If you want to curb new HIV infections in a specific group, like young gay men of color, what’s the best way to do it? You could fund prevention and treatment groups staffed by people from that community. Or you could expand HIV testing for hospital patients. The CDC is thinking carefully about this question—and is considering whether the answer runs counter to our first instincts.

“If you do routine screening in hospitals and emergency departments, you diagnose a lot of people—and it can be much cheaper per person diagnosed than implementing stand-alone programs for a specific group like black gay men,” says Jono Mermin, Director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. “Programs specifically designed to reach one highly affected group can also be inexpensive and very effective—but it depends how they are designed and implemented.

Mermin is one of the architects of the current U.S. approach to the epidemic—what the CDC calls High-Impact Prevention (HIP). It includes programs that have been in place for over a decade as well as new strategies, so dating its launch is a little tricky. But 2011 is when the CDC published a booklet called High-Impact HIV Prevention: CDC’s Approach to Reducing HIV Infections in the United States (search cdc.gov for “High-Impact HIV”).

The basic principles are clear: Look at the desired outcome (increasing HIV testing, identifying new infections, supporting HIV meds adherence, etc.), look at the cost per intervention, find the most cost-effective bang for your buck, and do it, even if it means departing from conventional wisdom. “The way to get the job done may be to do something different,” Mermin says.
How It Works

High-Impact Prevention isn’t a single program. It’s a set of principles with its fingerprints on a range of programs. One of the core principles is that strategies need to target areas with the greatest numbers of new infections. To do this, the CDC distributed $339 million in 2012 – almost half of its annual prevention budget – to state and local health departments based on the number of people with HIV in each area. “HIV prevalence isn’t equal,” Mermin says. In each state, the counties with the highest HIV burden received the most funding and reported individually.

The CDC will also focus on “cost-effective, evidence-based, scaleable” approaches: in other words, approaches that are affordable based on the cost per infection prevented and the medical costs saved by keeping someone HIV-negative. “Evidence-based” is key – the impact of the strategy must have been studied and evaluated. “Scaleable” means it can done on a larger scale.

There are many examples of how HIP plays out. For example, in 2012, a $339 million funding stream made grants to state and local health departments in areas with the highest HIV prevalence in the country. 75% of this funding had to be focused on four core strategies: HIV testing, prevention with positives (including linkage to care, retention in care, HIV medications, adherence counseling, and behavior change), policy change that facilitates prevention, and condom distribution to high-risk populations. (The funding wasn’t rigid – additional money was available for other strategies, based on local epidemiology and cost-effectiveness.)

To see what’s happening so far, check out the CDC’s Enhanced Comprehensive HIV Prevention Planning (ECHPP)

Are you HIP? continued from first page

GMHC is deeply grateful to ACRIA for our multi-year collaboration producing Achieve. While Achieve will continue and we will collaborate on other projects, GMHC will no longer produce Achieve with ACRIA. Instead, GMHC will produce an expanded quarterly insert in POZ magazine. GMHC thanks ACRIA, the writers, and all those who worked with us during this partnership!
Project, an initiative that began in September of 2010 and just finished. These were three-year grants given to help 12 cities scale up prevention strategies that the CDC classifies as effective. The CDC publishes regular reports on these projects at cdc.gov (search for ECHPP Year One). These reports present a picture of how health departments are starting to stretch to meet the ambitious targets laid out in the National HIV/AIDS strategy, which is the overarching plan for the U.S.

“Capacity Building Assistance for High Impact Prevention” is a five-year, $130 million investment to implement HIP “to high-risk populations in high-impacted geographic areas.”

The majority of grantees met targets in areas like testing, condom distribution, and keeping people with HIV in care. But they lagged behind in implementing post-exposure prophylaxis (PEP – see article on page 6), even though this is a required intervention for ECHPP grantees. PEP has been recommended by the CDC for some time now, but its report on ECHPP progress says that slow PEP rollout might be because “PEP is relatively new to most health departments” and they have only recently begun to do planning and implementation. Now that it is required by CDC in at least one of its funding streams, perhaps this will change.

The CDC is also taking another look at the “Diffusion of Effective Behavioral Interventions” (DEBIs) – programs that have been the basis for U.S. HIV prevention since 2000. For example, Mermin says that the DEBIs that focused on preventing heterosexual transmission often don’t make the cut for HIP because of the high pricetag per infection prevented. Other DEBIs are cost saving, and are listed at effectiveinterventions.org.

Another piece of HIP is the HIV Care Continuum, which President Obama signed into law last July. It directs federal agencies to accelerate efforts to “increase HIV testing, services, and treatment.” DHHS, CDC, and OSHA launched a demonstration project that will put $8-10 million a year into community health centers, health departments, and other grantees to improve the care across the continuum of health services.

**Figuring It Out**

Sorting out which parts of HIP are new and which older programs have come along for the ride has advocates’ heads spinning. In our conversations with them, there was confusion as to what HIP was all about. “There are a bunch of different messages and strategies that have been labeled as HIP. So oftentimes the broader community is not in tune with the lingo,” said Kieta Mutepfa of the UCLA Center for Clinical AIDS Research & Education.

Among those we interviewed, some were familiar with different CDC initiatives, like “HIV Prevention for Young MSM and Transgender Persons of Color”, which gave grants to community-based organizations (CBOs) to start testing and linkage to care in 2011. Right away, we see the challenge of putting HIP into practice. In the first year, only seven of the 30 funded CBOs achieved their target of testing at least 600 young gay men of color; only two of six CBOs achieved the target of testing at least 75 young transgender people of color. The CDC notes that this was the first year of the program – and that start-up delays happen in many new programs. But it does highlight the challenges for organizations that may not have experience in providing testing services in meeting ambitious targets. The HIP model (which stresses linkages between testing and services like HIV treatment) emphasizes medical interventions. CBOs that don’t work in that area will need to build their capacity to work within the “medicalized” framework of many HIP targets.

The CDC noted, “These findings indicate that the majority of CBOs had difficulty targeting the highest-risk clients, and

**Federal HIV Funding by Category, 2014 Budget Request ($Billions)**

- **U.S. Prevention** 3% ($9.95)
- **U.S. Research** 10% ($2.9)
- **U.S. Cash & Housing Assistance** 10% ($3.0)
- **Global** 22% ($8.5)
- **U.S. Care & Treatment** 55% ($16.4)

*Categories may include funding across multiple agencies - global category includes NIH international research.*

The funding is meant to “strengthen the capacity of the HIV prevention workforce to optimally plan, implement, and sustain high-impact HIV prevention interventions and strategies” across health departments, CBOs, AIDS service organizations, and health care organizations. In simpler terms, the grants are meant to get organizations ready for HIP by providing resources to build programs and create an infrastructure to sustain them. The first awards are scheduled to be made in April 2014.
What Do We Know?

The struggles of the CBOs that engaged in previous CDC programs doesn’t mean they will be cut out of future funded prevention initiatives. But prevention efforts are becoming increasingly medicalized, because it is more cost-effective to test, link to care, and treat in the same facility. Advocates are concerned that cultural competency and skills built up over years of providing nonmedical services may be lost, simply because many of these organizations don’t provide medical care.

Kenyon Farrow of Treatment Action Group said, “Most medical providers are ill-prepared to treat people with HIV, or to even offer a set of services for people at risk. It would be a real shame if the expertise and cultural competency of CBOs is lost to health care reform. How many jobs of people who actually come from the groups we’re trying to reach will be lost to people with MPHs or MSWs who have no experience in these communities?”

Advocates and CBOs also have a role to play in asking what gets classified as evidence-based. How can they implement an “evidence-based” intervention when there isn’t any evidence? Right now there are eight interventions that the CDC considers as having “good evidence” for improving adherence to HIV medications (search cdc.gov for “good-evidence MA interventions”). But there are no strategies that meet this criteria for recruitment or retention. In other words, we don’t yet know what constitutes “evidence-based” or “high-impact” strategies for getting more people into care and on treatment. The ECHPP demonstration projects described above could shed some light on this, but it’s important to recognize that there’s plenty we don’t know about what HIP really is.

Some of the specific issues that emerged in interviews with advocates revolved around the structural factors that affect HIV risk — housing, substance abuse, mental health issues, etc. Addressing these can reduce HIV risk and lead to improved adherence to meds for people with HIV, but they may not be highlighted in the biomedically oriented landscape of HIP.

Specifically, advocates note that efforts like ECHPP don’t ask grantees to report on provision of mental health services (other than alcohol treatment) or for linkage to housing. More than one advocate we spoke to said that the impact of targeted interventions could be lost if the underlying causes of HIV risk are not addressed through partnerships with local housing departments, and by lobbying for more housing assistance from federal agencies. Ebony Johnson of The Women’s Collective in D.C. says, “Health does not become your primary focus when you don’t have your basic needs met.”

It will also be key to watch emerging strategies such as pre-exposure prophylaxis (PrEP) with Truvada (see article on page 6). PrEP doesn’t make the cut as a cost-effective option, since the pricetag per infection prevented is too high for people who get the drug through private insurance or Medicaid. But Mermin notes PrEP is available for free (for those who qualify) from the drug’s manufacturer, Gilead — a little-known option that could make it cost-effective in poorer communities where it might be a powerful new tool.

There are also little real-world data on the acceptability of PrEP among high-risk groups. There are PrEP demonstration projects and clinical trials happening in the U.S., including Project PrEPare and HPTN 073, which are studying PrEP in black MSM and young MSM. Recent data from Gilead show that more than half of the PrEP prescriptions in the U.S. were for women in the South. Putting together real-world data like that with data from demonstration projects might point to the niches where PrEP could be high impact, and it will be important to watch whether this translates into action.

Advocates and CBOs also have a role to play in asking what gets classified as evidence-based. How can they implement an “evidence-based” intervention when there isn’t any evidence?

Given the slow movement on PEP within ECHPP, there is cause for concern that newer, less-familiar options might not be taken up without some pushing from advocates and the CDC.

Fundamental Challenges

Doing the most with limited resources is essential in a country where “real” HIV prevention dollars haven’t increased since 1991.

According to the Kaiser Family Foundation, the 2014 U.S. HIV budget includes only $98 million for prevention out of a total of $23 billion (see chart on page 3). That figure is a little misleading, since 55% of the budget goes to HIV treatment, which is a potent prevention strategy in itself. People with HIV who are taking treatment and have an undetectable viral load have a much lower risk of passing the virus to their sexual partners.

But the prevention benefit of treatment works only if people with HIV know their status, are linked to care, and stay on a treatment that keeps their viral load close to undetectable. Those steps (see the chart at right) are known as the “treatment cascade.” Currently 1.1 million people are living with HIV in the U.S., but only 25% have undetectable viral loads.

HIV Testing

Testing is a large focus of HIP and is one of the first elements that rolled out in the three-year Expanded Testing Initiative. It provided nearly 2.8 million HIV tests from 2007 to 2010, and diagnosed more than 18,000 people with HIV. The CDC estimates that the ETI saved almost $2 in medical costs for every dollar invested.

HIP pays attention to how testing is offered. For example, the HIV testing model named “Counseling, Testing, and Referral” (CTR) is being promoted by the CDC as an example of “high-impact test-
ing” intervention. CTR offers risk reduction counseling, testing, and connection to care. It also refers high-risk HIV-negative individuals to preventive and psychosocial support. “Personalized Cognitive Counseling” (PCC) is another approach CDC is highlighting as a high-impact HIV testing intervention. PCC targets HIV-negative MSM who repeatedly test for HIV and engage in unprotected anal sex. Through PCC, they will receive 30 to 50 minutes of counseling that explores the thoughts, attitudes, and beliefs they use when making decisions about sex.

Since HIP promotes cost-effective strategies, its programs make use of organizations that already have linkages to care, which means a continued trend to what some NGOs and CBOs say is a “medicalization” of the HIV response. That means moving testing from CBOs into medical facilities. There’s a fear that the move toward clinical settings – which do have the strength of connecting individuals to health services – may strip resources from CBOs with the cultural competency to deal with certain populations.

Prevention for High-Risk Negatives

To get a flavor of what types of behavioral interventions make the cut under HIP, we looked at Many Men, Many Voices (3MV), an intervention that uses small group discussions to give gay men tools for identifying HIV risk factors like racism, homophobia, substance use, high-risk sex, and inadequate health care. Researchers evaluated 3MV in 300 black MSM – the first behavioral intervention for this group to be tested in a randomized trial. They found that men in 3MV reported significant reductions in their number of partners and in unprotected anal sex with casual partners; a trend for consistent condom use during receptive anal sex; and increased HIV testing. These are self-reported data, so they must be taken with a caveat, but in the realm of behavioral interventions, that’s relatively strong evidence.

The use of social media for outreach and education are also being explored through CDC initiatives, such as using phone texting to provide appointment or adherence reminders and to answer sexual health questions in real time. Beyond social media campaigns, the new funding can support sex education in schools. This includes developing curriculum that are tailored to specific communities and age groups, as well as training and development for educators.

Condoms remain a core part of HIV prevention, even as other approaches including PrEP and treatment as prevention garner additional attention. Supply is key. Effective condom programming is guided by the three As: Available, Accessible, and Acceptable. Lube also needs to be freely available.

Future HIP

Going forward, it will be critical for advocates to track the reporting of HIP programs. Are grantees reaching the targeted groups? Are groups like transgender women – who are highlighted in HIP but are not the focus of any DEBIs – well served? How will organizations that address structural factors or are trusted allies survive if they do not provide medical services?

“Before HIP, the shrinking funding for CBOs meant that cultural competency has been lost. Competency was lost even before that, when people were trying to fit everything into a DEBI framework,” says Julie Davids of the HIV Prevention Justice Alliance at the AIDS Foundation of Chicago. “There has been an undocumented and unassessed loss. There is a need to look carefully at what competencies need to be built up to reach distinct and overlapping groups.”

Conclusion

It’s key to keep an eye on how your organization or community defines HIP and how this does (or doesn’t) align with the HIV prevention approach in your area. According to Julie Davids, “I think HIP should be understood as a political and policy term. I think we all need to keep our sights on effective prevention and realize that the CDC has come up with a brand called HIP. I’d like to see the two things overlap but remain distinct.”

These cautions shouldn’t overshadow the approach though. It is high time that HIV prevention be held to a high standard of effectiveness. Historically, impact has often been reported in indirect measures, like the number of condoms distributed or people reached with safer sex messages. To turn the tide of the epidemic in the U.S., it is essential to look at more concrete measures – community viral load, HIV incidence in populations where HIP programs are rolling out, etc. High-impact prevention will need robust community responses, focused on more than just medical services, to make progress. Only time will tell whether it achieves its goals.

The authors are staff members at AVAC (avac.org), a non-profit advocacy group focused on research on and implementation of new HIV prevention tools.
It’s clear that the U.S. is failing when it comes to HIV prevention. Infections are rising among gay men, and new biomedical approaches are either not being promoted or are actively discouraged by providers. The AIDS activist group ACT UP/NY has documented numerous instances of people being denied these new approaches or being forced to confront real barriers to their use, as well as a shocking lack of concern among government health bureaucrats.

**An Ongoing Crisis**

Each year, over 2 1/2 million people are infected with HIV worldwide. Even in the U.S., where the epidemic has not widely spread beyond fairly defined groups, the number of new cases remains a problem. The CDC estimates that in 2010 there were 47,500 new infections. While the overall rate of infections has remained steady for several years, it’s been decreasing for most groups but rising for men who have sex with men (MSM), a category that includes transgender women. Between 2008 and 2010, new infections increased by 12% among MSM, and by 22% among young MSM aged 13-24. In 2010, two-thirds of all new infections occurred among MSM. A gay man was 30 times likelier to get infected than a straight man. African American MSM were 6.6 times likelier to become infected than white MSM.

Most new infections in the U.S. occur as the result of sex. In 2010, 78% of infections in men and 63% of all infections were from male-to-male sexual contact. While clinical trials have shown that biomedical approaches like circumcision reduce HIV transmission, there is little evidence that supports behavior-based prevention efforts like safer sex classes and counseling. When those efforts are directed at MSM, some data show a short-term reduction of sexual risk (accompanied by a drop in new infections), but the reduction of risk behavior vanishes after several months. Condoms are highly effective, but studies estimate that MSM use them less than half the time when they have anal sex. (Straight men use them about 5% of the time.)

**The Promise**

Given the persistence of sexual transmission of HIV and the low rate of condom use, it’s not surprising that the world of AIDS has turned toward pharmaceutical prevention. For many years medications have successfully treated HIV. Could they also prevent infection?

Treatment as Prevention (TasP) targets people living with HIV. When people with HIV take medications regularly, their viral load often drops to undetectable levels. HPTN 052, a large clinical trial, found that HIV treatment reduced the sexual transmission of HIV by more than 96% in HIV serodiscordant couples (in which one partner has HIV and the other does not). Further data have bolstered these findings. A 2013 review of three studies that included 991 heterosexual couples estimated an HIV transmission rate of almost zero when the positive partner has an undetectable viral load.

ACT UP has documented numerous instances of people being denied PEP and PrEP or being forced to confront real barriers to their use, as well as a shocking lack of concern among health bureaucrats.

These encouraging findings have to be taken with some caution. Only 2% of the couples in the HPTN 052 study were male couples, and the great majority of new infections in the U.S. occur through male-to-male sex. There are good medical reasons for thinking an undetectable viral load greatly reduces risk in MSM as well. But we should also remember that anal sex has about 18 times the risk of vaginal sex. Another caution is the presence of HIV in the semen of some men who have undetectable viral loads and the risk for transmission this represents.

These cautions do not constitute an argument against TasP. But more than 17 years after highly effective HIV treatment was introduced, only 25% of people with HIV in the U.S. have undetectable viral loads. We will not put an end to HIV transmission anytime soon if we rely on TasP alone. So two types of prevention target HIV-negative people with HIV drugs.
PEP

Post-Exposure Prophylaxis is a 28-day course of HIV drugs (often Truvada and Isentress) that, if started within 72 hours after exposure to HIV (and the sooner the better), can prevent HIV infection. There has never been a clinical trial that established its effectiveness, because it’s unethical to randomize someone to no treatment after an HIV exposure given that PEP may be effective. But one non-randomized study of over 200 gay men estimated that PEP reduced HIV transmission by 83%. In 2005, the CDC issued recommendations for non-occupational PEP (nPEP) for exposures from sex or sharing a needle. In New York State, guidelines for both occupational PEP and nPEP call for the use of Truvada with Isentress. But more than eight years after the CDC first published nPEP guidelines, it remains largely unknown and unused in the communities most at risk.

PrEP

Pre-Exposure Prophylaxis is a daily dose of HIV meds that can prevent HIV infection if taken before exposure. In 2012, the FDA approved Truvada for PrEP in HIV-negative people who are at high risk for HIV from repeated sexual exposure. According to the FDA, “Truvada for PrEP is meant to be used as part of a comprehensive HIV prevention plan that includes risk reduction counseling, consistent and correct condom use, regular HIV testing, and screening for and treatment of other sexually transmitted infections. Truvada is not a substitute for safer-sex practices.” A year later, the CDC expanded its guidance on the use of PrEP to include the prevention of HIV through shared needles. It has promised final clinical guidelines by the end of the year.

Truvada gained its approval as PrEP due to two large clinical studies. In iPrEX, 2,500 HIV-negative MSM from Latin America, Thailand, and the U.S. took either Truvada or a placebo pill once a day. The study found that Truvada reduced the risk of HIV by 44%. But many people assigned to Truvada missed doses or never took it at all. In people who took it consistently, the reduction was 73%. It’s estimated that people who took two doses a week reduced their risk by 76%. Taking four or more doses a week might have reduced risk by over 95% – but these are only estimates.

The Partners PrEP Study enrolled over 4,700 couples in Uganda and Kenya, with one negative and one positive partner. Those who were negative took Truvada, Viread, or a placebo. Viread reduced infections by 67% and Truvada by 75%. In people who were found to have drug in their systems, Viread reduced infections by 86% and Truvada by 90%. So both studies found that Truvada can be protective, but showed that many people find it hard to take a pill every day to prevent a future infection.

The Barriers

In 2011, the CDC introduced “High-Impact Prevention”, the prevention component of the National HIV/AIDS Strategy. But in the booklet that accompanied the rollout, PEP is not mentioned.

A recent article in POZ magazine reported that only 15% of hospital emergency rooms in Massachusetts had a protocol for nPEP, and only 13% of health care sites in Los Angeles had PEP on location; only 3% would provide it to uninsured patients. In the summer of 2013, ACT UP/NY called on the New York State Department of Health (NYS DOH) to revise its outdated nPEP guidelines. That same year, activists in New Jersey and Chicago reported searching in vain for their state’s guidelines. Across the country advocates complain that, although nPEP has long been the standard of care, few people are aware of it and even fewer know how to get it.

It’s hard to find out how extensively nPEP is used in the U.S. POZ magazine found only 800 reports had been filed in a national surveillance registry that the CDC established in 2008. Some hospitals in New York City report a few hundred nPEP patients a year. After ACT UP’s call for updated nPEP guidelines, NYS DOH brought them into line with guidelines for occupational exposure. But the situation surrounding nPEP in New York City remains far less than ideal. ACT UP has uncovered many significant mistakes that have occurred recently, including:

• A doctor in the E.R. of a world-class Manhattan teaching hospital told a man who sought PEP after condomless receptive anal sex that he didn’t need it. Only after 11 hours and a friend’s intervention did he receive it. His insurance did not pay for the drugs.
• A Manhattan clinic turned away a 19-year-old seeking PEP because he had no government-issued ID.
• A young, undocumented immigrant was sent from one Brooklyn E.R. to another, and was told to return the next day. A friend got the drugs for him only after contacting a hospital administrator and paying $750 for the drugs.
• A young man, worried that his time was running out, left a Brooklyn E.R. after several delays and mistakes in his care. He later received PEP at a Manhattan E.R.
• A young, homeless queer youth received only a three-day starter pack of PEP from a Brooklyn E.R., with no counseling. He seroconverted.
• After two days and much stress, the wife of a man with HIV received only a three-day starter pack from a Manhattan E.R., with no follow-up.
• A Manhattan clinic’s PEP hotline, closed for a holiday, sent a young caller to that institution’s E.R., where he was told there was no such thing as PEP. Only an ACT UP member’s intervention secured the PEP, after much delay and patient stress.

When members of ACT UP argued for a public health campaign about PEP, an official of the city’s Department of Health and Mental Hygiene (DOHMH) countered that such a campaign would not be cost-effective, since the number of actual infections prevented would be small. ACT UP argued that people who seek out PEP are a valuable HIV prevention resource. They may be at high risk for HIV and often do not have access to regular health care, but are interested enough in their health to seek out treatment. They are on the front lines of new HIV infections. In the U.S., new infections appear to be concentrated into sub-groups with little access to health care. To extend care to high-risk people who are HIV-negative would prevent human misery and lower HIV treatment costs.

Other Concerns
Paymen for PEP is piecemeal. Even though PEP is considered the standard of care, it has not actually been approved by the FDA. Medicaid coverage varies from state to state, and some but not all private insurers pay for it. And for the uninsured? Gilead and Merck own the drugs specified in the NYS DOH PEP guidelines and both have plans that provide drug to the uninsured. NYS DOH has a useful fact sheet on payment options for nPEP (search for “Payment Options” at health.ny.gov). The National Alliance of State and Territorial AIDS Directors put out a fact sheet on the Patient Assistance Programs (PAPs) of all the companies whose drugs are recommended in state PEP and national PrEP guidelines (search for PEP at nastad.org).

When it comes to PrEP, some suggested barriers to its use have not been seen. It was feared that people who took Truvada and then became HIV infected might develop drug resistance. Yet, in the PrEP trials, the only people to show resistance were those who began taking Truvada after they’d already been infected. They tested negative because they were still in the “window period” and had yet to produce antibodies to HIV. Mathematical models have confirmed that the risk of PrEP leading to drug resistance is almost nonexistent.

Another frequently voiced fear is that people taking PrEP (gay men in particular) would “risk compensate” – that is, use condoms less frequently. But in iPrEX and Partners PrEP, reports of condom use actually went up. Self-reporting on sexual activity isn’t always accurate. But in both trials the number of sexually transmitted infections went down, which wouldn’t have happened if most people in the studies had abandoned condoms. Another PrEP trial reported similar findings: risky behavior declined or remained stable, whether or not participants started taking pills immediately or months later, as the trial’s design required.

There has been one problem across all PrEP trials. A significant number of participants took the pills only sometimes, or never. Adherence was so poor in two PrEP trials in women in Africa that the trials had to be stopped early. The FEM-PrEP trial found drug in fewer than half of the women taking it. The VOICE trial found drug in less than 30% of participants. Many trials and demonstration projects tell us that PrEP is highly protective if taken according to directions, but that many people do not take it as prescribed, even when they get especially extensive counseling. Before PrEP can play a significant role in HIV prevention, poor adherence will have to be addressed.

Since its approval, the rollout of Truvada for PrEP has not been swift. In September 2013, Gilead released information about early PrEP use from 55% of U.S. pharmacies. There were only 1,774 users (about 3,200 when expanded to all pharmacies).
median age of users was 37, and about half were women. About half received the drug before FDA approval, meaning they were participants in a clinical study. And almost none of them were the young gay guys or transgender women – groups where the new-infection crisis is concentrated.

Gilead’s numbers confirm what activists know: people with the highest risk for HIV know little about PrEP. Many doctors are wary of prescribing it. Representatives of Gilead have complained that the lack of a network of providers who will prescribe it is a major reason for its slow rollout. Few U.S. doctors were involved in the PrEP trials, and many HIV docs (who normally prescribe Truvada for treatment) see few, if any, HIV-negative patients.

Much of the commentary on PrEP in the gay press and in gay social media has been by old-school safer-sex advocates who have a dim view of pharmaceutical prevention. Truvada’s side effects and the chance of resistance are frequently exaggerated. PrEP users have been caricatured as out-of-control, drugged-up sex fiends. Many in the community fear that Big Pharma wants to put every gay guy on drugs. In fact, Gilead has refused to advertise Truvada for PrEP, and the paltry numbers of people taking it show that.

Integrating PEP, PrEP, and HIP
As a longtime AIDS activist of the generation that invented safer sex, I want to say to my community: Yes, HIV drugs are strong and can have long-term toxicity. But the HIV virus is diabolical. Unchecked, it takes over the body at the cellular level. If low-dose drugs, taken for a period of time, can prevent infection in a core group of people who are at high risk for HIV and who cannot or will not alter their behavior, then that’s preferable to infection. In my personal life, I will continue to practice behavioral rather than pharmaceutical prevention. But I know that not everyone shares my sex habits or my personal philosophy – or is as old as I am. Everyone who is HIV negative and at risk deserves to know about the full range of HIV prevention tools available in 2013, and to have access to those tools.

I want to tell my community that the recent spike in gay HIV rates is an emergency. The first version of safer sex that we invented stressed self-empowerment: In a dark time we were making sex possible again. Somewhere along the way, the message became one of deprivation – “don’t do this!” – rather than possibility. We have to restart a conversation about the kind of sex we are having, putting HIV prevention in a wider discussion of pleasure and health. This conversation should rechannel the strengths of the first generation of safer sex messages and talk about condom use, lower risk sex, risk reduction, and other risk factors like drug use.

Because knowing your HIV status is the first step toward getting treatment and making smarter sex decisions, we have to make testing a natural part of the lives of people at high risk for HIV. These are often people who have no contact with the health care system. With a robust testing campaign, San Francisco has been able to drive down the number of its residents who are HIV positive and unaware of it to about 7%. We must demand similar results from all our cities.

We must educate our communities about meds to prevent HIV. Our local Departments of Health must promote PEP guidelines based on the latest science, and see to it that local providers follow them. States must mandate that when uninsured patients seek PEP, providers connect them with drug companies’ Patient Assistance Programs. And states would be wise to connect them as well to counseling and care that might keep them HIV negative. Uniform PEP guidelines across the country could improve care.

The future of PrEP depends on increasing adherence. The Open Label Extension of iPrEx and PrEP Demonstration Projects around the country are studying what kind of counseling maximizes adherence. Further trials will study the effectiveness of intermittent PrEP – taking the drug a couple of times a week, or just before sex. Unlike HIV treatment, PrEP will be taken for a limited time. Further studies will have to identify whether it should be used for a few years or months, based on individual sex habits. Other trials are looking at longer lasting drugs like injectables that could improve adherence, and at other methods of delivery such as gels and rings. Because so many infections are happening beyond the reach of traditional care, engagement between the health care bureaucracy and communities at risk could help identify who are the best people to take PrEP.

DOHs must promote PEP guidelines based on the latest science, and see to it that local providers follow them. States must mandate that providers connect patients with drug companies’ Patient Assistance Programs.

Conclusion
This is a moment of promise for HIV prevention. But that promise is fragile. The Affordable Care Act at last gives disease prevention official standing. Will it bring with it the funding we’ll need to enact truly High-Impact HIV Prevention? Will it bring widespread, easy HIV testing, sex-friendly counseling, and care for people at high risk for HIV? Longer lasting, low-toxic prevention drugs, and skilled providers to prescribe them? Innovative prevention research, vaginal and rectal microbicides, alternatives to the condom, even a vaccine? In reality, HIV service providers don’t know how they are going to continue providing services. We’re living with the budget cuts caused by sequestration, uncertainty about the future of the Ryan White CARE Act, and a campaign to defund Obamacare before it’s fully begun. If this campaign is successful, it will dash the best hope that we will any day soon put a dent in the ongoing scourge of more and more HIV infection.

Jim Eigo is a writer and activist who works on HIV prevention issues with ACT UP/NY.
I'd like to start by citing the most recent stats on new HIV infections. The CDC reports that HIV diagnoses increased in young people aged 15 to 24, despite decreases in rates in older age groups. Men who have sex with men (MSM) aged 13 to 24 had the greatest increase in diagnoses from 2007 through 2010. Among young black MSM, new HIV infections increased 48% from 2006 through 2009.

Donna: I want to highlight that black MSM are being infected at a rate four times their percentage of the population. I think we are all somewhat perplexed as to why this is hitting them so hard. In 2007, Greg Millet looked at 53 studies and found that black MSM were not having more unprotected sex than white MSM. But they did have a higher rate of STDs, and fewer of them were on HIV meds that can lower the risk of transmission. Also, fewer identified as gay. So I think the depth and legacy of racism is a factor here. Every social and health outcome is worse among African Americans, whether it’s STDs, higher rates of high blood pressure, incarceration, etc. We’re still a fairly segregated society, and people are more likely to have sex within their own community, so racism, poverty, like with like, higher rates of STDs, higher viral loads are all factors you could point to adding to the risk, but bottom line is that the overwhelming difference doesn’t really make sense.

In our research, African American youth were more likely to drink than they were to use pot. Among the kids we see in the Bronx, we’re not seeing meth at all. So that’s not a driver in this group. But one thing that I think is still very common is the “visual AIDS test”. It’s magical thinking – I can look at my partner and tell if he has HIV. Doctors use it too, to see who they’re going to test.

Linda: And unfortunately, young people’s idea of safer sex often doesn’t include condoms. The tool they’re using to protect themselves is the test. Clients say, “We both tested negative so we thought it was okay to stop using condoms.” They may use condoms when they’re not sure, but often they just ask, “Are you clean? When was your last test?” I’ve seen so many cases: “We’re both getting tested...

Donna: I don’t think “over” is the right word. It hasn’t begun for this generation. In order to make a change as drastic as using a condom every time you have sex – it’s impossible to internalize that if you’re not getting consistent messages from society, music, culture, churches, your family, and even the gay community. We haven’t put the effort into it that is required. Remember, there is a new generation every five years and the youth in high school today have not heard the message of HIV prevention. They need constant reinforcement from multiple sources.

And it’s a more complex message today. If you get HIV, we want you to feel hopeful. We want you to know we’re...
every three months and he’s only with me. So we’re fine, right?” The problem with that statement is that he was not only with you, because you just tested positive. Regular testing is important, but we need to get the message out there that testing is not a condom – it’s not a seat belt. It does not protect you – it’s just a snapshot of what’s going on. Love messes up all sorts of thinking. We see that a lot – I trusted him and we had both tested negative. His last test was a year ago, but...

Donna: We disentangled counseling and risk assessment from testing because testing is a health screen and should be treated like every other screen. If it’s too cumbersome, it doesn’t get done in clinical settings. So how do we reach gay men and let them know that regular testing is great, but it’s not a prevention strategy? The scale-up of testing has to be matched by a scale-up of prevention programming.

Is peer pressure a problem?

Donna: It’s less peer pressure than it is peer ignoring – they just don’t talk about it. There isn’t peer pressure to avoid condoms, and there’s a lack of pressure to use them and to have HIV be an open topic. This generation is growing up in a world in which HIV is not an imminent death threat, so it’s not talked about.

Linda: But I still think they’re afraid of it. There’s enough stigma for them to be afraid of it. They don’t want to be one of those guys who has to tell his partners he has HIV. And there’s a lot of homophobia, especially in African American, Latino, and Caribbean families. Even those who have come out really young, their parents say, “It’s fine if you’re gay, just don’t get HIV.” They tell me, “I can’t tell my mom I’m positive. And I can’t ever date again, and I’m going to die by the time I’m 30.” That’s a big thing. They feel like they’re a pariah and they never will meet anyone or kiss anyone again. The fear is there, but in a different way.

Coke and Apple are the biggest brands in the world – there’s not a person on the planet who doesn’t know what they are – yet they refresh their messages all the time. We’re expecting young people to somehow get this message without doing what it takes to deliver the message across many platforms. Part of the problem with HIV is we always want to do the new thing, so we never finish the job. With youth, by definition, you have to keep doing the same thing. Every few years there’s a new group of kids. You have to repeat what’s worked and get better and smarter.

**Part of the problem with HIV is we always want to do the new thing, so we never finish the job. Every few years there’s a new group of kids. You have to repeat what’s worked and get better and smarter.**

Linda: We need to talk to young people and see what they think the message should be. If we think that we know what kind of message is going to work for a young black gay man, we’re going to fail. We need to ask them, “What is it that you think needs to happen? It’s messed up that your peers are being disproportionately affected.” We need to talk about how unfair this is and ask them what they think their friends need to hear. Is it a social media campaign? How do we frame the conversation? I don’t know. Let’s ask them.

**Donna:** At a meeting last week, there was a debate about whether we should have role models of young people who have stayed negative. For a long time, the CDC hasn’t wanted to fund things

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like that because that talks about young people having sex. And there's resistance from the HIV-positive community: “If you do that, you make us look bad.” We haven’t figured out a way to promote that you can be gay and grow up and never get HIV. The interesting new social marketing stuff is about positive people coping and being strong. Somehow we need to create equally powerful, “I’m gay, I’m proud, I’m gonna stay negative” messages. But the government won’t let us talk about teens who are sexually active.

Are the schools doing their job when it comes to HIV education?

Donna: By the time they’re seniors in high school, more than half the kids in America have had sex. But we’re still constrained from giving accurate information about the details of sexuality – I don’t think that information is being given in schools today. Most young people that are newly diagnosed said they did not learn about HIV in school.

Linda: I agree. A lot of them go to community-based organizations where they get relatively competent sex ed. But MSM who don’t identify as gay are missing out on that because they don’t go to those places. I’m pretty sure that the things young gay men we see know, they didn’t learn in school. They learn from wherever they’ve been hanging out, the gay-friendly spaces.

Did your newly diagnosed clients know they were at risk or were they uninformed?

Donna: Both. I don’t think that most young gay black men are aware that they are the group that is at highest risk, and that the rates are going up. We’re seeing mostly gay kids from the Bronx and there’s often a surprise factor that they ran into this. I’m most struck by the fact that it’s not an ever-present part of their life – it’s not part of their discussion. We’ve recently lost major social spaces like the Bronx Community Pride Center, so it’s harder for them to find a place to talk about it.

Linda: I think a lot of them knew the risks. But they made decisions based on the fact that their partner had tested negative. That doesn’t automatically equal reality, because when you get infected there’s a window of time before you test positive. For a lot of the young MSM that I talk to, their positive test was one of many in recent years. They say, “But I don’t need condoms when I’m with someone who I know is negative. I don’t know how this happened.”

Donna: There’s this dual feeling among young people that “I’m invincible” and the flip side that HIV is inevitable. I don’t think young people are empowered enough to know that HIV does not have to be inevitable for them if they’re gay. It’s not the outcome of being gay.

Linda: Exactly. I have clients who say, “Yeah, I figured this would happen” and others who say, “No, this was never supposed to happen. I’ve only ever had unprotected oral sex. How did this happen?” Whenever I hear that I question whether they’re being honest – and the truth comes out eventually. Or the condom broke. A condom breaking is a great way of making your doctor think you’re being responsible. Actually, the people who always use a condom are the people who try to get PEP if it breaks.
Do young people know about PEP — that there are meds that can prevent HIV infection if you take them immediately after an exposure?

Linda: They know about it — we see them here. The hard part is getting them the PEP, because they’re on their parents’ insurance, and they’re not going to tell their parents. We’ve had some challenging situations with minors. I had a 17-year-old whose boyfriend was infected at birth — the condom broke and they definitely knew what to do. We had to figure out how to tell her mom. There are drug companies that will help, but this kid had a drug-resistant strain, so the regimen was very complex.

Are young people being infected by their peers or by older adults?

Linda: Half and half, I think. Older men may not be paying them for sex, but they’re giving them housing, or they bought them a watch, or they’re paying their cellphone bill. They’re coming from families that don’t have a lot of resources. So poverty is a huge driver. A lot of young men who come from very difficult situations are having sex for money. And they get paid more if they’re unprotected.

Donna: Gay youth who have had to leave home are really at risk. Caitlin Ryan of the Family Acceptance Project found that young people who are rejected by their families are three to four times more likely to have adverse health and mental health outcomes. But she also learned that parents can be taught to embrace their gay kids, and that leads to better outcomes.

If you were the HIV Prevention Czar, what would you do?

Donna: I would concentrate the major resources in the cities and in the South. Half of the major metropolitan areas with new infections are in the South. I’d create new, fresh messages and programs for gay kids, and social spaces like gay/straight alliances — places where kids can hang out and be comfortable being gay.

We need major outreach in the black churches, and I think that’s growing. The NAACP has a project. I would do outreach to the music industry and other cultural forces to continue giving them messages that their lives are important and that HIV is real. Having fun condoms would be great — you can’t just stick them on the shelves and expect them to be sexy. And I would do another round of education for doctors about how important this is. I’ll let Linda speak about some of the other social forces.

Linda: School, jobs, housing, food, and condoms — in no particular order. They’re equally important. And testing. If all our funding is going to social messaging campaigns without addressing those other problems, it’s a waste of money. I can’t imagine how that’s helpful. If we’re spending a million dollars on some billboards or some text messaging system and kids still can’t find a place to sleep every night, what’s the point?

The fact is, it feels good to have sex. They have low self-esteem, so how are they going to take care of themselves if this other homeless kid they met is the only one taking care of them? It feels good to have sex without a condom, and they think, “He was tested last month, and we’re gonna make it through this together. I don’t care if you have it or if I have it.” It’s the reality of their life.

When you’re homeless and you feel lonely and your family kicks you out or if they’re poor or drug addicts, stopping HIV isn’t at the top of your list right now. It’s surviving every day.
first heard about HIV in high school in Far Rockaway, Queens. But not as much as I would have liked. They showed us a movie called “Kids” and I felt scared about what the main character, a straight female, went through. Her appearance terrified me!

But I didn’t connect with the information they gave me because they only focused on straight relationships. I began to feel attracted to boys at age ten, so I felt like my feelings were not counted or accepted. I kept my thoughts to myself and just listened to what everyone else said. There was nothing in the sex ed class about gays.

I came out to my friends and some cousins when I was in 10th grade. In December 2011, I came out to my family after the school contacted my mom about a rumor about me and another boy. I felt scared and alone, and I was afraid that I was going to get kicked out of my house because I was gay. Fortunately, that didn’t happen. But my parents didn’t want to accept that I was gay, so I never brought it up again. Since my family didn’t really talk about sex, I never talked about it with them either.

I had my first boyfriend when I was 17. He was my age and we always used condoms when we had sex. But after we broke up a year and a half later, I wanted to try new things. I found a new boyfriend who was a couple of years older, and the condoms just kinda came off. I had a little bit of concern about that, but I just put it in the back of my head and didn’t think about it. He told me he was tested for HIV every three months and was negative.

To be honest, I wasn’t thinking about HIV because I never really learned about it. The only thing they talked about was that you could die from it. They never talked about anal sex. And everyone they showed us who had HIV looked really sick. They were all thin and looked like they were dying. My boyfriend looked healthy, so I never thought he could have HIV.

I had an HIV test in July 2012 and I was negative, but when I tested again in November, I was diagnosed with HIV. My heart stopped, and all I could think about was death. I felt scared. I told my boyfriend the same day and he said he didn’t have it but he still loved me and stuff like that. He eventually admitted that he did have HIV. I didn’t think to talk about it when we were dating. Now I know you can’t tell if a person is infected or not.

I feel like society failed me because people don’t teach you truthful information about STDs and HIV. People teach more about straight sexuality and not about LGBT.
I feel like society failed me because people don’t teach you truthful information about STDs and HIV. I wish society could teach better about LGBT-specific issues because not everyone lives a straight life and they’re hurting kids that might feel lost, like I was.

The other gay guys I knew in high school never talked about HIV. I think they thought like I did, that you could tell who has HIV because they looked unhealthy. I honestly thought I would never get HIV, because I learned to think that you can tell if somebody has HIV, the skinny body and pale face. But I was so stupid to believe those stories I heard. I never knew that there were medications that could keep you healthy when you have HIV so no one could tell if you had it. The only thing I learned is that HIV kills you.

Now I speak to my friends about HIV a lot. Some of them are partners that I told. They didn’t even know about it and they said we could be friends, but they shut me down. Some of them think you can get it just by sharing things, to this day. I showed them some info and told them that wasn’t true.

There should be a spokesperson who is living with HIV who goes to schools to show them that you don’t have to look unhealthy if you have it. The school should let you know that it’s unnoticeable and that you can catch it without knowing that your partner is infected. Advertise it – do a TV commercial about it – there’s not much of that. There should be books about it in schools that tell the whole story. They should give out more information and not just scare the kids.
s other articles in this issue of Achieve point out, the old adage of “Use a Condom Every Time” is not working. Rates of HIV infection are rising among men who have sex with men (MSM), not just in the U.S., but around the world, and especially among young MSM of color and transgender women. As Jim Eigo writes in the article on page 6, Truvada, when taken by HIV-negative people as PrEP, can significantly lower the risk of infection. But it has two serious drawbacks: to be fully effective it should be taken every day (whether or not you’re planning to have sex), and it’s hugely expensive (over $1,000 a month retail).

I recall a conversation with a fellow activist years ago, as we were bemoaning the persistent rate of new infections in gay men. “It feels like we’ll never get a handle on this thing until we get either a vaccine or a lube that will prevent HIV,” I said. The former remains, unfortunately, years away (last April, yet another vaccine study, HVTN 505, was shut down early due to a lack of effectiveness), but the latter may be closer than we think.

The Problem

Among 24,787 MSM who completed an online survey in the U.S. in 2010, 36% reported having receptive anal intercourse the last time they had sex, but only 45% said they had used a condom. Of course, it’s not only gay men who have anal sex. In a 2009 U.S. survey, nearly 13% of women said they had had anal sex in the past year. That number rose to 20% in women aged 20 to 39, but only 11% said they had used condoms. Clearly, we need new tools to fight HIV, since anal sex carries the highest risk of HIV transmission among all sexual practices.

The Hope

A new study, MTN 017, is looking at a rectal microbicide (RM) that contains tenofovir, one of the drugs in Truvada. Rectal microbicides are gels that are being studied to see whether they can lower the risk of HIV when used in the rectum. This Phase II study opened in October and will enroll 186 HIV-negative MSM and transgender women in Peru, South Africa, Thailand, and the U.S., including Puerto Rico. While the purpose of the study is not to prove whether the gel is effective at preventing HIV transmission, it will hopefully answer some very important questions about the gel’s safety and acceptability.

“Using an applicator to deliver a rectal microbicide may be a ‘deal breaker’. It is one thing to use an applicator in a trial; it is quite another to ask men and women...to use an applicator in their real lives.”

First, do people like the gel? The first microbicide study to show some effectiveness was CAPRISA 004, which found that a tenofovir gel, when used by women vaginally, reduced the risk of HIV infection by 39%. Unfortunately, when that gel was used rectally in MTN 006, it caused gastrointestinal problems. So the gel has been reformulated to include less glycerin, and an earlier study, MTN-007, found that it was safe and acceptable to both...
men and women who used it daily for one week. MTN-017 is a larger study that will further explore the gel’s safety and whether people like it, and compare it to Truvada pills.

People in the study will cycle through three regimens, each lasting eight weeks: the gel used daily, the gel used before and after anal sex, and daily use of Truvada pills. This will allow researchers not only to collect data about the gel’s safety and acceptability in the rectum, but also to compare it to the use of Truvada pills, which were approved for HIV prevention by the FDA in 2012. Throughout the study, researchers will do blood tests to see if people are actually using the gel and Truvada. Similar tests done during trials of Truvada pills found that most people in the trials were not taking the drug as prescribed. But those tests were not done until the trial had ended.

“By monitoring product use as the study is underway, we will have a much better sense of whether participants are adhering to the assigned study regimens,” said Ian McGowan, MD, PhD, co-principal investigator of the MTN. “The unique design of our study, which does not include a placebo, allows us to address any concerns or issues with adherence in a more real-time fashion, rather than waiting until after the study has concluded.” The trial should go a long way toward answering the question of whether more people will use a microbicide as opposed to a daily pill.

As we wait for the results of MTN-017 and later follow-up studies that will look at the gel’s ability to lower the risk of HIV infection, we can examine the two other roadblocks to PrEP and condoms: Will gay men use it, and can they afford it?

Many studies have already looked at the first question. A 2008 survey in Peru found that of 532 MSM and transgender women who had receptive anal intercourse, 29% would prefer a pill, while 57% would prefer a microbicide (14% had no preference). Clearly, an effective RM would be popular.

Of course, we don’t know exactly how the first RM will be used. Ideally, it would be similar to the lube that most people who practice anal sex already use. But to ensure accurate dosing, MTN-017 will require people to use an applicator similar to the one pictured below. A 2010 study compared the reaction of 92 men and 25 women to three different methods: an applicator, a suppository, and an enema. The authors concluded:

Among females, the applicator was the preferred product across all ages…whereas both the applicator and the suppository were preferred to the enema among older females…. Younger males preferred the applicator to the enema and suppository, while older males did not appear to prefer any product over another. These findings suggest that the marketing of RM products and the counseling of adherence to their use for HIV prevention may need to be age and gender specific.

But would people use an applicator when they usually use their fingers to apply lube? In Biomedical Advances in HIV Prevention – Social and Behavioral Perspectives, Marc-André LeBlanc and Jim Pickett write:

Using an applicator to deliver an RM may be a “deal breaker.” It is one thing to use an applicator in a trial; it is quite another to ask men and women…to use an applicator in their real lives. After all, people who use lube most commonly use their fingers to apply it, utilizing the “dab will do ya method.” And if more lube is needed, “another dab will do ya.” … If we are to have products that real people are going to use in their real lives, scientists and impacted communities must continue to engage with one another. Tapping community wisdom before, during, and after trials is not a luxury, or something nice to do – it is absolutely essential.

That may depend on how effective it is at preventing HIV. Even though MTN-006 found that the vaginal form of a tenofovir gel had too many side effects when used in the rectum, it also found that people in the study reported a high willingness to use the product in the future if there was some indication of actual protection. So even though younger gay men have not seen the devastation of AIDS that was evident in the ’80s and ’90s, the desire to avoid infection may still be strong enough to lead them to use a less-than-100% effective RM.

Cost

When it comes to cost, condoms are of course the big winner. Not only are they cheap, they’re often free, and if not are easily available over the counter. Truvada is the loser here, costing thousands of dollars a year, although its manufacturer is providing the drug free to people in the U.S. who do not have it covered by insurance or Medicaid.

Fortunately, in 2006 Gilead assigned a royalty-free license for tenofovir gel to CONRAD and the International...
The first RM will also have to be marketed effectively. According to Jim Pickett, “I think when we do have an RM, it will be best to market it first and foremost as HIV prevention. It should be marketed as a sexy, fun lube that happens to offer protection. It absolutely should not be called a microbicide – we need to create desire and have people want to use the product because it is pleasurable. That word doesn’t conjure desire – so it will need to go.”

Harriet Langanke, director of the German Sexuality and Health Foundation, adds, “To encourage microbicide adherence among these populations, first, the microbicide must be shown to work and the protection must be effective. Availability is a significant issue, as these products must be easily at hand, at least as easily available as the male condoms, and when it comes to marketing, the product packaging itself has to either be very discreet or evoke a positive image.”

**It absolutely should not be called a microbicide. We need to create desire and have people want to use the product because it is pleasurable. That word doesn’t conjure desire – so it will need to go.”**

**Stigma**

Since RMs may never be as effective as using a condom every single time you have sex, one barrier to its use could be the stigma that we are currently facing with Truvada for HIV prevention. Many people, even in the gay community, can’t understand how people can put themselves at risk for HIV when such a cheap, effective tool as the condom is readily available. Gay men can have a hard time admitting to their doctors that they’re being unsafe, and that can be even harder to admit to peers. Carrying an RM with you for casual sex could carry the same stigma that condoms hold for some now. “If you don’t have HIV, why do you have this kind of lube? Do you think that I do?” We’ve had to fight these battles for men using PrEP, and we need to find ways to avoid the same ones being waged when it comes to RMs.

**Conclusion**

Rectal microbicides, like condoms and PrEP, are not going to be the ultimate answer to stopping HIV. Even the first FDA-approved HIV vaccine will probably not be 100% effective. But, if proven safe and effective, and when used in combination with other methods, it is hoped that RMs will soon make a significant difference in turning around the stubbornly high infection rates we live with now. The important thing is to start asking the questions about them now, so that when the first one does emerge, we’re ready to use it in to maximum effect.

Mark Milano is the Editor of Achieve.
Slipping Through the Cracks
Why Does Mother-to-Child Transmission Still Happen?

by Pamala Ellis, RN, BSN, CMC, ACRN

She had just arrived at Woman’s Hospital in Baton Rouge and was already in labor. As I did my screening, she told me her boyfriend was HIV positive, but she had not had an HIV test, received any prenatal care, nor taken any HIV meds to prevent transmission of the virus to her baby. “Why not?” I asked. “He told me that I couldn’t get it from sex – only if we shared utensils.”

Unfortunately, her story is not uncommon. Many people in the South don’t see pregnancy as something that needs medical care. They’re very untrusting of health care in general, are often uninsured, and only enter the health care system when absolutely necessary.

Her baby was born with HIV.

The “Mississippi Baby”
You’ve probably heard about the first baby born with HIV who has been “functionally cured”. The child began HIV treatment 30 hours after birth. A series of tests showed diminishing virus in the infant’s blood, until it reached undetectable levels 29 days later. The infant remained on the meds until 18 months of age, but was then lost to follow-up for a while and stopped treatment. Upon returning to care ten months after treatment stopped, the child underwent repeated HIV tests, none of which detected virus. The child continues to do well and remains free of infection 18 months after all treatment ceased, according to the October. 23 New England Journal of Medicine.

I’m sure some of you thought, “Why are babies still being born with HIV in this day and age? We have all this research, there are national guidelines, medications, services, etc. This can’t still be happening.” But the reality is that it is still happening. The CDC estimates that over 800 newborns were infected with HIV from 2007 through 2011. Why? There’s an endless laundry list of reasons why this problem persists, despite our best efforts.

The Challenges
The CDC says that HIV testing should be routine for all pregnant women, and that medication to prevent transmission should be started as soon as possible. With early testing and treatment, we can lower the chance of an HIV-positive pregnant woman passing the virus to the infant to about 1%.

But the challenges affecting women and newborns here in Louisiana and the South in general are staggering: Louisiana ranks third in the nation for HIV cases – 30 per 100,000. In 2011, over 1,280 people were diagnosed with HIV in Louisiana, a 14% increase from 2010. It has one of the highest numbers of children living in poverty – 29% in households with an income below the federal poverty level, compared to the national estimate of 23% of all U.S. children.

In United Health Foundation’s America’s Health 2011 Rankings Report, Louisiana ranked 50th out of the 50 states in overall health. This is mainly due to low high school graduation rates, high infant mortality rates, the large number of children in poverty, and our rate of infectious diseases. In 2011, an estimated 21% of our residents lacked health insurance, compared to a national average of 16%.

Beginning in January 2014, the Affordable Care Act (ACA, or Obamacare) will allow states to expand Medicaid eligibility to most people who make less than $15,856 a year. This should help reduce the spread of HIV, since research shows that HIV treatment not only improves the health of the individual but also reduces the likelihood of transmission by up to 96%. More than 17,000 Louisianans are living with HIV and around 40% are not connected to any treatment. Expanding Medicaid would have a great effect on our state’s HIV epidemic. But, unfortunately, Louisiana – like most states in the South – does not plan to expand Medicaid at this time.

She told me her boyfriend was HIV positive, but she had not had an HIV test, nor taken any HIV meds to prevent transmission to her baby. “Why not?” I asked. “He told me that I couldn’t get it from sex – only if we shared utensils.”

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Each Case Unique
In a perfect world things would be very organized and would go according to plan. All pregnant women would start receiving prenatal care in their first trimester. All OB/GYNs would follow national guidelines, which state that providers should test women for HIV as early as possible during pregnancy and should give a second test during the third trimester.

But we do not live in a perfect world. We live in a world where poverty, stigma, discrimination, drug use, violence, mental illness, and any number of other barriers to care exist. I spoke with Dr. Karen Williams, a pediatric infectious disease physician in Baton Rouge, who treats children and youth with HIV, about why we can’t get the numbers of infants born with HIV lower.

“Every story is different,” she said, “but when an infant is infected with HIV today, it is usually because the mom did not receive prenatal care or had inadequate care during her pregnancy. This can be due to mental illness (including depression), substance abuse, chaotic living arrangements, and stigma.

“Sometimes a mother is not diagnosed with HIV until after she delivers. We recently had an infant whose mother had a negative HIV test early in her pregnancy. But the baby had poor weight gain after birth, so an HIV test was done on the infant at four months of age. It came back positive, and a repeat test on the mom was also positive. This underscores the need to test women for HIV early in pregnancy and again in the third trimester, especially in areas with high HIV rates. The best chance to prevent HIV transmission is during pregnancy, rather than at the time of delivery.”

Poverty
This is just one example of why infants are still being born with HIV. Statistics bear out the harsh reality for women in Louisiana. People living in poverty do not have adequate access to health education, preventive services, and treatment – all of which increase their risk of HIV.

Adolescents from poor families tend to drop out of school early, which in turn lessens their access to well-paid, stable employment. That can lower their sense of self-worth and draw them into activities like drug use that put them at risk for HIV.

Poverty can also force people, particularly women, to use sex as a form of payment or as a way to earn money. A study by the National Campaign to Prevent Teen Pregnancy found that a significant number of young black women engage in “transactional sex” – relationships with older men to secure gifts, money, or financial security. Often a woman in such a relationship is not in a position to dictate condom use, making it more likely she could get HIV and pass it on to her baby.

Louisiana’s crime rate is 5% lower than the national average rate but our incarceration rate is an incredible 2015 times higher than the national average. We rank #1 in the nation, with 867 per 100,000 adults incarcerated, the overwhelming majority young men of color. The National HIV/AIDS Strategy stresses that the gender imbalance in communities with high rates of incarceration results in an “increased likelihood that the remaining men will have multiple relationships with female sex partners” and therefore an increased risk that a single man will transmit HIV to multiple women. Women, especially those who are poor or have little education, can feel dependent on men, leading them to tolerate their partners having sex with other women.

Similarly, women whose regular partners are incarcerated are more likely to have other sexual partners. Risk factors like drug use and sex with an infected partner are increased if a person lives in an area where those risks are concentrated. According to the CDC, this situation, referred to as “residential segregation”, partly explains the disproportionately high level of STDs among African Americans.

Late entry into prenatal care is also a problem, along with our high teen pregnancy rate. Add to this the large number of uninsured people in our state, a sizable undocumented population, and high rates of drug use, domestic violence, mental health problems, etc., and you have a “perfect storm” that can increase the likelihood of a mother transmitting her infection to her child. Finally, limited or no access to transportation is a real problem – if you can’t get to the clinic, you’re not going to get any prenatal care.

Another woman came to Woman’s Hospital knowing that she had been exposed by her partner, who she knew was HIV positive. She was clearly aware
that she was at risk, since she had been getting tested for HIV every three months since 2005. We can endlessly wish or expect that people will use condoms consistently, but that’s unrealistic. The high rates of unplanned pregnancies we see are evidence enough that people are not always in perfect control of their sexual behavior in the face of love, lust, or even pressure. This woman was stressed and sad about her diagnosis, and had already begun to read up on it, but neither she nor her partner had been in care for several years, largely due to stigma. This is a textbook case where PrEP (see article on page 6) could have helped this mom-to-be avoid becoming HIV positive.

**Stigma**

In Baton Rouge, we see the many obstacles pregnant women must face when it comes to HIV. Stigma, whether real or imagined, is alive and well in the South. It can have serious consequences, including poor interpersonal relations, stress from hiding a positive diagnosis, anxiety, depression, guilt, loss of support, isolation, difficulties with family, and emotional or physical violence.

Disclosure is a real problem, and the reasons for failing to disclose vary. Some people are reluctant to say anything to even their closest family members or to come to a clinic where they may be recognized or may know someone. There are very strong feelings connected to the whole concept of being told they have HIV.

According to Dr. Williams, “Stigma is a big issue. Many patients worry about coming to a facility where they may be recognized as receiving HIV care. The mother of one of our children started working in the same building that houses our clinic. She put her own health at risk because of concerns about being seen as having HIV. Other patients have refused transportation, believing that certain taxi services are seen as being for patients with HIV.

“Even among medical providers and institutions there’s a reluctance to treat HIV as a chronic illness, and to screen for it as you would for high cholesterol or high blood sugar. In 2006, the CDC recommended routine “opt-out” HIV testing in health care settings for everyone aged 13-64. Widespread testing, including routine emergency room testing, can have a huge impact in diagnosing patients with HIV, getting them into care, and preventing transmission. So stigma is still a big issue.”

**Our Program**

For any prenatal care program to be successful, all of these issues must be taken into consideration. These can be very complex cases — spending 15-30 minutes with a pregnant woman once a month at a prenatal visit is simply not enough. We have found that to be really successful, you need to develop a relationship with them so they trust you enough to be honest about their needs as well as to trust the information you share with them.

We often see adolescent girls who are sexually active but are oblivious to the risks they are taking. There are any number of reasons a pregnant teen would not enter prenatal care: denial that they are pregnant, fear of family finding out, distrust of the health care system, etc. Stigma and ignorance play a huge part in the epidemic in the South by allowing the spread of myths and untruths. The most effective ways to avoid transmission are through proper prenatal care and education.

Woman’s Hospital’s Mother-to-Child HIV Transmission Prevention Program was started in 2002 to meet our patients where they are individually and to provide an environment in which they feel safe, so that each woman’s needs can be met. An HIV diagnosis demands lifelong management, so each patient needs to be linked to local community resources after delivery.

Of course, one of our main goals is to help a mother-to-be have a baby who is HIV negative. This is done with extensive patient education about HIV and the meds she is given. We closely monitor adherence to meds, using self-reports and regular lab tests. The staff also works to help patients with ADAP and drug company Prescription Assistance Programs as needed. We help them to get Ryan White Services, housing, or transportation if needed.

We link each patient to community resources to develop a strong health care network after delivery. HIV is now considered a chronic disease, so it’s important that each patient develop a strong relationship with her provider. Our case managers work with local organizations and providers so that each patient has a medical home and case management after delivery. We also provide education and support aimed at removing some of the stigma surrounding this disease, and we work to empower each patient to advocate for themselves and play a pivotal role in their own health care.

“One mother dropped out of care for months because a family member started working in the same building that houses our clinic. She put her own health at risk because of concerns about being seen as having HIV.”

**Conclusion**

Reaching zero in the number of infants born with HIV will require facing down many demons: lack of access to health care, stigma, poverty, ignorance, drug use, poor self-esteem. From 2007 to 2012, there were nine babies born with HIV in the Baton Rouge area. We’ve made tremendous progress over the years, and I’m proud to report that since the inception of our program, only two women enrolled in our program transmitted HIV to their newborns, and we’ve had zero transmissions since 2005. But getting everyone enrolled in a program like ours will require tackling the many issues that women, and our country, face every day.

Pamala Ellis is the Clinical Services Coordinator at Woman’s Hospital in Baton Rouge, LA.
**My Baby Has HIV**

*Name Withheld*

I didn’t even know I was pregnant until I was about three months along. I was in a situation where I was being abused. In order to stay where I was staying, I had to have sex with the man who lived there. He drank heavily and hit me several times. Sometimes, he would lock me in closet. It was terrible but I had nowhere else to go.

I was staying with my sister before that but she had so many problems that I couldn’t stay there anymore. So this man who was just a friend told me he was going to get a place and I could stay there. But I didn’t know he expected me to have sex with him. If I wouldn’t have sex with him, he would throw out my clothes and put me out on the street.

I was drugging all the time. I wouldn’t eat or even take a shower. I would just stay out all night long. I knew I was pregnant, but I never went to the doctor. I was afraid of going out to the “real world” because I was drugging so bad. Every penny I got went to buying cocaine. I never thought about going to the clinic to get prenatal care.

My sister got me prenatal vitamins and iron and I was taking them. I was trying to do the right thing for my baby. I finally went back to my sister’s house and asked her if I could stay with her, because I knew I couldn’t take any more abuse from the man I was living with.

One day, I went to the bathroom and there was something coming out of my vagina. My water had broke and my baby was starting to come. It wasn’t time yet for her to be born, but I was in labor already. My sister called an ambulance and they took me to Woman’s Hospital in Baton Rouge. It was the first time I had gotten any medical care in months. Before that, I just wasn’t able to.

I had my baby, and after that the doctor and nurse came in the room and told me I was HIV positive and my baby was, too. I felt like everything was over for me. I didn’t have a place to raise my baby, but I didn’t want to let her go.

They told me about the HIV clinic and gave me a booklet with a whole lot of numbers. I was so down and out I just didn’t want to go through all that. I couldn’t face it. In the next couple days, I told them I wanted to make an adoption plan for my daughter and signed all the paperwork. Lord knows it took a lot but I did believe I did what was best. I was discharged and went back to my sister’s house.

I visited my baby a few times because she had to stay in the hospital since she was premature. I never went to the clinic for myself. It was just like I was running away from everything and I didn’t want to hear anything. The drugs were taking over my life.

I finally stopped the drugs and was living in Baker with another friend. He was really good to me and was right by my side trying to help me. I got really sick and had lost about 50 pounds. I screamed to God, “Help me! Help me!” I was admitted to Lane Hospital and they helped me get into an assisted living residence for people who need support due to HIV. They’ve helped me get on my feet with different programs.

I finally got the help I asked the Lord for and my life has changed dramatically. I am eating well, praying well, making all my appointments, taking my medicine, and I have a life I never thought I could have being HIV positive. My life is getting better each day. I strive for more. HIV changed my whole life and my way of thinking, so now I seek counseling when I need it. I’m even getting my GED.

I want other women in my situation to know that there is hope and there are people out there who will help you. Don’t give up. Be strong. Don’t quit. There is a life as long as you do the work. HIV is not the way people say it is. If you take your medicine, there is hope. Keep going to your appointments and taking your medicine. If you have sex, make sure you have safe sex.

I reached out to other people and God let me know that I was not alone.
Love, hope, and care are expectations among married women and those in relationships. Marriage and childbearing are highly valued in African cultures, and girls are expected to be married by age 16. When that age comes and goes and no suitors are making marriage proposals, she becomes the talk of the village and faces ridicule and name-calling.

In our parents’ day, married women were safe in their homes, and their key threat was domestic violence. Childbearing was required to protect their marriages — if they chose not to have many children, they could lose their husband as he might marry a second wife who was willing to have more children. Women who refused birth control did so not because they wanted more children, but because their husbands demanded it.

The tide of AIDS has changed the African journey for women and now young girls as well. Up until the ’90s married women had few fears of contracting HIV — that was a song for sex workers or single people. They never considered that their husbands were sleeping with people who are vulnerable to HIV. But recently, there has been a call for women to wake up and see that they have no bargaining power to protect themselves from the virus by demanding condoms as singles are able to.

The Facts
According to the World Health Organization, 50% of all people living with HIV are women. In sub-Saharan Africa, that number rises to 61%. Young women (15–24 years) are three to six times more likely to be infected than men in the same age group. Worldwide, HIV rates are high among sex workers (the great majority of whom are young women), ranging from 6% in Vietnam to 73% in urban parts of Ethiopia. In some Asian countries such as Cambodia and India, women are increasingly infected with HIV within the context of marriage.

Eastern and Southern Africa continue to be the epicentre of the HIV epidemic. Southern Africa in particular experiences the most severe HIV epidemics in the world, with 34% of all people with HIV globally residing in its ten 10 countries.

Surveys in several countries show that more men than women have multiple partners. But the number of women using condoms with their partners is lower — only 38% use them regularly. Testing rates are low too. In 2007, only 18% of pregnant women in low- and middle-income countries received HIV tests.

While only 33% of pregnant women living with HIV received meds to prevent transmission to their children, this was a substantial increase compared with only 10% in 2004. Fortunately, access to HIV meds is increasing, from 7% in 2003 to 37% in 2010. In some countries, women have access to treatment in proportion to the expected need. But though women live longer than men in most parts of the world, WHO estimates that AIDS has driven women’s life expectancy below that of men in Kenya, Malawi, Zambia, and Zimbabwe.

Marriage and childbearing are highly valued, and girls are expected to be married by age 16. When that age comes and goes, she becomes the talk of the village and faces ridicule and name-calling.

Sub-Saharan Africa
My country, Malawi, has a population of over 13 million, and nearly a million are living with HIV — as many as in the U.S. More women (13%) than men (10%) have the virus, and women get infected at a younger age — 4% of women aged 15–19 have HIV compared with less than 1% of men that age. The number of women with HIV remains higher than men until age 30 and again outpaces that of men after age 40.

In 2011, 9% of Malawi women who had never married were HIV positive, 12% of married women, 19% of those who were divorced, and 41% of widows. While 71% of sex workers are positive, it may be surprising to learn that 56% of all new infections in continued on next page
Malawi occur in people in stable sexual relationships – people who were previously considered to be at low risk.

About 88% of all new HIV infections in Malawi and other sub-Saharan countries, including Zimbabwe, South Africa, Uganda, and Zambia, are acquired heterosexually. Several factors account for this, but one significant driver is that more people are having sex with multiple partners: in Malawi, 26% among men and 8% among women. The root causes for this are poverty among women and girls and a lack of information on the dangers of this practice.

Surveys in Malawi show that only 47% of men and 30% of women have ever used a condom. Among those aged 15–24, that drops to 13% and 2%. There is limited education on condoms and limited availability, especially in rural areas. This has serious implications for women and girls, since disempowerment, along with the traditional feminine and masculine roles, makes them unable to negotiate safer sex.

The situation in South Africa and other African countries is also very much the same, with young women being at greater risk. In 2005, 17% of women aged 15–24 had HIV, compared with 4% of men. This results from a number of factors: poverty, violence against women, cultural traditions that promote intergenerational sex, a preference for “dry sex” (without using a lube), and a high prevalence of sexually transmitted infections (STIs). In addition, an aggressive government response against HIV began only recently in that country.

Labour migration has played a major role in the spread of HIV in Southern Africa. During the era of apartheid, South Africa was a major recipient of migrant labour from neighbouring countries like Zimbabwe, Botswana, and Swaziland, and even from countries farther away, like Zambia and Malawi. Some authors have described “circular migration”, where individuals cycle through urban and rural areas in search of jobs. The number of men and women migrating is very different – over 90% of migrant workers are men, who often have other partners while away from home and then infect their spouses.

This has at least three important implications. First, the men transmit HIV and other STIs to their wives back home during their holidays or upon their return. Second, they also bring infections acquired in their homeland to the migrant labour camps in the host countries and infect women there. Finally, since there are more men than women, female sex workers have multiple partners, and 70% of their clients are married men. Some men have multiple partners to prove they are “real men”.

Gender Inequality

Women and girls are also affected by gender-based violence such as rape and are often unable to negotiate for condom use. Due to male dominance in certain societies, women have little or no access to HIV testing and meds to prevent transmission of HIV during childbirth without the approval of their husbands. Some cultures continue to subject women and girls to forced marriages, in which unprotected sex is usually required. Although sex work is criminalized in Malawi, transactional sex is common and informal. Women and girls acquire their daily needs – money, food, phone cards, rent, and clothes – in exchange for sex. When hunger strikes, many men leave their homes without saying anything and women are forced to sell their bodies for food. Some of these girls are orphans who have no one to support them, forcing them to marry at younger ages. Most of them are abused and their rights are violated.

In a study of 200 girls in Zimbabwe, those without a mother were more likely to be sexually active, to have had an STI, to have been pregnant, and to have been infected with HIV. Girls without a father were more likely to have been homeless and to be out of school. Another study reported higher HIV rates among orphaned girls aged 15 to 19 years (17%), as opposed to non-orphan girls (14%). These authors also found that orphans had an earlier age of sexual debut and were likely to have multiple partners. Survival mechanisms are very different between the sexes because boys have opportunities for work while girls often have sex work as their only option.
The high HIV prevalence among girl orphans in sub-Saharan Africa might be explained by sexual exposure or they may have been infected at birth. The latter, however, could not be the case in Zimbabwe, since HIV treatment has not been used long enough to affect the survival of infants and children who acquire HIV at birth. Such a possibility is likely to be increasingly probable as HIV treatment expands in southern Africa and more children infected at birth survive to reach adolescence.

“Property grabbing” is another problem. When a woman’s husband dies, his relatives will come and claim ownership of the family property and demand a share of whatever money and household goods are left. This leaves the wife with limited or no resources, forcing her into transactional sex. Another barrier is limited information about HIV and individual rights. Studies have shown that 66% of women in sub-Saharan Africa are educated about HIV, compared with 80% of men. Among young people aged 15–24, however, only 37% of boys and 25% of girls were able to correctly identify ways of preventing sexual transmission of HIV and to reject myths about the disease.

**Constitutional Rights**

Women are made particularly vulnerable by cultural practices that stigmatize them as the ones who infect their spouses. They are often divorced and driven out of their homes upon testing positive.

I checked the Republic of Malawi Constitution to see how my country’s laws address the discrimination many women face. I discovered that it prohibits this kind of discrimination on a number of grounds. Section 19 enshrines the right to human dignity, protecting people from discrimination on the basis of their HIV status. But these provisions are not enforced, so there is an imperative need for advocacy to demand their enforcement. We must also empower women and girls with the knowledge of the mechanisms available to address instances where their rights have been violated.

Section 22 of the Constitution enumerates several rights relating to marriage. It prohibits forced marriages and recognizes the family as the natural and fundamental unit of society. In spite of this, forced marriages are common in Malawi. A major drawback to Section 22 is that even though the minimum age for marriage is 18, it also states that people between 15 and 18 can get married with the consent of their parents. With that provision, girls become vulnerable to early marriage because of the social and economic challenges their parents face. It’s estimated that in 2002, 38% of girls aged 15 to 19 were married. Early marriage increases their vulnerability and subjects them to family life at the expense of education and economic independence. Such social and economic dependence on men makes them unable to negotiate safer sex.

The rights of women to equality and protection from abuse are expressly guaranteed in Section 24. But there are gross violations of the rights of women in Malawi when it comes to access to property, right to health care without approval from husbands, marital rape, etc. We must educate them on their rights and responsibilities, and mobilize as a community to change the cultural perceptions of women.

Treatment for HIV-positive mothers as well as their children is essential, since motherless children are far less likely to survive. In high-income countries, widespread testing and treatment has cut mother-to-child transmission rates to about 2%. But in low- and middle-income countries, only 45% of the 1.4 million pregnant women with HIV received HIV treatment in 2008.

**Recommendations**

Efforts from global partners like the Global Fund, PEPFAR, WHO, and African countries with high HIV rates should prioritize interventions that empower women to make informed choices and that address the key drivers of their vulnerability.

Abstinence entails either delaying the initiation of sex or practicing secondary abstinence (a prolonged period without sex for people who have previously been sexually active). But evidence for the success of this approach is sparse despite widespread abstinence messages, particularly through schools and faith-based efforts. In areas with a high number of people with HIV, postponement of sex simply delays infection. But abstinence does enable young women continued on next page
to complete school and increase their economic opportunities, increases the chance of informed decision-making about when, with whom, and how to have sex; and can empower them to communicate their desire to prevent HIV and unwanted pregnancies.

**Monogamy** To reduce HIV risk among women, we also need more efforts targeted at men, who must take greater responsibility for their actions. The risk of relationships that involve frequent partner change needs to be addressed. This requires engaging men as much as possible, as research has shown that more men are in polygamous relationships and a larger percentage of men have multiple sexual partnerships than women.

**Condoms** Among women, condoms are generally viewed as less acceptable in long-term partnerships based on love and trust, but more acceptable in casual relationships. Negative attitudes toward condoms are often grounded in traditional sex roles, unavailability of condoms, and a lack of self-esteem leading to difficulties in negotiating condom use. Furthermore, peer pressure and stigma inhibit their use. Limited access to female condoms and their higher costs have limited the use of this woman-initiated method. The need for coaching and mentoring, peer talks, and interpersonal communication on condoms is worth investing resources on.

**Livelihoods** HIV interventions alone without addressing women’s economic situations will take much longer to achieve change. HIV is highly linked to poverty and food insecurity among women and girls in Africa, so approaches like village savings and loans, help with income-generating activities, distribution of food during the dry season, introduction of modern farming techniques, livestock production, farmer cooperatives, and training from agricultural services staff, must be used hand-in-hand with HIV prevention efforts.

**Gender Inequalities** Cultural beliefs, traditions, and religious practices negatively affect women and girls more than men. We must be more proactive in confronting these practices as they also increase gender-based violence, property grabbing, and the spread of HIV and STIs. All services targeting women should involve men as well, including HIV testing, family planning, and prevention of HIV during childbirth. It is imperative for African nations to increase a more open dialogue between men and women if we are to change the practices that socialization has placed on them. Community talk shows, social forums, and direct campaigns should be promoted to deal with the negative role of governments. Programs must go beyond seeing women as passive recipients and engage them as active participants in decisions that affect them. Funders, including PEPFAR and the Global Fund, should support interventions that aim for high levels of empowerment, ownership, and meaningful participation by putting beneficiaries in charge of development.

## Conclusion
Reducing the impact of HIV requires that the needs of women be addressed globally, nationally, and locally. Reversing the factors contributing to their HIV risk — inequality, poverty, lack of economic and educational opportunity, lack of legal and human rights protections, traditional gender roles — is critical for success. HIV prevention targeting women and girls is a priority that the developed world should focus on. We are achieving a lot and saving lives, but greater resources could bring the epidemic to an end in our lifetime.

Dan Eddie Nthara (2013 Community Solutions Program Fellow) is the Executive Director of FOCCAD
less than two years after AIDS was first identified, New York State took the lead in the fight against the epidemic when Governor Mario Cuomo signed Executive Order 15 on May 16, 1983, establishing an Interagency Task Force on AIDS. Within two months, the NYS DOH AIDS Institute was created and given “the central responsibility for...coordinating the state’s policies with respect to AIDS.” Thirty years later, his son, Governor Andrew Cuomo, has the chance to once again take the lead – this time to actually end the epidemic in New York State.

In May 2013, Treatment Action Group and Housing Works convened a meeting on how to revitalize the HIV response in NYS. The meeting, held with the support of Columbia University, brought together advocates, health and social service providers, researchers, and government representatives to discuss ending the AIDS epidemic in New York State. Since then, there have been several community meetings to define what it means to end the epidemic, organized by the AIDS Institute, ACRIA, and advocates from across the state. Five pillars have been identified (treatmentactiongroup.org/policy/NYS-end-aids):

1. **Adopt 21st century surveillance strategies:** Know who is living with HIV and where HIV is being transmitted, and intervene quickly to stop chains of transmission. The State should invest in fourth-generation antigen/antibody test machines. They can detect recent HIV infections (just before and right after seroconversion), which is important for detecting early HIV infection and preventing transmission.

Screening for HIV is now recommended for all persons 13-64 in the U.S. About half of Americans (and more among high-risk groups such as young men who have sex with men) have never been tested for HIV, and nearly 200,000 people with HIV in the U.S. are unaware they are infected. This number must be lowered if we are ever to reverse the course of the epidemic.

2. **Reduce new infections through evidence-based prevention:** Routine, voluntary HIV testing is a gateway to prevention for those who test negative. Treatment for people with HIV lowers viral load and reduces the chance of transmission. Both groups benefit from interventions to address behavioral risk factors. HIV prevention services should include:
   - High-quality HIV and sexual health education at all levels
   - Post-exposure prophylaxis (PEP) in pharmacies and clinics available within two hours of exposure
   - Pre-exposure prophylaxis (PrEP) for those who need it
   - Treatment for substance use, mental health, and violence for those at risk
   - Housing, needle exchange, and other harm reduction services

3. **Maximize the number of people with HIV able to suppress their viral load:** U.S. guidelines recommend HIV treatment for everyone with HIV, regardless of CD4 count. While NYS is doing better than the nation with respect to the HIV treatment cascade (p. 5), in 2011, only 55% of New Yorkers with HIV received any HIV care during the year, and only 39% had an undetectable viral load.

New York State’s Medicaid reform, plus the advent of the Affordable Care Act including Medicaid expansion, offer the opportunity to fill some of these gaps, and must use the expertise of HIV care providers. This can lead to near-universal health care access and earlier treatment, which has been shown in Massachusetts to generate billions of dollars in savings while reducing HIV transmission and deaths.

Using the State’s market power to negotiate better drug prices with industry is essential. Generic HIV meds enabled PEPFAR to treat 3 to 4 times as many people in 2012 as were treated in 2009 while maintaining a flat budget. The savings from earlier testing and treatment, better prevention, and switching to generics can be used to pay for increased health coverage and needed support services.

4. **Support health, prevention, and retention in care for all New Yorkers with HIV:** For HIV-positive New Yorkers, retention in care requires addressing a cluster of issues. Homelessness, hunger, and other needs are powerful barriers to prevention and care. Eliminating new infections and retaining all New Yorkers with HIV in care will require continued reliance on the Ryan White CARE Act and HOPWA, as well as treatment for other health conditions such as diabetes, drug use, mental health, trauma, and viral hepatitis.

Housing and food security are essential components of an effective HIV response. Clean needles, harm reduction, and opiate substitution therapy are essential as well. Other approaches also play a role, such as the decriminalization of non-violent drug use, consensual sex work, and carrying condoms, while reducing the burden of incarceration for young men.

5. **Commit political leaders and all communities to the plan:** Community activism and service provision have been essential to the HIV response from the beginning. We will not end AIDS without a combined commitment by government at all levels, including NYCs newly-elected Mayor de Blasio. Community organizations, the private and non-profit sectors, and service providers must work together until there are no more infections and no more deaths.

By investing now in these strategies for better surveillance, prevention, treatment, support services, and community ownership, NYS can lead the way to ending the AIDS epidemic and set an example for other states, and countries, to follow. The time to end the epidemic is NOW and we urge Governor Cuomo to lead the fight!
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WHY New York State has borne the highest U.S. burden of the HIV epidemic since its beginning in 1981.

NYS has the people, institutions, resources, and political will to end our AIDS epidemic and to become a leader nationally and globally in ending AIDS.

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