine and I will wind up back in the hospital.”

– Individual with Mental Health Needs from New Jersey

Dual eligibles with mental health needs are particularly distressed with many responding emotionally, feeling vulnerable, angry, and scared. A few mention that these changes exacerbate feelings of paranoia, and one had to call her therapist at night after hearing about these changes to help cope with the information. Fear of change, a natural part of the human condition, lies beneath many of the concerns expressed by participants.

Many worry about private plans providing the Medicare drug benefit, but some think it will be a good thing.

Some dual eligibles focus on the fact that their medications will be covered by private plans under the new Medicare program. “Why does it have to be private?” asks a low-income senior from Tulsa. Most participants assume that they will somehow be worse off under a private plan. Some feel that plan will “not look after them” and will “only be concerned about making a profit.” This view was expressed by an individual with HIV/AIDS from Los Angeles

when she commented, “I don’t trust private industry or corporations because it’s all about the bottom line.”

“I do believe...the statement that if a private company was going to make money by doing this well, then they’d do it better than the government could do it.”

– HIV-positive individual from Los Angeles

But, a few of the participants cite positive aspects of privatization, including that private plans perhaps will have a greater incentive than the government to provide high quality prescription drug coverage. When considering whether the government or private plans are better equipped to provide the Medicare drug benefit, one HIV-positive man from Los Angeles notes “It’s more like six in one hand and half a dozen in the other so to speak. I do trust private corporations that are interested in making money. And so therefore, I’m kind of swayed toward maybe they might do a little something...for you, but I don’t know...I’d have to see what is happening.”

Many question their ability to choose the right plan, but a few are confident.

When it is explained that they will need to choose among different private drug plans in Medicare, some dual eligibles worry about their ability to choose well. These participants say that they are confused by health insurance information generally and fear they will make a bad choice. “It would really scare me because I wouldn’t know what I’m up against. I mean, I would deal with it of course, but it would be frightening just out of the clear blue,” says an individual with HIV/AIDS from Los Angeles.

Choosing the right plan is especially disconcerting for dual eligibles with mental health needs. These participants express a need for a lot of advance warning and time to choose a plan so they can deal with the information at times when they are equipped and mentally able. They also need help in identifying the best plan: “If I have to make a decision on which company or plan is the right one for me...at times I don’t think I can make a decision,” says one participants with mental health needs from New Jersey. While many say they would turn to their doctor or psychiatrist for guidance in selecting a plan, some doubt the efficacy of that strategy: “When I go to see my psychiatrist and he puts me on a certain medication...are they going to know every single plan, every single medication covered?”

Others are concerned that they will not be provided with information about plans in a format that makes it possible for them to readily compare them and make a selection. One low-income senior from Tampa expresses his concern this way:

“If they give me five at once and say here are the plans available [and] you could lay them down and compare them, fine. Okay I can accept that. But if I get one from the insurance company. One from the drug company. One this week, one next week, one a month later and one a month earlier, I won’t know what I’m talking about.”

Another issue is the future – while their ability to make informed decisions about drug coverage is fine now, what about the future? This is a particular concern for the low-income seniors. “Right now, I am confident enough to make choices, but in a year from now, who knows?” comments a low-income senior from Tulsa.

“Well I don’t think it would be hard for me as long as I’m looking at the plan, seeing what they’re offering, and I can make the choice and of course I’m going to make the choice with the one that’s giving me the most for my money.”

– Low-income senior from Tulsa

However, a few of the participants express confidence that they can pick a plan that will work for them. They perceive themselves to be savvy health care consumers and persistent enough to get answers to their questions. These dual eligibles say they would likely ask their doctor, family members, or even pharmacists or caseworkers to give them advice about which plan is best. Some say they will even call the 1-800-Medicare number to obtain information. But they worry about friends and other dual eligibles they know – will they be able to wade through insurance information and make the right choice?

Many in the focus groups want to know if they will be able to switch plans easily.

Most participants want to know whether or not they will be able to switch plans if they enroll in a plan that does not cover their medications. They fear being locked into a private drug plan that does not meet their needs. This is why so many dual eligibles in the focus groups feel pressure about choosing a private drug plan – if they make a mistake, they worry it could put their health or even their lives at risk. When they learn that dual eligibles will be able to switch plans if they want to – and will not be locked into a plan – this relieves much of their concern.

Many focus group participants are torn about the idea of auto-enrollment.

One element of the changes to Medicare that concerns some dual eligibles is the idea of the government choosing a health plan for them if they fail to do so before January 1, 2006. Many do not initially focus on this element and it is only when asked specifically that some express concern. “Because you shouldn’t have to be in something that you don’t choose yourself. That’s not fair,” says an individual with HIV/AIDS from Los Angeles. These participants wonder aloud if the government will pick the plan that is best for them. More likely, they feel the government will enroll them in the least expensive plan rather than the one best suited to their needs.

After discussing this issue further, some dual eligibles come to see that having the government select a plan for them is better than having no drug coverage at all. These participants understand that if their Medicaid drug coverage ends on January 1, 2006, that will leave them with *no* drug coverage unless they are enrolled in a Medicare plan. When these trade-offs are considered – no drug

In regard to auto-enrollment:

“They’re going to choose the one that best suits their program [interests].”

-Individual with a physical disability from Baltimore

coverage vs. enrolled in a plan the government picked out for you – they choose the latter.

However, most dual eligibles feel that the best approach is to give them enough advance warning so that they have enough time to make informed choices. Since most say they will seek the advice of someone else – a family member, doctor, and pharmacist – they want time to seek input and make this choice.

Most participants concerned about any “glitch” in the transition from Medicaid to Medicare drug coverage.

A number of the participants express anxiety about the transition process from Medicaid to Medicare drug coverage. They are concerned they will go to a pharmacy in early January to fill a prescription and be told by the pharmacist that they no longer have drug coverage. Some say they do not know what they would do. “Well since I haven’t been without [medication] I wouldn’t know what I would do. Maybe just somehow I have to get it,” says a low-income senior from Tampa. Others say they would contact their doctor and ask for free samples, or for them to intervene with the drug plan on their behalf. Others would try to negotiate something with their pharmacist so that they can at least obtain a few of their medications. Many simply do not have a back up plan if there are glitches in their new drug coverage. Individuals with HIV/AIDS in the focus groups are particularly worried about potential gaps in their drug coverage during this transition because of their immensely complex health conditions.

Many in the focus groups worry about higher co-payments

When the participants are told that they will pay a fee of \$1 to \$5 dollars when filling a prescription, many comment that they have not been paying a copayment under Medicaid. “Well, it just complicates my life a little bit more because I would have to get to some other resources to compensate for that because I’m on SSI, Social Security,” explains an individual with HIV/AIDS from Los Angeles. While \$1 or \$2 can seem manageable, \$5 is clearly too expensive for many. Many point out that they must take 7 or 9 or even 12 medications daily, which means they would be paying \$35, \$45, or \$60 extra per month for their medications. This could mean skipping meals or doing without other basics in life, say some participants. Some say they will even have to forego medications even though that puts their health at risk. However, some dual eligibles in the focus groups already have been paying a \$1 or \$2 copayment under Medicaid, while a few say they have been paying \$7 copayments. The latter group does not seem as concerned about the \$1 to \$5 copayment under Medicare since they have been paying close to this amount already under Medicaid.

“We’re all on Medicaid which means we’re low-income. We budget a small amount each month for drugs... we’ll really have to tighten our belts if we have to pay more.”

-Low-income Senior from Tampa

The breaking point for almost all of the dual eligibles in the focus groups is about \$10 per medication. Given the numerous medications that they have to take daily, a \$10 copayment could quickly add up, particularly given their fixed incomes. In the words of a low-income senior from Tulsa:

“I’d just have to cut down on some of my breathing medicine. I’ve got like 3 or 4 besides this [medication] and so... I couldn’t pay it and I’d have to take the consequences because I take about four with the inhaler and then I’m on the nebulizer and then I’ve got one for my emphysema. It’s all to help you breath better and so you just have to cut down on some of them.”

Among the focus group participants, the low-income seniors express the most apprehension over copayments. “There is no consideration given to how much gas costs, utilities cost... they all add up in our daily lives and we’re on fixed incomes,” explains a low-income senior from Tulsa. For many of these participants even a \$1 or \$2 copayment causes alarm. However, in some cases, there also is a surprising willingness to endure more “tightening of the belts.”

In New Jersey, many of the dual eligibles with mental health needs are participants in a special state-funded pharmacy assistance program that allows them to work part-time and still qualify for help with their prescription drug costs. One strategy for coping with Medicare drug co-payments would be to quit their jobs in order to meet the state’s stricter income eligibility for more assistance. As one participant explains:

“[If I had to pay co-pays, I’d] quit work also so I can be under the Charity Care guidelines to get my medication covered. [I’d] try writing letters to the pharmaceutical company as a hardship case, or ask the United Way for some money. But you know what? That takes so much time. And in the meantime I’m going to be in the hospital or I’m going to be homeless on the street, or dead.”

They, however, are reluctant to consider that they might be forced to adopt such a strategy. There is a feeling of unfairness among these participants – both that they feel productive working and it would not be fair to be forced to quit to afford their medications, as well as a sense of unfairness that those people with disabilities who are only on Medicaid (i.e, not also getting Medicare) do not have to have to switch prescription plans. Another clearly articulated outcome of increased co-pays among this population is discontinuing the use of needed medications and the risk of hospitalization. As one individual says, “I’m right on the edge now. I don’t know what I’d do [with increased co-pays]. I’d probably have to give up taking one or two [medications]. I’d be back in the hospital again, that’s what would happen.”

Many unsettled by prospect that their Medicare drug plans may not cover all of their current medications.

Other than the copayment amount, the aspect of the new Medicare plan that concerns dual eligibles most is that their medication may not be covered under the drug plan they choose. This would be a new experience for most of them since they say they have had not problems obtaining the medications they need under Medicaid. “[My] fear [is] of a drug that is really needed being dropped off [the plan] and not be covered. This is huge; the fear of the unknown,” explains an individual with HIV/AIDS from Los Angeles.

“[If there was a problem getting my medication] I’d go to the doctor and if he couldn’t change it I’d have to be on the mercy of the kids.”

-Low-income Senior from Tulsa

Most in the focus groups say they would work hard to choose a drug plan that did cover their current medications. However, they worry that the drug plan will change its drug formulary or that their doctor will prescribe a new medication that might not be covered. “We’re only discussing medications that we’re currently taking. How is that when we get into this program, I need a new medication? What do I do now?” asks a low-income senior from Tulsa. If they find that a medication they need is not covered under their Medicare drug plan, most say they would feel comfortable enlisting their doctor to argue on their behalf to try to get the medication covered. Or, many say again that they would rely on their doctor to provide free samples if their plan does not cover it.

Among the focus group participants, concern about being able to secure particular medications is particularly acute for those with mental health issues. A number of them noted that it has been a long process of learning what medications or “cocktails” work best for their needs. Until they figured out their medication regimes, they often were unable live a functional life. Thus, these participants fear that a plan may not cover one of their medications, which could put them at risk of losing their ability to function or even of hospitalization. An additional concern for some of the dual eligibles with both mental and physical health needs is that they will be forced to choose one sphere of health over another. As one individual explains, “A lot of people who suffer from mental health needs have different problems. And what are you going to say, ‘I’ll go with my health problems? I’ll go with my mental problems?’ Either way you’re going to land up in the hospital. It’s like you have to be a rocket scientist to figure it out.”

Many anxious about the prospect of being required to switch medications

Most of the dual eligibles in the focus groups express a preference for brand-name medications. When asked about their willingness to try a generic or an alternative medication if they needed to under the new Medicare drug plan, many are initially hesitant. They mention bad side effects, some from personal experiences of switching to generic drugs, and many are convinced

“[W]e have a suppressed and compromised immune system... what affects him can affect me differently. And when we’re taking a generic drug, who knows what’s going to happen?”

- Individual with HIV/AIDS from Los Angeles

generics do not have the same chemical compounds and therefore may not be as effective.

In addition, and this comes particularly from those individuals with HIV/AIDS and mental health needs in the focus groups, there is anxiety about their ability to obtain the newest medications under a Medicare drug plan. One man explains that if he or others with HIV/AIDS exhaust all of their drug alternatives and nothing appears to be working, they would need to have access to new medications and drug therapies. The same is true for those with mental health needs who have not yet found success with existing drugs. If one of these emerging medications is not covered by their new drug plan, this could have dire consequences for them. Finally, many dual eligibles say that they would try a generic or alternative medication if their doctor approved of it because they trust their doctors.

Participants' biggest concerns are copayments and coverage of their medications

The focus group discussions about changes to Medicare concluded with a conversation about choosing a drug plan. Dual eligibles were asked what factors would determine which drug plan they choose. Would it be cost? Would it be the medications covered under the different plans? Would it be which plan their doctor recommended? Across the focus groups, participants say that cost and whether their medications would be covered would be the deciding factors. If there is a distinction among participants in the focus groups it is that the low-income seniors in Tampa and Tulsa seem most concerned about new copayments, while those with HIV/AIDS in Los Angeles, physical disabilities in Baltimore and mental health needs in New Jersey are most concerned about keeping access to all their medications.

III. Communicating about Medicare Changes

Some important insights emerged in the focus groups about how to communicate with dual eligibles about the new Medicare drug law and how it will affect them. Below is a summary of the advice provided directly by the dual eligibles, and, in some cases, additional issues implied by the way they articulate their concerns about the new law.

Traditional Medicare communication efforts will not work.

Most dual eligibles are critical of the way Medicare communicates currently. Most admit they do not read the mailed information they receive or just store away their Medicare booklet. Those who do read their Medicare booklet find the information too dense, too technical and too confusing to understand. Those who have called Medicare's toll-free number say they have had to wait on hold for very long periods. Some say they just gave up and hung up. The

"[I]t takes a lawyer to dissect this stuff."

-Individual with a physical disability from Baltimore

current wave of Medicare advertising on television about “drug discount cards” has been confusing to dual eligibles, particularly because they do not understand how that relates to their current Medicaid drug coverage. These comments suggest that traditional communication methods may not be effective for dual eligibles.

Give ample warning.

Most of the focus group participants say they want to hear as soon as possible if their drug coverage is going to change. They prefer receiving information earlier so that they can confer with their doctors and others about choosing the best Medicare plan for themselves. The more time they have, the more they will be able to make smart decisions.

Reach out to the less-connected dual eligibles.

The focus group participants are likely more connected, assertive health care consumers than the typical dual eligible. In fact, many of them mention this in the focus groups – they are impressed by the knowledge level of the other participants and believe this is not usual for the dual eligible community. In every focus group, dual eligibles express concern about their less informed peers – individuals who do not advocate for themselves or seek out information about their health coverage. They worry these individuals will miss information about Medicare drug coverage or think that it is not relevant to them. For this reason, they strongly urge those conducting outreach to focus specifically on the less informed and connected dual eligibles.

Keep the drug plan information clear, simple and brief.

Most dual eligibles say they want simple, clear information from the various drug plans about their coverage. They also want this information to arrive at the same time so that they can compare plans easily (as opposed to have the information on plans dribble in one at a time). First and foremost they want to hear about cost – how much will their copayments be? Next they want to know what drugs are covered under the plan – are my medications covered? Then they want to know if there will be any limits on the pharmacies they can use to fill their prescriptions – can I keep going to my usual pharmacy? They recommend that drug plans refrain from using technical or legal language and to consolidate the most essential information to just a few pages. They say this will make their decision making process much easier.

Consider one booklet of plan information that is *standardized*.

One concern expressed in the focus groups is receiving information from different health plans over the course of many weeks and then having to compare different kinds of information. Their preference would be to receive information only once and having it compiled in a booklet that would present

the information in a standardized format. They say this would make it easier to compare plans and to ensure that they actually read the materials instead of throwing them out mistakenly when they arrive in the mail.

Make the information stand out.

“Honestly, if it was clear that it was something that I needed to read, then I would pay attention to it. If it was a packet, like typical packets of information from insurance companies or whatever else, I have the tendency to put it on the bottom of the file.”

- Individual with HIV/AIDS from Los Angeles

Because they routinely throw away or ignore information from Medicare, many are apprehensive they will miss important information about changes to their drug coverage. For this reason they propose that Medicare make this information stand out from their other communications. Some suggest putting the notices on specially-colored paper while others want a label saying, “important insurance information enclosed.”

Spotlight dual eligibles.

Another recommendation is to spotlight dual eligibles specifically in communication efforts, highlight that their existing drug coverage is going to change. For example, a few mention they want Medicare to say specifically, “If you have Medicaid and Medicare, your drug coverage is going to change as of January 1, 2006.” Such language is important because the focus groups suggest that dual eligibles currently believe that their drug coverage is *not* going to be affected by changes to Medicare. To break through this misperception, Medicare may need to pay particular attention to dual eligibles in its communications.

Keep in mind most do not self-identify as “dual eligibles.”

While most dual eligibles recommend special outreach, it is vital to recognize that they do not see themselves as *dual eligibles* (the exception is the well-informed dual eligibles in New Jersey who were connected to networks of advocates). Rather, they recommend referring to them as “people who receive both Medicaid and Medicare” and to explicitly mention that there will be changes to their drug coverage.

Tailor communications to dual eligibles with mental health needs.

The focus group participants with mental health needs note they are particularly vulnerable to missing information about changes to their prescription drug coverage. Some highlight that the medications they take for their conditions can impair their cognitive abilities to absorb information, as well as that news of a change in drug coverage could greatly alarm them or friends with mental health issues. Thus, it may be helpful to seek advice from mental health professionals and advocacy organization on how best to communicate these changes to people with mental health issues, as well as how to prepare doctors, psychiatrists, and others who work with this population for the pending changes.

Use multiple media – TV, radio, mailings, and local seminars.

Dual eligibles recommend that Medicare use multiple media to spread the word about changes to their drug coverage. They mention TV, radio, direct mail, and seminars at local health clinics, senior centers, and AIDS organizations. They believe it will take each of these media to reach the diverse dual eligible population. And, once again, they suggest that some communications focus distinctly on dual eligibles, not Medicare enrollees in general, since they are experiencing loss of their current drug coverage.

Work through doctors.

Since these dual eligibles have such good relationships with their doctors, they strongly recommend spreading the word about Medicare changes through physicians. Most say they will look to their doctors to advise them about which plan to choose, so they would like it if he/she is already informed about these changes to Medicare. A few, however, note that their doctors are unlikely to have the time to wade through their plan choices with them in any detail.

Also work through pharmacists, caseworkers, advocates, and local disease organizations.

In addition to doctors, many dual eligibles say they trust other professionals involved in their health such as pharmacists, caseworkers, and local organizations and support groups. They recommend enlisting the help of these other providers in spreading the word about Medicare changes.

Improve 1-800-Medicare.

A number of dual eligibles say they are likely to call the 1-800-Medicare number if they have questions (despite concerns about long waits). Because of this, they urge Medicare to consider putting more trained callers on these lines in the short-term to cut down on the long waits.

The vast majority do not use the Internet.

Most of the low-income seniors in the focus groups say they do not use the Internet and are unlikely to use it to learn about changes to their drug coverage. This is also true for those with physical disabilities in Baltimore – most are not regular users of the Internet and this is not an effective way to reach them. Individuals with HIV/AIDS and those with mental health needs in the focus groups were more likely to use the Internet to gain information about drug coverage, but they also recommended television or mailed information as a good way to reach them.

Conclusion

The voices of the dual eligibles in this report demonstrate their heavy reliance on medications to function on a daily basis, stay out of the hospital, and, in many cases, to stay alive. With the exception of those from New Jersey, the participants know little if anything of the pending changes to their drug coverage. When informed about the change from Medicaid to Medicare drug coverage, many are surprised and often worried, expressing that they now reliably secure prescription drugs through Medicaid and do not understand why there is a need to change a system that works well for them. Their biggest concerns include that they will have to pay more for medications than they do under Medicaid and that it will be more difficult to secure the medications that they need. The fear of not being able to secure a specific medication is greatest for those who use a carefully calibrated mixture of medications or who have conditions for which emerging medications are currently being developed.

Many note that other dual eligibles who have not participated in a focus group are likely to be unprepared for the change and may have even greater difficulty learning about and handling the transition. Most participants feel that to cope with the transition, they will need ample warning of the changes specific to those dually-covered by Medicare and Medicaid. They would like to see clear, concise information directly targeted at dual eligibles so that they can be well informed of the changes in coverage, the actions they must take, and the timeframe within which they must act. They are likely to seek substantial assistance from their allies, especially physicians and pharmacists, caseworkers, and local organizations and support groups so educating these entities about upcoming changes will be critically important. Additionally, participants suggest using multiple media like TV, radio, direct mail, and seminars at local health clinics, senior centers, and AIDS organizations to reach the diverse dual eligible population.



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