



MEDICARE PART D PROGRESS REPORT: SIX MONTHS LATER HEADACHES PERSIST

July 19, 2006

EXECUTIVE SUMMARY

This Center for Medicare Advocacy report contains stories from real Medicare beneficiaries. The stories are illustrative of the thousands of people who are experiencing problems and high costs due to the lack of a uniform prescription drug benefit in the Medicare program. The design of Medicare Part D promotes enormous variation in the type of plans offered, enrollment experiences, covered drugs, what counts toward the Donut Hole coverage gap, plan costs, and appeals. While some people are better off than they were before Medicare Part D, many people remain confused and frustrated by its complexity and limitations.

The Center for Medicare Advocacy makes the following recommendations to ease the burden on beneficiaries and taxpayers:

1. CMS should develop a required formulary (list of covered drugs) and specify limited, standardized restrictions that plans can place on each drug.
2. Congress should eliminate the “Donut Hole” gap in coverage. If the Donut Hole is retained, the amount beneficiaries actually pay for each drug, not the retail price, should count toward reaching the Donut Hole. Further, Congress should allow expenses that beneficiaries incur for drugs both on and off their plans’ formularies to count toward satisfying the Donut Hole cost-sharing requirement.
3. Congress should remove the restriction on Medicare negotiating with drug companies and, instead, should require Medicare to negotiate prices on behalf of all 43 million Medicare beneficiaries.
4. Congress should authorize sufficient funding to correct systems problems. Congress should require and fund well-trained customer service representatives at CMS and Part D plans, as well as proper backup systems, and real-time, accurate data transfers among CMS, the Social Security Administration, plans, and states.
5. At a minimum, Congress should allow open enrollment in plans until these issues are resolved, and should consider a permanent open enrollment policy. If beneficiaries are to be “locked in” to their plan choices, plans should not be

allowed to change formularies, raise prices, or increase cost-sharing during the period that beneficiaries are locked-in.

6. Medicaid should provide coverage for people eligible for both Medicare and Medicaid (dual eligibles) who are not properly enrolled in a Part D plan and should pay beneficiaries when premiums are improperly deducted from their Social Security checks. Further, co-pays should be eliminated for dual eligible individuals.
7. CMS should implement an effective problem-correction system for dual eligibles that is designed to resolve issues at the point-of-service (the pharmacy counter). Pharmacies should be required to use this system and the system should be widely publicized and readily accessible.
8. CMS should establish one standard, simplified process for coverage determinations and appeals, including Prior Authorizations and Exceptions, that all Part D plans must follow.
9. CMS should monitor plans, use its authority to direct plans, and exercise its enforcement powers to sanction plans that do not comply with mandated coverage rules, appeals processes, and time frames for issuing decisions. CMS oversight of Part D plans has been far less directive than appropriate. Instead of issuing only “guidance” and using language that “recommends” or “suggests,” CMS should issue rulings and regulations that are binding on the plans and that can be cited by beneficiaries and their helpers.
10. *Even with such changes, beneficiaries will be shortchanged. The best solution for the problems with Part D is a redesigned prescription drug program that is standardized, available throughout the country, and administered through the traditional Medicare program. This system would be more valuable for more beneficiaries and more cost-effective for taxpayers.*

INTRODUCTION

Since enrollment for Medicare's new Part D prescription drug program began, the Center for Medicare Advocacy has assisted thousands of Medicare beneficiaries and their helpers to understand and utilize the Part D benefit, plan options and rules. Not all of these efforts have been successful. The Center has heard from people throughout the country, including Medicare beneficiaries and those who assist them, policy-makers, and others concerned with access to health care. They have raised concerns about difficulties in enrolling in a Part D drug plan, obtaining access to medically necessary drugs, and reigning in spiraling drug costs.

The Centers for Medicare & Medicaid Services (CMS), the agency that administers Medicare, continues to tout Part D as a resounding success, while attributing persistent and systemic issues to small glitches in the system. While CMS claims to have fixed the major problems, and purports to be solving individual beneficiary problems in a timely and satisfactory manner, the Center's experience shows otherwise. This report highlights some of the most glaring issues including:

- Enrollment and coverage problems for people dually eligible for Medicare and Medicaid;
- Ineffective and unreliable enrollment tools;
- The "Donut Hole" coverage gap that is costly to beneficiaries;
- Problems accessing medically necessary drugs;
- Complicated, time consuming and non-standardized processes for challenging plans' non-coverage decisions.

ENROLLMENT PROBLEMS CONTINUE FOR DUAL ELIGIBLE INDIVIDUALS

A Breakdown in Communication

Prior to January 1, 2006, beneficiaries eligible for both Medicare and Medicaid, or dual eligibles, received drug coverage through Medicaid. On January 1, all dual eligibles lost Medicaid for their drug coverage and were switched to Medicare drug coverage. This was not a seamless process. Many dual-eligibles, in fact, have experienced multiple and persistent problems with enrollment in a Part D plan. For example:

Mr. R is a dual eligible individual and is entitled to the low-income subsidy (LIS, also called "Extra Help"), which provides assistance with premiums, deductibles, cost-sharing, and coverage through the "Donut Hole." Although auto-enrolled in a Part D plan, Mr. R called a second company to explore his options. During his inquiry, he was asked for and provided his Social Security number to an agent. He later learned that he had been enrolled in the most expensive option with that plan - without his permission. Mr. R's subsidy does not fully cover the premium for this "enhanced" plan option. The difference between the subsidy and the Plan's premium continues to be deducted, without permission, from Mr. R's Social Security disability check, his sole source of income. This deduction occurs

each month, despite the fact that CMS's records do not show him enrolled in this second Plan.

Due to the confusion and the unexpected incurred expenses, Mr. R and his wife have experienced devastating consequences. All of the money they were able to save in order to pay their property taxes has been used to pay for drugs instead. As a further consequence, Mr. R has forgone taking medications needed to treat chronic conditions.

Mr. and Mrs. F, low-income beneficiaries from Connecticut, have experienced similar problems:

Mr. and Mrs. F. have a combined gross income of under \$1450 per month. As participants in an SPAP and a Medicare Savings Program, and recipients of the LIS, their premiums should be fully subsidized. Nevertheless, \$62.80 is being erroneously deducted from their Social Security each month for their combined premiums. Because of their very low income level, this deduction constitutes a serious hardship and cuts into their budget for food and other household expenses. According to CMS, they have been unable to correct this erroneous deduction because of incompatibility of the CMS and SSA electronic data exchange systems.

These stories shed light on systemic problems. In order for an LIS eligible beneficiary to be charged the proper premium and cost-sharing amounts, states, CMS, the Social Security Administration, and drug plans must exchange information about dual eligibility status, LIS eligibility, and plan enrollment. Unfortunately, when this chain of information is broken, individuals may appear to be enrolled in two or more plans at once, plans may not have correct subsidy information, and Social Security may incorrectly deduct premium payments from their checks.

Dual eligible people encountering these problems often experience dangerous consequences. When problems with plan enrollment, co-payments, or improperly charged premiums become too overwhelming, many beneficiaries simply forego obtaining basic drugs. As a result, many dual eligible individuals are worse off with Part D than they were when their drug coverage was provided by Medicaid.

POLICY RECOMMENDATIONS:

Congress should modify the law to allow states to continue to provide Medicaid coverage for dual eligible people not properly enrolled in a Part D plan and pay beneficiaries when premiums are improperly deducted from Social Security checks. In addition, CMS should clearly inform people who become dually eligible how to obtain their prescription drugs during the 1-3 months it may take them to become enrolled in a Part D plan. Part D co-pays should be eliminated for dual eligible individuals. Finally, there should be improved, real-time data sharing among all the players: CMS, SSA, plans, and states.

Gaps in Coverage

Many dual eligible beneficiaries have experienced lapses in drug coverage, despite the fact that the transition from Medicaid to Medicare is supposed to be “seamless.”

C.L. is one of many beneficiaries who had problems moving to Medicare Part D from Medicaid:

C.L. was on Medicare and Medicaid when Part D took effect. In December 2005 he was auto-enrolled in a Part D plan, but in the months since he has been disenrolled and reenrolled several times from that same plan. He has never been able to obtain his medications. C.L. has contacted the Plan, Medicare, and Social Security several times, but is told that he disenrolled December 12, 2005 and must pay cash for his drugs. The Plan, Medicare, and Social Security all claim they cannot resolve his problem. Since January he has been required to pay \$220 a month, or 1/3 of his monthly income, for his medications even though he is a dual eligible and qualifies for the low-income subsidy.

To protect dual eligibles who lost Medicaid drug coverage January 1, 2006, Part D is supposed to provide access to prescription drugs in a “seamless” manner through auto-enrollment in a Part D plan. Many dual eligible individuals, however, have actually experienced a gap in coverage once their Medicaid coverage ended. Indeed, CMS released a State Medicaid Directors letter dated May 25, 2006, which provided the proper process by which Medicaid beneficiaries subsequently eligible for Medicare were to be covered by a Part D plan the very month they became eligible for Medicare. Unfortunately problems continue.

Despite these ongoing problems, the Department of Health and Human Services (DHHS) and CMS declared victory at the close of the initial enrollment period for Part D. Yet hardships are mounting for Medicare’s most vulnerable, including beneficiaries dually eligible for Medicare and Medicaid and those eligible for the low-income subsidy. Though the problems encountered in January were supposedly isolated start-up glitches, duals continue to face problems enrolling in a Part D drug plan, receiving the low-income subsidy, accessing reliable information from both 1-800-MEDICARE and www.Medicare.gov, and gaining access to medicines that were previously covered under state Medicaid programs.

POLICY RECOMMENDATIONS:

CMS should implement an effective problem corrections system for dual eligibles that is designed to resolve issues at the point-of-service (at the pharmacy counter). Pharmacies should be required to use this system and the system should be widely publicized readily accessible.

INEFFECTIVE AND UNRELIABLE ENROLLMENT TOOLS

Problems with 1-800-MEDICARE and www.Medicare.gov

Beneficiaries contacting the Center have described 1-800-MEDICARE as a largely unreliable tool for enrollment. For example:

D.R. has been a Medi-Cal (California's Medicaid program) recipient for over 20 years. Because of his eligibility for Social Security disability benefits as an adult disabled child, D.R. was notified in March that he would become eligible for Medicare on June 1 and that he would have to choose a Part D plan. At the end of March his mother called 1-800-Medicare on his behalf to enroll him in a drug plan. She was incorrectly informed by the customer service representative that he could not enroll in a drug plan until June 1 when he was actually on Medicare. The director of the program in which D. R. is enrolled was also told by 1-800-Medicare that D.R. could not enroll in a drug plan until June 1. As a result, on June 1, when D.R. became eligible for Medicare, Medi-Cal stopped paying for the five medications, including psychotropic medications, he requires, and he was without any drug coverage.

A similar complaint came to the Center for Medicare Advocacy from a beneficiary in Utah who tried to enroll using www.Medicare.gov :

On May, 12 2006, Mr. Y used the Medicare website to enroll in a Medicare Prescription Drug plan. A confirmation page with the title "Medicare Prescription Drug Plan Enrollment Center" and the Medicare Rx Prescription Drug Plan Coverage Logo appeared. It clearly stated "Enrollment Successful." Mr. Y copied and printed this confirmation page (with confirmation number). The next week Mr. Y contacted the plan to check on his enrollment status and was told it had no record of his enrollment. He then contacted Medicare and was informed that the problem was with the plan. Mr. Y did not have prescription drug coverage as planned on June 1, 2006, and cannot enroll now because he missed the deadline.

Many beneficiaries attempting to enroll in a Part D plan have been barred as a result of inaccurate and unreliable information provided by both 1-800-MEDICARE and "Medicare.gov." This ongoing problem was documented in May 2006, by the General Accounting Office (GAO) in its study on the accuracy and clarity of information CMS provided to beneficiaries through literature, 1-800-MEDICARE and Medicare.gov. [GAO, *Medicare: Communications to Beneficiaries on the Prescription Drug Benefit Could be Improved*. May 2006, GAO-06-645. See www.gao.gov/new.items/d06654.pdf.] The GAO found that of the 500 calls made to 1-800-MEDICARE, it received "a substantial number of responses that were inaccurate, incomplete, or inappropriate and that sometimes involved an extensive wait before speaking to a customer service representative."

POLICY RECOMMENDATIONS:

Congress should authorize sufficient funding to correct systems problems. Congress should require and fund well-trained customer service representatives at CMS and the Part D plans, as well as proper backup systems, and real-time, accurate data transfers among CMS, the Social Security Administration, plans, and states. At a minimum, Congress should allow open enrollment in plans until these issues are resolved and should consider a permanent open enrollment policy.

ENROLLEE EXPERIENCE WITH THE DONUT HOLE

Paying For Drugs In The Donut Hole

The infamous “Donut Hole” is a gap in prescription drug coverage during which beneficiaries are responsible for 100% of their drug costs. Many beneficiaries are finding they cannot cover their costs during this period. For example:

Ms. L is a transplant patient in New Jersey. She takes several costly medications for the transplant and for other conditions, including Crohn’s disease. The drug plan she had before Part D covered these medications at a price she could afford – about \$45 per prescription. Now, with Part D, her costs have gone up to \$617 a month for one prescription and \$1132 for another. A third prescription she is taking costs her \$300 a month. Because she cannot afford the spike in costs during the Donut Hole, she is paying for her medications with her credit card. If she goes without the medications, she will have to go to the hospital.

Situations like Ms L’s are common and, according to a recent article in the *New England Journal of Medicine*, are, in fact, predictable. The research reported in the article found that patients with caps on Medicare drug benefits had lower prescription drug spending, but also had higher rates of emergency room visits and unfavorable clinical outcomes. The article concludes, “the savings in drug costs from the cap were offset by increases in the costs of hospitalization and emergency department care.” [Hsu, et. al. “Unintended Consequences of Caps on Medicare Drug Benefits.” *NEJM* 354;22, 1 June 2006.]

POLICY RECOMMENDATIONS:

Congress should eliminate the Donut Hole and provide a uniform drug benefit through the traditional Medicare program.

Anticipating Costs

While many beneficiaries are coping with unmanageable costs in the Donut Hole, others are trying to figure out when exactly they will reach it. For example, Ms. N from Pennsylvania describes her frustrations with unpredictable costs and the Donut Hole:

Ms. N called two Part D plans to find out the total price of her friend's medications - information she needed to calculate when her friend would reach the Donut Hole. Both plans said they could tell her what the co-payment for the drugs would be, but not the actual price. Therefore, Ms. N has not been able to accurately calculate when her friend will reach the Donut Hole; her friend, therefore, cannot accurately anticipate her drug costs for the year.

Calculating total drug costs and out-of-pocket costs is challenging, making it difficult for beneficiaries to plan ahead. Being able to anticipate future drug costs is especially critical to Medicare beneficiaries on fixed incomes.

Calculating the Donut Hole is complicated by the fact that drug plans are allowed to change the price of the drugs on their formulary at any time. Because the *total price of the drug* is what counts toward the \$2250 coverage limit that puts a beneficiary into the Donut Hole, when drug prices increase, beneficiaries reach the Donut Hole faster, regardless of whether their co-payments change or not. A June 2006 report by Families USA found that, for the 20 drugs most frequently prescribed to seniors, almost all plans raised their prices from November 2005 to April 2006. [Families USA (June 2006). *Big Dollars, Little Sense: Rising Medicare Prescription Drug Prices*. Available at <http://www.familiesusa.org/resources/publications/reports/big-dollars-little-sense.html>]. Since plans change their prices throughout the year, a beneficiary can never actually know when he or she will reach the Donut Hole.

POLICY RECOMMENDATIONS:

Pricing information should be accurate and easily accessible. Plans should not be allowed to change formularies, raise prices, or increase cost-sharing during the period that beneficiaries are locked-in to their plan choice. The amount each beneficiary actually pays out of pocket for medication ought to be what counts toward reaching the Donut Hole gap, not the retail price.

Hidden Costs

Beneficiaries often do not realize that only certain expenses count toward the cost-sharing requirements once an individual reaches the Donut Hole. For Mr. C in Florida, this has led to enormous complications:

Mr. C has AIDS. On the advice of his pharmacist, he chose a particular plan because it covers all of his HIV medications, as well as his medications not directly treating HIV. However, each month the plan tries to charge him the full price of certain non-HIV medications, or to get him to switch to a lower cost medication. One of his medications is to prevent pneumonia. The plan's online formulary says it will pay for the drug, but Mr. C continues to receive letters from the Plan that say they will not pay for it. Every month it's a different story and a different medication is denied. Mr. C cannot forgo these medications, but when

he pays out of pocket for them, they do not count toward reaching the Donut Hole.

Each time Mr. C is denied a drug, he pays the full price of the drug out-of-pocket. Yet, the amount he pays for these “uncovered” drugs does not count toward his out-of-pocket costs. As a result, he will pay much more than the CMS publicized \$3,600 to get out of the Donut Hole coverage gap and into catastrophic coverage.

Part D drug plans often do not cover all of a beneficiary’s prescription drug needs. When a drug is not on a plan’s formulary and the beneficiary is unable to persuade the plan to make an exception and cover it for him or her, the beneficiary must pay the full price of the drug, or forego taking that drug. Plans, when calculating how much a beneficiary has contributed to their out-of-pocket costs (beneficiaries must spend \$3,600 of their own money to get out of the donut hole), do not count money spent on drugs not on the plan’s formulary (non-covered drugs). In such a situation, a beneficiary may well have out-of-pocket costs that greatly exceed the already exorbitant Donut Hole amount of \$3,600.

In addition, beneficiaries cannot count help received in paying for co-payments toward out-of-pocket costs. Indeed, contributions from retiree coverage, AIDS Drug Assistance Programs (ADAPs), and pharmaceutical companies’ Patient Assistance Programs (PAPs) do not help a beneficiary get out of the Donut Hole.

The Donut Hole poses numerous problems for Medicare beneficiaries, as these experiences illustrate. The Donut Hole results in poorer health outcomes and higher cost emergency room visits, is difficult to calculate, and does not account for all *actual* drug costs. For beneficiaries with fixed and limited incomes and chronic conditions, and for those who had coverage prior to Part D, the donut hole spells even more hardship.

The Donut Hole was created to save the federal government money. Without it, the cost of Part D would have been far too high to assure passage by the Congress. However, it serves neither the beneficiary nor any sound policy purpose when the outcome is increased hospitalization due to lack of necessary drugs. There are better ways to lower the costs of a Medicare drug program and provide more complete coverage to beneficiaries.

POLICY RECOMMENDATIONS:

CMS should allow expenses beneficiaries incur for drugs both on and off their plans’ formularies to count toward the Donut Hole. CMS should also develop a required, formulary (list of covered drugs) and a limited, standardized set of restrictions that plans can put on each drug. Finally, Congress should remove the restriction on Medicare negotiating with drug companies and, instead, require Medicare to negotiate prices on behalf of all 43 million Medicare beneficiaries.

GETTING COVERAGE FOR MEDICALLY NECESSARY DRUGS

A Complex and Burdensome Process for Getting Drugs Covered

Overall, the Part D processes for getting a plan to pay for medically necessary drugs that are not on its formulary are complex and varied. For example, one nurse in Tennessee expressed her frustration with the many different processes:

“Getting prior authorization for patients’ existing medications is a nightmare. I work in a very busy clinic, short staffed, like everywhere, and I do not have the 45 minute hold time to wait to speak to a customer service representative that is just going to tell me to give them my fax number so they can fax me a form to fill out for the patient, fax back, wait a day, receive new fax, have doctor sign, fax back, cross my fingers for the patient and wait to find out if they are going to cover the medication. What nurse has that time? In the meantime, I have phone call after phone call of people complaining that they don’t have their medication. It has made for really stressful days at work.”

According to CMS, everyone who enrolls in a prescription drug plan will have access to all medically necessary prescriptions. The catch is that in order to have such access, plan enrollees may have to go through different processes and file five levels of appeals in order to get necessary drugs. As the nurse from Tennessee explained, these processes are complicated, time-consuming, uncertain, and lacking in uniformity. In addition to varying by type of request for drug coverage, the processes for requesting a plan to pay for a drug vary from drug plan to drug plan.

A drug plan may refuse to pay for drugs that are listed as being *on* the plan’s formulary unless and until prior authorization is sought. In other words, the drug plan may disapprove a prescription for a formulary drug if the doctor does not first ask permission from the drug plan – and even after prior authorization is sought, and provided, the plan *still* may not agree to pay for the covered drug.

POLICY RECOMMENDATIONS:

CMS should establish one standard, simplified process for coverage determinations, including Prior Authorizations and Exceptions, that all Part D plans must follow. If Prior Authorization is required and provided by the physician, the burden should be on the Plan to demonstrate why the drug should not be covered.

Getting a Timely Decision from the Plan

Though plans are required to respond to Exceptions and appeals requests within a certain timeframe, many do not. For example, Ms. C from Virginia writes:

“I take Coreg, Benicar, and Aciphex. My plan doesn’t cover Aciphex, or Benicar. I’m presently out of Aciphex and am waiting for a decision on them from my plan. I’m also waiting on a decision on [a medication] for my glaucoma, been waiting for weeks.”

Ms. D from New Mexico has also had to wait for excessive times to get approval for her medications:

“I am on Medicare, Plan X, and they are denying me... medication and adequate medical care. They have ... repeatedly tried to charge me for meds that were approved, and took 4 months to approve a necessary medication. They are generally very difficult to deal with and have rules that make no sense. The four month approval time was with help from the State and my Doctors.”

A plan is supposed to issue a Coverage Determination, an Exception, or Prior Authorization within 72 hours of the request or within 24 hours if expedited review is required. The specific time frames are set forth clearly in CMS’s Part D implementing regulations and guidelines. Yet despite these clear statements, many plans do not comply with the time frames, as the nurse, Ms. C, and Ms. D have discovered. An enrollee cannot proceed with appeal until the plan issues an unfavorable Coverage Determination, which includes an unfavorable Exception or unfavorable Prior Authorization decision.

An appeal is often confused with an “Exceptions request” and Exceptions with a “Coverage Determination”. An Exceptions request is used to obtain an exception to the design of a plan’s formulary, or list of covered drugs, and has its own process and procedure, including the requirement of physician participation. Ms. C. from Virginia asked for exceptions to her plan’s formulary to get her drug plan to pay for the prescribed drugs she takes that are not on her plan’s formulary. A different process applies to another type of Coverage Determination, a request for Prior Authorization.

POLICY RECOMMENDATIONS:

CMS should monitor plans and use its enforcement powers to sanction plans that do not comply with the coverage determination or appeals processes, or the time frames for issuing decisions. Thus far, oversight by CMS over Part D plans has been far less directive than appropriate. Instead of issuing only “guidance” and using language that “recommends” or “suggests,” CMS should issue binding rulings or regulations that are binding on the plans and that can be cited by beneficiaries and their helpers.

CONCLUSION

The stories here are illustrative of the thousands of beneficiaries who are experiencing problems and high costs due to the lack of uniformity in Medicare Part D. There is enormous variation in the types of plans offered, enrollment experiences, covered drugs, what counts toward the Donut Hole, plan costs, and appeals. While some people are better off than they were prior to Medicare Part D, many remain confused, frustrated or stranded by its complexity and limitations. All beneficiaries would be better off with a redesigned benefit that is standardized, available throughout the country, and administered through the traditional Medicare program. Such a system would be more valuable for more beneficiaries and more cost-effective for taxpayers.

THE CENTER FOR MEDICARE ADVOCACY

The Center for Medicare Advocacy assists thousands of individuals to gain fair access to Medicare and necessary health care. The non-profit, non-partisan organization responds to over 6,000 calls annually from elders, people with disabilities, their families and support networks. The Center provides training and support for Connecticut's SHIP (state health insurance and assistance program, known as CHOICES), that includes training and direct assistance with Medicare Part D. Since November 15, 2005, when beneficiaries could first enroll in Part D, through May 15, 2005, when enrollment closed, the Connecticut CHOICES program handled over 38,000 calls, more than two-thirds of which were about Part D. As the CHOICES backup center, the Center for Medicare Advocacy handles, or provides guidance about, a significant portion of these calls. As a result of a grant from a national foundation, the Center for Medicare Advocacy also provides training, telephone, and on-line assistance regarding Part D for beneficiaries and their helpers throughout the country. Requests to the Center for assistance have increased dramatically because of Medicare Part D.