

INSIDE

THE EPIDEMIC AT HOME: A CONSPIRACY OF NEGLECT 5

The longstanding estimate of 40,000 new HIV cases a year in the U.S. was a massive undercount.

HEALTH CARE IN THE U.S.: CLOSING THE GAPS, OPENING THE DOOR 9

The United States is failing when it comes to health care access.

PEPFAR, THE SEQUEL 10

THE POLITICS OF ADAP 11

ADAPs have had to serve more people than ever before.

Personal Perspective: BECOMING A VOICE FOR CHANGE 14

The fight to end ADAP waiting lists in South Carolina.

MANAGING MEDICAID 16

Personal Perspective: ADAP ALLOWED ME TO LIVE 18

MEDICARE PART D: FIXING PART OF THE PROBLEM 20

EDITORIAL 23

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The U.S. response to the AIDS epidemic has been hampered by public health approaches based on ideology rather than science. Anti-gay, sexist, and inaccurate “abstinence-only” sex ed programs have been promoted over comprehensive sex education. Restrictions on syringe exchange have also interfered with proven prevention strategies.

AIDS and the Next President

by Sean Cahill, PhD

It is estimated that about a quarter of Americans who have HIV are not aware of it. This is a public health disaster, since 50 to 70% percent of new infections are transmitted by people who don't know they have HIV. People who know their HIV status are much more likely to practice safer sex and to avoid infecting others.

In August 2008, the Centers for Disease Control and Prevention (CDC) announced that over 56,000 people are infected with HIV each year in the U.S., and that this has been the case since the early 1990s. Men who have sex with men (MSM) made up 53% of new infections reported in 2006. Another 4% percent of new infections were among MSM who use intravenous drugs. Blacks, and to a

lesser extent Latinos, are also overrepresented among new diagnoses. This news has underlined the country's inadequate response to the domestic AIDS crisis, and the opportunity that exists with the upcoming Presidential election.

A NATIONAL AIDS STRATEGY

The U.S. requires countries receiving funds under the President's Emergency Plan for AIDS Relief (PEPFAR) to have a national AIDS strategy, yet 27 years into the epidemic, we have never created one for ourselves. Numerous government and private studies have pointed to the need for better planning of U.S. AIDS policy. In 2004, the Institute of Medicine determined that federal financing of AIDS-related health care “does not allow for comprehensive and sustained access to quality HIV care” in the U.S. Our failure to bring down new infec-

continued on page 3

ACRIA Trials In Progress

Pomegranate Juice

People who have not taken HIV meds for at least 90 days will drink pomegranate juice or placebo juice daily for 10 to 18 weeks to study its effect on the heart, quality of life, and HIV viral load.

Ibalizumab

People who have taken HIV drugs will receive infusions of ibalizumab (a monoclonal antibody designed to block HIV entry into CD4 cells) once or twice a month for 48 weeks, along with other HIV drugs.

Crofelemer for Diarrhea

People 18 and older who have persistent diarrhea will take crofelemer (a new anti-diarrhea drug) or placebo tablets for 6 weeks. Then everyone will take crofelemer for 5 months.

Avandia and Serostim

People with insulin resistance will take Avandia (rosiglitazone), or Serostim (growth hormone), or both for 6 months to see how they affect blood sugar, insulin levels, and body shape.

Isentress in Pregnant Women

Pregnant women who are already taking Isentress will give several blood samples on two separate days in order to find the optimum dose of the drug during pregnancy. Compensation is provided.

IMPACT: Reyataz Resistance

People who have developed resistance to Reyataz will come in for one day of blood tests to study the I50L mutation.

For more information on these trials, contact us at 212-924-3934, ext. 121.

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LETTERS TO THE EDITOR

To the Editor:

I received a copy of your Summer 2008 issue and think it was great. I especially liked the readability of Mark Milano's piece on treatment. I am passing it along to our chronic care partners. My boyfriend, a journalist with little knowledge of HIV, read Mark's article and understood it – a sign of good writing.

Lisa Cardinale, LMSW

Senior Public Health Education Coordinator
Dutchess County Department of Health

To the Editor,

I am writing because I just received a copy of your Summer 2008 issue. I've never seen so much information in 23 pages. Some articles I read because I couldn't stop, and others I read to get some sides and hear voices from a group (gays) many hate. Your magazine opened my mind to new things, such as "The Battle for Global Treatment Access" and "People with HIV Not Welcome Here." I didn't know many of the topics and I love the way you just came out and didn't hide names and such.

Don't change a thing! Just keep it coming. I let people read my copy but I get it back when they're done. If you continue to publish more issues, please send me one!

Always and forever a changed heart,

JAE

To the Editor:

I am a 40 year old gay man and unfortunately I am HIV and hepatitis C positive. But I plan to live 40 more years – I will not let AIDS or hep C kill me without a fight.

I am currently an inmate at the Arizona State Prison and they do not have the proper HIV diet that one needs to stay healthy. But my HIV and AIDS specialist, Ann Belzer, does so much for me and I have nothing to give her back. I do want to be an HIV and AIDS peer educator. There is just not enough peer educators in the world.

One more thing: I am truly sorry I can not send a generous donation to you, but I can not even afford a \$200 TV to make my time go by quicker.

But anyway, I would very much appreciate it if you could keep me informed on any and all new medications that get approved.

God Bless You – Stay Safe,
Name Withheld

Achieve would love to hear from you! Please send your comments to: Letters to the Editor, *Achieve*, 230 W. 38th St., 17th floor, New York, NY 10018, or email them to: achieve@acria.org.

Photos used in *Achieve* imply nothing about the health status, sexual orientation, or life history of the models.

tion rates has a fiscal as well as a human cost: a 2003 study found that failure to meet the CDC's then goal of reducing HIV infections by half would lead to \$18 billion in excess expenses through 2010.

The next administration must develop and implement a national AIDS strategy that is comprehensive across federal agencies; sets timelines and assigns responsibility for implementing changes; identifies targets for improved prevention and treatment outcomes; reduces racial disparities; prioritizes gay and bisexual men (especially MSM of color); and mandates annual progress reporting.

Barack Obama has committed to creating and implementing a national AIDS strategy if elected. In August 2008 this commitment was written into the Democratic Party National Platform. As of this writing, John McCain has yet to make such a commitment, despite repeated outreach from AIDS activists since summer 2007. Gay rights and AIDS activists, however, including the Log Cabin Republicans, are still pushing him and the Republican Party to endorse a national AIDS strategy. The plan has bipartisan support in Congress.

HIV PREVENTION

Preventing people from getting HIV is the best way to stem the epidemic nationally and globally. We will not be able to keep pace with the disease if we focus mainly on treatment. Currently only 4% of federal funding devoted to AIDS goes to prevention efforts. Since 2001, federal prevention funding has declined 19% in real, inflation-adjusted dollars. We cannot continue funding at such low levels if we ever hope to eradicate HIV in the U.S.

For the past eight years, the Bush administration has focused its prevention efforts in ways that have been proven ineffective. Millions of U.S. tax dollars have gone to fund "abstinence-only" programs that study after study have shown do not work. It is clear that comprehensive sex education and the widespread availability of condoms are the only means to ensure that young people learn and practice healthy sexual behaviors.

Providing clean needles to IV drug



users has proven effective, dropping infection rates by 78% in New York City from 1990 to 2002. This has occurred without an increase in drug use or crime, defying opponents' predictions. Yet the prohibition against federal funding of such programs remains.

In the area of prevention, the differences between the two nominees are stark. Obama supports an end to federal funding for abstinence-only education with those funds redirected to comprehensive sex education, and an end to the ban on federal funds for syringe exchange. He is also the lead sponsor of the Microbicides Development Act, which would support research and development of new vaginal and rectal technologies that could prevent infections.

McCain supports abstinence-only programs and does not support comprehensive sex education. He has not taken a clear position on syringe exchange and has not signed on as a co-sponsor of the Microbicides Development Act.

THE ENTRY BAN

In the recent PEPFAR reauthorization bill, a provision was included to allow for the lifting of the U.S. entry ban for people with HIV. The ban undermines public health in the U.S., as immigrants and visitors avoid seeking HIV testing and treatment for fear of jeopardizing their ability to stay here.

President Bush signed PEPFAR II into law in July 2008. While the lifting of the ban from statute is a promising development, it is clear that Senator McCain did not support that provision of PEPFAR. In 1993, McCain voted for a bill that prevented people with HIV from entering the U.S., whereas Obama completed a survey from GMHC and aidsvote.org indicating he supports lifting the entry ban.

While McCain and Obama were united in their support of PEPFAR (which funds prevention and treatment outside the U.S.), questions remain about McCain's positions on the domestic epidemic. Perhaps most troubling is that McCain's

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key advisor on AIDS is the staunchly anti-gay Senator Thomas Coburn.

HEALTH CARE REFORM

The candidates' proposals for reform of the overall health care system have stark differences ranging from accessibility and taxation to financing and state contribution.

Obama would create a new national health plan available to all Americans. According to his campaign, this health care plan, released May 29, 2007, would save the American family \$2,500 per year by "providing affordable, comprehensive and portable health coverage for every American;

Palin opposes comprehensive sex education and is a supporter of "abstinence-only" education. Her position on other AIDS policy issues is unknown. Biden supports comprehensive sex education as well as syringe exchange.

modernizing the U.S. health care system to contain spiraling health care costs and improve the quality of patient care; and promoting prevention and strengthening public health, to prevent disease and protect against natural and man-made disasters."

McCain announced his health care plan on October 11, 2007. It stressed three goals: the importance of paying only for quality health care; having multiple insurance choices; and personal responsibility. In the speech announcing his health care plan, Senator McCain stated, "The 'solution,' my friends, isn't a one-size-fits-all-big government takeover of health care. It resides

where every important social advance has always resided – with the American people themselves, with well-informed American families, making practical decisions to address their imperatives for better health and more secure prosperity."

THE RUNNING MATES

Sarah Palin and Joseph Biden have very different records on HIV/AIDS. Palin is a staunch opponent of comprehensive sex education and a supporter of "abstinence-only" education. Her position on other AIDS policy issues is unknown. Biden supports comprehensive sex education as well as syringe exchange. Most recently, Biden worked to ensure that the recently passed PEPFAR legislation included a repeal of the entry ban for people with HIV. It also promotes prevention among MSM, along with research on HIV incidence among MSM. While Biden supports civil unions, Palin opposes domestic partner health insurance benefits for state workers in same-sex relationships.

CONCLUSION

Twenty-seven years into the AIDS epidemic, the situation in the U.S. is getting worse, and we continue to fight AIDS with one hand tied behind our back. The gay, lesbian, bi, and transgender communities need to reconnect with the AIDS movement and work closely with black and Latino organizations to address health disparities affecting all of our communities. We need to use all the tools available, including sex education, condoms, and syringe exchange, to reverse the tide and bring down the rate of new infections. The science shows that these approaches work. We need a renewed focus on the domestic HIV epidemic, and to embrace science-based prevention, treatment, and care fully. We need a president who will lead a domestic emergency plan for AIDS relief. ■

Sean Cahill is Managing Director of Public Policy, Research and Community Health for GMHC.



by Julie Davids

That same week, the Black AIDS Institute published *Left Behind! Black America: A Neglected Priority in the Global AIDS Epidemic*. This document showed that more blacks are living with HIV in the U.S. than in seven of the 15 countries served by PEPFAR. In fact, if Washington D.C. were a country, it would have the 11th highest level of HIV cases in the world – one of every 20 residents.

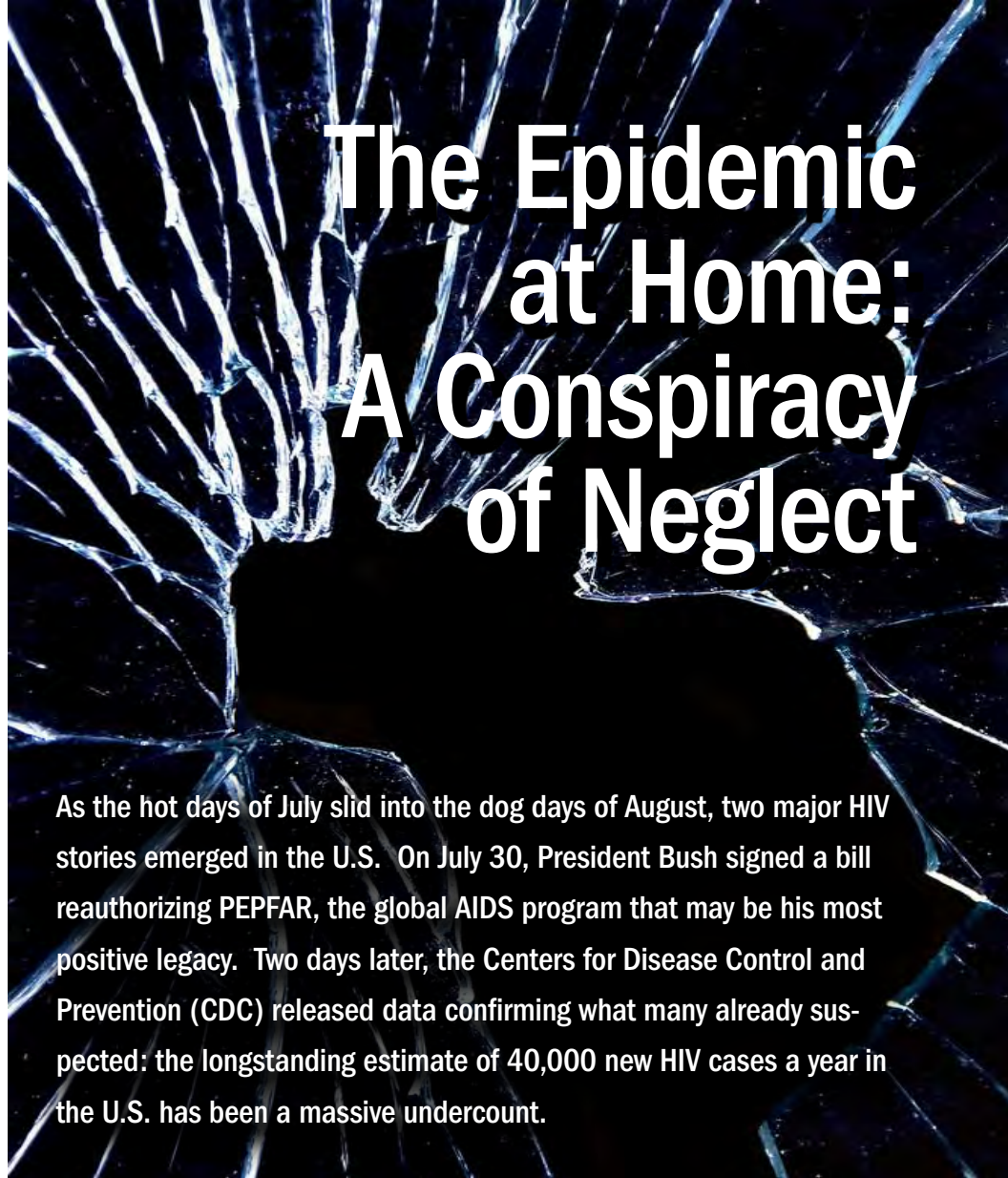
Using improved techniques that can sort out new infections from older ones, the CDC now estimates that 56,300 people became HIV positive in the U.S. in 2006 – about 40% more than previously thought. And while the CDC says the epidemic is “stable,” that stability shows that infections among African-Americans are much greater than their percentage of the population and that those in gay men and other men who have sex with men (MSM) have steadily increased since the early 1990s.

CDC also did a “back calculation” that showed that the long-held 40,000-a-year figure was never right. Since 1991, HIV incidence (new infections) has been 25-50% higher than that figure, and the CDC is now preparing to revise its estimate of the number of people with HIV in the U.S. But the current estimate leaves out data from territories with high HIV rates, such as Puerto Rico and the U.S. Virgin Islands. This exclusion might mean an even higher total, especially among people of color.

Some people believe there’s a government conspiracy that allows, or even assists, the spread of HIV in gay men and communities of color. But conspiracies are hidden. When it comes to HIV, the reasons for such high incidence rates – and for levels of infection in some communities that are among the worst on the planet – are plainly visible to anyone who cares to look.

A Continued Failure of Leadership

Despite over a quarter century of signs that HIV would become a severe public health crisis, there has never been anyone at high levels of the U.S. government with the power or skills to craft a strategy to fend off reactionary politics, defeat vested interests, and move money where it needs



The Epidemic at Home: A Conspiracy of Neglect

As the hot days of July slid into the dog days of August, two major HIV stories emerged in the U.S. On July 30, President Bush signed a bill reauthorizing PEPFAR, the global AIDS program that may be his most positive legacy. Two days later, the Centers for Disease Control and Prevention (CDC) released data confirming what many already suspected: the longstanding estimate of 40,000 new HIV cases a year in the U.S. has been a massive undercount.

to go – not just through traditional health programs, but across all parts of government and society.

HIV prevention has always been the least-funded aspect of the epidemic in the U.S. It was the slowest to grow in the years of HIV funding increases, and prevention funding has declined each year since 2001. State and local HIV prevention agreements were cut by \$26 million from 2003 to 2007 and may be cut by an additional \$5 million this year. And key HIV prevention measures, like anti-homophobia efforts and syringe exchange, have either been starved for resources or explicitly banned from receiving federal funds.

The Cost of Delay

While waiting for the new estimates, David Munar of the National Association of People with AIDS wrote:

“For months, AIDS advocates called for the public release of the data, which CDC

admitted ... it had finalized in October 2007. An earlier release might have given the Bush administration second thoughts about requesting a \$1 million decrease for CDC’s domestic HIV prevention programs; spurred presidential candidates to talk more readily about HIV/AIDS in the U.S.; persuaded media pundits and debate moderators to quiz candidates on plans to end the epidemic; led Congress to pass even one of the dozen domestic HIV prevention bills languishing on Capitol Hill; or motivated appropriators to finally boost HIV prevention funding or end long-held restrictions on how funding can be used.”

We may never know if the CDC deliberately delayed the new estimates (perhaps at the insistence of the Bush Administration). But it’s a valid question in light of the troubling suppression of other public health data. CDC’s explanation – that they needed rigorous peer review by a major scientific or medical journal – is plausible,

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given the new methodology and the complexity of the statistical model. But it most likely could have been done faster.

In any case, the wait for the new estimates is finally over. We now know that someone becomes HIV positive every nine minutes in the U.S. There are over 150 new infections a day, more than a third of them in people under 30. Will we point fingers at them and cast blame, further fueling stigma? Or will we finally take a long, unflinching look and ask why we tolerate this open conspiracy and the absence of a national AIDS strategy that includes bold HIV prevention measures?

The bottom line is that the HIV epidemic in the U.S. continues to spread at a rate greater than previously thought. The U.S. has never provided HIV prevention education to a large part of its population nor invested in the research needed to find better prevention tools. The news of higher incidence shows this shortfall has brought about an even greater tragedy than we'd realized.

Eyes Wide Open, But Do We Have Vision?

The real measure of political leaders and the people of the U.S. will be whether this bad news spurs good action. People with HIV and their advocates are calling for a national AIDS strategy that confronts the homophobia, violence, and bias at the heart of the U.S. epidemic.

We need a compass to find our way to real solutions. And like any good compass, it must point in at least four directions:

- Increasing prevention strategies that we know are effective, such as behavioral interventions and needle-exchange programs.
- Eliminating policies that take us in the wrong direction, like abstinence-only funding and bans on condoms in prisons.
- Scaling up research to figure out what new prevention strategies will confront this complicated, diverse epidemic.
- Broadening our understanding of HIV prevention to tackle the social ills that contribute to the spread of HIV, including persistent homophobia and anti-gay violence, mass imprisonment, homelessness, and other consequences of poverty.

Does HIV Prevention Work?

In the past decade, it's been fashionable to say that it doesn't. But the reality is far more complicated. To dismiss all prevention efforts is to throw out the proverbial baby with the bathwater.

Our frustration at the high rate of new infections shouldn't cause us to overlook the success it reveals in holding the epidemic at bay. As more people live with HIV each year, we might expect new infections to increase. Yet they've held steady for almost a decade. So something – most likely a combination of things – is keeping overall infection rates steady while the number of people with HIV is rising.

Many of our current interventions succeed in reducing HIV risk behavior by 20-40%. That's not a home run by any means, but it's on par with the effects of cholesterol and diabetes drugs. Yet HIV prevention programs have never been scaled up to meet the need. For example, it's estimated that HIV prevention programs have reached less than 20% of gay men.

Let's not forget that mother-to-child HIV transmission has decreased by 95%, from a peak of 954 cases in 1992 to an all-time low of 48 cases in 2004. To keep it that low, we need to overcome the public health challenges that allow pregnant women to slip through the cracks – a goal achieved in many states without mandatory testing laws that throw out crucial protections like informed consent.

For some parts of the prevention challenge, we know what works – like syringe exchange, long known to decrease HIV transmission without increasing drug use. Yet the federal ban on funding syringe exchange prevents scaling up the very programs that have helped decrease infection rates in injection drug users.

Despite the need to support condoms with a range of HIV prevention tools (just as there are a range of choices to prevent pregnancy), they do work. Each new generation needs easy access to them and education on their use – even if strapped AIDS organizations strip them from budgets and schools shy away from sex ed that places condoms in broader discussions of healthy relationships, power dynamics, and sexual decision-making.

CDC studies have revealed that an average of 46% of black MSM in certain cities are living with HIV. This is one of the highest infection rates in the world.

We do know at least one thing that has failed miserably in the fight against HIV: abstinence-only programs spread misinformation about HIV transmission, use outdated stereotypes of gender roles, and encourage anti-gay stigma.

Despite copious evidence that these programs don't protect young people from HIV, the federal abstinence-only program was granted a one-year extension by Congress two weeks before the release of the CDC numbers. The government is inviting groups to apply for a total of \$50 million, as long as they agree that "a mutually faithful monogamous relationship in the context of marriage is the expected standard of all human sexual activity" and that "sexual activity outside the context of marriage is likely to have harmful psychological and physical effects."

Our current menu of HIV prevention programming has too few selections, and the portions have become skimpier due to underfunding. CDC says that its primary impediment in not reaching its 2005 goal of cutting the incidence of new infections in half is a lack of funds.

It's Not What You Do, But Who You Are

There's more to the prevention puzzle than meets the eye – and our very concept of risk and safety must be questioned to meet the challenge of overcoming the epidemic.

Although the new estimate shows that the vast majority of new HIV cases are in African-Americans and gay men, the CDC has not yet released figures bridging race and sexuality. So we don't know exactly how many of the new infections are in African-American gay and bisexual men.



But other CDC studies have revealed that an average of 46% of black MSM in certain cities are living with HIV.

This is one of the highest infection rates in the world – and it’s not because these men engaged in “riskier” behaviors than their white counterparts. They reported the same or even lower rates of risky sex. Similarly, a large study of adolescents found that black youths had much higher rates of sexually transmitted diseases, including HIV, even if their risk-taking was much lower than that of white youths.

Thus, the much-touted AIDS awareness slogan, “It’s not who you are, it’s what you do,” is a dangerous oversimplification, or even mischaracterization, of HIV risk in the U.S. In reality, risk in the black community is greater in spite of lower levels of risky behaviors.

When CDC researchers looked at 12 possible factors that could explain the higher rates in black gay men and MSM, they found evidence that it could be related to higher rates of STDs, which make people more likely to get HIV if they are exposed to it. It could be that the men had lower rates of HIV testing, so more of them did not know they were positive. The CDC was able to cross off other possible causes, such as not identifying as gay, not disclosing HIV status, or using drugs or alcohol.

But there were not enough data to evaluate other possible reasons.

This mystery is just one example of the pressing need for more research that looks beyond traditional concepts of risk and considers new interventions. Much work remains to figure out what is going on – and what to do about it. Epidemiologist Walt Senterfitt explained, “Once there’s a much higher prevalence of HIV in your pool of partners, your risk of getting infected is much higher.”

Recent vaccine and microbicide trials have encountered roadblocks that have set back the timeline for finding effective agents. We need to look at new approaches that combine biomedical strategies – like using HIV meds to prevent infection or having them made into microbicides – with behavioral approaches that help people take fewer risks. After the U.S. part of the HIV Prevention Trials Network (HPTN) was slashed, prevention activists organized, and won new trials to explore next steps for the domestic prevention research agenda – but much work remains to be done.

Synchronized Epidemics?

People on the front lines of the epidemic know that HIV is much more than a medical condition. At last year’s Prevention Justice Mobilization at the National HIV

Prevention Conference, hundreds of people marched through the streets of downtown Atlanta bearing a banner reading, “HIV is Not Just a Disease. It’s Proof Positive of Injustice.”

Prevention efforts have largely focused on individual behavior. But personal health is affected by social and economic realities often out of the control of any individual. To tackle the HIV epidemic, we must broaden our concept of prevention. The apartments that allow formerly homeless people to control their own sexual destiny rather than to trade sex for a roof over their heads are just as much a part of HIV prevention as the condoms that they carry in their pockets.

In the mid-1990s, anthropologist and syringe exchange activist Merrill Singer coined the term “syndemics” to refer to the interaction between two or more health concerns that can make each condition worse. For example, someone with a history of substance abuse may fall deeper into addiction when receiving an HIV diagnosis. Not surprisingly, syndemics more commonly occur in groups experiencing poverty, stress, or violence.

Rather than blaming gay men for high rates of HIV infection, researcher Ron Stall and others point to the stigma experienced by young gay men and other MSM that sets the stage for a syndemic.

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There are clear data showing that gay men who experience bullying and violence in adolescence have higher rates of drug use, intimate partner violence, and HIV later in life. These researchers believe that effective HIV prevention for gay men must confront the syndemic itself, by supporting the health of gay people of all ages through programs that confront homophobia.

As people from around the world learned at the 2008 International AIDS Conference, Mexico's national AIDS program sponsors public campaigns against homophobia in subways and buses, television spots, and school programs, and by working with telenovela and movie producers. This socially conservative country has far fewer resources than we do, yet it chooses to challenge homophobia ambitiously with government funding.

But the U.S. government refuses to confront homophobia. Throughout the AIDS epidemic, we've seen politicians of both parties and the Department of Health and Human Services cave in to pressure from right-wing politicians, squelching not only sexuality research but also anti-homophobia messages.

The U.S. now can boast of having the largest prison population in the world. In fact, we imprison more people than any country in history. HIV can be, and is, transmitted behind bars, yet access to condoms and prevention information in prisons is rare. But what may be an even bigger contributor to the spread of HIV is the disruption of communities that comes with locking up so many African-Americans, Latinos, and immigrants. This massive dislocation of people creates ideal conditions for increased HIV rates in areas with high rates of imprisonment.

Who's In Charge?

The Need for a National AIDS Strategy

HIV prevention is a complex, national crisis that requires a response that cuts across all sectors of government – one that is guided by the knowledge of communities on the frontlines. But it's been fragmented across agencies that are often unaccountable to top levels

of leadership and unresponsive to the realities of fighting HIV.

When one of every four people with HIV is involved in the criminal justice system each year, we need the Department of Justice involved. When stable housing has been shown to decrease HIV disease progression and help people protect themselves from infection, we need HUD there.

An unprecedented range of local, state, and national AIDS groups are calling for a National AIDS Strategy at the federal level, with the power to make real change.

When escalating rates of deportation and detention are fueling the epidemic, we need to reevaluate our immigration policies. And when the increase in HIV rates in gay men echoes increases in anti-gay violence, it's long past time to integrate LGBT health and anti-stigma efforts across government programs.

Perhaps most important, this work requires collaboration with those in the thick of the epidemic. An unprecedented range of local, state, and national AIDS groups are calling for a National AIDS Strategy at the federal level, with the power to make real change. But given the long history of government neglect and misconduct, AIDS activists must hold onto our well-founded skepticism as we move forward. We must ensure the participation of people with HIV and the communities most affected by the epidemic as central decision-makers in the strategy itself.

We must insist that the bad news on HIV incidence is understood in the context in which it has occurred:

- in a country without a comprehensive national AIDS strategy;
- during a decade of flat or declining prevention funding;
- with restrictions on effective prevention tools like syringe exchange;
- along with major social injustices such as imprisonment of the racial and ethnic groups most affected by the epidemic.

We must demand HIV prevention justice, understanding that the failure to make progress in lowering incidence can be answered only by a strategic plan to combat HIV as a social, economic, and public health challenge.

Prevention activism, which has lagged behind other areas of AIDS advocacy, is coming to the fore. There are opportunities to work together to fight for a National AIDS Strategy that will:

- confront homophobia and gender bias;
- fund researchers to work with communities on better, expanded HIV prevention research;
- tackle the intersection of prisons and HIV;
- end AIDS by ending the economic, racial, and social injustices that fuel it.

The way ahead is not easy. But one thing is sure: if we don't come together to demand HIV prevention justice, we can anticipate that the pain, suffering, and loss that accompany this "stable" epidemic will be with us for a very long time. ■

Community HIV/AIDS Mobilization Project (CHAMP) recently hosted a panel discussion that explored research on why black MSM are at higher risk for HIV despite similar or even lower rates of individual risk behavior. The panel also examined how government policy should change to reflect these findings and how they affect prevention work within our communities. To watch the forum, visit: www.champnetwork.org/bmsm.

Julie Davids was a longtime member of ACT UP Philadelphia and is the founder of CHAMP.



Health Care in the U.S.

Closing the Gaps, Opening the Door

by Robert Greenwald, Gina Pak, Amy Rosenberg, and Sage Teton

The United States is failing when it comes to health care access. According to a report from the Commonwealth Fund (a private foundation promoting health care), the U.S. scored only 58 out of 100 points for access to care. This is a significant decline since 2006, despite the fact that we spend twice as much per person on health care as most other industrialized countries.

For people with HIV, access to health care can be a matter of life and death. Sadly, those who live in underserved areas or who lack insurance often have poor quality health care and limited services. People with HIV currently get care through several programs, including Medicaid, Medicare, Ryan White, and various state programs. This approach leaves significant gaps in coverage. Closing these gaps is a top priority for advocates. The upcoming elections for President and Congress offer important chances to focus the nation's attention on improving access to health care.

National Health Care Reform: The Obama and McCain Plans

Both presidential candidates have offered outlines of what they would do to reform our health care system. Senator Obama's plan would build on the current system

of employer-sponsored health care. It would also create a new health plan similar to what is offered to federal employees. His plan would require employers to offer health insurance or to help with its cost. It would also expand Medicaid and provide money to make the new plan affordable for people with low incomes. Insurers would be required to cover everyone, regardless of health status. This is especially important for people with HIV.

Senator McCain's plan would replace the tax break for employees who get health insurance from their employers. It would provide a refundable tax credit (\$2,500 for individuals, \$5,000 for families) for everyone who purchases health insurance. McCain's plan focuses on individual choice, insurance competition, reforming malpractice law, and changing the way providers are paid, in order to make health care affordable. Advocates are concerned that the McCain plan offers little to those with pre-existing medical conditions.

Earlier Access to Care

A 2004 Institutes of Medicine (IOM) report found that a large percentage of HIV-positive adults do not get regular medical care, and that many were not getting care in the early stages of the disease. This is partly due to the fact that the systems for HIV/AIDS care were put in place when care was mostly given in the hospital. New medications allow many to manage HIV as a chronic ill-

ness, but the programs that pay for care have not evolved to reflect this change.

Take Medicaid, for example – the largest payer of HIV care in the country. Current Medicaid policy requires an individual to be disabled by AIDS before becoming eligible for the care and treatment that could have prevented HIV disease from progressing to AIDS. Ironically, this puts Medicaid (a federal program) at odds with federal guidelines that recommend early treatment of HIV.

Receiving treatment early in the disease preserves health. Evidence also indicates that early treatment helps prevent the spread of HIV. A major goal for advocates is for more people with HIV to receive good care as soon as they are diagnosed. There have been several proposals for how to do this. The 2004 IOM report recommended creating a new \$7 billion federal program. In the current economic climate, however, a more likely approach may be to expand Medicaid coverage to low-income people with HIV before they become disabled.

Early Treatment for HIV Act

The most promising option for expanding Medicaid coverage is the Early Treatment for HIV Act (ETHA). This bill is currently pending in Congress with support from both parties (Senate Bill 860, House Bill 3326). ETHA would give states the option to extend Medicaid coverage to low-income people who are HIV positive but who do not yet have AIDS. ETHA is a cost-effective plan that would bring Medicaid guidelines in line with the U.S. government's own standard for treating HIV. House Speaker Nancy Pelosi is a sponsor and long-term supporter of ETHA. Advocates are hopeful that ETHA will become law soon.

Protecting Medicaid Coverage

Another ongoing priority is to protect current Medicaid benefits from cuts. The Bush administration has consistently tried to reduce funding and restrict Medicaid's ability to provide HIV services. One example of a harmful proposed change is a rule that would restrict case management benefits for people with HIV. Another would restrict services covered by hospital outpatient clinics, removing care for those

who can't obtain it otherwise. This would especially affect people of color, who rely heavily on outpatient clinics. Congress recently approved a freeze on the latest round of changes proposed by the Bush administration. Without ongoing education of our elected officials, however, such proposals will remain a threat.

Fixing Medicare

Many people with HIV depend on Medicare's new drug program, Part D, for their medicine. Advocates were recently successful in getting a new Medicare law passed that ensures that Part D plans will cover all HIV medications recommended by the federal HIV treatment guidelines. Under the new law, if a plan wants to exclude any of these drugs from coverage or to limit access, it must request an exception from the government after public notice and comment.

The second change sought by advocates is to include the money paid by AIDS Drug Assistance Programs (ADAPs) to Medicare clients as a part of their true out-of-pocket (TrOOP) expenses (see page 11). Counting ADAP as TrOOP would save ADAPs up to \$44 million. This provision was not included in the recently enacted Medicare reform bill. Advocates will need to argue to the next Congress and President that it's reasonable to count ADAP payments as TrOOP.

Mending the Safety Net

As they try to mend the holes in the safety net of publicly funded health care programs, advocates should seek to expand coverage by programs such as Medicaid and Medicare. At the same time they should advocate for funding of the care and services provided by other programs, like Ryan White. Congress and the new administration need to recognize that ensuring early, comprehensive access to care and treatment for all people with HIV is a crucial step towards ending the epidemic. ■

The authors work together at the Health Law Clinic of Harvard Law School.



PEPFAR, The Sequel

On July 30, President Bush signed into law a five-year continuation of the President's Emergency Plan for AIDS Relief (PEPFAR). Since 2003, PEPFAR has provided HIV medications to nearly two million people, mostly in Africa. While the new law contains many improvements, it still falls short of the need.

The new law does not include a target for the number of people who will receive treatment. It relies instead on a complicated formula that could lead to fewer people on treatment overall and may actually lower funding levels. Advocates are calling for the U.S. to support treatment for four million people by 2013.

In many places in Africa, people receiving HIV treatment must take drugs that have harsh side effects, even though better versions are available. These higher quality medications should be made available through PEPFAR. This will also have the effect of reducing the cost of these better treatments.

PEPFAR now includes provisions calling on countries in the program to offer HIV-prevention programs for men who have sex with men (MSM), and research on HIV rates among MSM. This will address the fact that MSM are at much higher risk for HIV than the general population.

The new legislation also affects the response to HIV in the U.S. It removes the ban, passed by Congress in 1993, on HIV-positive noncitizens gaining immigration status and travel visas. The U.S. is one of only 13 countries to ban short-term HIV-positive visitors. Until the final call to pass the bill, conservative policymakers threatened to propose amendments to strike the language that lifts the ban. At the time this article went to print, the decision to remove the ban completely rests within the Department of Health and Human Services, since HIV remains on a list of "communicable diseases of public health significance."

PEPFAR countries must still spend 50% of their prevention funding on unproven "abstinence-only" programs or do burdensome reporting to justify other approaches. Failure to do so could lead to defunding. The legislation also fails to support integration between family planning services and HIV programs for vulnerable populations like women and youth. Lastly, groups seeking funding must still oppose commercial sex work, even though prevention programs for sex workers have been proven to reduce HIV infection dramatically.

The renewal of PEPFAR and its increased funding is a remarkable step in the fight against HIV around the world. However, the importance of prevention efforts cannot be overstated. For every person who starts HIV treatment, two to three more become infected. It is critical that countries be able to both treat and prevent HIV without ideological restrictions. ■

The Politics of ADAP

The arrival of effective HIV treatment in the mid-90s created new challenges – among them how to provide these lifesaving medications to those who needed them. Enter the AIDS Drug Assistance Programs, or ADAPs, designed to provide medications for people without health insurance whose incomes are too high for Medicaid.

by Brandon M. Macsata

ADAPs were created by the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1987 – the nation’s only legislation aimed at providing healthcare for people with HIV. The Act currently provides about \$2 billion dollars annually for healthcare, support services, and drug assistance programs.

As the legislation has changed over the years, so has ADAP. For example, 1996 saw the introduction of the earmark formula, meaning that funding is distributed using a complex calculation based on each state’s actual number of people living with AIDS. Four years later, the law was modified to allow ADAPs to buy insurance coverage for their clients.

There are 58 ADAPs (for each of the 50 states and eight territories), with total spending of \$1.4 billion (of which \$775 million comes from the federal government), serving nearly 146,000 clients each year. Over 43% of those on ADAP live below the Federal Poverty Level (FPL – a yearly income below \$10,400), and 75% live below 200% of the FPL.

Once designed as the safety net of last resort, ADAPs have had to serve more people than ever before, and this growth shows no signs of slowing down. Yet ADAPs remain vastly underfunded at both the federal and state levels.

One Size Does Not Fit All

ADAP funding is awarded in the form of

grants, but implementation varies from state to state. Each state determines who can enroll, how its program is run, what drugs are covered, and what it will do to control costs. Unlike Medicaid and Medicare, ADAPs have a fixed budget, so in order to avoid running out of money at



the end of the year, programs have sometimes had to adopt extreme measures like waiting lists, which have led to patients literally dying while awaiting coverage.

Every state requires that ADAP clients have HIV. However, that’s pretty much where the similarities end. Some states tie eligibility to CD4 counts, while others do not. All states have income limits, but they vary widely.

Medications covered also vary from state to state. For example, California, Louisiana, and Wisconsin cover 31 HIV

drugs and drug combo pills, while Illinois covers 28 and Virginia only 26. And in some states with tight budgets, other medications required to combat side effects (such as prescription-strength antacids, statins to control cholesterol, and pain medications) have been dropped altogether.

The complexity of the ADAP model does not stop at the state level. It is compounded by the existence of other federal programs that offer access to care for people with HIV but which add an additional and unnecessary level of bureaucracy and red tape.

The Interplay Between ADAP, Medicare, and Medicaid

Navigating the ADAP maze is made more complicated by connections with other federal programs such as Medicare (the federal health insurance program for the aged and disabled) and Medicaid (the federal and state health insurance program for the poor). ADAP enrollment is often

temporary, as clients are forced into ADAP when their existing benefits change, or as they await their acceptance into other programs like Medicaid.

Medicaid provides a wider range of care and services than ADAPs, and its price tag is much higher. On average, ADAPs spend about \$12,000 annually on each person with HIV, compared with \$40,000 spent by Medicaid. And Medicaid has its own challenges, among them finding health-care providers who are willing to accept its low payments. Providers may also stop

continued on next page

accepting Medicaid, leaving their patients to find new providers on their own.

Another important source of HIV care in the U.S. is Medicare, serving over 100,000 people with HIV who are over the age of 65 or who are disabled. On January 1, 2006, Medicare Part D prescription drug benefits went into effect – but the program is clearly not designed to fully cover the high cost of HIV medications (see article on page 20).

Medicare clients who also receive any ADAP services are required to enroll in Medicare Part D, and some also rely on ADAP for help with premiums, deductibles, and co-payments. This can be a problem because ADAPs cover far fewer drugs than Medicare.

Also, Part D clients who are not eligible for low-income subsidies may be required to pay a large part of their drug costs. Many are left with “true out-of-pocket expenses” (TrOOP) totaling more than \$2,500 each year. You see, Part D stops paying for medications when a certain cap is reached. People must then pay for their drugs themselves until “catastrophic coverage” kicks in. This is called the “donut hole” and recurs year after year. In some cases, ADAP can pay for drugs during the donut hole, but this does not count toward filling in the hole.

Richard Fortenbery, Director of the Tennessee AIDS Care and Treatment Improvement Coalition (TACTIC), said, “The law does not allow ADAP expenditures to count toward the donut hole, leaving these people in limbo. They can literally go broke trying to pay for their deductibles and co-payments. Worse, many ADAPs refuse to provide lifesaving drugs to those in the donut hole, though this is allowed by the federal government.”

According to the Congressional Budget Office, this problem could be fixed for as little as \$100 million, but until there is political pressure to change the current policy, many Medicare clients remain stuck in the hole.

ADAP, Activism, and Politics

Despite its wealth, the U.S. is all too familiar with people waiting in long lines to

obtain “life, liberty and the pursuit of happiness” as articulated in the Declaration of Independence. In the 1930s, long lines formed to receive food during the Great Depression. In the 1960s, poverty-stricken areas of the South stirred the national conscience, and the “Great Society” was launched to alleviate poverty, hunger,

increased from \$51.9 million to \$460.6 million. Gingrich certainly didn’t achieve this success alone – bipartisan support for the increases was common. The last major influx of funds occurred in 2003, when Congress approved an increase of nearly \$100 million. Since then, however, ADAPs have been perpetually underfunded at



and homelessness. Yet in 2008, hundreds of Americans are still waiting to receive access to life-saving HIV medications.

Like every other federal program, ADAPs have found themselves competing for their share of a shrinking pie. The politics behind this competition is bipartisan, in that both parties have won small victories for ADAPs. But just as often, both parties have failed this vital program. Some might argue that politicians are willfully blind when they fail to provide ADAPs with the funding needed. The perpetual waiting lists are evidence enough!

Under the direction of former House Speaker Newt Gingrich from 1995 to 1999, federal funding for ADAPs fared relatively well, as that conservative icon understood the preventative importance of the program. During that time, ADAP funding

the federal level as both Republican- and Democratic-controlled Congresses have passed only small increases. These increases have not kept pace with demand, resulting in waiting lists and in some cases even death.

Both Presidents Bill Clinton and George W. Bush have supported ADAP funding increases – but many argue that both should have done more. In 2004, the waiting lists became so large that President Bush approved a one-time influx to the tune of \$20 million to alleviate the problem. While it fell far short of what was needed (an estimated \$180 million), Bush at least could have continued the additional funding. But he failed to do so, and the problem has only worsened. Currently, ADAPs are in need of an additional \$168 million (\$135 million in federal funding and \$33 in state

funding) to serve their approximately 386 new clients per month.

“Unless ADAP supporters adopt a different advocacy approach, I’m afraid we’ll continue down the path of small increases to the program,” said Bill Arnold, Executive Director of the Title II Community AIDS National Network (TIICANN) and Director of the National ADAP Working Group. “A coordinated, aggressive campaign is the only thing that will lead to adequate funding next year and beyond. Advocacy must start at the grassroots level in communities, where the need is felt first, and then move upward to our national leadership.”

In the battle for more ADAP funding, policy leaders have emerged in both parties. In recent years, however, it is regional politics that have prevailed over partisan politics. Rural politicians – mainly from southern states – have found themselves at odds with those representing larger metropolitan areas. This is not a partisan battle, with friends and foes in each political party.

Members of Congress from states with high numbers of AIDS cases argue that diverting funds from their large cities would prove disastrous. But trends in rural communities, as well as communities of color, have changed the face of AIDS. This transformation is evidenced by increasing new infections and AIDS-related deaths in rural communities, especially among African-Americans.

According to the Southern AIDS Coalition, 9 of the 15 states with the highest rates of new HIV infections are in the South. Additionally, 58% of the AIDS cases reported in 2006 among blacks occurred in the South, yet blacks represent only 19% of Southerners. As of 2006, 52% of people living with HIV and 41% of people living with AIDS were from the South.

“The South has become the new HIV epicenter in the U.S.,” noted Kathie Hiers, Executive Director of AIDS Alabama and Co-Chair of the Southern AIDS Coalition. “As HIV programs continue to be underfunded, the health disparities faced by impoverished Southerners with HIV have grown. If the U.S. sees 50,000 new infections each year, then 22,500 of those are in the South.” Hiers questions how these

For a brief moment in April 2008 all seemed wonderful in the ADAP world, as waiting lists nationwide were eliminated. But the champagne was no sooner flowing when the news flash came in: WAITING LISTS RETURN! Now the AIDS community found itself back to an all-too-familiar truth.

people, most of whom are living in poverty, can obtain proper medical care without increased funding. And since HIV treatment has been proven to reduce new transmissions, she argues that health care in America must become a priority if we ever hope to end this epidemic.

During the latest round of Ryan White debates in Congress, southern and western Congressional delegations battled northeastern delegations for a larger piece of the pie. Some advocates argued that the majority of people with HIV in the U.S. still live in the same states where the epidemic first took hold. More than half of all people with AIDS live in New York, California, Florida, Texas, and Pennsylvania; and almost half of new AIDS cases reported in 2006 were in these same five states. States like New York argued that they have an older, more costly epidemic, with thousands of new cases reported each year, and both urban and rural epidemics.

As the HIV community scrambled to find a middle ground that would appease both sides, it became clear that the process would fail those who needed it most – people living with the disease. Important issues like the ability to continue ADAP coverage when moving to a new state, and the difference in drugs covered by different states (and other federal programs, like Medicaid), got lost. Sadly, after all the debate Ryan White funding received only a paltry bump – in fact, one of the lowest in history.

AIDS advocates can agree on one premise – robbing Peter to pay Paul is not the solution. The ongoing failures have led them to change their tactics and renew their commitments.

Ongoing Problems and Possible Solutions

For a brief moment in April 2008 all seemed wonderful in the ADAP world as waiting lists nationwide were eliminated. What had once seemed like an impossible dream was now a reality. But the champagne was no sooner flowing when the news flash came in: WAITING LISTS RETURN! Now the AIDS community found itself back to an all-too-familiar truth.

In July 2008 it was reported that two states, Indiana and Montana, had a total of 35 people waiting to receive ADAP. Despite federal grants being awarded to those states just three months earlier, poor economic conditions and the lack of infrastructure reforms resulted once again in people with HIV waiting for their medications. The ADAP fiscal year ends on March 31 and ADAP grants were released on April 7 – so it didn’t take long for waiting lists to return. And it’s only a matter of time before more states follow suit.

What Next?

Our nation awaits the end of an era: the White House has been occupied by either a Bush or Clinton for 20 years. For some, that end cannot come soon enough. We don’t yet know what the new era will bring. One thing is certain though – AIDS activists are taking nothing for granted as they prepare for an aggressive movement to improve Ryan White and the ADAPs. People with HIV deserve nothing less. ■

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Becoming A Voice For Change

My favorite quote is one by Coretta Scott King: “Women, if the soul of the nation is to be saved, I believe that you must become its soul.” In 2006, in South Carolina, those words took on real meaning for me.

by Deadre Lawson-Smith

The journey started for me in upstate New York, when I was diagnosed with HIV in 1988. I vividly remember being told that my test results came back positive and then being sent on my way with little direction or hope. I was finally trying to get my life together after battling drugs, domestic violence, depression, and homelessness. The only thing I knew about HIV was that the people who had it were gay, white, and male. So it made no absolutely sense to me.

About 16 years later I was living in North Carolina. My condition had changed from simple follow-up care to follow-up with HIV medication. I was in a Safety Net Medicaid Program, but after getting ill and not working for a couple of months, I was no longer eligible and had to rely on another program to assist me with my meds – a Patient Assistance Program.

The constant worry about how to get my meds and the fear of disclosure at my job caused me to go into depression and added stress that affected my health. So I changed jobs, but now I had to wait 60 days for my new insurance coverage to kick in. I knew how dangerous it was to miss doses of my HIV meds, but it was a risk I was forced to take.

As God would have it, I got a job offer from the South Carolina HIV/AIDS Council, with Project F.A.I.T.H. (Fostering AIDS Initiatives That Heal). I was so excited that I finally could stop worrying if my employer knew I had HIV. I was also excited to work under Dr. Bambi Gaddist. For whatever reason, she saw something in me that I did not think possible myself.

Things were different in South Carolina. The stigma and discrimination were high, and at one point I felt like I was

starting all over again. But one of the reasons Project F.A.I.T.H. came into existence was to help reduce HIV stigma, so I knew I had my work cut out for me.

I explained to my new case manager that I needed a doctor that was direct and to the point – but I also needed someone with compassion for people living with this disease. Dr. Michelle Rojas was just what I needed.

But after my second doctor’s appointment I received a notice from my insurance company that my HIV was a preexisting condition, so they would deny all of my claims unless I could prove that I had insurance for the previous 12 months straight. I hadn’t. I had hoped to restart my HIV meds in January and now it was July. Deep inside, I could feel that things with my health were changing.

Now the battle began for me. My anxiety and stress level grew higher and higher and I began to feel like I had to go back to New York to get the assistance I needed. That bothered me because I was not looking for a handout – I was looking for a hand up.

I was told I would have to change doctors because I did not have insurance coverage, but that the Patient Assistance Programs would not help because I did have insurance! On top of everything else, I was informed that there was a waiting list for ADAP in South Carolina.

I was told I would have to change doctors because I did not have insurance coverage, but that the Patient Assistance Programs would not help because I did have insurance! On top of everything else, I was informed that there was a waiting list for ADAP in South Carolina. This really made me feel that I was caught between a rock and a hard place. Finally, with help from the North Carolina Department of Social Services, I was able to straighten out the insurance problem and get coverage for my doctor visits.

But I still didn’t have prescription coverage, and I was afraid. I am a single mother with a lot of responsibility and didn’t have a clue what would happen to my children if I didn’t start my meds again soon. How would I pay my bills if I got sick and could not go to work? How would I feed my children? How



would I keep the heat and lights on? These questions constantly plagued me.

I finally got insurance approval for my meds in December, but my co-pays were \$120 a month – money I didn't have. ADAP could help with that, but...I was still on the waiting list! Then I came down with pneumonia and it was imperative that I start the meds right away. At that moment, I decided that I didn't want anyone else to go

through what I was going through. It seemed that the government was spending money on so many other things that clearly didn't have anything to do with saving lives, including mine.

I was excited when the South Carolina AIDS Crisis Task Force was formed to end the ADAP waiting list. I knew I had to use my voice to help the cause. Even though I was trying to get over pneumonia, I felt empowered and pushed past my circumstances to make a difference. I knew that there was no turning back, and I joined the Task Force.

I had done a lot of speaking engagements over the years, but I was still not on the frontline. This was a call for something bigger – being the voice of people who had no voice. I asked myself if this is what it meant to become the soul of a nation. I had learned that we are survivors, not victims. My decision to disclose has given me the greatest freedom I've ever known, but I know that real freedom is not free.

When I was first asked to speak in the rotunda of the South Carolina State House, I thought to myself, "What is the problem? Why do we have to go to such extremes to get people to take action when people are dying?" Four people had died while on the ADAP waiting list. So there I stood before the press that day with a lot of microphones and cameras in my face. Showing my face was the least I could do for all the people who have passed on!

After we won, I was able to thank the South Carolina legislature for releasing the funds necessary to clear the ADAP waiting list. It gave me an opportunity to let them know that even though my insurance company finally agreed to pay for my medications, I still needed ADAP to help with my co-pays. I let them know that those of us who receive assistance from ADAP are not just faceless and nameless people. We have families and most of all we have hopes and dreams.

For all that we have accomplished in this nation in the fight against AIDS, one major hurdle still remains: PWA empowerment. Those of us living with HIV must continuously ask ourselves, "Where is our voice? Am I a voice, and if not, why not?" Have we given up our power when a case manager or some other advocate speaks on our behalf? The ADAP crisis in South Carolina has convinced me of one critical thing: People with HIV, including those of us living in the Bible Belt, must step up to the plate. For no one will save us ...we must help ourselves if we are to survive.

And I have a personal mission today as a result of going through this struggle: I want to live, I want to love, and I want to leave a legacy. ■

Deadra Lawson-Smith is a Community Liaison and PWA Advocate for Project F.A.I.T.H., a legislatively funded faith-based initiative coordinated by the South Carolina HIV/AIDS Council.

Managing Medicaid

WHAT NEW YORKERS NEED TO KNOW

by Alexandra Remmel, MA, and
Howard L. Schwartz, Esq.

In recent years, states across the country have looked for ways to provide Medicaid to more people; to offer satisfactory payments to medical providers; and to maintain high-quality care in the face of government cost-cutting and spiraling expenses. Beginning in 1994, New York State sought to meet this challenge by offering Medicaid Managed Care (MMC), which is similar to health maintenance organizations (HMOs). Hopefully, MMC will be looked to as a model to lower costs and improve health outcomes.

Enrollment in MMC became mandatory in 1998 for most New York Medicaid clients, but not for people with HIV. That is about to change, and it is important that HIV-positive New Yorkers understand MMC and how it will change how they receive their health care.

What is Medicaid Managed Care?

New York's MMC system is based on many of the concepts used by HMOs. Each client enrolls in a specific plan and obtains health care through that plan's network

Enrollment in Medicaid Managed Care became mandatory in 1998 for most New York Medicaid clients, but not for people with HIV. That is about to change.

of providers. The providers, whether in private practice, a clinic, or a hospital, agree to provide care for Medicaid clients enrolled in the plan. Laboratories can also agree to be part of a plan's network. There are also services available without regard to a plan's network, including emergency room care, family planning services, and prescription coverage.

For primary health care and regular check-ups, clients can choose from each plan's list of primary care physicians (PCPs). The PCP can refer to specialists when needed, and if hospitalization is necessary the client will be placed in a network hospital. Each plan also has a 24-hour phone number, staffed by medical personnel who will help clients get care when the PCP's office is closed and an emergency room is not necessary.

MMC was created to improve care and lower costs by reducing duplication of services, using specialists more wisely, and lowering hospitalization and emergency room use. In addition, it is hoped that regular check-ups by the PCP will catch illnesses early, before they become serious and require expensive medical care.

Enrollment

In New York State, clients can choose from more than 10 plans as part of the MMC enrollment process. To help clients enroll in or change plans, New York State hired Maximus, Inc. Maximus mailed letters to Medicaid clients, telling them they had to mail back an enrollment form or call a toll-free phone number to enroll in a managed care plan. Medicaid clients were given 60 days to respond to the letter. Clients who failed to respond in 60 days were automatically enrolled in a plan.

For the clients who were auto-enrolled, the change to MMC was not always welcomed. Some clients were enrolled into plans that their current doctor did not accept, or found that the hospital near their home did not participate in their plan. Some who received the letter did not read through the information and were not aware of the need to act. Others had difficulty understanding the letter, especially if their primary language was not English.

In many cases, clients learned of their auto-enrollment at a time of medical need, such as a doctor's visit or hospital admission. Some providers and hospitals would



not provide medical care because they did not belong to the network of the client's new plan. People faced gaps in medical care and interruptions in medications. In addition, people were confused by the requirement to use a separate plan for managed care services and another for medications.

Community-based organizations (CBOs) in New York responded to clients who were confused by MMC. Staffs at CBOs and at Maximus helped people change plans in order to keep their doctors and continue their treatment. In New York City, a group of CBOs joined together to form a network to educate Medicaid clients. Together they developed a training curriculum in a variety of languages for CBOs to use when educating clients about MMC.

SNPs

In the mid-1990s, an enhancement of MMC was created in New York, in response to feedback from people with HIV, their advocates, and the State Department of Health AIDS Institute. Special Needs Plans, or

Special Needs Plans, or SNPs, were created to provide services for Medicaid clients who have HIV. The SNPs program also establishes quality-of-care standards, and links medical and social services.

SNPs were created to provide services for Medicaid clients who have HIV. The SNPs program also establishes quality-of-care standards, and links medical and social services. This is particularly important for the many people with HIV who have other medical diagnoses.

SNP enrollment is limited to Medicaid clients who have HIV and to their children up to the age of 19, regardless of HIV status. HIV-negative spouses or partners are not eligible to enroll in a SNP.

Mandatory MMC Enrollment

Enrollment in MMC was voluntary for people with HIV, but that will change next year. In 2009, New York State will require nearly all New York City Medicaid clients who have HIV to join a MMC plan or a SNP. This could be a problem for people who are not now in a SNP or MMC plan and who do not want to change the way they receive care. Some may worry about having to find a PCP. Others may not like having to obtain

referrals to see specialists.

Although New York has not yet released the details of the enrollment process for people with HIV, it will probably be similar to the process used for other Medicaid clients. So Medicaid clients with HIV need to understand the importance of responding to the enrollment letter from Maximus. Those who do not respond could be upset when they go to their provider and learn they have been auto-enrolled in a plan their doctor does not accept. In addition, they run the risk of an interruption in HIV medication regimens, which carries the serious risk of drug resistance.

Medicaid clients with HIV need to learn about the available plans. Clients choose providers for many reasons, and people should choose the plan that is best for them. They need to see which plans most closely match their health needs, find out which ones have the doctors and hospitals they want, and learn the basic concepts of how to obtain services.

Some doctors are not enrolled in any SNPs or MMC plans, which presents a real barrier to their clients. People who must change doctors will need to decide what is most important to them: Things to consider may include:

- Location
- Languages spoken
- Quality of the office staff
- The hospital where the doctor has admitting privileges
- Where the doctor went to school
- Bedside manner
- Experience and number of patients with HIV
- Ability to explain things in understandable language

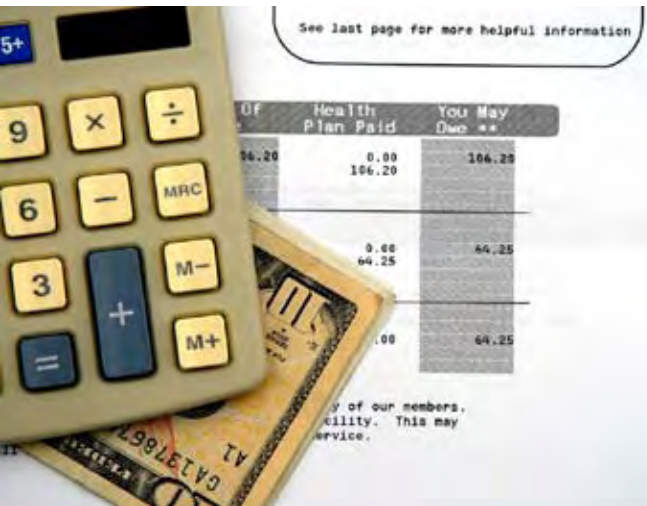
The list of what is important can change from person to person. When it comes to HIV medical care, choosing a PCP who makes you feel comfortable and reduces stress is one of the most important points to consider.

The answers to these questions will help people with HIV prepare to get the care they need to remain healthy. CBOs need to prepare to handle questions, complaints, and compliments about the new plans. For clients who enroll in MMC or SNPs, the time and effort spent managing their own health care is expected to be greatly reduced. If the health of HIV-positive plan members improves, that should outweigh the problems caused by the enrollment process. After all is said and done, better health is the outcome that would be the best result.

To learn more about SNPs, call 212-367-1125 or read *Strengthening New York's Special Need Plans for People with HIV/AIDS*, available at: gmhc.org/snp.pdf ■

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ADAP Allowed Me To Live

by Juan C. Carrillo

It had been a tough year since I decided to move forward with my case seeking political asylum from Ecuador, based on sexual orientation. It was emotionally and financially stressful, and I felt alone in Chicago, not really having any personal contact except for some furtive encounters that I had because I was feeling hopeless. I was working long hours just to make enough money to pay my lawyer, and I was always fearful that if I needed medical services I had no way to pay for them. I was working at a job that didn't offer medical insurance to any employees, much less someone like me who was working "under the table."

After I started the asylum process, I felt a sudden decrease in my energy. I thought it was just that my body was finally feeling all the stress. I hoped I would get better, but it just seemed like I was getting worse. I was coughing, had a fever, and started seeing some white stuff in my throat and on my tongue. I was also losing weight since I couldn't eat properly.

A friend of mine who has HIV noticed and tried to get me to a doctor, but I didn't have insurance and wasn't sure where I could go that wouldn't be expensive. He said at least I should get an HIV test, so I went to a gay health center a few blocks from where I lived. The counselor there thought that it would be a good idea for me to see the doctors there. I told him that I didn't have any way to pay, but he said that if I felt sick I shouldn't hold off. I was stubborn and let him know that I would go to an emergency room if I felt any worse.

I received the results of my asylum case rather quickly. Great news – I was granted asylum. But a couple of days later I picked up my HIV results, and they weren't so great. I was positive. I was prepared for the results – my friend had taken the time to talk to me about what he went through,

and his experience put me somewhat at ease, knowing that I could receive medical care and treatment if needed. I was diagnosed with bacterial pneumonia and thrush, and told I had a CD4 count of 176 and a viral load of 150,000 – I was a walking HIV factory. I was told I needed to take HIV meds and said that I would do as needed.

I met with a case manager who began asking a lot of questions. When he asked me for my Social Security number, I told him I didn't have one yet but that I would soon get one. I'm not sure if he believed me, or if he even understood me (back then I didn't speak English that well). He told me that they couldn't help me and that my case would need to be transferred to Cook County Hospital. I think he thought I was lying about my legal status. In the end, it was best that I walked away from that clinic, because I heard that case manager reported anyone who walked in without a Social Security number to the authorities. Maybe it was just hearsay, but that's a major fear among immigrants. Moreover, the language barrier was a real problem there.

I really didn't like the idea of going to a county hospital – it was too far away and I wasn't sure about the care I would receive there. And I thought that I would be better served in a clinic that served the gay and lesbian community.

Fear began to set in. What if I couldn't get the treatment I needed? What if I was

placed on a waiting list? I had heard horror stories from friends who were not in the U.S. legally and who had not been able to get HIV treatment out of fear of being reported. They held off from getting care until they felt that they couldn't work any longer and then returned to their home countries. One was even told that it was time for him to return home so he could die surrounded by family and friends instead of dying alone in the U.S. His case manager was even able to find an agency that would pay for a one-way ticket back home.

What if I couldn't get the treatment I needed? I had heard horror stories from friends who were not in the U.S. legally and who had not been able to get HIV treatment out of fear of being reported. One was even told that it was time for him to return home so he could die surrounded by family and friends instead of dying alone in the U.S.



I thought this couldn't happen to me – I had already been granted asylum. But then I remembered friends in Virginia and North Carolina who were put on ADAP waiting lists to receive medications. One friend who was not here legally was never able to receive treatment and ended up leaving when he was unable to work. The other one had gained legal residency, but it took him about a year to receive medication. He didn't have insurance, so he depended on ADAP. I began asking questions about ADAP, and fortunately for me Illinois had an ADAP that would allow me to receive treatment. That calmed me down, but now I knew I had to get more involved to speed up the process. I was told that "if and only if" I was sick enough would I be allowed to receive care via the emergency room. I was still healthy and didn't want to pretend I was sick enough to go to the ER. Besides, in the long run I would have had to pay out of pocket – money that I didn't have.

Reluctantly, I went to my first appointment at Cook County Hospital and I was impressed. I found doctors who spoke Spanish, and the providers were immediately able to enroll me in ADAP so I could receive medications. The facilities were impressive and they had a well-established group of medical and social service providers that made sure that I quickly received the attention I needed. They gave me referrals to support groups that served gay and bisexual men, in Spanish, at an agency called CALOR. I met a lot of

good people there. The hospital also provided a nutritionist and a mental health counselor in case I needed to talk to someone. I was provided with protein shakes that helped me to gain weight and made eating easier, since I had been diagnosed with thrush. It was a "one-stop shop," and I think they showed concern and care for me as an individual.

I always wondered why the other clinic didn't provide the same service and enroll me in ADAP. I think it was lack of knowledge about asylum and also that the worker wasn't willing to do the work needed. In reality, the process of getting my meds through ADAP wasn't difficult, since I was eligible after all.

I owe my life to ADAP. I still hear stories about ADAP waiting lists in other states. I'm not sure what would have happened to me if I had been placed on a waiting list. I probably wouldn't be alive now.

Since 2001, I have been able complete my undergraduate degree and most recently began a Masters Degree. I don't find myself struggling or living in fear that I will not receive medical care or treatment. I guess I owe this to ADAP, too. To all those that test positive and who need treatment, I tell them to insist on receiving care and treatment. Somewhere and somehow there are systems set up that will allow you to receive the care you need. ■

MEDICARE PART D



FIXING PART OF THE PROBLEM

by Robert Hayes and Michealle Carpenter

Following his landslide election in 1964, President Lyndon Johnson promised a “Great Society” that would include, as its crowning jewel, health security for older Americans. President Johnson worked hard and fast on the Medicare legislation, and in July of 1965 he signed Medicare into law, promising affordable health care coverage to Americans 65 and older.

Medicare became a national success story and quickly gained bipartisan support. In 1972, Medicare was extended to people under age 65 with serious disabilities. It was a first step in providing what other developed nations of the world enjoy: a national health insurance system.

Medicare Part A provides coverage for hospital services. Part B covers outpatient care, such as doctor’s visits and physical therapy. Part C, referred to as Medicare Advantage, allows people to receive Medicare benefits through a private insurance plan.

But none of those Parts included prescription drug coverage – leaving those on Medicare to fend for themselves when it came to paying their often large medication bills. So, after much public debate and political wrangling, the Medicare Prescription Drug Benefit (Part D) was passed and took effect in January of 2006. The Bush administration and its allies praised it as a way for people with Medicare – including 100,000 people with HIV – to get the medicines they need to stay healthy. And it has helped them. But, given people’s needs and the vast amount of public dollars committed to the program, we should be getting more.

A Corrupt Process

Part D’s problems have their roots in the corrupt process that gave birth to it. In late 2003, there was much political pressure to add a prescription drug benefit to Medicare. The White House and its Congressional allies had promised to deliver a Medicare drug benefit

in the 2002 election. Older Americans with Medicare were too strong a political force to dismiss.

The House and Senate enacted very different Medicare bills in the summer of 2003. Congressional leadership refused to convene a traditional conference committee that would work out the differences in the bills. Instead, nearly all Democrats were excluded from weeks of secret meetings held behind closed doors. Public interest voices were not invited into the process, while lobbyists for drug makers and insurance companies were. These meetings resulted in a program with substantial benefits for both the drug and insurance industries. And once the law was enacted, to no one’s surprise, a number of the people who wrote the bill accepted high-paying jobs lobbying for drug and insurance companies.

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Members of Congress were given almost no time to read the 692 pages of complicated legislation, known as the Medicare Modernization Act (MMA), before they were required to vote on it. Even worse, the Bush administration kept secret its own cost estimates showing that the plan would cost \$534 billion over ten years, rather than the \$400 billion lawmakers

ers were told it would cost. A top administration official told the civil servant who did the estimate that he would be fired if he released the information showing the program would cost more than \$400 billion. The low cost of the MMA, compared to other proposals to add prescription drug coverage to Medicare, led many conservative Republicans – who would not support the bill if it cost more than \$400 billion over 10 years – to vote for it. In the end, after three hours of arm twisting and deal making, Republican leaders forced the bill through in the middle of the night.

The fingerprints of the drug and insurance companies are all over the law. For example, the MMA allows only pri-

THE LAW PROHIBITS MEDICARE FROM BARGAINING WITH DRUG COMPANIES FOR LOWER PRICES. THIS MAKES DRUGS MORE EXPENSIVE IN MEDICARE THAN IN OTHER FEDERAL PROGRAMS LIKE MEDICAID. THIS OF COURSE BENEFITS DRUG COMPANIES, BUT NOT PEOPLE WITH MEDICARE.

ivate insurance companies, not Medicare itself, to offer Part D coverage. There is no way to receive drug coverage through Medicare. And the MMA prohibits Medicare from bargaining with drug companies for lower prices. This makes drugs more expensive in Medicare than in other federal programs like Medicaid. This of course benefits drug companies, but not people with Medicare. Since Medicare cannot negotiate lower prices for drugs, people pay more and reach the coverage gap (see below) faster.

While Part D does not cover all drugs, its drug plans must cover HIV drugs without limitations. For example, plans may not require a doctor to get permission from the plan before prescribing a drug.

This is an important consumer protection. HIV drugs often cannot be switched, and changes in treatment may allow the virus to become resistant or lead to side effects.

But a 2007 survey by the American Academy of HIV Medicine showed that, despite this protection, many people with HIV faced problems getting their drugs fully covered. The protection existed only as an administrative guidance from the federal government. Advocates worked quickly to ensure that Part D plans actually complied with the protection by having it added to recently passed “Medicare Improvements for Patients and Providers Act” (MIPPA).

The Donut Hole

Once a person with Medicare and the drug plan spends \$2,510 on prescription drugs, he or she reaches the coverage gap (known as the “donut hole”) and must pay for all drugs until out-of-pocket costs reach \$4,050. Then, “catastrophic coverage” kicks in. After catastrophic coverage starts, people pay \$2.25 for a generic and \$5.60 for a brand-name drug, or a flat 5% coinsurance, whichever is greater.

Like much of Part D, however, management of the donut hole requires people to avoid numerous trap doors. For example, not all drug expenses count toward a person’s true out-of-pocket payment (TrOOP). Only drugs that are paid for by the Medicare client, a family member, a state pharmaceutical assistance program, or some charities count towards TrOOP. Drugs paid for by AIDS Drug Assistance Programs (ADAPs – see page 11) do not. As a result, people may have to spend more money in the donut hole while waiting to reach catastrophic coverage.

ADAPs provide coverage for anti-HIV drugs and drugs that treat HIV-related infections. But they do not cover drugs for other illnesses that people with HIV often have, such as high blood pressure and heart disease. This can be a big problem, because people on Part D who are also covered by ADAP often fall into the donut hole by March of each year. This means they must pay the full cost of non-ADAP drugs for the rest of the year.

Often people cannot afford to pay for their drugs and stop taking them or get samples, which means they can remain in the donut hole and never reach catastrophic coverage.

In addition, ADAPs do not have enough funding to provide coverage to everyone in need. Some states assist people with ADAP with the cost of Part D copayments, deductibles, and premiums, but many states do not. If the Medicare law was changed and ADAP expenses counted toward TrOOP, it would save ADAPs between \$25 and \$44 million, since people would reach catastrophic coverage faster. ADAPs could then use the savings to eliminate the waiting lists that exist in some states.

ONCE A PERSON WITH MEDICARE AND THE DRUG PLAN SPENDS \$2,510 ON PRESCRIPTION DRUGS, HE OR SHE REACHES THE “DONUT HOLE” AND MUST PAY FOR ALL DRUGS UNTIL OUT-OF-POCKET COSTS REACH \$4,050.

Off-Label Coverage

While anti-HIV drugs must always be covered by Part D plans, some drugs are not allowed to be covered, such as some “off-label” drugs. Off-label drugs are drugs that are used to treat an illness or symptom for which they have not been approved by the FDA. Part D plans do not cover off-label usage unless it is listed in specific databases, even if it has been reported to be safe and effective in well-respected medical journals. This problem commonly occurs when a person with HIV seeks coverage for drugs like Marinol (for wasting), Lyrica (for peripheral neuropathy), and Zofran (for nausea). This exclusion is not contained in the Medicare law, but is included in its regulations. The Medicare Rights Center is challenging this regulation in federal court.

continued on next page

MEDICARE PART D

continued from page 21

The recent Medicare Improvements Act makes an important change to off-label coverage. Part D will now cover off-label anticancer drugs if there is support for this use in well-respected medical journals. While the change is limited, it is an important first step. Advocates should let Congress know how this limitation affects people with HIV and why it is important to expand access to off-label drug coverage in other circumstances.

Next Steps

While the Medicare prescription drug program has improved access to drugs for millions of people, there are still improvements that need to be made.

A key reform would be to allow Medicare to bargain with drug makers for lower prices and to allow people with Medicare to obtain their drug coverage from Medicare itself. This

A KEY REFORM WOULD BE TO ALLOW MEDICARE TO BARGAIN WITH DRUG MAKERS FOR LOWER PRICES AND TO ALLOW PEOPLE WITH MEDICARE TO OBTAIN THEIR DRUG COVERAGE FROM MEDICARE ITSELF.

would result in lower prices and a more stable program with consistent rules and coverage. Senator Richard Durbin and Representatives Jan Schakowsky and Marion Berry have introduced the Medicare Prescription Drug Savings and Choice Act of 2007 (HR3932 in the House and S2219 in the Senate). This bill would create a drug coverage option under Medicare.

The Medicare Rights Center has published a handbook that offers some helpful tips and suggestions on how to build partnerships and do grassroots organizing. The handbook offers ideas on media outreach, and how to educate elected representatives about the problems with Medicare Part D. It is available online at medicarerights.org. For information about how you can obtain Medicare, go to medicareinteractive.org.

People with Medicare who are experiencing difficulty obtaining medications can download the Medicare Rights Center Part D Appeals Manual at:

medicarerights.org/partd_appeals_manual.pdf ■

Robert Hayes is President and General Counsel of the Medicare Rights Center.

Michealle Carpenter is Deputy Policy Director and Counsel for the Medicare Rights Center.

Free HIV Trainings

ACRIA offers free HIV-related trainings in NYC as a NYS DOH AIDS Institute Regional Training Center.

For a list of all the trainings and to download a registration form, visit:

www.acria.org/treatment/rtc.html

You may also contact Gustavo Otto for more information at 212-924-3934, x129.

For listings of all trainings offered by the NYS DOH AIDS Institute, visit:

www.nyhealth.gov/diseases/aids/training

ACRIA and GMHC Launch Older Adults Study

In addition to *Achieve*, ACRIA and GMHC have worked together on a NYC Council-sponsored HIV education program in senior services programs, an AIDS awareness campaign targeted to middle-aged and older adults, and a research study of depression in people with HIV over 50.

In October the two organizations will begin an online and in-person study of the role family, friends, and neighbors play in the lives of older adults living with HIV. Areas to be examined include health status, caregiving resources, social network interaction, and how clients use GMHC's services and other services in NYC.

The study will include a random sample of 250 GMHC clients aged 50 and older. The survey was developed by staff at both agencies, with input from the Maxwell School of Citizenship and Public Affairs at Syracuse University. Aside from its research goals, this effort is also a first step toward further collaborative research efforts between ACRIA and GMHC.

A National AIDS Strategy for the United States

HIV remains one of the greatest public health problems in the U.S. More than one million people are now living with the disease. New HIV infections are happening at a rate 40% higher than previously thought. Half of those living with HIV are not getting health care. One quarter of Americans who have HIV don't even know it.

There is no "magic bullet" in the fight against AIDS. The response needs to confront the disease on all levels. This includes prevention, treatment, and research. The federal government currently works to combat HIV on all of these fronts, but the responses are often not well coordinated. That's why advocates have been pushing for a national plan that guides the government's response. The upcoming elections pose a unique opportunity to address this call for a National AIDS Strategy.

Many studies have pointed to the need for better planning of national policy and programming. In 2004, the Institute of Medicine determined that current federal financing "does not allow for access to quality HIV care" nationwide. A 2003 study found that failure to meet the government's goal of reducing HIV infections by half would lead to \$18 billion in expenses through 2010.

A national plan can address the unequal impact HIV has on the communities most affected. For example, half of new infections are among African-Americans, and half are among gay and bisexual men. African-Americans also suffer poorer treatment outcomes. Between 2000 and 2004, deaths among whites living with HIV declined 19%, compared with only 7% for blacks.

The U.S. government appears to agree a central strategy is important and requires that any country receiving AIDS relief have such a plan. Under the President's Emergency Plan for AIDS Relief (PEPFAR), countries cannot receive funding without a plan.

Other countries, such as Brazil and Thailand, have had success with national strategies. Through a coordinated response, Thailand reduced its number of new HIV infections from 143,000 in 1991 to 19,000 in 2003.

PEPFAR itself is prime example of the U.S. government's use of a strategic approach to HIV. PEPFAR should serve as an example for a strong domestic strategy.

Several hundred organizations have declared their support for a National AIDS Strategy. Together, these advocates state that a successful plan will require clear objectives, strategies, monitoring, and evaluation. Individuals and organizations can add their support at www.NationalAIDSstrategy.org.



Looking forward to the presidential elections, both Senator Obama and Senator McCain have committed to a National AIDS Strategy. Senator Obama indicated his willingness in the fall of 2007, saying he would institute such a policy within the first year of his presidency. In a September 2008 interview with the *Washington Blade*, Senator McCain also committed to developing a National AIDS Strategy if elected.

Also in the summer of 2008, Congress approved \$1.4 million to pay for the implementation of a National AIDS Strategy through the White House's Office of National AIDS Policy. These developments are strong evidence of broad, bipartisan support for a U.S. National AIDS Strategy.

After years of evidence that the U.S. response to the HIV crisis has been less than ideal, it appears progress is finally being made. In the near future, the U.S. government will unveil its National AIDS Strategy and work to achieve it. This will be a serious milestone in fighting one of the greatest public health challenges in our history. ■

ACRIA Drop-In Support Groups

The popular groups formerly offered by Body Positive have found a new home. These peer-led drop-in support groups are held every Thursday and Friday from 6:30 to 8:00 p.m. at the LGBT Community Center, 208 West 13th St., NYC. For more information, call Gustavo Otto at 212-924-3934, x129.

You may have noticed that we are publishing under a new name. ACRIA and GMHC have decided to rebrand our unique, collaborative publication with a truly fitting title, one which reflects the remarkable spirit of this HIV prevention, treatment, and policy quarterly: *Achieve*. We hope you enjoy the new name – and this new issue – as much as we do!

National AIDS Strategy A CALL TO ACTION

Did you know that the U.S. requires other countries to develop an AIDS strategy in order to receive funding, but the U.S. has no plan of its own?



Join our national advocacy partners in calling on each candidate for President to create a strategy to end the AIDS epidemic. Our next President must demonstrate leadership in the fight against AIDS.

To add your name to the call for a National AIDS strategy, visit NationalAIDSstrategy.org.

achieve

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