

INSIDE

ENDING HOMELESSNESS TO END AIDS 5

The battle for housing for those living with and at risk for HIV.



Personal Perspective: CAUGHT IN THE MIDDLE 9

I found myself in a Single Room Occupancy (SRO) building – a real dumping ground for people with AIDS.



RECTAL MICROBICIDES 11

How do we rethink decades of prevention programs that equated condoms with safer sex and left few other choices?

THE BATTLE TO END AIDS: SHOW ME THE MONEY! 14

Will we increase global AIDS funding or listen to the “fiscal cliff-jumpers” and continue flat-funding?



Personal Perspective: THE ROAD LESS TRAVELED 18

THE CLOCK IS TICKING: PREPARING FOR THE ACA 20

In less than a year, major parts of the Affordable Care Act will go into effect.

EDITORIAL 23

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AIDS Activism

Fight Back! End AIDS!

by Matt Sharp

Approaching the long line of cars at the Tijuana border, Jim Corti was not afraid, even though his trunk was packed with boxes of medications from Mexican pharmacies. As he reached the checkpoint he hoped he would be waved through once again.

He was on a mission to bring potentially lifesaving HIV drugs, not yet approved here, to the U.S. It was the late 1980s and many said that using unproven drugs was unsafe, but there were no approved treatments and little research to find them. People were dying, so they took action in order to survive. Ultimately, this illegal smuggling proved futile in stopping HIV, but forced the FDA to revise the laws around importing drugs for personal use.

Three Decades of Treatment Activism

In the early days of the epidemic, people with AIDS and their advocates set the stage for many victories in government and institutional policy, scientific research and clinical trials, treatment access, and drug pricing. Corti was one of the first activists who went to such extremes. But he was only one of an unprecedented wave of activists, some of whom met in the boardrooms of drug companies and in the offices of health policy makers while others committed civil disobedience in the streets.

Few treatment activists had science, statistics, or policy backgrounds. Most were just passionate to live and took the time and energy to learn everything they could by reading, studying, attending journal clubs, and engaging in long debates with their comrades. AIDS activists knew that in order simply to stay alive they had

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Treatment Activism *cont. from previous page*

to unleash their power by educating and mobilizing their own communities.

Drugs Into Bodies

On a cold day in October 1988, ACT UP stopped all work at the FDA in one of the most remarkable AIDS demonstrations ever. "SEIZE CONTROL OF THE FDA!" centered on "getting drugs into bodies". The action was incredibly sophisticated, with media and legal coordination, street theatre, and civil disobedience outside while activists from the Treatment and Data Committee of ACT UP met with the FDA on the inside.

In those days only AZT had been approved, and experimental drugs were simply not accessible. Treatment activists felt that there were safe ways to provide early access to new drugs, but the FDA wouldn't

budge. Despite the massive protests, changes were not seen until months afterward. But access to experimental drugs was eventually approved by the time of the second AIDS drug, Videx. A mechanism that allowed access to a new drug in a "parallel track" to clinical trials was put in place by the FDA. It was a win-win situation.

Pricing Battles

Drug company greed has always been a huge focus of AIDS activists, since prices were so extreme. One of the first major battles was over AZT, the first approved AIDS drug. Burroughs-Wellcome had no idea the anger its price – an astonishing \$10,000 a year – would trigger. Several ACT UP actions culminated in the famous New York Stock Exchange demonstration in September 1989, when activists chained themselves to the trading floor balcony and stopped trading by dropping a banner that read "SELL WELLCOME". Days

The Robert Mapplethorpe Clinical Research Program

Prolastin-C

People with HIV aged 18 to 65 will receive weekly infusions of the proteinase inhibitor Prolastin-C or a placebo for 8 to 16 weeks, to study its effect on CD4 counts. People who are HIV negative will have lab tests done.

BMS-663068

People with HIV who are 18 and older will take BMS-663068 (an experimental HIV attachment inhibitor) or Reyataz for up to 96 weeks. Everyone will also take Isentress and Viread.

BI 201335

People aged 18 to 70 who have hepatitis C virus will take BI 201335 (an experimental HCV protease inhibitor) with peg-interferon and ribavirin for 12-48 weeks.

Cenicriviroc (TBR-652)

People with HIV who are 18 and older and who have not taken HIV meds will take either Cenicriviroc (an experimental CCR5 inhibitor) or Sustiva for a year. Everyone will also take Truvada.

Ibalizumab

People with HIV will receive infusions of ibalizumab (a monoclonal antibody) to study its safety and effect on the immune system.

Selzentry

People with HIV who are 18 and older and who have not taken HIV meds will take either Selzentry or Truvada for 22 months. Everyone will also take Prezista with Norvir.

For more information on these trials, contact us at 212-924-3934, ext. 100.

Compensation is available for some studies.

later, Burroughs-Wellcome lowered the price to \$6,400 a year. It was the beginning of a tedious fight with the industry that continues today.

Today, sophisticated meetings regularly occur between expert drug pricing activists and drug companies. The Fair Pricing Coalition (fairpricingcoalition.org), started by Martin Delaney and others in 1998, has become the consumer watchdog of HIV and, more recently, hepatitis drugs. These activists have had a major impact on pricing policy.

According to Lynda Dee, a member of the FPC, “HIV is the only disease for

Activists, who were at the table at every step of Fuzeon’s development, were nevertheless furious when it became the highest priced AIDS drug up to that time, at \$25,000 a year.

which industry consults the community before a price is set.” The group has also helped to ensure that all companies have decent patient assistance and co-pay assistance programs. It’s a “kindler-gentler” form of AIDS treatment activism than street protests, but a critical part of changing stubborn pricing policies.

Research

The scientific knowledge AIDS treatment activists have gained is unprecedented. This self-education was necessary to force scientists to take notice and change policy. There have been hundreds of meetings with treatment activists, researchers, and drug companies over the years, and they still occur. Meeting face to face on mostly friendly terms, companies learned how engaged and smart activists were about complex science, clinical trials, and regulatory issues.

Fuzeon came along at a time when people who had become resistant to older HIV drugs needed new ones. But its approval wouldn’t have happened without constant advice from treatment activists, who advised Trimeris in its early development. The compound was bought by Roche, approved, and no doubt saved lives – at the very least extending them until better drugs were approved. Activists, who were at the table at every step of its development, were nevertheless furious when it became the highest priced AIDS drug up to that time, at \$25,000 a year (see picture below).

The meat of its work is interaction with the pharmaceutical industry and the FDA. Veteran activists created the group because treatment activism was lagging and there was a need for a national coalition, including the mentoring of a new generation of treatment activists.

AIDS treatment activists have provided a model for representation in the FDA drug approval process. For years there has been a seat at the table at FDA advisory hearings where HIV drugs are given the “once-over” by researchers and community members. The hearings are a very sophisticated process that have a



Clinical Trials: At The Table

AIDS treatment activists have been a powerful voice in the design and implementation of clinical trials. From writing background documents to the creation of Community Advisory Boards, they changed the clinical trials process. Participation in research meetings and conferences forged relationships with researchers and policy makers, and community members are now rarely left out of the discussion. From the early days of the NIH’s Community Constituency Group to today’s grassroots AIDS Treatment Activist Coalition, a watchful eye has remained on clinical trials.

The AIDS Treatment Activist Coalition (atac-usa.org), created in 2001, focuses on HIV treatment research.

direct impact on the lives of people with HIV. Combing through clinical trials and understanding the complexities of safety and effectiveness data are not simple tasks, but the responsibility of representing people with HIV is equally difficult and necessary. This would never have happened had it not been for the early activists who demanded community representation at this very critical point of the drug approval process.

Women have also been a formidable force in treatment activism since the days of the Treatment and Data Committee of ACT UP/NY and Project Inform in San Francisco. From the ACTG 076 trial (when activists demanded that the lives of women were just as important as those of fetuses) to the GRACE study (the first

continued on next page

trial designed exclusively for women with HIV), important lessons have been learned. Because of activists, GRACE has set a precedent and much more data will be available on how better to inform and include women in HIV research.

Global Activism

There are enormous and complex barriers to HIV treatment outside the U.S., and the basic health care infrastructure remains an impediment. The first major step forward came in 1997, when South Africa passed the Medicines and Related Substances Control Act, allowing it to make or import cheaper generic versions of HIV drugs. The drug companies were not happy – they wanted South Africa to buy drugs directly from them. Of course, virtually no one in Africa could afford the drugs at full price, and without them millions would die.

The media were virtually silent on the issue, so members of ACT UP/NY and F.U.Q. (Fed Up Queers) planned actions targeting Al Gore, who was announcing his presidential run in June of 1999. Despite being progressive on other issues, Gore had worked with drug companies to block the South African law, making him a perfect target.

After several months of activist “zaps” resulting in wide media coverage, the U.S. changed its policy toward South Africa in September of 1999. And in May of 2000, after continued pressure (including taking over the offices of the U.S. trade representative), Bill Clinton expanded the policy to all nations, issuing an Executive Order that “...the United States will henceforward implement its health care and trade policies in a manner that ensures that people in the poorest countries won’t have to go without medicine they so desperately need.”

Today groups like Health GAP (healthgap.org) fight for drugs and necessary resources for people with HIV across the globe. According to Health GAP’s website, “We work with allies in the global South and in the G-8 countries to formulate policies that promote access, mobilize grassroots support for those policies, and con-

front governmental policy makers, the pharmaceutical industry and international agencies when their policies or practices block access.” Their multi-pronged strategy includes advocacy for the importing of generic drugs without the need for industry-controlled charity programs, and work to ensure that the Global Fund to Fight AIDS and PEPFAR remain well funded. The list of Health GAP accomplishments is huge – it has led the international battle for drugs in parts of the world where HIV treatment was just a dream.

The Future

Many AIDS treatment activists have moved on to professional careers or are simply taking time for themselves after years of thankless work. But there are many others who continue to follow the latest developments in cure-related research and Hepatitis C.

Activists have provided a model for representation in the FDA drug approval process. For years there has been a seat at the table at FDA advisory hearings where HIV drugs are given the “once-over” by researchers and community members.

AIDS activists in the U.S. and abroad have tracked AIDS cure research closely since the first case study of a cure was reported in February 2008. Several activists, including the late Martin Delaney, set off a new wave of AIDS activism focusing on the complex goal of eradicating HIV. Community Advisory Boards are being formed to follow the latest cure research being done through the NIH Martin Delaney Collaboratory. While much of the research is still in the basic science stage, activists have been invited to the table at this early stage once again, a testament to years of activist expertise and trust in patient collaboration.

AIDS activists joined hands with HCV (hepatitis C virus) activists in developing the watchdog group known as

HCAB (Hepatitis Community Advisory Board). Tackling the challenge of HCV drug development has not been an easy task, but HCAB has done incredible work monitoring it on a national and international scale. At this stage of the game, with huge improvements in HCV treatment looming, HCAB has been involved with almost every new drug and helped guide clinical trials with most of the major drug companies.

Finally, ACT UP San Francisco has reformed after years of stagnation and apathy. Recently, it held a street action protesting the exorbitant price of Gilead’s new drug, Stribild. We have come full circle from the days of the Wall Street AZT pricing action. During this time, many lives have been changed and thousands saved. But some things still haven’t changed, highlighting the urgent need for a new force backed up by past successes.

Conclusion

These are obviously not the only stories that can be told of an exceptional group of activists over three decades of AIDS. Many people have not been acknowledged by the executive directors or fully supported by AIDS service organizations and they never asked for accolades or awards. They understand that the real reward is the lives saved. These are the activists who changed the course of the epidemic and thankfully they remain alive and effective today. ■

Matt Sharp is long-term survivor, activist, writer, and educator.

Ending Homelessness to End AIDS



by Nancy Bernstine
and Christine Campbell

James, a 61-year-old former skydiver, was on a six-year journey bouncing from one health crisis to the next. For three years he lived in a tent in the woods, his belongings constantly stolen or destroyed. He had been out of medical care for over a year and had a CD4 count in the 200s. After a hailstorm caused him to slip and break his arm, he moved into transitional housing. That injury was his path to an HIV housing provider. Since then, his health and overall quality of life have improved dramatically.

The transformational impact of housing on James's ability to manage his HIV and other health issues is disturbingly common and unfortunately not well understood by policy makers.

Beyond Behavior

For decades we have focused on people's behavior to stop the spread of HIV. That is important – we should make sure people know how HIV is transmitted and how they can reduce their risk. But there are other powerful forces at work, referred to as “social determinants of health”. The World Health

Organization defines them as “the conditions in which people are born, grow, live, work and age, including the health system.” Examples of social determinants include poverty, social attitudes like racism, availability of employment, education, and housing, and exposure to violence, to name a few.

The social determinants of health actually affect the cause and course of disease more than genetics or behavior. This is true for conditions like diabetes or obesity, but they have an especially

Housing is the greatest unmet need. At least half of people with HIV have experienced homelessness or unstable housing.

strong effect on the spread of infectious diseases like HIV. That means we must address these broader aspects of health, along with behavior change and medical care, if we are ever to see the end of AIDS.

Why Housing?

Addressing such deep-rooted issues can be overwhelming, since there is no quick fix and real change can take many

years. But we have to start somewhere. At the National AIDS Housing Coalition (NAHC) and Housing Works, we advocate for housing for people with HIV. But with so many social ills, why concentrate on homelessness?

Homeless and HIV+?

The fact is, each fundamentally affects the other. Not only is housing the greatest unmet need of people living with and at risk for HIV, *at least half* of people with HIV have experienced homelessness or unstable housing. There are many rea-

sons: homophobia, intimate partner or family violence, poverty, discrimination against ex-offenders, addiction, mental illness, inadequate services for runaway and foster youth, and a severe lack of affordable housing.

Being homeless also makes it much more difficult to protect yourself from HIV. Among homeless people, the rate of HIV infection is 16 times higher than in the general population. Unfortunately,

continued on next page

no matter what makes someone vulnerable to HIV infection, being homeless magnifies the risk.

Housing IS Prevention

Research has shown that whether or not someone is housed has a greater effect on HIV (both being infected and staying healthy after infection) than mental illness or substance abuse. People with stable housing are more likely to enter care, take their medications as prescribed, and have safer sex – all behaviors that lower HIV risk or help manage HIV disease.

people would save the city of Los Angeles \$80,000 per year in substance abuse and mental health services, medical care, housing, and criminal justice costs.

Current Policy (And How to Win It)

Several programs are already in place to address affordable housing for people with HIV. The most well-known, the Housing Opportunities for Persons with AIDS (HOPWA), is run by the federal government through the Department of Housing and Urban Development (HUD). HOPWA was created in 1992 to provide housing assistance and other supportive services to low-income people

following example, it was not a policy that needed to be put in place, but rather one that had to be stopped.

In late 2006, a proposal was made to change part of the Ryan White CARE Act's housing policy by imposing a lifetime limit on housing benefits of just 24 months. Knowing that such a limit would be catastrophic (partly because of the cyclical nature of HIV disease),

Stable housing is not only an effective HIV prevention intervention, it is also very cost-effective. Each prevented HIV infection saves \$400,000 in lifetime medical costs.



Stable housing is not only an effective HIV prevention intervention, it is also very cost-effective. Each prevented HIV infection saves \$400,000 in lifetime medical costs. For homeless people with HIV, providing housing saves money that would be otherwise spent on crisis services like emergency hospitalization, prison stays, and emergency shelters. A University of Southern California study showed that providing permanent housing to just four chronically homeless

with HIV and their families through grants to organizations around the country. The importance of housing was acknowledged again in 2010 with the release of the U.S. National HIV/AIDS Strategy. Housing was singled out among the many basic needs of people with HIV, one that must be provided to fully address the U.S. epidemic.

How can we advocate for this critical need? Well, advocacy takes on many forms and uses many strategies. In the

the National AIDS Housing Coalition (NAHC) fought back with research that provided overwhelming evidence of the necessity of housing for maintaining the health of people with HIV. Armed with science-based evidence, and faced with a struggling economy and a maddening lack of affordable housing, NAHC began mobilizing to stop this policy.

NAHC started by presenting the research to members of Congress, earning important allies from both parties. Representatives DeLauro, Nadler, Waters, Hirono, Soude, and Abercrombie agreed to send letters opposing the policy to Dr. Elizabeth Duke, then Administrator of the Health Resources and Services Administration (HRSA). Over 100 concerned organizations also submitted comments protesting the rule. As a result, HRSA agreed to postpone its decision.

A year later, however, despite receiving hundreds of comments against the rule from organizations and over a

dozen members of Congress (including then-Senator Obama), HRSA decided to implement the rule. With only one month remaining, strong action was needed. It was time for both organizational advocacy and grassroots action. Congresswoman Rosa DeLauro (D-CT) spearheaded Congressional action opposing the rule. NAHC sent a letter opposing the 24-month rule to then-Secretary of Health and Human Services Mike Leavitt with copies to every member of Congress who supported NAHC's position. A day later, NAHC and Housing Works organized a nationwide call-in, mobilizing activists across the country. HRSA knew the public was watching, and those who would be hurt by this policy made their voices heard.

The proposed rule was dropped.

The Fight Isn't Over

The example above is typical of advocacy in many ways – reaching a goal often takes a long time and requires patience, persistence, and vigilance. Many voices are always more powerful than one, and this requires collaboration. Flexibility is essential, because different strategies will be effective at different times.

What Next?

Although many improvements have been made in housing policy for people with HIV, there is still much work to be done. Advocates are working on a variety of policies even now. While the creation of the National HIV/AIDS Strategy was a critical step, it still must be implemented. The AIDS community is holding the government accountable for steady progress and actually prioritizing housing as a key intervention against AIDS. NAHC will continue advocacy to pass legislation introduced to Congress and to follow up on a Resolution passed by the House in 2010, titled “The Role of Housing as an Essential Component of HIV Prevention, Treatment, and Care”.

Changes must also be made to the way HOPWA distributes funds to reflect what the epidemic looks like today. Funding must be based on the number of HIV diagnoses, not AIDS cases, since the latter grossly underestimates the true need. We must also demand a fairer grant-making process – one that recognizes variations



People with HIV also need to be front and center when talking about policy. Ensuring that they are seen and heard beyond just telling a success or victimization story not only strengthens advocacy but breaks down the stigma of living with HIV.

across the nation by factoring in rates of poverty and housing costs in each community.

Making It Happen

Whether you work in an organization or you're an individual trying to make a difference, there are many ways to get involved. Successful advocacy depends on diverse strategies. This article focuses on national policy, but the following ideas will work equally well on the local level.

Education, both internal and external, is an essential first strategy, and it's something anyone can do. Internal advocacy means educating the HIV community itself. For example, it's important to

find ways to combine housing advocacy with efforts to ensure access to care and prevention. A coalition makes each issue stronger, especially when everyone understands how they are related. External education is also essential. People who can move policy forward, like those in Congress, may be unaware how many of their constituents need housing assistance, or may not understand how effective housing is in preventing HIV. Anyone can call, email, or visit their representatives to provide this kind of education. NAHC is a member of the Federal AIDS Policy Partnership and works to ensure that housing is

continued on next page

included as a priority in its work. NAHC also regularly holds Congressional briefings to educate new representatives and ensure that those returning keep our issues on their radar.

When it comes to educating government representatives, it is absolutely essential that people with HIV are included, and in meaningful ways. Often they are simply asked to share their personal stories. This is certainly important to humanize the issue and can be quite powerful, but it's not enough. People with HIV also need to be front and center when talking about policy. Ensuring that they are seen and heard beyond just telling a success or victimization story not only strengthens advocacy but breaks down the stigma of living with HIV.

Community or "grassroots" organizing is invaluable. While education is important, we can never forget that education alone is not advocacy! The goal is change, not awareness. And for that to happen people need to join together, since their collective voice can make all the difference. To stop the 24-month rule discussed earlier, it was crucial that HRSA hear from the community itself. Grassroots organizing has traditionally meant groups of people meeting in person. Now, it increasingly includes social media and online networking to bring people together.

But what happens when a community has joined together, educated decision-makers, and offered a solution, but nothing happens?

Direct Action

Direct action takes many forms and is used by activists to "turn up the volume" when they are not being heard. There are many different direct action tactics, but all of them are more public than education-based advocacy. An effective action always has a specific target: someone who can make change happen. Media coverage is often a major goal.

Using the media helps in several ways. Elected officials, concerned with staying in office, are very image-conscious and aware of what the media is saying about



them. Media attention can bring an issue to the public's attention, which can create more support and help put pressure on the target. After all, it is much easier to ignore activist demands if no one else knows about them.

When advocating against the 24-month rule, direct action involved a call-in campaign to Members of Congress. Other types of direct action include Twitter and letter-writing campaigns, rallies and protest marches, and civil disobedience for those willing to risk arrest. Housing Works, among several other AIDS activist groups, is well known for creative and nonviolent civil disobedience.

Ready to Advocate? Start Here!

Advocates are well aware of the truth in Frederick Douglass' words: "Power concedes nothing without a demand. It never did and it never will." The evidence shows us that to end the epidemic we will need to address housing and other community needs, along with biomedical interventions. We have the science, the treatments,

and the resources - all we need is the political will. If you're ready to join the fight, look at the resources below and get in touch with us.

We can and will end AIDS. ■

National AIDS Housing Coalition Policy Toolkit:

nationalaidshousing.org/policy-toolkit
Fact sheets, sample letters, and other tools to help advocates demonstrate the link between housing and HIV health.

Campaign to End AIDS: www.c2ea.org
Resources, action alerts, blogs, and more.

Housing Works: housingworks.org

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Christine Rodriguez, Program Associate at Housing Works, also contributed to this article.

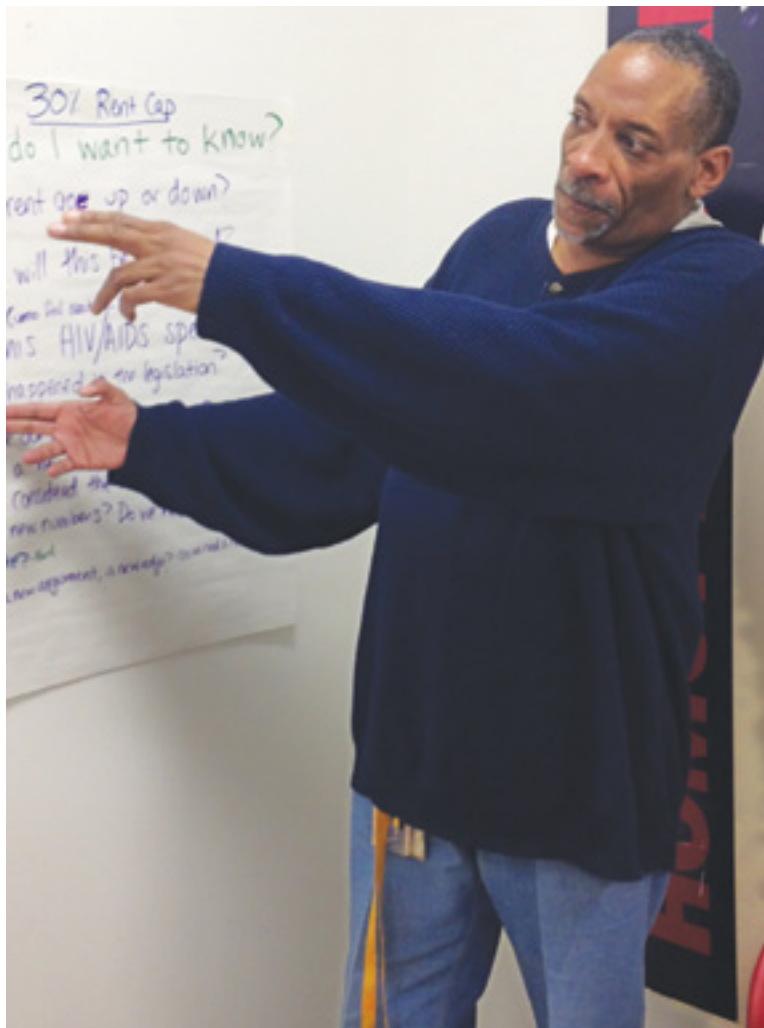
Caught in the Middle

by Todd Livingston

I have HIV and live on a fixed income. I'm currently living in a 15x15-foot studio apartment, in transitional housing for people with HIV. It's meant to be short-term, until a resident is ready to move someplace more permanent. But most people, like me, end up living in these units for two or more years because they can't afford to pay the thousands of dollars in rent needed in the New York City housing market for a decent one-bedroom apartment.

HASA will pay up to \$2,300 a month for people with disabilities to live in 5x7-foot rooms but will not spend that same money to keep people in their own homes.

But my life wasn't always like this. In 1997 I was hospitalized with AIDS. At that time, I lived in my childhood home, owned by my family. Because of my work history, and being responsible in paying bills, my mother put me on the deed to the house and I was paying the mortgage. For some time, I tried to make repairs on the home and found inventive ways to pay the bills. For a while, my Social Security Disability Insurance and my mother's Supplemental Security Income paid most



of the bills. Still, it was hard to make ends meet. There was no help from agencies such as the NYC Human Resources Administration (HRA) and HIV/AIDS Services Administration (HASA), or adult protective services for people on fixed incomes that own property. So for 15 years my mother and I struggled to keep our home.

In 2006, my mother's health worsened and the house was not suitable for an elderly person and a person with a health condition like HIV. It became clear that something had to be done, but no help from city or state agencies was available. As a

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result, my mother went to live with my aunt in California and we had to sell our home of 40 years.

I was distraught over this, and in 2009 I hit bottom. I found myself in a Single Room Occupancy (SRO) building – a real dumping ground for people with AIDS or drug addictions. It's so strange to me that HASA will pay up to \$2,300 a month for me and other people with disabilities to live in 5x7-foot rooms but will not spend that same money to keep people in their own homes, or just half that amount to let people find decent apartments on their own. I find that really wrong.

Since this all happened to me, I have become involved with housing issues affecting people with HIV. I have been really active with the Action Center of GMHC, attending their weekly meeting for the last two years. It was there that I learned about the campaign for a 30% rent cap for people on fixed incomes. I found out that people with AIDS in New York City are just about the only New Yorkers who are forced to pay more than 30% of their public benefits (like Veterans' or disability benefits) toward rent. We were asking for legislation to cap their rent at no more than 30% of their benefits.

People in the group, who are also HIV-positive, were talking about it and really working to get the law passed. With the Action Center, and other groups like VOCAL and Housing Works, I went up to Albany three or four times to lobby for the rent cap. I also went to Washington, D.C., three times, and to New York City Hall too many times to count!

It felt so empowering to be part of this. I felt like we were getting our message across. There was such a sense of community. I knew then I wasn't alone. And it gave me a platform to have own my voice heard and to be a voice for others.

One time we did a sit-in at HRA Commissioner Robert Doar's home in Brooklyn to drive home the point about housing issues. It was a really thrilling experience. At the time, Governor Paterson was in office. When we spoke with him, he said he would sign the bill if it came before him. We thought there was a good chance that we could pass the rent cap. We thought we were on the verge of having something to celebrate in 2011. And it did pass, but at the twelfth hour Governor Paterson vetoed it. He lied to us.

When he didn't keep his promise I was filled with anger and sadness. I was in the process of transitioning to independent housing at the time, but wasn't financially stable enough to maintain it. I'm functionally independent but not financially. So I had to stay in a group facility in the Bronx, and I'm still there. I felt deflated, disappointed, and confused. I thought, "What am I going to do now?" For me to move on I have to be in a better situation that's affordable and safe. Staying in congregate living just keeps me stagnant. It's so hard to function when you're crowded in that space if you have health issues or a disability. It's so hard to live out of a box.

Being forced to go to an SRO or congregate living situation or a run-down tenement building doesn't work. It's depressing and triggers relapses of drug use.

A 30% rent cap would go a long way to help people with HIV and others on fixed incomes to have decent, affordable housing with some hope for a more normal life. Being forced to go to an SRO or congregate living situation or a run-down tenement building doesn't work. It's depressing and triggers relapses of drug use. Until HASA changes the way it operates to help people with a fixed income, this same cycle will continue.

I think there is a very good chance that if we keep building our advocacy Governor Cuomo will work to pass the 30% rent cap. I'm hopeful that I can move on this year and be able to venture out to other goals I have, like going back to school and then to work. Gearing up for 2013, I've strengthened my resolve to double my efforts as an advocate. I've also recruited others to take up the cause. Until we can get the 30% rent cap I will keep fighting. We all have a right to decent, affordable housing in this city. Living with HIV is stressful enough. We shouldn't have to deal with stressful housing issues, too! ■

MEN & WOMEN DEMAND RECTAL MICROBICIDES

by Jim Pickett and Mitchell Warren

Recent scientific developments have both inspired and challenged everyone engaged in the fight against AIDS. Much-needed new methods of HIV prevention have been shown to work. But while there has been much excitement, there has also been significant concern and controversy.

For more than 30 years, the belief was that “safer sex = condoms”. But what happens when science shows that pills and gels can also prevent HIV? How do we rethink decades of prevention programs that equated condoms with safer sex and left few other choices? What does “protected sex” mean now? And how has the definition of “unprotected” sex changed?

Of course, condoms work really well – when they are used consistently and correctly. But for a host of reasons, condoms often stay in the wrapper even when people know better. Several studies report that about 50% of gay men in the U.S. use condoms regularly, and that number is only around 25% among heterosexuals.

One could argue that we’ve reached our limit with condom promotion. For U.S. gay men, we’ve seen 50% use for decades now. Condoms alone are clearly not up to the task of preventing enough infections to turn the HIV epidemic around. In reality, no single option can ever end this epidemic. There will never be a “magic bullet”. Indeed, there is nothing magical about HIV prevention!

Three Years of Change

Around 8 million people worldwide are now receiving lifesaving HIV treatment. Nearly 7 million more are eligible but not yet on treatment. At the same time, 2.5 million people became infected in 2012, and almost 2 million people died due to AIDS in 2011. Imagine the fourth largest city in the U.S., Houston, emptied – wiped off the map.

Around the world, more people need to know their HIV status. And we must link those who test positive to care. We must also link those who are negative to the widest possible range of prevention options. Yes, we need to continue promoting condoms. But we also need to expand people’s options.

In mid-2010, a microbicide gel containing an HIV drug called tenofovir showed a modest benefit in preventing HIV infection in a study of South African women who applied the gel before and after sex. Later that year, a global trial in gay men and transgender women showed that the HIV med Truvada could prevent HIV infection when taken once a day – a strategy called PrEP (pre-exposure prophylaxis). But two other studies showed that PrEP did not work because people did not actually take the

Condoms alone are clearly not up to the task of preventing enough infections to turn the HIV epidemic around. In reality, no single option can ever end this epidemic.

pill every day. When the FDA approved Truvada for PrEP in July 2012, it was a moment to celebrate science – the first new HIV prevention tool since the FDA approved the female condom in 1993! It was also a moment to look at the hard work needed to make prevention work for people.

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The State of PrEP

PrEP is starting to be implemented, though very slowly. While studies have shown that it can work, we need to understand who can benefit most, how to use it safely and efficiently, how to integrate it with other methods such as condoms, and how to maintain high levels of adherence, which research has shown to be essential for PrEP to work properly.

Challenges include ensuring that PrEP will not hurt access to HIV drugs for people with HIV, identifying who could most benefit (many of whom don't have access to health care), finding the money to pay for it, and educating insurance companies, government programs, health care providers, and individuals about its benefits and limitations.

We know daily Truvada is not for everyone. So we must continue to research the next generation of prevention options. Here are some of the questions being explored:

- Can taking a pill every few days instead of daily, or only when you might be exposed, still provide protection?
- Would women prefer to use a vaginal ring containing an HIV drug that only needs to be replaced once a month?
- Can a once-monthly injection of an HIV med provide enough protection?

The pipeline of longer-acting, easier-to-take prevention products needs to move swiftly. Several vaginal rings are currently in development. There are also early trials of long-acting injectable drugs. The history of family planning teaches us that more people use protection as the choices expand.

Rectal Microbicides

Until recently, microbicide research has focused on vaginal microbicides. If scientists and advocates considered rectal microbicides at all, it was strictly in the context of the need to test vaginal products for rectal safety, since an approved vaginal microbicide would likely be used in the rectum as well.

But anal intercourse is common among both gays and straights, and is a significant factor in the spread of HIV. In the U.S., the majority of new HIV infections can be attributed to unprotected anal intercourse among gay men. Due to the biology of the rectum, unprotected anal intercourse is 10 to 20 times more likely to result in HIV infection compared with unprotected vaginal intercourse.

Initially, the majority of the HIV community – scientists and advocates alike – dismissed the possibility of a rectal microbicide that was safe and effective. Its pursuit seemed hopeless, even laughable.

Biological challenges played a role in this lack of enthusiasm. The vagina is essentially an enclosed pouch, whereas the rectum leads to about five feet of colon, which is a lot of territory for a microbicide to cover. The vaginal lining is approximately 40 cell

layers thick, while the rectum's lining is only one cell layer thick. The rectum also has a large amount of cells that HIV directly targets. Protecting the vagina from HIV infection seemed possible – protecting the rectum appeared much more difficult, maybe even impossible.

Politics and culture reinforced the dismissal of rectal microbicides. Pervasive homophobia has resulted in a lack of adequate resources devoted to gay men, including in the U.S. People also wrongly assumed that anal intercourse was exclusive to gay men, and that women would not need a rectal microbicide. So why develop a specific prevention tool for an ignored or hated population?

Despite this array of challenges, and despite low funding for rectal microbicide research, the field has moved from being simply an adjunct to vaginal research to a force in its own right. This is due to a handful of visionary, passionate, and dogged scientists; funding from the U.S. (which has supported the lion's share of rectal microbicide research); and community advocacy.



Current Trials

Small Phase I trials, designed to determine whether products are safe and if people actually like using them, have led to the first-ever Phase II trial of a rectal microbicide. In the first half of 2013, the MTN-017 trial of a tenofovir gel is set to launch in the U.S., Thailand, South Africa, and Peru. The gel is similar to the gel being studied among women in Africa, but has been modified to be more “rectal friendly”.

The 186 gay men and transgender women in this trial will more than double the total number of people who have participated in all rectal microbicide trials to date. Also, the trial is the first to include sites outside the U.S. The study will investigate the safety and acceptability of the gel, and will compare it to daily PrEP. Everyone in the trial will try three different regimens, each lasting eight weeks. In the first regimen, people will

apply the gel to the rectum daily. In the second, they will apply it before and after anal intercourse. In the third, they will take Truvada daily, with no microbicide. The order in which participants will follow the regimens will be assigned by chance, with a rest period between each one.

The study will also look at how much of each drug is absorbed in the blood and rectal tissue, and will look for changes in cells or tissues. People will be asked about any side effects, what they liked and disliked about using the gel either daily or with sex, and whether they would use it in the future. The results won't tell us whether the product works to prevent HIV. But this important study could lead to another first: the launch of a large-scale trial to test whether a rectal microbicide can prevent HIV infection.

What Do We Need?

Advocacy around rectal microbicides needs to concentrate on a variety of things. One of the most important priorities is adequate funding, especially as the field moves toward large-scale trials. Funding is important for earlier phases of research as well, and to support laboratory studies, where new products are dreamed up. We also want a variety of microbicides to choose from, and a variety of ways to apply them. Women want microbicides that also provide birth control. And we need microbicides that protect against other sexually transmitted infections, not just HIV.

People with HIV want microbicides, too. But they may not be able to use ones based on HIV drugs, as that could interfere with their own treatment. We need microbicides without HIV meds. Positive folks want choices for protection too!

Finally, there is a strong desire to have microbicides that work in both the vagina and the rectum. We need products that are safe and work wherever you put them, whether you have anal or vaginal intercourse. Plenty of women have both, so providing one microbicide that could be used for both would be best. Having one product would also reduce the stigma associated with anal sex. People may be afraid or ashamed to ask for a rectal microbicide because that could label them and cause discrimination and even harm.

For this reason, rectal microbicide advocates have also prioritized education efforts, to reduce the ignorance and stigma associated with anal sex. Promoting anal health and wellness is also important. It is a part of our body many of us prefer to ignore – out of sight, out of mind. But that's not a good recipe for keeping the anus healthy. We all have one, and we all should have one that is healthy!

Conclusion

HIV prevention is complicated and controversial. Whenever you talk about sex, there will be strong reactions. Now that we have these new methods, and more strategies on the way, we're seeing lots of powerful positive and negative feelings about the idea of expanding our prevention toolbox to make room for but new approaches.

“New” can be threatening. “New” takes us into uncharted territories. There is a lot we don't know about something that is new, and that can be frightening. But prevention advocates must fight for more choices, so people have more opportunities to have sex that is protected. That is what this is all about – con-



Tia IRMA (Auntie IRMA), created by IRMA's chapter in Peru to create awareness about rectal microbicides in a fun way.

doms for some, pills for others, and gels, rings, injections, and future things we can't yet imagine for others.

The prevention “buffet” has basically consisted of one thing – let's say potatoes – for the last 30 years. Plenty of people like potatoes. Others enjoyed them for awhile, but are now skipping the buffet because they are sick and tired of potatoes, potatoes, potatoes. Others never liked potatoes in the first place, never ate them, and never will – no matter how hard we try to make those spuds appealing.

So the answer is “yes” to potatoes. And “yes” to other tasty things to reach the non-potato crowd. No one should go hungry. And no one should only have one option to protect themselves during sex. ■

Jim Pickett is Chair of IRMA (International Rectal Microbicides Advocates). Mitchell Warren is the Executive Director of AVAC.



by Brook K. Baker

The grand arc of the global HIV treatment movement has revolved around lowering drug prices, increasing funding, and scaling up health services for people with HIV. Activists have tried to find the right balance of prevention, treatment, and care and have responded to new discoveries by demanding that policy makers create programs that match the science.

But today we are at a crossroads. Will we increase funding and provide universal access to HIV prevention, treatment, and care – and break the back of the AIDS epidemic – or listen to the “fiscal cliff-jumpers” and continue flat-funding, ensuring a global epidemic that will affect generations to come?

Activist Wins

Activists won the initial fight to lower prices on life-saving HIV treatment. Those medicines now cost pennies on the dollar in sub-Saharan Africa, compared with their costs in the U. S. (a generic version of Atripla costs \$197 a year, whereas the brand-name version can cost \$30,000). But a treatment time bomb is ticking, as newer medicines are more widely patented in low- and middle-income countries, and as the U.S. and European Union coerce developing countries into allowing stronger and longer drug patents.

By 2012, activist campaigns led to \$16.8 billion in funding to fight global AIDS – roughly half from rich nations and half from developing countries. Activists spearheaded the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), and their persistent demands led George W. Bush to create the President’s Emergency Plan for AIDS Relief (PEPFAR). They also used “insider-outsider” strategies, organizing public protests while fighting their way onto the Board of the Global Fund, into positions at UNAIDS, and into PEPFAR meetings.

Just before World AIDS day last year, naked AIDS protesters seized the office of U.S. House leader John Boehner to demand that Congress fully fund domestic and global AIDS programs.

During the 2008 Presidential campaign, activists “bird-dogged” candidates Obama and Clinton by relentlessly showing up at their campaign events. Both candidates eventually committed to PEPFAR funding of \$50 billion over five years. They then hounded President Obama, demanding that PEPFAR provide treatment for 6 million people by the end of 2013 – a goal he finally announced on World AIDS Day, 2011. During the International AIDS Conference in Washington, D.C., last July, thousands poured into the streets calling for policy changes and increased funding. And just before World AIDS day last year, naked AIDS protesters seized the office of U.S. House leader John Boehner to demand that Congress fully fund domestic and global AIDS programs.

Along with international allies in Europe, activists are now campaigning for a small “Robin Hood Tax” on the transactions of financial institutions, which could raise hundreds of billions dollars. That campaign has succeeded in establishing a beachhead in 11 European countries, but the fight in the U.S. will likely take much longer.

New Hopes

There have been breathtaking advances in AIDS science in the past two years. The HPTN 052 study compared the benefits of starting HIV treatment at a CD4 count of 550 versus 250. It found that earlier treatment delayed progression to AIDS, and reduced the risk of heterosexual HIV transmission by 96%. Follow-up studies are looking at the risks and benefits of earlier treatment, at treatment fatigue, and at drug resistance. Broader studies are hoping to confirm the effect of “treatment as prevention” on community viral load, HIV incidence, and death rates, and its cost-effectiveness. Finally, Truvada has been approved to prevent HIV infection, and we have seen promising studies on microbicides and even on vaccines.

In addition, it was reported on World AIDS Day that nearly 8 million people (including nearly 6 million in sub-Saharan Africa) were taking HIV treatment as of December 2011 – a 64% increase since 2009. New infections were down 21% from a decade earlier and deaths had decreased by 24% since 2005. And 57% of pregnant women with HIV had received effective treatment both to protect their own lives and to prevent transmission to their newborns.

Much of this progress is the result on U.S. funding. In fiscal year 2012, the U.S. PEPFAR program:

- Supported HIV testing for over 49 million people, including 11 million pregnant women.
- Subsidized circumcision for 2 million men.
- Distributed more than 600 million condoms.
- Funded HIV treatment for over 5 million people, preventing more than 1 million deaths while preventing over 270,000 new HIV infections.
- Provided HIV meds to 750,000 HIV-positive pregnant women, preventing more than 116,000 transmissions to infants.
- Prevented nearly 2 million children from being orphaned and provided care and support to more than 4.5 million orphans and 10.5 million adults.

At the insistence of activists, PEPFAR has worked to reduce any negative impact its programs may have on non-AIDS health services and to strengthen care for TB. Global Fund results announced at end of 2012 include:

- The number of people on treatment increased by 900,000.
- 1.7 million pregnant women received treatment to prevent transmission.
- HIV testing sessions increased by 60 million, to 250 million.
- Condoms distributed jumped from 3.5 billion to 4.5 billion.
- Care and support services rose to 19 million and services for the most at-risk groups rose to 30 million.

New Needs

Despite these dramatic successes, the cup is only half full. Well over seven million people with CD4 counts below 350 (making them eligible for HIV treatment under World Health Organization guidelines) are waiting in line to die. And if WHO treatment guidelines move higher – as U.S. guidelines have – the number eligible for treatment jumps, and we’re only a third of the way home. At present, children are undertreated (28% receive meds), as are men compared with women (47% vs. 68%).

AIDS activists have been less successful fighting for equal and respectful services for men who have sex with men, sex workers, injection drug users, prisoners, people with disabilities, migrants, and other “outsider” groups. These groups consistently have less access to services and often face not only stigma but criminalization as well. As an example, the U.S. government continues to defend its antiprostitution pledge requirement (a demand that any organization receiving PEPFAR funds has a policy opposing prostitution), expanding it to U.S.-based organizations and taking the case all the way to the Supreme Court.

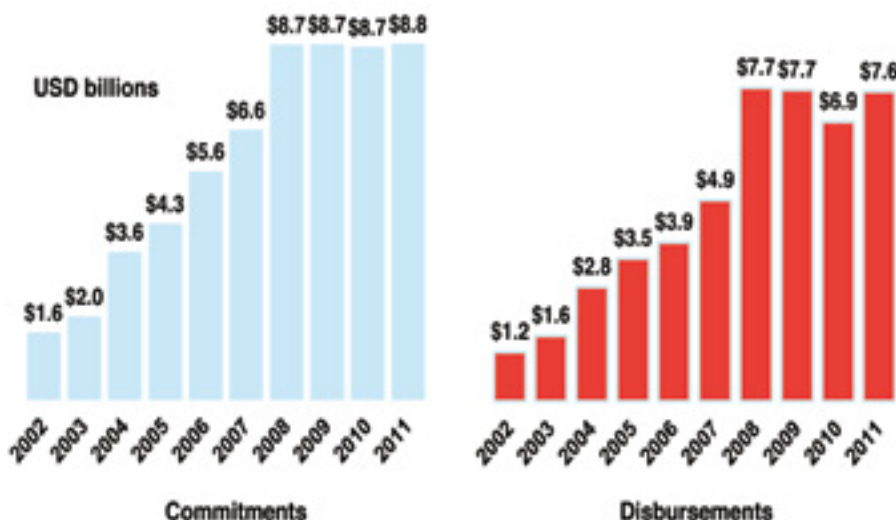
Filling the Cup

Funding from rich nations has stagnated over the last four years, at roughly \$7.5 billion a year, while PEPFAR funding has actually decreased over the past four years. What is particularly troubling is that the 2013 budget proposes a half billion dollar cut for PEPFAR programming, which is only partially offset by a proposed increase to the Global Fund.

Surprisingly, the short-term needs are not that great and could actually result in cost savings. One reason is that scattershot spending is no longer justified. Spending should be tailored to local conditions and focus on the most cost-effective interventions. According to the most recent projections, the gap in needed funding is only a few billion dollars a year. Even more convincing is that studies show that early investments will have a big payoff in terms of long-term cost savings.

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International AIDS Funding 2002 – 2011



Source: Kaiser Family Foundation

Defeating the Lame Excuses

To fund the half-full funding glass, we must confront the four excuses that continue to dog our work:

“We have no money.”

Fiscal cliffs, financial crises, debt-ceiling showdowns, Medicaid on the ropes -- if you believed the pundits, you would think that AIDS funding was dead in the water. They say we should turn our attention solely to doing more with less.

But these claims of financial Armageddon can be debunked by looking at the reality of record corporate profits, huge amounts of money spent on weapons of war, and a culture of rampant financial speculation. Corporate profits in the U.S. are at an all-time high and the richest 100 people in the world got \$241 billion richer in 2012. The U.S. defense budget is \$633 billion. A tiny Robin Hood tax (less than half a percent) on financial transactions could raise over \$350 billion a year. And supposedly we don't have money for AIDS – what a laugh!

“Do more with less.”

There has been impressive efficiency in global AIDS programs. Over 90% of drugs are low-cost generics, supply systems have been streamlined, and patient information and laboratory systems are starting to work. The cost of treating patients in many African countries has plummeted to less than \$300 a year per person. But the era of easy fixes that can make up for flat funding are over. Future cost drivers include:

- New and improved facilities.
- Expanding the number of healthcare workers.
- Greatly expanding HIV testing.
- Adding viral load and drug resistance testing.
- Reaching the hard-to-reach and underserved.
- Potential higher costs of patented medicines.
- Increased costs of aging patients with multiple illnesses.

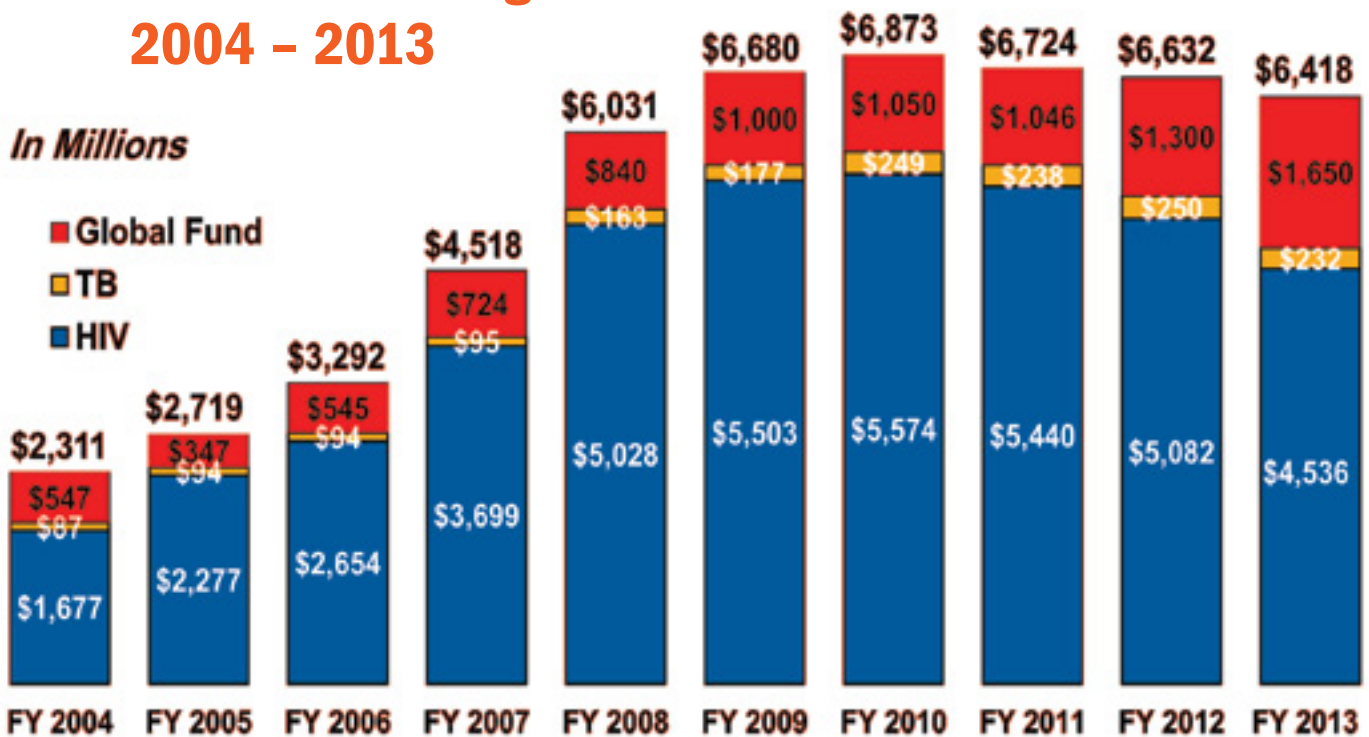
PEPFAR funding has decreased over the past four years. The 2013 budget proposes a half billion dollar cut for PEPFAR, which is only partially offset by a proposed increase to the Global Fund.

“What promises?”

At the United Nation's 2011 High-Level Meeting on HIV/AIDS, prior commitments to provide universal treatment, intensify prevention efforts, and fight stigma were reaffirmed. More specifically, governments committed to treating 15 million people with HIV by 2015.

Despite these promises, leaders have begun to turn their attention elsewhere. Policy apologists, using the dismal argument of

U.S. PEPFAR Funding 2004 – 2013



Source: Kaiser Family Foundation



Photo courtesy of Dennis Daniel

cost-effectiveness, argue that commitments on AIDS should be abandoned in favor of more limited and cost-effective interventions like vaccines for children. Instead of acknowledging that adequate resources are needed for all neglected diseases, health pundits like Zeke Emanuel (who has the ear of Obama) propose a zero-sum game of limited resources and ruthless defunding of AIDS. These false arguments must be fought head on.

“Can’t we wait?”

The AIDS crisis is not over – globally or domestically. But the Global Fund is driving on fumes. Although it needed \$20 billion for scale-up during its last funding cycle, it received only \$11.7 billion in pledges.

The upcoming debt-ceiling fight could result in an 8.4% cut across-the-board cut in most federally funded programs. As a result, amfAR estimates that 387,000 fewer people with HIV would be treated – leading to 80,000 deaths, 122,500 new orphans, and 21,000 infants being infected. In the U.S., the CDC would lose \$64 million in funding for HIV prevention, the Ryan White program would be cut by \$196 million, \$77 million would be cut from the AIDS Drug Assistance Program, AIDS-related research at the NIH would be cut by \$251 million, and funding for HIV housing would drop by \$27 million. These cuts will only fuel the fire.

Conclusion

Waiting is not an option. Every day 7,000 people are infected with HIV and 4,700 die. Every day new people are added to the waiting list for HIV treatment. So activists must not and will not give up.

We are still fighting for a Robin Hood tax and other taxes on the rich, and for reductions in defense spending.

We are agitating for an expansion of funding that will begin the end of AIDS, especially by expanding treatment-as-prevention, male circumcision, condom promotion, and needle exchange.

We are demanding policy changes that will fight stigma, discrimination, and criminalization of neglected groups, and that will expand programs to improve connection to care and end the drivers of the epidemic.

We are demanding revised treatment guidelines and the increased use of the latest drugs, the reversal of counterproductive intellectual property and trade policies by the Obama administration, the strengthening of local health systems, and a scaling up of commitments by country partners.

To win these fights, we make common cause with international allies and seek deeper alliances with domestic AIDS campaigners. We cannot afford to lose this fight. ■

Brook Baker is a professor at the Northeastern University School of Law and a Policy Analyst for Health GAP.

The Road Less Traveled

by *Bambi W. Gaddist, DrPH*

In 1989, when I was working for the South Carolina Department of Education, I met a State Senator from one of the most politically conservative regions. As we stood in the lunch line during a training, she pleasantly asked me about my views on HIV and our state's approach to our growing epidemic. Being a novice to politics, I was open in sharing my impressions, which were based upon my grassroots advocacy work with DiAna DiAna (a controversial hair dresser who created the first HIV prevention efforts done in a beauty salon) and what I had learned from students I met as a state health consultant.

She indicated that she wanted to talk more and invited me to meet at her office. When I did, I was escorted into a large board room and saw at least ten other individuals. I was taken aback to recognize several health officials. No introductions were made and I was invited to sit at the head of the table. I realized I was being ambushed.

I was questioned about my views on sex education and AIDS. Over an hour later, the interrogation ended with the State Senator basically questioning whether I wanted to keep my job.

That event continues to shape my HIV advocacy. It taught me never to go into a situation without asking questions about the who, what, and why. It solidified my understanding that in any struggle, we must each find our unique place. Some must be ready to take a direct hit, perhaps even committing civil disobedience. Others can work within the system. But everyone must ask: What type of advocate am I? What am I prepared to sacrifice? The answers to these questions will shape our thoughts, actions, and effectiveness.

I shared with my family that I would not deviate from my mission. I knew my employment might be the sacrifice, but my spirit would not let me move from what I knew was true. The fact is, I was competent in my subject matter and knew I was following the mandates of state law. But I was being asked to use my expertise and years of experience in human sexuality on behalf of a government agency mired in conflict. In addition to teaching students about HIV, STD, and pregnancy prevention, I was charged with educating school administrators and teachers on

school health law. But I was challenged far too often by local school districts that had no intention of following a state law designed to curtail the spread of a highly stigmatized disease. So I let my final days at the department become my training field. I constantly addressed with my superiors the most effective strategies to inform teachers and students about HIV.

But whenever I left the state, I seemed to face a political crisis upon my return. It was as if the conservatives who hated sex education knew when I was out of town. In 1992, while attend-

I was called to testify before the South Carolina Education Subcommittee, where Dr. George Rekers claimed that viewing a plastic penis could break down young girls' "natural reluctance to view male nudity and make them more likely to have sex."

ing an AIDS conference in San Francisco, I received a call from Dr. Nielsen, the State Education Superintendent, on a matter she deemed highly sensitive. She said I was to report to her office immediately upon my return. When I did, she informed me that I had been called to testify before the South Carolina Education Subcommittee to answer allegations that I was corrupting the morals of minors. The basis for the charge was my use of a penis model to demonstrate the proper use of condoms with high school students.

On April 22, 1992. I faced five members of the subcommittee to respond to allegations that my methods were creating "monumental risks". Dr. George Rekers, a behavioral science professor at the University of South Carolina School of Medicine, testified against me. He claimed that viewing a plastic penis posed significant risks for young girls. He said that seeing it could break down their "natural reluctance to view male nudity and make them more likely to have sex." He went to say, "Viewing the penis could even lead to sexual arousal or trigger post-traumatic stress disorder in girls with a history of sexual assault."

I was told to demonstrate my methods, but I respectfully refused, noting that it would only distort the purpose and context of the activity. I instead invited them to attend an entire health education session that evening for unwed teen mothers, during which I would use the penis model. Not one chose to attend.

But the media did show up in full force, resulting in a front-page article. Numerous articles, letters to the editor, and personal opinion pieces were published in the months to come. Many were supportive, some not. More important to my survival were the number of professionals in the fields of health, psychology, and sociology who boldly and publicly supported me. Others, concerned about their personal job security, distanced themselves from me. In the end, the state Department of Education did not ban use of the model. They were aware of South Carolina's high rates of HIV, STDs, and teen pregnancy, and felt that detailed lessons were needed to prevent them.

I knew I had done the right thing. I never defined that moment as "advocacy", but I knew someone had to stand up and ensure that young people in South Carolina had an opportunity to get accurate HIV/STD information. So, several other African-American leaders and I created the South Carolina HIV/AIDS Council (SCHAC). I've served as Executive Director since 1995.

And we have never abandoned advocacy. It is not unusual for me to read the local newspaper to locate meeting spots frequented by legislators and leaders and then ensure that we are on the scene. We've spent over a decade nurturing relationships with legislators who have served as mentors. We can't afford a lobbyist, so we request advocacy help from lobbyists willing to get "the lay of the land" on our behalf. Pharma partners like Janssen, Gilead, and Bristol-Myers Squibb have provided skills training, underwritten advocacy expenses, and helped make our state mobilization efforts successful. We are not afraid to ask for help, because we know what happens to community-based organizations that have an ego bigger than their bank account.

Working with national advocates like the Ford Foundation, Southern REACH (AIDS United), and the Southern AIDS Coalition, we took on the task of increasing our state's ADAP funding. We orchestrated six local community forums with mayors, hospital administrators, business owners, political strategists, and neighborhood association heads, who had never entertained the notion of AIDS-related advocacy. In the end, we were successful, with funding rising from just \$500,000 to over \$5 million.

South Carolina remains one of several southern states that have made it clear that the expansion of Medicaid offered under health care reform will not be accepted. So last December, I spearheaded our state's first press conference and community



forum on the Affordable Care Act and Medicaid Expansion. It was the result of a coalition of the South Carolina HIV/AIDS Care Crisis Task Force, the Harvard Legal Center for Health Law and Policy Innovation, and the newly formed Accept ME (Medicaid Expansion) Coalition, which is comprised of over 30 community health advocates.

Today, like many other community-based agencies, SCHAC faces tremendous uncertainty due to health care reform. I've committed myself to advocating for my agency. If I fail to advocate for those I serve, then I've taken the path of mediocrity. Instead, I'm taking the road less traveled – a road I have often taken. I chose to stay in a southern state with a deep history of slavery and economic oppression. I chose to fight for people with HIV in a state that often ignored their needs. And I chose to fight for them when others said it was a losing battle.

My journey in AIDS advocacy has taught me that we must not take the easy road. Interruptions, hardships, and problems should be anticipated. And I've learned that the road less traveled actually has many positives. If nothing else, I know who does and does not have my back. I know that my choice to be an AIDS advocate will be my greatest achievement and that I went out boldly and gave it everything my soul could muster. ■



Ryan Rodrick Beiler / Shutterstock.com

The Clock is Ticking Preparing for the Affordable Care Act

by Amy Killelea

In less than a year, major parts of the Affordable Care Act (ACA, also known as “Obamacare”) will go into effect, and many people with HIV will have health insurance for the first time. Increased access to insurance, and to the regular care and treatment that it provides, offer an incredible opportunity to make strides against the epidemic. We know that access to early treatment not only provides health benefits to an individual, but also greatly reduces the risk of HIV transmission.

These massive changes to the health care system also present challenges, and there are still many questions that must be answered. Will every state accept the large Medicaid expansion that is a part of the ACA? Are there other options to increase access to care in states that don’t? Will private insurance plans meet HIV treatment needs? Will that coverage be affordable? Will there be effective outreach to people with HIV to make them aware of and help them enroll in the new insurance options? And finally, will we as a community have the leadership and vision to ensure that the Ryan White Program has a place once the ACA is completely in place?

With less than a year to go, much needs to happen. We are truly flying the plane as we are building it, and the HIV community must be a part of the process. We are already seeing the incredible impact that local advocacy efforts have had, as more states opt into the Medicaid expansion. But more advocacy is needed to ensure that the ACA is able to improve access to HIV prevention, care, and treatment.

Medicaid Expansion

The Medicaid expansion allows states to offer Medicaid to people with incomes up to 138% of the federal poverty level (FPL), meaning that a single person making about \$15,000 a year could qualify in 2014. Currently, in most states, a person must be disabled to be eligible for Medicaid, but in states that expand Medicaid, this disability requirement is eliminated. Here are the top three issues to watch:

State decisions to expand Medicaid

In June 2012, the Supreme Court limited the ability of the federal government to enforce the Medicaid expansion. That means states have the option of not expanding Medicaid in 2014. But the expansion is actually a good deal for states and there are many reasons to expand, including the fact that the federal government pays almost all the costs of the expansion – 100% in the first three years and 90% after 2020.

Advocacy for the Medicaid expansion is uniting broad coalitions of those who have a stake in making sure their state does the right thing. Hospital associations in particular have been strong allies in making the case for expansion to state legislatures because “safety net” hospitals will bear the cost for caring for the uninsured if a state does not expand. It is important for HIV advocates to join forces with these broad coalitions to present a strong voice for expansion to state decision makers.

Even with strong advocacy, we know that it may take some states longer than others to expand (states can opt in to the expansion at any time). In states that do not expand, the status quo continues, which leaves many people with HIV unable to qualify for coverage. Because federal subsidies to help people purchase private insurance are only available starting at 100% of the Federal Poverty Level, many could still be without health insurance. Some state legislatures are now debating whether to expand, and it will be important for the HIV community to make the case that expansion matters to people with HIV.

Currently, several governors have stated they are opposed to the expansion, and many more are still weighing their options. One governor recently rejected it in spite of a unanimous recommendation to expand from a commission he appointed. We clearly have more work to do in the approximately 25 states in which governors have either expressly rejected expansion at this time or have yet to declare a position.

But in some states that were initially opposed, we are seeing the effects of strong advocacy. Governors in New Mexico and Arizona have been the most recent converts to Medicaid expansion, largely

due to advocacy that focused on the individual and public health benefits, as well as its economic importance. We clearly have more work to do in the states that either have expressly rejected expansion at this time or have yet to declare a position. But with broad coalitions and strong advocacy, these are winnable battles.

Medicaid benefits for the newly eligible

In states that decide to expand Medicaid, the next big decision will be which benefits will be offered to those who are newly eligible. States will have a great deal of flexibility to design the benefits for the expansion, and they could differ from traditional Medicaid benefits. Advocates are urging that coverage for prescription drugs, case management, and mental health and substance use services in particular are comprehensive enough to meet HIV care and treatment needs. In Illinois and Texas, for example, HIV advocates teamed up with a broad coalition of Medicaid advocates to beat back harmful cuts to Medicaid prescription drug coverage. State legislatures are listening, so now is the time to make the case for benefits that work for people with HIV and other chronic conditions.

Outreach and enrollment

States will need to make sure that people know that they are eligible for Medicaid, that they understand how to apply, and that they are able to enroll. Understanding the eligibility rules and the different types of plans will be very important to ensure a smooth enrollment process. HIV providers should use the training and outreach resources developed by their state's Medicaid office to ensure that Ryan White case managers have the training necessary to inform their clients about their insurance options.

Private Insurance Expansion

The ACA will also greatly increase access to private insurance. First, the law requires each state to have an “insurance exchange” – a marketplace where people can compare and buy insurance. Second, the law makes it easier for people to afford private insurance by providing tax credits to people with incomes between 100 and 400% FPL. It also allows people with incomes between 100 and 250% FPL to receive cost-sharing benefits that will reduce out-of-pocket costs like co-payments.

Third, the law prohibits many discriminatory insurance practices. Starting in 2014, plans will not be able to deny coverage to anyone based on their health status. They also will not be able to charge people higher premiums based on their health status or gender. Plans are already prohibited from imposing lifetime limits on coverage, and in 2014 they will also be prohibited from imposing annual limits. All of these reforms mean that many people with HIV will finally have access to private insurance. The following are the top three issues to watch:

Insurance Exchange roll-out

In 2014, every state will have an exchange where people can shop for private insurance and obtain federal subsidies to help pay for

it. Open enrollment in these exchanges begins in October of 2013. States have the option of running their own exchange, letting the federal government run it, or setting up a “partnership exchange” with the federal government.

As of January, 24 states had submitted plans for either a state-based or partnership exchange. This means that over half of all states will have exchanges run by the federal government. But even in these exchanges, state insurance departments will still play a significant role. The ACA requires that exchanges provide strong opportunities for community input, and it is essential that decision makers hear from the HIV community.

HIV advocates must ensure that these exchanges have standards that meet HIV care and treatment needs. For instance, exchanges should offer access to HIV providers and should work with AIDS Drug Assistance Programs (ADAPs) to cover any gaps in affordability that exist even after federal subsidies. Improving the ability of ADAPs to help clients get private insurance will be even more important in states that do not expand Medicaid.

We clearly have more work to do in the approximately 25 states in which governors have either expressly rejected Medicaid expansion at this time or have yet to declare a position.

Essential Health Benefits

In 2014, private insurance plans must include ten categories of essential health benefits. States will choose a “benchmark” insurance plan that will become the standard for the coverage required by all plans. (The Center for Consumer Information and Insurance Oversight has published a list of state benchmark choices on its website, ccio.cms.gov.) There will be few additional federal standards on top of the coverage required by the benchmark plan.

Thanks to advocacy efforts, the federal government strengthened prescription drug requirements so that all plans must cover the same amount of drugs in each class as the benchmark plan. Because most of the benchmark plans cover all HIV medications, this was a big win. On the other hand, coverage for other crucial HIV services – such as case management or mental health and substance use services – will vary depending on the state and plan. Given the lack of federal standards, it will be vitally important for advocates to monitor insurance plans in their states to make sure they do not discriminate against people with HIV.

Outreach and enrollment

Exchanges will need to do outreach to make sure people know they are eligible and how to apply. Exchanges will put in place

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a variety of insurance assistance programs, including a “Patient Navigator Program”. It will be very important for Ryan White providers, particularly HIV case managers and benefits coordinators, to be a part of these new insurance assistance programs so that they understand the options and can assist people with HIV in choosing the best insurance plan.

Ryan White

As we prepare for the ACA, we must ensure that the Ryan White Program continues to provide the vital enabling services needed to link people with HIV to and retain them in care. No major program or funding changes should be made until we finish building the ACA and have a better idea of the impact it will have on HIV services. We must think now about the role of Ryan White after 2014 to ensure that the models of care that have been built over the past thirty years are preserved and strengthened. Issues to watch include:

Ryan White Reauthorization

The Ryan White Program is up for reauthorization in September 2013. Congress has several options. First, it can do nothing. Because there is no sunset provision in the legislation, even if Congress decides not to vote to reauthorize, the program will continue and Congress can continue to fund it. Second, Congress could make small tweaks to the current legislation. And third, Congress could open up the legislation for a full rewrite, and make any number of changes, big and small. Given the political reality in Congress today, there is community support for the first two approaches.

Transition

Thousands of Ryan White clients will make the transition to Medicaid and private insurance coverage in 2014. Most of the clients moving to new insurance options are currently uninsured. But clients currently in high-risk insurance pools, and those in Pre-existing Condition Insurance Plans (programs that provide insurance to people with pre-existing conditions) will also move to new insurance coverage in 2014. For some, this will be not only a shift to private insurance, but also away from a government-funded safety net. Ryan White case managers will need to help clients navigate the complicated world of insurance – making sure that if they are eligible, they apply and enroll. The Ryan White Program has a vital role to play as these new systems go into effect, and it will be crucial to work in coordination with state exchanges and Medicaid programs to ensure the transition is smooth.

A long-term vision for the Ryan White Program

The short-term stability of the Ryan White program is important so that HIV providers and consumers can monitor the ACA and develop a long-term vision for the Ryan White Program. Even with improved insurance, there will be gaps in coverage. In order for people with HIV to access the “whole-person” model that has been so successful in getting people into care and keeping them there, the Ryan White Program will need to continue to provide vital enabling services like case management, peer support, and transportation.



In addition, the ACA does not address the health care crisis for undocumented immigrants, so the Ryan White program must continue to provide a safety net. The future of Ryan White must be one that recognizes the value of this whole-person model of care. The “one-two punch” of access to insurance coupled with the Ryan White Program’s vital services is the key to maintaining the strides we’ve made.

Conclusion

Last year, President Obama called the opportunities we have in developing alternative energy sources our generation’s “Sputnik moment”. We face a similar moment when it comes to making progress against the HIV epidemic. But it will take leadership and vision from all of us. Our federal partners – the Obama administration and Congress – must support states in using the ACA’s many tools to increase access to HIV prevention, care, and treatment. Ryan White providers and state health leaders must innovate and change with the changing health care system. They must ensure that the expertise that has been built over three decades is preserved and integrated into new health systems. And advocates must engage in the decision-making process at every opportunity to ensure that HIV needs are taken into account as these new systems are built. We are assembling the science and policy tools that we need to end the epidemic, and with leadership and vision we will realize that goal. ■

Amy Killelea is a Senior Manager with the NASTAD Health Care Access Program.

Stop the Cuts! Fight Back! End AIDS!

Just when we thought we'd been saved from the "fiscal cliff", we again face several scary cliffs. The deal that was reached in January did little more than postpone the battle to reduce the annual deficit. Medicaid and Medicare were spared cuts, as President Obama and Congressional Democrats stood firm, but we can't be sure this won't change. And key programs, notably Ryan White, seem much less secure. As debt negotiations move forward, HIV prevention and treatment programs remain in danger of severe cuts.

The deal that averted the fiscal cliff extended the Bush tax cuts for individuals making under \$400,000 a year – all but the top 1% of taxpayers. But unless the President and Congress come to a deal by March 1st to avoid "sequestration", we will see automatic across-the-board spending cuts totaling \$109 billion in each of the next ten years.

These cuts would be devastating to people with HIV. The cuts (currently estimated at 5.1%) would affect Ryan White, Housing Opportunities for People With AIDS (HOPWA), NIH research, CDC prevention grants, and many other federally funded programs. It would cause tens of thousands to lose ADAP services, and affect thousands more with substance use issues. The cuts would also affect case management, food banks, and other services that people with HIV depend on.

We need to present a clear and united vision. First, we must support President Obama's position: no new cuts, since the Budget Control Act already cut \$1.5 trillion. This includes no further cuts to Medicare and Medicaid services, and no cuts to programs that assist low-income people. And we must bolster our demands with real-life stories. Elected officials need to hear what a difference these programs make in their constituents' lives and how destructive it would be to cut them. And they should understand that these dollars represent good jobs for those who provide these vital HIV services. We must call, write, and visit the offices of our representatives to tell them our personal stories.

Still, there are many reasons to be optimistic about the future of HIV care in the U.S. The Affordable Care Act (ACA) will go far in improving care for people with HIV. Already, insurance companies cannot deny coverage to children with HIV or drop coverage of anyone with HIV who becomes ill. They cannot place limits on spending for "essential health benefits" (a list of services developed by state and federal governments) for people with HIV. ADAP expenses

now count toward the out-of-pocket expenses of people on Medicare. In 2014, insurance companies will not be allowed to deny coverage to anyone with HIV. Perhaps most importantly, states that choose to expand Medicaid will guarantee coverage for people with HIV who earn 138% of the federal poverty level.

In addition, some states are choosing to create "Health Homes" under the ACA. Health Homes will consist of networks of providers delivering holistic care and making coordination among providers easier. Covered services include ADAP, case management, mental health and substance use counseling, food, housing, transportation, and many others.

Unfortunately, the Supreme Court made Medicaid expansion under the ACA optional. As of mid-February 2013, 21 states have indicated that they will expand Medicaid or are leaning in that direction. Despite generous federal funding (100% in the first few years and decreasing to 90% in 2020 and beyond), nine states (including several in the South with high HIV rates and poor existing Medicaid programs) have so far declined to expand Medicaid, while 21 other states remain undecided.

With strong advocacy, particularly in collaboration with allies in these states and across the country, we can drive change. Hospitals and providers

in states that don't expand Medicaid stand to lose millions in vital federal health dollars unless those states expand Medicaid. In addition, we must advocate with state and federal policy makers to ensure that the "essential health benefits" package for Medicaid and for the state-based insurance exchanges meets the needs of people with HIV. For example, it is very important that current Ryan White providers are included among the "essential community providers" in every state-based health insurance exchange. Together with our allies, we can be powerful voices for people with HIV as health reform is implemented.

Between now and January 2014 a host of important Medicaid and state-based health insurance exchanges decisions will be made that will have a profound effect on people with HIV. We must stay informed and engaged in shaping these decisions. Two great resources are NASTAD's Health Reform Watch blog (www.nastad.org – search for "health reform") and Kaiser Family Foundation (www.kff.org/hiv/aids). With our active and informed advocacy, life-saving HIV services and programs will not only continue, but improve. ■



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