

# ADAP Advocacy Association Newsletter – September 2008

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## Why TrOOP Hurts!

*By Brent B. Shimmin*

An estimated 80,000-100,000 Americans living with AIDS rely on Medicare for their medical treatment and prescription drugs – including ARVs (Anti-Retrovirals) and others used to treat side-effects and the other health issues people living with AIDS experience. Medicare Part D, meant to address prescriptions specifically when introduced in 2006, was not conceived with this population in mind and has significant flaws relative to it, most especially the coverage gap, or “donut hole”. This gap is an impossible burden to these patients due to the special nature of treating HIV/AIDS, which focuses primarily on medications.

ARVs rarely if ever have generic equivalents and are extremely expensive. The cap on the cost of prescription medications for Medicare Part D is \$2,510 per year, which is easily met in the first month or two of coverage. As written, beneficiaries of Part D must amass \$4,050 in true, out-of-pocket expenses (TrOOP) for their medications before “catastrophic” coverage kicks in. Even though 59% of people living with AIDS relying on Medicare have house-hold incomes below \$10,000 (according to the Henry J Kaiser Foundation), this is still an impossible burden for the many patients with incomes that are just slightly higher.

One possible solution to this conundrum is allowing ADAP (AIDS Drug Assistance Program) funds to fill the TrOOP coverage gap. But because of the way ADAP is budgeted nationally (as an earmark, not an entitlement), this will require a change in legislation. Here’s some history:

What we now know as ADAP started with HRSA (Health Resources and Services Administration) grants in 1986 to assist the four American cities hardest-hit by AIDS: New York, San Francisco, Los Angeles, and Miami. This initial \$15.3 million grant was the first governmental response to what had already become a public health problem of epidemic proportions.

The AIDS Service Demonstration Grants (as they were initially called) were patterned after what became known as the San Francisco Model, focused on case management and community-based responses to the epidemic through ASOs (AIDS Service Organizations). ASOs were originally volunteer efforts that grew to become the main source of information and support for those living with HIV/AIDS, providing everything from counseling to complementary therapies to emergency foodstuffs. Dr C Everett Koop, then US Surgeon General, lauded this approach: “These projects emphasize case management and a coordinated approach to caregiving, by bringing together local, State, and Federal resources.... What we learn from these demonstration projects will be very helpful to us in assisting other States and localities to understand their needs and to respond to their problems.”

It wasn’t until 1987 that AZT, the first medication developed for treating HIV was introduced, and was quickly approved by the FDA. Soon thereafter, HRSA launched its \$30 million AZT Drug Reimbursement Program. As AZT was both expensive and considered experimental, government involvement was necessary if those suffering from AIDS were to benefit from its development: not all insurance companies paid for it, and even fewer private individuals could pay for it out-of-pocket.

Although all fifty states were made eligible for grant funds and made responsible for their distribution, allocation was based on need, with the largest share of the funds, \$21.1 million, going to five states—New York, California, Texas, Florida, and New Jersey. This system laid the foundation for the method still used today in the allotment of ADAP funds.

In 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed with overwhelming majorities in both the House and Senate. Named for a boy who died of AIDS complications at the age of eighteen and who became a household name following his legal battles to overcome the then-common bias preventing him from attending school. By the time the bill became law, more than 150,000 AIDS cases had been reported in the United States and more than 100,000 had died. By 1995, with the advent of PIs (Protease Inhibitors) and AIDS “cocktails”, the toll had risen to almost 295,000.

ADAP is a discretionary budget program and, unlike Medicaid and Medicare, is not an entitlement. The availability of funds is contingent on the Federal budget and is subject to renewal every five years. The intent is that funds be used to serve populations who are low-income, those with no health insurance or those whose insurance is inadequate to their needs, ADAP was, and still is, the payer of last resort; and funds may not be used to supplant other resources.

In 1995, the arrival of HAART (Highly Active Antiretroviral Treatment) cocktails and the sudden availability of choice in medications, gave new hope to hundreds of thousands of Americans living with HIV/AIDS (AIDS mortality rates dropped by 40% the first year alone). But this very positive news had a giant string attached: people's lives were being prolonged by medications that were (and still are) astronomically expensive: far out of the reach of anybody without institutional (private insurance or governmental) budgets. And the business practices of many insurance companies were evolving in response to ever-increasing costs. HMOs, limited drug formularies and other cost-saving "innovations", perhaps sufficient for otherwise healthy Americans, pushed thousands more into government programs which were not equipped to handle the increasing demand.

In 1996, when the Ryan White CARE Act was reauthorized, Title II (Part B), the AIDS Drug Assistance Program (ADAP) was enacted to replace the old AZT Drug Reimbursement Program, responding to the new reality of HAART, and it was earmarked at \$52 million. Since then, the budget has risen slowly, and never at the pace of demand. Waiting lists have become all-too common in the twelve years since ADAPs were established, with the shameful deaths of three people in South Carolina in 2006 being only the most egregious example of the failure of ADAP funding to keep pace with the needs of Americans living with the virus.

And because there are no national standards regarding HIV/AIDS care, each state is left to its own devices to allocate the money that it receives, meaning that protocols of regular testing, inclusion of basic ancillary services and drug formularies vary widely from one place to another, as does the upper-limits of poverty required by the financial eligibility criteria. With the Federal Poverty Level (FPL) within the forty-eight contiguous states at \$10,212 in gross annual income for a single person, the eligibility cut-off can range from \$20,800 in ID, IA, NE, OK, OR, PR and TX to \$52,000 in AR, DE, ME, MD, NJ, and OH.

In 2004, Congress passed Medicare Part D that created a "donut hole" in prescription drug coverage for "richer" patients—but not poorer patients, who face no donut hole at all— with incomes over 150% FPL (\$15,318 for one person). Medicare now pays, on average, for about two month's worth of medications before such "richer" patients fall into a gap in coverage, when, presumably, they are to self-pay for their ARVs (Anti-Retroviral medications) and other required medications up to a point where they are covered once again. Although 75% of ADAP clients are at or below 200% of FPL and 43% are at or below 100% FPL, this is an unrealistic burden to bear for some of those between 150% and 200%.

A simple solution would be to allow ADAP funds to fill this gap, except for one thing: as an earmarked line in a discretionary budget, Ryan White CARE funds cannot be used funds cannot be used to supplant other resources without a change in the Part D legislation itself.

There are elected officials on both sides of the aisle who understand this, including Sen. Ted Kennedy (D-Mass.), Sen. Gordon Smith (R-Ore.), Sen. Hillary Rodham-Clinton (D-N.Y.), Sen. Richard Burr (R-N.C.), Sen. Orrin Hatch (R-Utah), Rep. Nancy Pelosi (D-Calif.), Rep. Barbara Lee (D-Calif.), former Rep. Jim Kolbe (R-Ariz.), Rep. Elliot Engel (D-N.Y.), Rep. Ileana Ros-Lehtinen (R-Fla.), Rep. Christopher Shays (R-Conn.), Rep. Jim Langevin (D-R.I.), and Del. Donna Christensen (D-V.I.), among others. They understand that the \$100 million required to allow ADAPs to fill the TrOOP (True Out Of Pocket) gap is quite literally a life-saver to thousands of Americans living with HIV/AIDS.

**In review, these are the issues:**

- Federal funding for HIV/AIDS programs is insufficient to meet the current demands.
- Absent clear, uniform Federal standards and protocols of care and consistent formularies of medicines, the medical treatment options available to those living with HIV/AIDS but without insurance varies tremendously from state to state, as does the forced poverty of income eligibility restrictions.
- Those with the least, in terms of health and financial resources, are made to shoulder the burden of their care when it is least likely they'll be able.
- The consequences of inaction in this matter are not merely greater inconvenience for the beneficiaries of ADAP, Medicare and Medicaid, but declining health and death for them.

These issues can be resolved by:

- Ensuring adequate funding of the Ryan White CARE Act (including ADAP) at levels greater than are currently earmarked;
- Establishing clear, national guidelines and higher standards for those who depend on Ryan White/ADAP for their medical care, including expanded formularies to cover medications used in combating side-effects and the ancillary health problems that affect those living with HIV/AIDS;
- Allowing ADAP funds to be used to fill the donut-hole gap (Troop) in coverage that exists under Medicare Part D through a change in its legislation; and
- Getting involved: contact your local representative and senators and tell them that this urgent matter needs their immediate attention. And support the ADAP Advocacy Association as we work to solve this urgent issue.





## **NEW STUDY EXAMINES IMPACT OF 'DOUGHNUT HOLE' ON PEOPLE ENROLLED IN MEDICARE DRUG PLANS IN 2007**

### **Approximately 3.4 Million Part D Enrollees, Including Many with Serious Medical Conditions, Reached the Coverage Gap in 2007, Leading Some to Stop Treatment**

Washington, D.C. - A [new analysis](#) from the Kaiser Family Foundation quantifies, for the first time, the number of Medicare Part D plan enrollees in 2007 who reached a gap in their prescription drug coverage known as the "doughnut hole," as well as the changes in beneficiaries' use of medications and out-of-pocket spending after they reached that gap. The analysis excludes beneficiaries who receive low-income subsidies because they do not face a gap in coverage under their Medicare drug plan.

The study of Part D prescription drug utilization finds that one in four (26 percent) Part D enrollees who filled any prescriptions in 2007 reached the coverage gap. This includes 22 percent who remained in the gap for the remainder of the year, and 4 percent who ultimately received catastrophic coverage. Applying this estimate to the entire population of Part D enrollees, the analysis suggests that about 3.4 million beneficiaries (14 percent of all Part D enrollees) reached the coverage gap and faced the full cost of their prescriptions in 2007.

Beneficiaries taking drugs for serious chronic conditions had a substantially higher risk of a gap in coverage under their Medicare drug plan. For example, 64 percent of enrollees taking medications for Alzheimer's disease reached the coverage gap in 2007, as did 51 percent of those taking oral anti-diabetic medications and 45 percent of patients on antidepressants. As noted above, these percentages are among Part D plan enrollees who did not receive low-income subsidies.

Conducted by researchers at Georgetown University, NORC at the University of Chicago and Kaiser, the study found evidence of patients changing their use of prescription drugs when they are required to pay the full cost of medications in the coverage gap. Across eight classes of drugs examined – used to treat a variety of relatively common chronic conditions – 15 percent of Part D enrollees who reached the gap stopped their drug therapy for that condition, 5 percent switched to another medication in the class, and 1 percent reduced the number of drugs they were taking in the class.

"The Medicare drug benefit has produced tangible relief for millions of people, despite the unusual coverage gap that was created to make the benefit fit within budget constraints," Kaiser CEO and President Drew Altman said. "But if a new president and Congress consider changes to the drug benefit, it will be important to keep in mind that the coverage gap has consequences for some patients with serious health conditions."

For people with a chronic condition such as diabetes, stopping a medication even temporarily can have serious and immediate health consequences. The study found that 10 percent of Part D enrollees taking oral anti-diabetic drugs who reached the coverage gap stopped taking their medications. In other cases, the potential consequences may be realized over a longer term. For example, among Part D enrollees taking a drug for osteoporosis who reached the gap, 18 percent stopped taking medications. In other instances, the health implications are less clear. For example, 20 percent of those taking Proton Pump Inhibitors who ended up in the gap discontinued their medications. Because there is some concern that such drugs (for ulcers and acid reflux) are overused for more routine gastrointestinal conditions, termination of therapy might not pose serious health risks in all cases.

Beneficiaries who reached the coverage gap faced substantial increases in out-of-pocket spending. For example, among Part D enrollees who reached the coverage gap, but did not receive catastrophic coverage, average monthly out-of-pocket costs nearly doubled from \$104 prior to the coverage gap, to \$196 in the "doughnut hole." The vast majority (84 percent) of the Part D enrollees who reached the coverage gap did not have sufficient additional drug spending during the year to receive catastrophic coverage, at which point their Part D plan would pay 95 percent of drug costs.

The study also found that people who reached the gap paid the full cost of their medications, without any help from their Part D plan, for an average of just over four months and received catastrophic coverage for less than one month.

This study analyzes retail pharmacy claims data, based on 4.5 million Medicare beneficiaries in Part D plans in 2007, the first year that most people would be enrolled in a Part D plan for a full calendar year. The analysis is based on 2007 data from IMS Health's Longitudinal Prescription Drug Database, which includes prescription drug information that represents half of all retail prescriptions filled in the U.S.

The report, [The Medicare Part D Coverage Gap: Costs and Consequences in 2007](#), is available online. The research team includes: Jack Hoadley of Georgetown University, Elizabeth Hargrave of NORC at the University of Chicago, and Juliette Cubanski and Tricia Neuman at the Kaiser Family Foundation.

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*The Kaiser Family Foundation is a non-profit private operating foundation, based in Menlo Park, California, dedicated to producing and communicating the best possible information, research and analysis on health issues.*

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## **IMPORTANT RESOURCES:**

Go to [ADAP TrOOP Fact Sheet](#)

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