

ADAP Advocacy Association Newsletter – January 2009

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ADAPs in Crisis: Waiting Lists Then and Now

By Brent B. Shimmin

As of November 25, 2008, fifty-three HIV-positive Americans in three states are currently unable to get the life-saving medications and other essential medical services they require due to ADAP waiting lists. As sobering as this news is, it is actually just the tip of the iceberg of a much greater problem, one that promises show itself over the next three to six months and play on into the foreseeable future. Before we address the larger problem, let's take a look at the facts as they stand right now:

The largest concentration of patients waiting for their medications is in Indiana, with thirty-two; next is Montana with sixteen, and finally Nebraska with five. These numbers represent not abstract concepts but real people, people for whom this "budget gap" could well have serious consequences. If they are part of the 4.4million workers who are currently receiving unemployment insurance due to having been laid off (many of whom lost their health benefits with their jobs), this could mean an unanticipated, involuntary interruption in the treatment they've experienced. If they are newly-diagnosed, delaying treatment can lead to greater risks of acquiring opportunistic infections; the consensus amongst medical professionals is to begin HAART (highly active anti-retroviral treatment) sooner rather than wait for issues to develop.

In either case, such treatment detours can be, and have been, fatal. In 2003, eight Americans (five in Kentucky and three in W Virginia) died while on ADAP waiting lists, and in 2006 four South Carolinians suffered the same fate. In fact, thirty-five people have died on APAD waiting lists since 2000. These tragedies were and are as inexcusable as they were preventable, and represent a shock to those who complacently believe that AIDS is a "manageable condition".

There are several causes for this predicament, with plenty of blame to go all around. Federal funds have been essentially flat-lined for several years, despite a steady rise in new infections. The 3% increase in the ADAP earmark for '07 did not make up for the 4% decrease in state contributions even where such comparisons can be made. Of the fifty-three ADAPs outlined on the Kaiser Family Foundation's website, thirteen were entirely dependent on federal monies for funding in 2007: AR, DE, DC, IN, LA, MD, MI, NM, ND, RI, SD, VT and WV. Another ten (AK, AL, CT, KY, MA, ME, MS, NJ, UT, WI) contribute less than 10% of their ADAP funds themselves. In total, less than a quarter (21%) of all ADAP dollars came from the states.

But these statistics cannot tell the whole story by themselves. While Indiana relies entirely on Washington for its ADAP budget, Montana contributes 26% and Nebraska 40%. With such relatively small populations overall (and correspondingly lower budgets), these latter two states can find even a modest increase in need difficult to meet. In Montana, for instance, the total ADAP budget (\$740,954) was .0025% of California's (\$288,106,287).

And as budgetary crises hit, in the five states with the largest concentrations of ADAP recipients (51% of the total patient load), New York (which contributes 19% of its ADAP budget), Texas (33%), Florida (11%), Pennsylvania (27%) and California (31%), advocates will be fighting for their piece of smaller pies. Indeed, the Center on Budget and Policy Priorities reports that at least 39 states are facing financial difficulties in their FY2009 and FY2010 budgets in all areas, and ADAP will surely be affected.

Additionally, NASTAD (National Alliance of State and Territorial AIDS Directors) reports:

Medical and other support services provided by Ryan White Part B programs are also impacted by these same factors and others that restrict access to services for those in need. These important programs, also administered by state health departments, enable ADAP services to benefit client health and include ambulatory medical services, case management, laboratory services, and an array of support services.

As of October 10, 2008, states report that insufficient funding, a lack of providers, difficulties with coordination, and administrative work burden are significant impediments to providing comprehensive client care. Four states report that 266 individuals are on either a medical or support service waiting list for services that include housing, mental health counseling, specialty medical care, and transportation. Five states report that funding is insufficient to ensure that all eligible patients attend medical appointments every three months, which is the standard of care. Eight Part B programs are also considering cost containment measures for their Part B services in light of high demand and reduced funding."

Comparing protocols of HIV/AIDS care between the states is tricky, as there are no universal federal guidelines to follow and each of the ADAP governing agencies (fifty states, plus DC and seven territories) manages its allotment as it sees fit. Legally, Ryan White/ADAP are funded as payers of last resort, but broad eligibility discrepancies exist. Income restrictions can vary from 200% to 500% of FPL (federal poverty level: \$10,210 for a single individual in 2007, though an estimated 40% of all ADAP beneficiaries live at or below 100% FPL), and eighteen states assess limits on the assets one can own.

Although congress finally mandated a base list of antiretrovirals be included in each ADAP formulary in 2006, a patient's access to other important medications, ranging from anti-depressants and other psychotropics to statins and pain medications (to combat side-effects) to insulin, depends on where he or she lives. Four states (MA, NH, NJ, OR) have open formularies, while two (ID and LA) have no drugs which are not antiretrovirals on their formularies whatsoever, and six (AL, MS, OK, TX, UT, WV, and the US Virgin Islands) pay for ten or fewer. These ancillary medications are an easy, obvious target for those looking to manage rising costs by reducing formularies instead of initiating waiting lists, but for the states listed above, which already have extraordinarily strict income criteria, there's no real fat to cut.

Another, similar issue involves cuts in services. In New York there was an attempt to cut back on transportation services to get patients to and from medical appointments and pharmacies which met fierce, organized resistance earlier in 2008. However, in mid-December, Governor David Patterson announced cuts amounting to \$65million to the state's ADAP budgetary contribution. Among the cuts reported by the Gay men's Health Crisis (GMHC) were a proposed cut of \$6.5 million from "the Office of Alcoholism and Substance Abuse Services for people living with HIV/AIDS," more than "\$2.5 million from programming for communities of color." Also included was a proposal to eliminate all "legal services funding for HIV/AIDS providers", which will severely hamper efforts to obtain government benefits for people with HIV, and other advocacy concerns from those who need them most yet can least afford them. These cuts will send a deep chill throughout the New York community of PLWA (one of the country's largest such populations), and may not prevent the tragedy of waiting lists anyway.

California, which is currently facing a \$40billion budgetary shortfall itself, will surely be the next fiscal flash-point: cuts are inevitable. As of yet there are no proposals in Sacramento to deal with this crisis as it relates to the care of those battling HIV/AIDS, but when they are announced, they'll surely be devastating to the millions who rely to some degree on state-funded assistance programs.

But for many states which are more rural and the needs are spread out far, transportation, legal services and such "frills" have never even been part of the deal. And whereas PLWAs in California or the Northeast can rely on decades of experience in dealing with the byzantine nature of funding procurement and enjoy effective leadership in advocating for them in times of crisis, the states in the South and Mountain West battle a greater stigma and marginalization with fewer resources to combat them, to the detriment of PLWAs living there.

Kentucky is an excellent example of this. Deborah Wade, program director for the WINGS Clinic at the University of Louisville says that back in 2005, "Kentucky had the longest waiting list of all states for the drug program". The state legislature began increasing its financial contribution to ADAP in 2004, and eliminated the waiting list in 2006. But the state has cut all ADAP contributions their latest budget, and federal funds have actually decreased from \$4.6 million in 2005 to \$4.3 million in 2008. Despite this contraction in monies, the number of new patients seeking ADAP assistance each month has climbed from 23 in 2006, to 35 in 2007, to 50 at present, according to Sigga Jagne, HIV/AIDS Program Branch Manager for the Division of Epidemiology, Kentucky Department for Public Health. "It's not the ideal situation," Ms Jagne says, and has announced that waiting lists are "inevitable".

Part of the shortfall has been made up by renegotiating pharmaceutical contracts and availing themselves of various drug-rebate programs: according to KFF, 23% of Kentucky's total ADAP budget comes from such efforts, but obviously they can only do so much, and the state is facing a deficit of more than \$450million. And the drug-rebate route is hardly ideal. Each medication requires its own application, and with most ADAP patients on multiple medications from different pharmaceutical companies, the process is laborious and temporary: they need to be renewed periodically.

This is not a solution to the crisis; it's a stop-gap band-aid. But for the 1,300-odd people living in Kentucky whose lives depend on it, it's the best (and only) option they have.

President-elect Obama is on the record as supporting increases in Ryan White/ADAP to meet the needs of Americans living with HIV/AIDS, but results will likely take months, by which time waiting lists can grow and spread, leaving those with the least just a little more vulnerable.

State-by-state ADAP budget comparisons:

<http://www.statehealthfacts.org/comparemaptable.jsp?ind=544&cat=11>

KFF HIV/AIDS Fact Sheet, April 2008:

http://www.kff.org/hiv aids/upload/1584_09.pdf

NATIONAL ASSOCIATION OF STATE & TERRITORIAL AIDS DIRECTORS (NASTAD) REPORT: The ADAP Watch
December 8, 2008

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ADAP Advocacy Association (aaa+)
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