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Bending The Curve

Can New York End Its AIDS Epidemic?

by Donna Futterman, MD and Terri Jackson

When will AIDS be over? It's a question that I have often heard from my patients. Usually, they're asking when there will be a cure or vaccine – and the answer is, unfortunately, not for some time. Vaccine trials are slowly moving forward and cure research is just now being seriously discussed for the first time in years.

But most people are unaware that we have the tools we need to end the AIDS epidemic right now. By “ending the epidemic”, we mean lowering the number of new infections until it drops so low that the epidemic peters out. HIV will still be around, and there will still be new infections, but far below the epidemic numbers we are seeing today. Eventually, the numbers could get so low that a new infection would be a rare occurrence. And all of this could be possible in just a few years – perhaps as early as 2025.

In June of 2014, New York's Governor Andrew Cuomo committed to the NYS Plan to End AIDS. He is to be applauded

for putting New York forward as the first state to commit to ending the epidemic by greatly decreasing new cases of HIV.

His announcement followed a proposal put forth in August of 2013 by a coalition of community groups including Treatment Action Group, Housing Works, and ACRIA. They submitted a working paper to New York State's Department of Health, describing five key elements of a plan to end AIDS in the state.

1. **Adopt 21st century surveillance strategies.**
2. **Reduce new infections through evidence-based prevention.**
3. **Maximize the number of people with HIV able to suppress their viral load.**
4. **Support health, prevention, and retention in care for all New Yorkers with HIV.**
5. **Commit political leaders and all communities to the plan.**

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Bending The Curve *cont. from previous page*

In response, Governor Cuomo issued the following statement:

Thirty years ago, New York was the epicenter of the AIDS crisis – today I am proud to announce that we are in a position to be the first state in the nation committed to ending this epidemic. New York State has reached an important milestone in controlling the AIDS epidemic, and through this comprehensive strategy, we are decreasing new HIV infections to the point where by 2020, the number of persons living with HIV in New York State will be reduced for the first time.

The announcement highlighted three main goals:

- 1. Identify undiagnosed people with HIV and link them to care.**
- 2. Retain people with HIV in care and support them so they can stay on treatment and keep their viral load undetectable. This will keep them healthy and dramatically decrease the chance they will transmit HIV.**
- 3. Provide access to high-quality prevention, including PrEP.**

Since HIV treatment can now keep people alive even into old age, the decreasing death rate (see graph at right) means every new case increases the number of people living with HIV. So, to keep the number of people living with the virus from continuing to rise, the plan is aimed at dramatically reducing the number of new infections.

The plan calls for dramatically altering the "Cascade of Care" in New York. In 2012, it looked like the graph on page 4.

Bending The Curve

To bend the curve of the epidemic, it's been estimated that the proportion of people virally suppressed would have to be over 80%, since being undetectable dramatically lowers the risk of HIV transmission. The plan also looks to use new prevention tools like PrEP (see article on page 14) to lower new HIV transmissions in NYS from their current level of 3,000 per year to 750 by 2020, and to an even lower level by 2025.

The plan offers great hope and makes HIV once again an important

The Robert Mapplethorpe Clinical Research Program

BMS-663068

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

BI 201335

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

Ibalizumab

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

Selzentry

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

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

Compensation is available for some studies.

public health priority. But phrases like “the end of AIDS” must be met with pause. To have any chance of success, any plan will require major efforts by multiple sectors of society. First, it will require an estimate of the actual costs of the proposal and an increase in funding to meet them. Then, it will require a much higher level of engagement and monitoring of medical institutions to ensure that “routine” HIV testing becomes truly routine. Finally, it will require a scale-up and strengthening of programs offering HIV prevention, care, support, and housing.

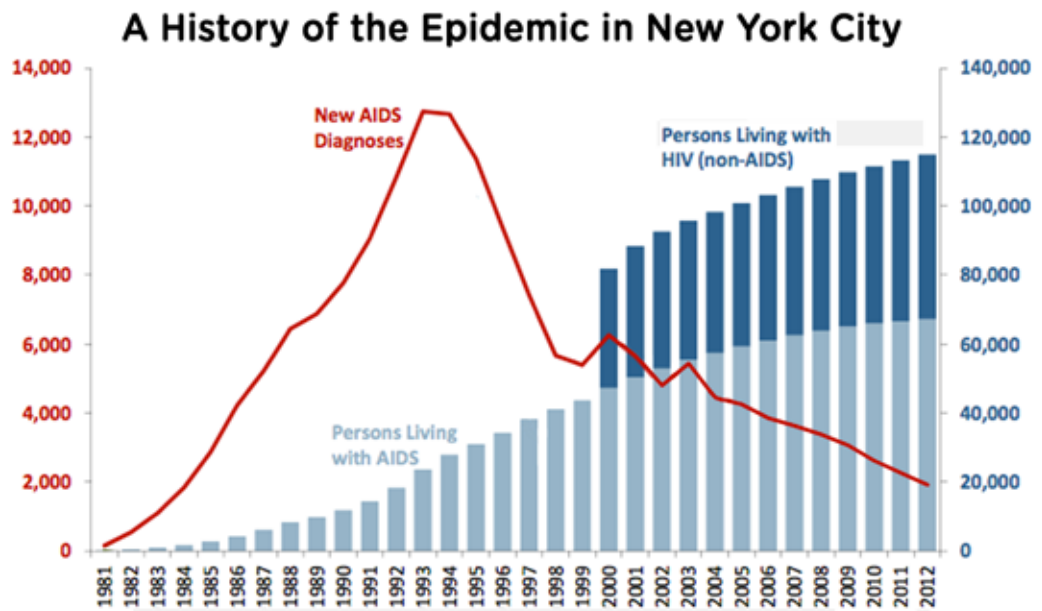
To bend the curve of the epidemic, it's been estimated that the proportion of people virally suppressed would have to be over 80%, since being undetectable dramatically lowers the risk of HIV transmission.

We can see this problem among people aged 13-29, who now account for 40% of new cases in NYS and who are mostly young men of color who have sex with men (MSM). Compared with the estimated 15% of HIV-positive adults who don't yet know their status, an estimated 60% of youth with HIV are still unaware they are infected. By failing to scale up targeted and effective prevention programs, we have seen the re-emergence of HIV in the next generation of gay and transgender youth. While there are many reasons for this rise, the bottom line is that HIV will continue to grow if we ignore the need to update and strengthen our approaches.

Alan Whiteside and Michael Strauss perfectly capture why we must take pause. In a recent article entitled “The End of AIDS: Possibility or Pipe Dream?”, they state,

We need a new sense of realism and commitment...The timeline for commitment is far longer than most politicians, strategists, and donor are willing to consider, even in their “long-term” plans.

offered HIV testing, but this has still not been fully implemented in medical sites throughout our state. It took until 2014 to update the confusing consent requirements for HIV testing. We must be willing to review policies continually and repeatedly to ensure that they meet current needs. (Interestingly, the call for routine screening for hepatitis C has not included a call for the strict consent requirements in place for HIV.)



The Ecosystem of HIV Care

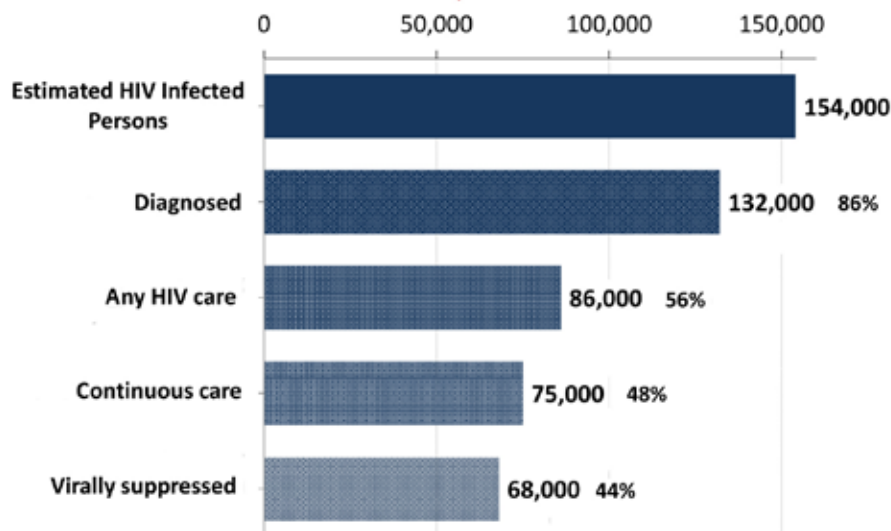
We cannot overemphasize the great effort needed to move people with HIV through the lifelong engagement that has become known as the HIV Cascade of Care. People first need to know they have HIV; then they have to become engaged in regular, continuous HIV care; and finally they must receive and adhere to effective HIV treatment to achieve viral suppression. This is a process, not an event. It requires highly sustained commitment by all actors within what we call the “ecosystem” (or environment) of engagement. The actors and commitments needed are:

- **Public health policies and laws that support access to high-quality health care that is integrated and coordinated.** But even with strong laws, implementation is not easy. In 2010, New York passed a law stating that all patients in the health system must be

- **A health care delivery system that has the human, technical, and financial resources to meet patients' needs for care and wrap-around supportive services.** As described in the article on page 6, these are not luxuries if we want to take full advantage of current HIV medications.
- **HIV medical providers who have the skills to communicate with their patients, and who can help them become active participants in their health care.** All providers must ensure that HIV testing is routinely offered and that those who test positive are linked to and retained in care. Additionally, HIV care must address all the barriers that patients, especially poor patients, face and that can interfere with their adhering to their meds.
- **Patients who are engaged in health care decisions with their providers and who**

continued on next page

CASCADE OF HIV CARE NEW YORK STATE, 2012



Bending The Curve *cont. from previous page*

have acquired the self-management skills they need to overcome the challenges chronic illnesses like HIV bring with them. HIV has hit hardest among the most disenfranchised people – the young, the poor, substance users, and people facing homophobia, transphobia, and racism. To be “successful” as an HIV patient means taking your medicines almost every day – no easy task for anyone, but much harder if you’re homeless or couch-surfing and have no regular routine, no money for transportation to the clinic, or no regular source of food.

Without all actors within the ecosystem working together over time, the environment is vulnerable to new HIV transmissions and to the risk of people with HIV falling out of care and becoming non-adherent. The mathematical models that have inspired the dream of ending the epidemic are based on assumptions and predictions. But models tell us only what is possible. A model is different from a plan, and a plan is different from its implementation. The heavy lift is increasing testing, getting everyone with HIV into treatment, and keeping them on treatment.

Working as an HIV doctor for almost three decades, I have often been asked why people with HIV don’t just get into care. Why is it so difficult and complicated, especially with all the great treatments? Why can’t we just end the epidemic and get on with solving other public health threats?

The answer, as eloquently noted in a recent editorial in *Science*, “End of AIDS – Hype versus Hope”, is that:

...the potential of antiretroviral treatment to control the HIV epidemic through a “test and treat” approach faces stark realities...and gaps in the HIV care continuum limit the potential of such an approach.

These challenges include:

- Health care settings that only slowly scale up and respond to legislation.
- Funding threats to wrap-around services such as substance abuse and mental health treatment, food, transportation, and housing.
- Pervasive stigma (homophobia, transphobia, racism) at the community level that triggers fear, preventing people from seeking testing, care, and treatment.
- Multiple illnesses, such as addiction and mental illness, that require intense levels of care coordination.

The Best Of Times

As two people who have been part of the HIV community for a combined 45 years, we can say with great certainty that these are the best of times. After more than 30 years of relentless struggle, much progress has been made. We now have:

- Strong medicines that can keep people alive for a full lifespan and greatly help to reduce the spread of new infections.
- Important new legislation, including:
 - The removal of written informed consent for HIV tests, allowing them to be

ordered through oral consent or opt-out, like most other medical tests.

- Allowing data collected by the health department to be shared with health care providers to locate people with HIV who have fallen out of care.
- Expanded insurance coverage via the Affordable Care Act for people with pre-existing conditions, as well as for preventive services like HIV testing.
- A 30% cap on the amount of the income of people with HIV that can be spent on rent, keeping them stably housed – which improves their ability to stay on medication.
- Public-private partnerships – New York State negotiated price reductions with three drug companies, representing 70% of the HIV market: AbbVie, Bristol-Myers Squibb, and Gilead. This agreement will go a long way to decrease the costs to the state of providing needed medication to all people with HIV.

Though these are the best of times, we need to be thoughtful, decisive, and honest about what it will take to end the epidemic, recognizing that a cure is not on the immediate horizon. Our job as HIV service providers and activists is far from done. Our social environment is a fertile ground for the growth of HIV. Transmission thrives on the convergence of chronic illnesses (mental illness and substance abuse), socioeconomic forces (violence and poverty), and stigma. These are critical barriers to care and substantially limit the effectiveness of “test-and-treat” strategies.

What Will It Take?

We must keep our eyes on the prize of a cure. But until then, the NYS plan holds the potential of preventing new infections and improving the lives of people with HIV. Outside of a cure, we need to:

1. **Expand HIV testing in emergency rooms, hospitals, and clinics.** There is often a lag between new policies and their actual adoption. To ensure that all health care providers offer routine HIV testing and linkage to care, we need more training, technical assistance, and regulatory oversight.
2. **Provide wrap-around services to lower the barriers to care** (mental illness,

substance abuse services, etc.). The need for integrated HIV treatment and behavioral health care is evident:

- About 50% of people with HIV have mental health problems that may have arisen independently of HIV infection. These may have predisposed them to HIV infection (through risky behaviors) or could be a consequence of HIV (depression).
- About 9% of all new HIV infections occur among injection drug users, and about 3% among MSM/IDU.
- Untreated mental illness and substance use are among the top predictors of poor adherence to HIV treatment.

3. Address poverty and health disparities due to race and sexual orientation. Addressing poverty to reduce new infections is not an option – it’s a necessity. It’s almost rhetorical at this point to say that inequality in economic status drives poor health outcomes – in this case vulnerability to HIV transmission and poor adherence to treatment. The fact is, we have not committed to sweeping, innovative interventions to reduce the economic inequalities that fuel health disparities. The data are alarming. According to a recent CDC study of HIV in urban communities:

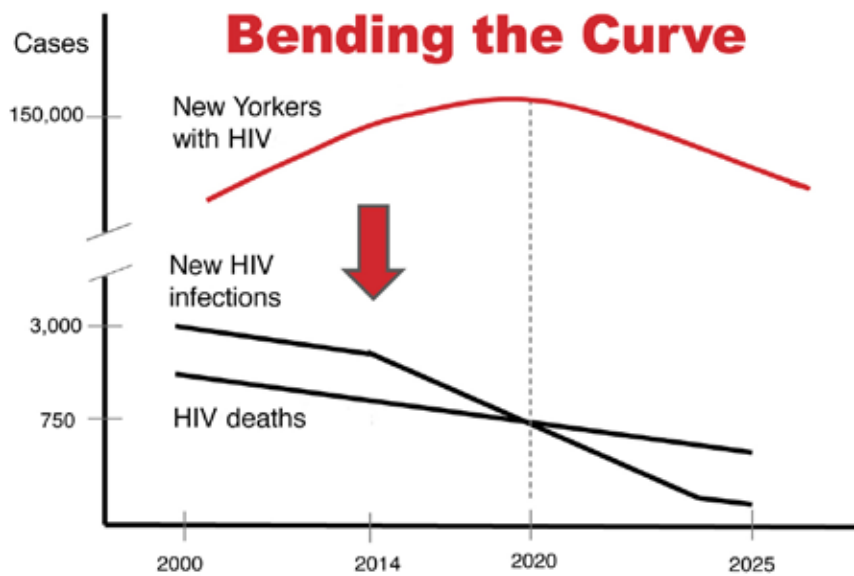
- Poverty was a key factor associated with HIV infection among inner-city heterosexuals.
- People living below the poverty line were twice as likely to have HIV as people in the same community who lived above the poverty line (2.3% prevalence vs. 1.0%).
- Prevalence for both groups was far higher than the national average (0.45%).
- In the U.S., African-Americans, Latino/as, and Caribbean-Americans (especially MSM and transgender females) account for the highest proportion of new cases.

4. Provide PrEP for all, including minors. NYS must ensure that there are no barriers to minors accessing PrEP, such as a requirement for parental consent. The right of minors to access screening and treatment

for STIs and reproductive health, such as plan B, must be incorporated into all plans to scale up PrEP.

5. Address Stigma. Stigma falls to the very bottom of the list in discussions of evidence-based interventions to improve access to care. Except in some advocacy circles, it usually doesn’t even make the list. The subject is poorly researched, and there is not one anti-stigma intervention that has made the CDC’s Compendium of Effective Interventions.

New York State must implement its own stigma index. Currently, much of what we know about stigma and discrimination is merely by way of our own experiences. We need evidence. Such an index would nicely complement “test and treat” strategies by providing a deeper understanding of how stigma and discrimination serve as barriers to testing, care, and treatment. Additionally, the findings could be used to engage vulnerable communities in discussions and problem-solving to change community norms regarding stigma.



What I do know, as an HIV doctor for over 25 years in the Bronx, is that stigma is a barrier to care and an extremely complicated concept to disentangle. It is entrenched in the areas of race, ethnicity, gender, sexual orientation, culture, religion, etc. Ending the AIDS epidemic means we cannot run from this complexity.

We applaud UNAIDS, the International Planned Parenthood Federation, the Global Network of People Living with AIDS, and The International Community of Women Living with HIV/AIDS for taking on stigma by developing the “People Living with HIV Stigma Index”. The Index is a tool that measures and detects changing trends in relation to stigma and discrimination and has addressed the issue in over 50 countries so far. For the first time in the history of the epidemic, we are beginning to have the evidence to start developing new messages and programs to appropriately challenge stigma.

Conclusion

We conclude with two challenges for the leadership of NY and its health care institutions:

- 1. Dig deep and have realistic discussions as to what it will really take to end the AIDS epidemic in NYS.**
- 2. Develop and implement a plan that focuses on the five strategies above so we can make real progress toward 2020.**

This challenge can be met by holding each other accountable and by ensuring that every lever is pulled. As President Obama said when introducing the National HIV/AIDS Strategy, “So the question is not whether we know what to do, but whether we will do it.” ■

Donna Futterman is Director of the Adolescent AIDS Program at Montefiore Hospital in the Bronx. Terri Jackson is a Senior Vice President at Rabin Martin.

Wrap-Around Care



A Necessity, not a Luxury

by Terri D. Jackson

James was diagnosed with HIV 25 years ago. He is 59 and struggling to make ends meet in New York City. He works full time in a minimum-wage job, but was evicted from his apartment because he couldn't cover a 20% rent increase. He tried to get legal help at an AIDS service organization before his eviction, but was told there was a long waiting list and no more money for emergency financial assistance.

James now "couch surfs", moving frequently among multiple friends' apartments. His friends are sick of the arrangement. His financial situation is very stressful, and James has gone back to drinking and using drugs to manage his stress. Over the years, he had a pretty impressive history of keeping his medical appointments, except for the times that he had personal challenges. Things are difficult again. James did not make his last medical appointment.

Unfortunately, James is not unique. Actually, his story of individual life challenges that threaten good health is quite common. James' HIV is a medical, social, and economic condition. In policy and academic

circles, the social and economic forces that keep people like James from staying in care are called the "structural drivers" of health.

The Missing Point

Governor Cuomo's recent three-point plan to "bend the curve" and decrease new HIV infections in New York State for the first time is historic (see cover story). As Housing Works CEO Charles King says, "This step by Governor Cuomo, setting a clear goal to end the AIDS crisis in New York State, is absolutely courageous. In doing so, the Governor is reshaping the way we think about the AIDS epidemic and is setting a new standard for leaders of other jurisdictions in the United States and, indeed, around the world."

The announcement of the plan highlighted these three points:

1. Identify undiagnosed people with HIV and link them to care.
2. Retain people with HIV in care and support them so they can stay on treatment and keep their viral load undetectable.
3. Provide access to high-quality prevention, including PrEP.

What's missing from the announcement is a fourth crucial point: providing access to wrap-around support services so that people are able to get both linked to and retained in care.

Within the world of the Ryan White program, wrap-around services are referred to as nonmedical services. They include things like nonmedical case management, child care, emergency financial assistance, food banks, housing services, substance use services, psychosocial support, and treatment adherence counseling. These are not luxuries, but core components of HIV medical care. They maximize the chance that clients will remain in care and achieve positive health outcomes, including viral suppression.

For James, 25 years living with HIV has had many ups and downs. He's faced many challenges along the way, including mental health issues, substance use, employment, housing, and a lack of social support. Each time a barrier arises, he becomes vulnerable to falling out of care. He needs the wrap-around services provided by case managers, patient navigators, and outreach workers to get him back on a healthy path.

Wrap-around services maximize the chance that clients will remain in care and achieve positive health outcomes, including viral suppression.

For example, we know from research that housing is one of the strongest predictors of health outcomes for people with HIV. Homeless or unstably housed people with HIV experience worse overall physical and mental health, have lower CD4 counts and higher viral loads, and are less likely to receive and adhere to treatment than those who have permanent,

suitable housing. Lack of secure housing interferes with the uninterrupted care so important for people with HIV, for whom even short interruptions in care can have significant negative effects on their own health and for the transmission of new HIV infections. An end to the AIDS epidemic requires both a biomedical response and action to address the social and economic drivers of HIV via wrap-around services.

Utah is an exceptional example of innovative problem solving around the drivers of health outcomes. In 2005, Utah’s Housing First program began with a very simple calculation: the annual cost of emergency room visits and jail stays for homeless people was about \$16,670 per person, compared to \$11,000 to provide each homeless person with an apartment and a social worker to coordinate health care, entitlements, and benefits.

Utah also ended the requirement that people solve their underlying issues (drinking, drug use, non-adherence, etc.) before they could qualify for housing. According to Nan Roman of the National Alliance for Homelessness, “If you move people into permanent supportive housing first, and then give them help, it seems to work better...People do better when they have stability.” The state began giving away apartments and providing participants with social workers to become self-sufficient. In eight years, Utah reduced homelessness by 78%, and is on track to end it by 2015.

Why We Need Wrap-Around

To understand why wrap-around services are an essential part of ending the AIDS epidemic, we must first examine the types of services needed to support people with HIV across the care continuum. Second, let’s engage in an example of demand for wrap-around services using New York City’s HIV Cascade of Care and the three-point NYS plan.

The Cascade (see graph on page 4) is a way to show, in visual form, how we are doing in the U.S. in terms of getting people into care, keeping them there, and achieving viral suppression. It has five main stages:

1. **HIV Diagnosis:** Wide-scale HIV testing is an essential first step. People who don’t know they are infected are

not getting the treatment they need to stay healthy. They can also unknowingly pass the virus on to others.

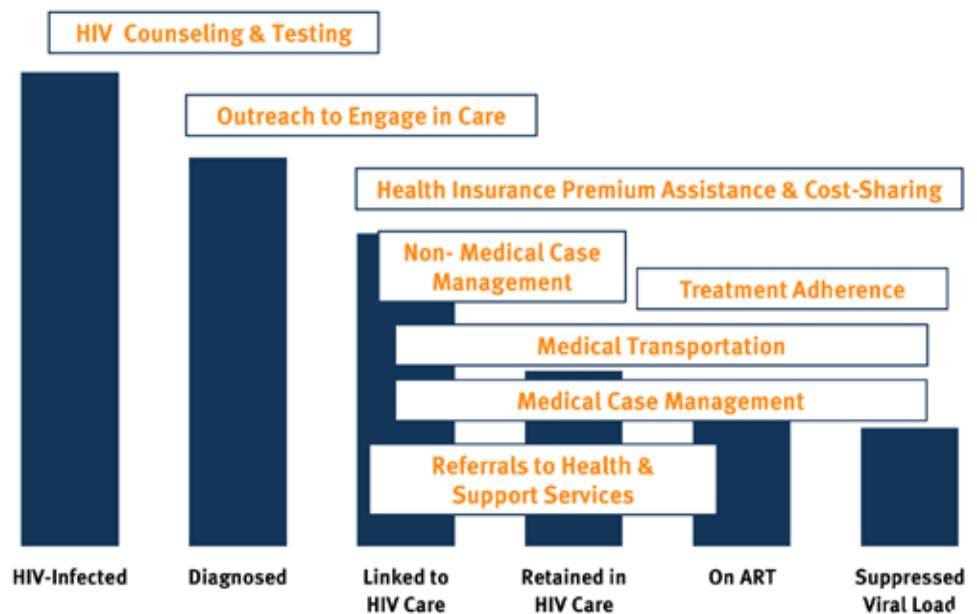
2. **Getting linked to care:** Once people know they have HIV, it’s critical to connect them to health care providers who can offer treatment and counseling to help them stay healthy and prevent further HIV transmission.
3. **Staying in care:** As there is no cure for HIV, treatment is a lifelong process. To stay healthy, people need to receive regular HIV medical care.
4. **Getting treatment:** HIV treatment involves a combination of three or more drugs taken every day.
5. **Achieving viral suppression:** Taking ART regularly usually leads to a very low level of HIV in the body, also known as an “undetectable” viral load. This has been shown to help people live longer and to greatly reduce their chance of passing HIV on to others.

patient navigation to follow up with him regarding medical appointments and adherence services to maximize his chances for viral suppression.

Getting more people with HIV diagnosed will mean more people entering the system and greater demand for wrap-around support services. Here is an illustration of how demand for wrap-around services along the Cascade affects our ability to achieve Cuomo’s goals:

- In 2011, there were about 3,000 new HIV diagnoses in NYC and about 95,000 people diagnosed earlier who already needed wrap-around services.
- This means that about 98,000 people were in need of some sort of wrap-around services to remain in care.
- But after first being linked to care, about 24,000 people were not retained in care. These are the people who need to be found and brought back into care, restart treatment, and receive wrap-around services

Ryan White Wrap-Around Services



As the graph above shows, there are significant drops at each stage of the Cascade, particularly between linkage to care and retention. This is the point where wrap-around support services become most important.

In the case of James, the needed wrap-around services should include legal assistance, housing assistance, substance abuse and mental health counseling, and

to support retention in care and to reduce their chance of passing HIV on to others.

- In 2015, the number of new HIV diagnoses could actually exceed 3,000, due to increased testing efforts. Again, this means more pressure on the health care system to appropriately invest in wrap-around services to support linkage and retention in care.

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It's clear that the goal of ending the epidemic faces major challenges. Business-as-usual policies and sustaining the response at its current level of investment cannot end the epidemic. We must create a response that addresses the structural drivers of the epidemic.

Wrap-Around at Risk

Currently, the safety net of wrap-around support services is vulnerable. Many HIV providers throughout the state face an uncertain future. This year, severe cuts in federal funding have undermined the ability of HIV service providers to provide wrap-around services. At GMHC, for example, food pantry bags were reduced by 47%, substance abuse counseling sessions by 20%, and mental health counseling sessions by 10%, while 500 hours of legal counseling services were cut.

The newly passed 30% rent cap is a landmark moment in New York HIV history, providing affordable housing protection that will prevent homelessness for over 10,000 low-income New Yorkers with HIV, and enable hundreds more to move out of the shelter system. But, if we examine broader trends in HIV funding in New York, we see stagnant or decreasing resources.

The AIDS Institute's funding has been reduced by approximately \$20 million since 2008. NYS's federal Ryan White grant, which supports the HIV uninsured care programs, has seen a cumulative loss of more than \$30 million since 2006. Ryan White funding is based on each state's proportion of people with HIV. As NYS has seen success in reducing the number of new infections, our proportion of cases nationally has declined, resulting in the loss of Ryan White funds.

The CDC Cooperative Agreement, which supports HIV prevention, education, and support services, has seen an approximate 40% reduction. Resources to address STIs are also limited, since the federal STI cooperative agreement has declined each year since 2006.



Recommendations

New York State needs to take its bold vision for an end to the AIDS epidemic further. We must:

- Add a fourth point to the plan: Provide wrap-around support services to retain people in care.
- Develop models to predict the need for and cost of wrap-around services as more New Yorkers are diagnosed and linked to care.
- Target wrap-around resources along the Continuum to ensure seamless continuity of care.
- Identify the types of services that are needed and most correlated with retention in care and viral suppression.
- Identify cost savings based on different scenarios and bundling of wrap-around services.
- Provide seed money to the AIDS Institute to launch innovative interventions related to:
 - HIV testing using fourth-generation technologies
 - Linkage to and retention in care

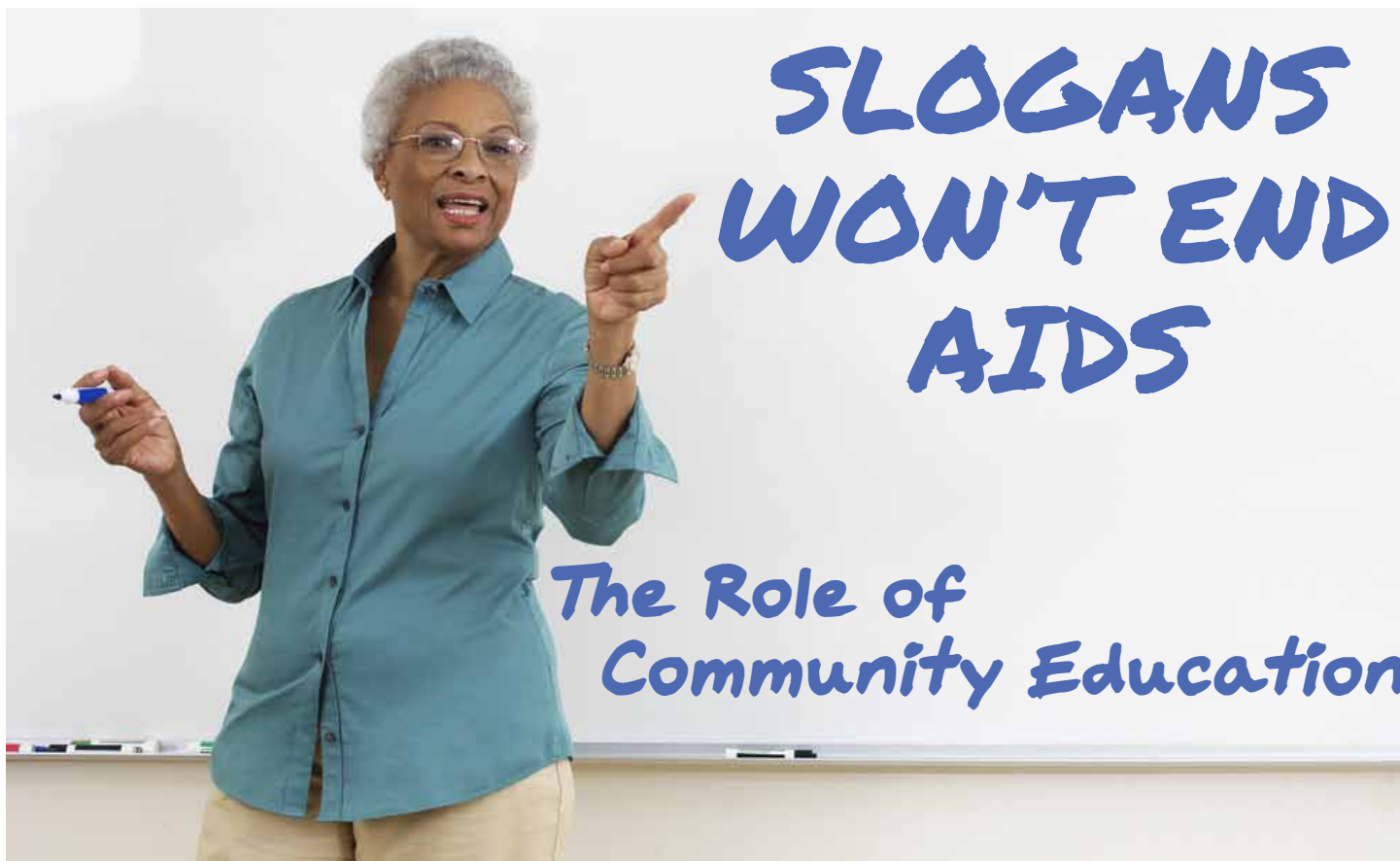
using social media and other innovative strategies

- Social marketing campaigns for PEP and PrEP
- Training for health care providers to scale up PEP and PrEP and HIV testing
- Develop innovative partnerships with the private sector to drive uptake of PEP and PrEP.

Conclusion

As we move toward ending the AIDS epidemic in New York by 2025, we see more than a tale of hype versus hope or possibility versus pipedream—it is a cautionary tale. We need to take stock of what we've learned in 30 years of an epidemic and the necessity (not luxury) of wrap-around services. It is a tale of how our zeal and aspiration to end the epidemic must be tempered by a deliberate and disciplined public discussion of the tough and gritty fiscal decisions that must be made to end the epidemic. ■

Terri D. Jackson is a Senior Vice President at Rabin Martin



by Joe Luniewicz

Even if we identified every person with HIV in New York, even if we got every one of them into care, even if the drugs were all free, we would still not achieve 80% viral suppression, because people must understand the “why” and the “how” of the meds, so that they work.

Mark Milano, ACT UP, ACRIA

To end an epidemic you need to think both big and small. New York State’s plan to end AIDS definitely takes care of the big thinking. It is both epic and visionary. Slogans such as Bending the Curve and We Can End AIDS are terrific banners to gather under. Just imagining a way for this to happen is incredible, and for Governor Andrew Cuomo to get behind it is even greater.

But how is it going to be done? What are the details? This is where simple slogans end and the complicated business of doing begins.

Why does Mark Milano’s comment to the White House representatives at the Office of National AIDS Policy community forum in Manhattan this summer make sense? Because education is the key to ending this epidemic.

I remember handing out condoms on World AIDS Day in subway stations in New York City in the early ’90s and wondering – as people threw them in the garbage, avoided me, or once in a while took one – how many actually used them? Was it an effective way to help people practice safer sex? If that was the case, shouldn’t the

epidemic be over by now? Why isn’t everyone using condoms all the time? We soon learned that changing sexual behavior was more complex than handing out condoms. It certainly was a great public service announcement and raised awareness about AIDS. But it didn’t make people change their sexual behaviors.

A community health educator is an important resource because information as personal as this requires someone who can speak on a level that is understandable, in familiar language, and in a nonjudgmental way.

We now know that getting people to change their behavior is much more complicated. We learned that we need community health educators who can assess risk behaviors, readiness to use condoms, and resistance to change. We need people who can teach correct condom use in an accessible and relevant way, and talk about the decision-making needed to adhere to the new behavior.

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A community health educator is an important resource because information as personal as this requires someone who can speak on a level that is understandable, in familiar language, and in a nonjudgmental way. Someone who establishes a relationship with the listener.

Knowing the right thing to do and doing it 100% of the time is harder than it seems. Victor Maldonado, theguardian.com

HIV Treatment Education

What do we know about taking medication? Here are some facts:

- A 2003 WHO report stated that at least half of all patients with chronic illnesses do not take their medications as prescribed.
- Typical adherence rates for medications prescribed over long periods of time are about 50-75%.
- Most studies of HIV adherence show around 70% adherence.
- HIV treatment requires 95% adherence to be effective.
- Most people with HIV report being more adherent than they actually are.

Community health education is essential to promote health and prevents disease within targeted communities. It goes into communities, and it comes from within them. It uses health promotion materials and interactions at understandable literacy levels. Health information is communicated in ways that are clear and that are able to be evaluated. Without these qualities – a “health literacy” approach – the information may not be useful.

Effective health communication uses plain, but not “dumbed-down”, language. It’s information people can understand the first time they read, see, or hear it. It helps them find what they need, understand what they find, and use it to meet their needs.

A doctor says to a patient prescribed HIV medication, “You have to be 95% adherent for viral suppression, so take this every day.” A community health educator says, “You have to take this medication once a day, every day, at the same time every day. If you miss more than two days a month the medication may not work.”

Research has shown that health literacy is a significant factor in the health and treatment of people with HIV. We know that people with HIV who have lower health literacy have lower CD4 counts, higher viral loads, are less likely to be taking HIV medications, have more hospitalizations, and are in poorer health than those with higher health literacy. In addition, after adjusting for years of schooling, lower health literacy is associated with poorer knowledge of HIV-related health status, poorer AIDS-related disease and treatment knowledge, and more negative health care perceptions and experiences.

Understanding complex topics like adherence to HIV meds depends on the abilities of those providing the education: often doctors, nurses, home health workers, etc. Unfortunately, they generally don’t have the time to discuss complex medical problems and they don’t have the needed teaching skills. Shorthand, acronyms, and jargon are common, and explanations are often not effective. In addition, many patients will not ask questions of clinicians, because of embarrassment at not being able to understand the information or for cultural reasons related to dealing with authority figures.

Care Coordination and Education

Community health educators are key to solving this problem. They come with slightly different job titles like patient navigator, patient educator, AIDS educator, peer navigator, and health promoter. A good example of how community health educators can work is the NYC DOH Ryan White Care Coordination program.

Key Terms

- **Community Health Education:** Education conducted by members of or from a community that promotes and maintains health by helping clients adopt healthy behaviors.
- **Health Literacy:** The capacity to obtain, understand, and use information and services needed to make appropriate health decisions.
- **Care Coordination:** The organization of patient care activities to assist with delivery of health care. A core principle of care coordination is that people with HIV should have a medical “home” to coordinate all their needs. Effective communication between the primary care provider and the patient navigator/care coordinator is crucial for supporting engagement in care and adherence.
- **Adherence:** The extent to which a person’s behavior in taking medication corresponds with agreed recommendations from a health care provider. For people with HIV, adherence means taking HIV medicines every day, as prescribed – including food requirements.

Based on the PACT (Prevention and Access to Care and Treatment) model from Boston’s Brigham and Women’s Hospital, the city’s 28 funded Care Coordination programs address HIV treatment adherence through a combination of care coordination and health promotion. Patient navigators provide one-on-one education on over 25 different subjects, including basic HIV information, HIV medications, resistance and how it develops, adherence skills, substance use, and disclosure issues. These patient navigators live in the communities where they work, speak the community’s primary languages, and understand the cultures of their communities. Many have

HIV themselves, are on treatment, and are virally suppressed. They've also been trained in health literacy approaches targeted at low literacy levels.

Although the percentage of HIV-positive New Yorkers who are virally suppressed is not yet 50%, at 44% it is higher than the U.S. average, due partly to the Care Coordination program and other community health educator programs.

Doctors, nurses, home health workers, etc., generally don't have the time to discuss complex medical problems and they don't have the needed teaching skills. Shorthand, acronyms, and jargon are common, and explanations are often not effective.

Bending The Curve with PrEP

Let's go back to the issue we started with and look specifically at the NYS plan. One of its major goals is to provide access to Pre-Exposure Prophylaxis (PrEP) for high-risk persons, to keep them HIV negative (see article on page 14).

Are we going to just hand out PrEP and expect that to prevent new infections? Will it be that simple? We've learned that starting medication and dealing with adherence are important to the long-term management of HIV disease. Now we're dealing with daily medication for prevention, and adherence will have a direct impact on its success. The difference with PrEP is that we're giving medication to people who are well.

How do you get a prescription for PrEP if you're HIV negative? Simply put, you can go to your doctor and ask for it – a “patient-initiated contact”. Or the doctor can suggest it – “provider-initiated” – because he or she thinks you're at risk. Or someone doing outreach might bring you to the doctor, where it's offered.

In order to ask for PrEP you have to identify yourself as being at risk for HIV, be ready to do something about it, and be knowledgeable enough to take action. This means you have to have heard about HIV, learned how it's transmitted, processed this information, applied it to yourself, and recognized that you are at risk. You also need to have a relationship with a primary care provider – a good enough relationship that you are comfortable disclosing sensitive information about your sexual behaviors – who will write the prescription without judgment.

Here's the kicker. It's HIV medication. HIV medication for someone HIV positive requires 95% adherence to achieve viral suppression. For PrEP to work at its best, it must be taken every day. In the iPrEx study, people who took only half their doses



had their chance of infection reduced by only 50%. At 90% or higher adherence – missing less than one dose every other week – PrEP reduced the chance of infection by 75%. A key statistic needs to see the light of day: While 93% of people in the trial reported taking PrEP correctly, only 51% actually did so, based on blood tests that checked the level of drug in their blood. People over report adherence for many reasons. In follow-up studies, the manner and approach of the trials counselor have been shown to affect how accurately people report their adherence.

The message from iPrEx is clear: whether you're HIV-negative or -positive, for meds to work they must be accompanied by effective and ongoing education.

Conclusion

Visionary and epic ideas are great. Sexy slogans that capture their grand qualities are great. But when it comes to implementation, the key element of the community health educator must not be left out. People can learn this complex information if given the chance. As Lisa Frederick, the Associate Director of the Training Center at ACRIA says, “Never underestimate the capacity of a person to understand medical information – if given to them in the right way.” ■

Joseph Luniewicz is Deputy Executive Director for Programs at ACRIA.

With a Little Help From The Choir

by Raymond

When the century turned, I was 44 years old and five years into a happy, open relationship with a man I couldn't love more. One June night, he sat next to me on the sofa and told me I needed to have an HIV test. Why? Because he had hooked up with a guy from out of town. In the heat of the moment, when no condoms could be found, with both men claiming to be negative, my partner violated a cardinal rule of our open relationship: skin-to-skin for us only, condoms with anyone else. The out-of-towner had just learned that a guy he regularly hooked up with tested HIV positive.

I had a lonely birthday, and when my meds ran out, I didn't refill them and never went back to see my doctor. I didn't consciously say "I give up", but at my core, that's what I did.

And so, a mistake in a city 1,800 miles away, between two men I'd never met, reverberated here in NYC. Even though I was fully aware of my partner's extracurricular activities, I naively trusted in our rule, believing I'd be told of any lapse in judgment. Essentially, I made the protection of my HIV status my partner's responsibility – never once asking if we needed to take any precautions.

A month later, when my diagnosis was confirmed, my doctor told me flat out that if I listened to him and didn't take this as a death sentence, I would more likely die from my high cholesterol than from AIDS. I believed him.

Three months later I started on my first HIV meds. With very few side effects, my viral load quickly became undetectable and my CD4 count rose to a high of 400. In 2005, I was in the best physical shape of my life – I hit the gym and raised my body weight from its normal 125 lbs. to 137 lbs. of muscle. And all along the way, my partner supported me, reminding me to take my pills and keeping me focused on the future – essentially, keeping me so busy living that I forgot to die. We celebrated our tenth anniversary on an Indonesian cruise. I had gone from surviving to thriving!

But over the next few years, we faced job and money challenges that tested our relationship. In the summer of 2008, my partner sat next to me on a bench in Central Park and told me he felt our relationship had changed from lovers to friends. He wanted to stay friends, but wanted to be free to pursue a new romantic relationship.

To say our break-up was unexpected would be an understatement. I knew we had hit some rocky times, but I had naively thought that my recent new job and apartment meant a renewed spirit for our relationship. Sadly, it came too late for my partner. For me, it was more devastating than the night in 2000 when HIV entered my life.

I refused to come to terms with it for many months. I told none of my friends or family. We worked for the same small company and never let on about the change in our situation. I remember thinking that if no one found out, it wasn't real and he might change his mind. But I knew that he had already started dating someone else. Feeling hopeless, I had already let my medical insurance lapse and stopped taking my HIV meds when they ran out, again telling no one.

I told my friends that the New Year brought a new outlook for me: I would be glad for what I had and stop focusing on what I lost. It was all a lie. This was the face I showed to people, but in truth, I'd given up. My partner had moved on, but I remained stubbornly in love with him. I still didn't tell people we had broken up. I did briefly get new medical insurance and a new doctor who got me on Atripla. But soon after starting it, I developed painful acid reflux. Adding to that, I had a lonely birthday at the end of February, and when my meds ran out (about the time when I realized I owed a fortune in taxes), I didn't refill them and never went back to see my doctor. I didn't consciously say "I give up", but at my core, that's what I did.

Then, a friend's relationship suddenly imploded. The vindictive man he loved did everything in his power to put him on the street, so I invited him to take my now-empty second bedroom. No one, including him, knew I had stopped my meds. Not even months later, when I developed feelings for him and playfully strong-armed him into a relationship.

I stealthily continued my abandonment of my health and HIV treatment, focusing on our new life together. I enjoyed myself: spending a small inheritance I had recently received, decorating our apartment, and routinely hooking up – but only with people I knew to be HIV positive. It felt like the “Roaring 20s” and I was living it up.

I let myself be saved by a chorus of three: my doctor, a social worker, and my boyfriend, who told me I could give up if I wanted to but that they had no intention of doing so.

The party ended when the money and my health ran out at the same time, in 2011. For several months I'd been suffering from chronic skin infections and daily diarrhea. By the end of the summer, I was so sick that I let my boyfriend sign me up at an HIV clinic.

When I went to the clinic, I weighed 98 lbs. and had thrush in my mouth and throat, giardia, dehydration, dangerously low potassium, a viral load that was through the roof, and a CD4 count of 2. My stomach hurt constantly and I couldn't eat. I told my boyfriend that I saw no way back and wanted to go home to die in my bed.

Fortunately, instead of listening to my own voice that day, I let myself be saved by a chorus of three: my doctor and a social worker who resolutely told me I could give up if I wanted to but that they had no intention of doing so, and a most stubborn boyfriend who insisted I owed it to him at least to go into the hospital for a few days. Under protest, and completely skeptical that I would ever again see my apartment, I submitted to the trio and was immediately swept off to the hospital.

I was lucky, and got well enough to leave the hospital in less than a week. In those first months after leaving the



hospital, whenever I felt tired or not sure how I'd survive being both broke and in such poor health, I would tell myself I had to try. I owed it to the people who had put so much effort into helping me soldier on.

For the last three years, I've been diligently adherent with my new HIV medication, Complera. I make all my doctor appointments, attend HIV education workshops (like those at ACRIA), and actively participate in my medical treatment. I also participate in regular mental health counseling to avoid isolating myself when I need help. I hope never to succumb to those dark thoughts again.

I am hopeful! Today, my HIV is again undetectable and my weight is a glorious 132 lbs. But my CD4 count has recovered slowly – it's still only 125, and it may be years before it gets above 200 again. I have made it a goal that I will not go to my grave with a CD4 count less than that, so I plan to stick around for a while. As I write this, I am making arrangements to get back to the gym, and my boyfriend (now my partner) and I will be moving into a new apartment within a month. And I owe much of this to a support team of friends and providers – I couldn't have done it without them. In addition, my partner, who is HIV-negative, has recently started PrEP. I am so thankful that I may never have to face him on the sofa for a life-altering revelation. I don't know if this is my last chapter in life, but I plan for it to be a happy one. It's the reward I give to myself and the many whose help I have accepted these past years: to live, and live well. ■

A Magic Pill to End AIDS?

by Anita Radix, MD

Deandre is 26, African American, and gay. He worries about HIV, especially since several of his friends have tested positive over the years. “I try to be safe and use condoms most of the time, but sometimes they just get in the way.”

Each year, about 50,000 U.S. adults and adolescents are diagnosed with HIV. The rates are highest among men who have sex with men (MSM) and they are climbing, especially among young African American MSM, like Deandre. Condom use has been the main focus of HIV prevention campaigns, but this message is not being heard, especially among those at highest risk. Studies in adolescents and young adults have shown that almost 25% of men and almost 40% of women had not used condoms during sex in the last month.

The NYS Plan to End AIDS aims not only to diagnose more people with HIV and improve their access to care and treatment, but also includes a goal to improve prevention of HIV using pre-exposure prophylaxis (PrEP). For this new prevention approach to be successful, there will need to be a major scale-up of resources by state and city health departments, as well as buy-in from legislators, other health sector partners, and communities at risk.

What is PrEP?

PrEP is a daily pill that HIV-negative people can take that greatly reduces their risk of becoming infected. In 2012, the FDA approved Truvada for use as PrEP. Although it made headlines at the time, using anti-HIV meds to prevent HIV transmission was not a new idea. Over 20 years ago, the ACTG 076 study proved that giving AZT to mothers with HIV and their newborns dramatically reduced HIV transmission, by about 67%. HIV meds have also been used to reduce transmission after workplace exposures like needlesticks, and after sexual or injection-drug use exposure. This is known as post-exposure prophylaxis, or PEP. In these situations, the drugs must be given within 72 hours (preferably 36 hours) and taken for 28 days.

Studies of PrEP in people began with the iPrEx trial. Starting in 2007, it enrolled 2,500 HIV-negative gay men and



transgender women from six countries who were at high risk for HIV. They took either a placebo pill or Truvada (a combination of two approved HIV meds, TDF and FTC). The study showed that the rate of HIV infection was reduced by 44% in people taking Truvada. But it is important to know that not all people who were given PrEP actually took the drugs. Based on tests of the level of medication in their blood, only 9% of people who became infected after being assigned to PrEP were actually taking it. Further analyses showed that people who took their pills consistently were more protected against HIV – up to 92%. Later studies, including the Partners PrEP and TDF-2 studies, have confirmed these results, including in injection drug users. It is important to note that in all these studies, people were also offered condoms, comprehensive risk reduction counseling, and STI treatment.

But two studies, FEM-PrEP and VOICE, failed to show any reduction in HIV infections with PrEP. In both, rates of HIV infection were similar among those who received PrEP or placebo. Blood tests showed that people in these studies had very low adherence to PrEP, and this was thought to be responsible for the negative results.

The FDA and CDC Weigh In

The results from these studies provided the evidence that led the FDA to approve Truvada for prevention of HIV among those at high risk. According to recent CDC guidelines, this group includes sexually active adult MSM, heterosexuals who are at substantial risk for HIV, and injection drug users.

Before starting PrEP, a person must have a negative HIV test, no evidence of recent HIV infection, normal kidney function, and must be tested for hepatitis B. Once PrEP is started, people should be tested every three months for HIV, STIs, and kidney function.

Truvada usually has few side effects, but nausea, vomiting, and headache can occur and generally resolve within four weeks. Some studies have also shown a small reduction in bone density among those on PrEP, but no increase in bone fractures. Truvada can be associated with changes in kidney function, so creatinine testing is done on a regular basis.

It's important to closely check for a new HIV infection before starting PrEP. If a newly infected person starts PrEP, it can result in their HIV developing resistance to Truvada. Although some people have been worried about people engaging in riskier sexual behavior while on PrEP, this doesn't seem to be the case. This was studied in iPrEx and a CDC safety study. Both showed that MSM did not engage in riskier behavior (condomless anal sex and higher numbers of sex partners) while on PrEP.

The main limitation of Truvada for PrEP is that it has to be taken every day, and adherence has been a significant issue in all the studies. A long-acting injectable integrase inhibitor is being studied as another PrEP option. GSK-1265744 has been shown to reduce the risk of SIV infection in monkeys. It is currently being tested in the ÉCLAIR study to examine its safety and acceptability (effectiveness is not being studied in this trial, but will be studied later if it is found to be safe). The benefit of this drug is that it may only have to be injected every 3 months, a much easier regimen for those who are unable to take a daily pill.

Real-World PrEP

But many hurdles have to be overcome before widespread access to PrEP can be achieved. Even with the publicity following the iPrEx results, knowledge about PrEP remains low among communities at risk. A study conducted among gay men in Denver showed that only 20% were even aware of PrEP. Public health campaigns need to be created to provide targeted and accurate information about the risks and benefits of PrEP, as well as to counter stigmatization of those who decide to take it.

Unfortunately, the lack of knowledge about PrEP also extends to health care providers. Despite the CDC guidelines, many providers are still not knowledgeable about PrEP, and most have never prescribed it. Some are not comfortable asking patients about their sexual orientation, sexual behaviors, and injection drug use – essential to establishing risk and eligibility. The NYS AIDS Institute recently published a PrEP provider directory that shows very few providers available to prescribe PrEP outside of New York City. Creating other venues for PrEP – through DOH STI Clinics or community health centers – may address gaps within and outside of NYC.

But it isn't just about a pill. Supportive and wrap-around services must be part of any comprehensive prevention plan. Clinical trials

showed that adherence to PrEP is absolutely necessary, and that daily dosing is best. We need to develop and test PrEP education and adherence strategies that can be used by clinicians and staff with busy practices. Ideal adherence interventions should be short (around five minutes) cognitive-behavioral interventions or should use new technologies such as text messaging, phone apps, and other electronic reminders. Counseling about risk behaviors and substance use must be included under the umbrella of comprehensive prevention services.

I heard about PrEP from a friend who worked for a center doing PrEP research. He told me about their study, and I was sold on the idea. But most of my friends ask why I put myself on it. They feel that there's no need to take prep because they think their bisexual practices are very safe. For me, it was important to have extra support in case I had a slip-up, even though I still use condoms. I've been taking it for about ten months now and I feel it's the best thing I could have done for myself. So far there have been no side effects except for a little queasiness in the beginning. I'd recommend this pill to anyone who may be at high risk.

Joseph, 45, gay, African American

Real-World Costs

PrEP is expensive. Truvada costs about \$1,200 a month retail (although most payers will pay less than that), and that doesn't include the cost of the lab tests and office visits that are needed every three months. Even with insurance, there are still co-pays for both medication and office visits. If a person has an insurance plan with a large deductible, this can result in high out-of-pocket costs. Truvada's maker, Gilead, has a patient assistance program for the uninsured, but to be eligible you have to meet specific income criteria. Although this program covers the cost of medication, condoms, and HIV testing, it doesn't cover things like STI and hepatitis B testing. Navigating the insurance requirements and preauthorization requests may create additional burdens for both doctor and patient. Funding for PrEP needs to cover not only treatment, but also the associated medical costs.

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A Magic Pill to End AIDS? *continued from previous page*

Real-World Barriers

The plan to end AIDS needs to take into account that the communities most at risk for HIV often face multiple barriers to health care, including lack of insurance, other cost-related hurdles, fear, stigma, and discrimination. These result in missed opportunities for HIV prevention services. For example, transgender women have an extremely high risk (about 20% have HIV), yet they are less likely to obtain health care due to discrimination in medical settings – including outright denial of care, verbal and physical harassment, and providers who are not knowledgeable about trans-specific health issues.

Many MSM attempting to obtain PEP or PrEP have encountered tremendous hurdles. This highlights the barriers that patients and providers experience when new medications come to market. Newly developed treatments are not immediately used by people in need. Introducing them and encouraging their adoption requires deliberate and coordinated efforts to raise patient and provider awareness, along with education to ensure that both have the information to make informed decisions. We need bold social marketing and educational programs to drive uptake and help the health care systems engage patients and providers.

Young MSM, especially young MSM of color, can encounter homophobia, stigma, and rejection from their families, which makes it difficult to be open about same-sex behaviors. About 10% of gay men do not disclose their sexual orientation to their medical providers. This is even more concerning for bisexual men. In a recent study in New York City, close to 40% of bisexual men did not disclose their sexual orientation to their medical providers, which means they may not get tested for HIV, nor get offered PrEP.

Access to PrEP also needs to be scaled up for women. Women now account for 25% of people with HIV in the U.S., and most acquired it from men. Despite this, heterosexual women may not be seen as being at risk unless they are known to be in a relationship with a partner who has HIV.

Finally, we need to improve the access of adolescents to PrEP. Adolescents and young adults are the group most at risk for new HIV infections, but they have largely been absent from the discus-

sion about PrEP. Minors' access to PrEP without parental consent is unclear, creating an additional barrier. State laws will need to ensure the right of minors to access PrEP.

My lowest point on my journey to get pregnant with my HIV-positive husband was the day my doctor told me she would not prescribe Truvada for me, because it was “unethical” for her to do so. Nor would she keep me as a patient if I continued to engage in such “risky” behavior. I was being judged for my sexual choices, my maternal calling, for my own decisions about my own body.

How different things would have been had I told that doctor I was just trying to stay negative. She probably would have prescribed it because it would have been “unethical” for her not to. I am not a human-sized uterus. I am a human-sized HUMAN.

Poppy, 39, white, heterosexual

Conclusion

Governor Cuomo has an ambitious plan to end AIDS. PrEP is an extremely important addition to HIV prevention services, but there needs to be a realistic understanding of the barriers to its use. Improving access to PrEP means that health care facilities and providers must create a welcoming environment for all patients, especially those who may feel unwelcome due to their gender identity or sexual orientation. Improved access also means that providers have to proactively address sexuality and sexual health with their patients, allowing them to make informed decisions about risk and prevention.

Rolling out PrEP on a large scale can happen only with a massive scale-up of resources, including educational campaigns for consumers, new access points for care, provider training, drug assistance programs for the under- and uninsured, wrap-around services to aid adherence, risk-reduction efforts, and programs that address mental health and substance use. ■

Anita Radix is Director of Research and Education at Callen-Lorde Community Health Center. Sarit Golub is Professor of Psychology at CUNY and directs the Hunter HIV/AIDS Research Team.

Moving Toward PrEP

by *Rafael Ribot*

I came of age during the deadliest years of the epidemic. It was 1994. I was a child becoming a man, and I figured out I was gay. But sex meant certain and horrifying death. Happy 16th birthday – you're probably going to die.

So I didn't deviate from the condom mandate. I withheld myself from sex. I partook only sparingly, but when I did, even with protection, I wondered...if...? That feeling stays with you.

I'm a geek. I educated myself about HIV and transmission. I fell in love during college and let myself experience sex without a barrier with someone I trusted. But there was still doubt. I came to terms with it. I made rules about when and how to take risks, some more logical than others. I chose to take the risk only in the context of commitment, something many couples do. I balanced my desire with my need for caution.

I did my best. We all do. Yet condoms can fail and people are imperfect, and a virus doesn't care how in love you are.

After my last breakup, I decided to try dating. In New York, you're just as likely to meet someone positive as negative. But people are engaging in condomless sex, especially the young. They're experiencing unreserved intimacy, something we all want. They're also getting HIV at a shockingly high rate.

I prepared myself for dating in the proverbial zoo. I would protect myself with a barrier despite many guys being resistant to condoms. Having just come out of a relationship, I had to be strict with myself again. I knew I would be constantly tempted. I told myself HIV status didn't matter. I knew what was a risk and what wasn't, so I went exploring. I could deal with being rejected for not wanting to go bare with a guy. I missed it, but you don't deviate.

It was something I didn't expect of myself that pushed me to look into PrEP. One day I found myself alone in the corner of dimly lit roof with a great guy. It felt electric. Laughter became warmth, and then heat. I remember feeling liquid when he touched me. I was filled with vivid fantasies of everything we would do.

But I didn't fantasize doing it with condoms. Who does?

He closed in and very softly told me he was positive.

I flinched...for a second. Reality crashed in. The color left my face, my mouth went dry. I got tongue-tied. It just happened.

I wanted to say it was fine. He knew it wasn't. A condom would protect me, of course, but my hesitation was unforgivable. Did he intend to use one? I'll never know. I knew I wasn't thinking of condoms at all, until he mentioned

He closed in and very softly told me he was positive. I flinched... for a second. Reality crashed in. The color left my face, my mouth went dry. I got tongue-tied. It just happened. I wanted to say it was fine. He knew it wasn't.

his status and I went numb. He pulled back and I saw the resentment and frustration in his eyes. He walked away before I could utter a word. I had wounded him, without meaning to, irrevocably. My heart sank, and I spent the night consumed with how he must have felt.

I think about how that moment became so joyless. It happens every day. The trauma is woven into the fabric of our community. Overt ignorance and stigma are easy to criticize, but subtle divisions are widespread and enduring. Each side creates a fortress around itself: life before HIV and life after. We forget that once upon a time we were all the same. The only real difference between us is circumstance.

I knew better, but I couldn't suppress the past, and that made me feel powerless. So I did something about it.

I had been hearing about PrEP on social media for a while and got a recommendation for a doctor that specialized in gay men's health. I knew he was already familiar with PrEP, so I asked him about it. He wanted to be certain of

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PERSONAL PERSPECTIVE

Moving Toward PrEP *continued from previous page*

my commitment. My risk was relatively low, but he was concerned about my having unprotected sex in relationships. He pointed out that most people are exposed to HIV in primary relationships. He ordered the required tests, but asked me to consider my decision carefully over the next few weeks. He pointed me to resources where I could review the science behind PrEP and the potential side effects. I ended up being a good candidate. All that was left was to decide.

I consulted close friends and family and found them cautiously supportive. They were concerned about my taking medication, but couldn't ignore the reduction in risk it offered. Neither could I.

I knew I was protected, but it took some getting used to the idea that I could explore intimacy without irrational fears taking the reins. It's a process...working through decades of grim memories takes time.

I started on a Saturday – 10 a.m. daily. I monitored myself closely, waiting for signs of side effects. None came. I knew that after seven days I would have full levels of the drug in my system, but I decided to wait until after my 30-day follow-up visit up to start having sex.

A month passed. I knew I was protected, but it took some getting used to the idea that I could explore intimacy without irrational fears taking the reins. It's a process. You can prevent the virus from infecting you, but working through decades of grim memories takes time. You have to be brutally honest with yourself.

I can understand why guys are conflicted over PrEP. Negative men are curious and wonder if it makes sense for them, but are skeptical. A few are hostile to the idea and refuse to even discuss it. For them, it has always been true that "sex equals risk", and if you fail to heed the warning you have only yourself to blame. Some positive men, who still feel the pain they went

through during the dark years, view anything that looks as hopeful as PrEP with distrust. There is a trail of broken promises leading right to their door.

PrEP can seem unbelievable – a fairy tale – but the research is clear. You take it daily and it lowers your risk dramatically. Socially, it flips the world upside down. The idea can be difficult to accept and requires us to suspend disbelief and look at the evidence without prejudice. Observing its efficacy in the real world will go a long way in convincing people we're on the right track.

There are practical and economic challenges associated with PrEP that cannot be overlooked. There will be people who can't take it or may take it improperly. There's a great deal of misinformation about PrEP, some of it deliberate. It's expensive. It requires self-management and commitment, and it's difficult to access for those who are most in need.

Still, it exists, it saves lives, and it has the potential to help reverse the epidemic if it gets to the people who need it. Moreover, it stands a real chance of breaking down the fortresses we've built around ourselves. We may stop viewing each other through a cloudy lens that makes us see a potential mate as positive or negative, promiscuous or virtuous, sick or healthy, barebacker or condom-only.

What about friend, brother, husband, father, or beloved?

I am more comfortable with my relationship with sex day by day. I am seeing intimacy and relationships through open eyes. I wouldn't say my sexual practices have changed very much, but what has changed is my willingness to fully engage with others. I have no trepidation. I don't see a plus or a minus sign, just people. That small change in thinking has profound implications. Wearing a condom or not no longer feels like choosing life or death.

Sex without a condom is still something I reserve for a relationship, but my motivation is no longer simply self-preservation. Instead, it includes the anticipation of something altogether different and wonderful. Maybe I'll choose to be more liberal in the future, maybe even adventurous. Maybe I'm getting ahead of myself. We'll see. I can make that choice knowing I've taken responsibility for my own health. There will always be risks involved in intimacy, but PrEP promises to help us focus on the rewards.

Imagine a world where HIV status is irrelevant and the only thing that matters between consenting adults is the bond between them. I think all the new prevention techniques being researched, including treatment as prevention, will help get us there. For now, PrEP is helping me move toward that future, one pill at a time. ■

Can We End AIDS in the South?



by Orisha Bowers

I am impressed by the recent proposal to end the AIDS epidemic in New York State. Moreover, I am inspired by the thought of ending AIDS in the South. But pondering whether we could accomplish this daunting task here in the South brings up a number of concerns.

When it comes to health disparities, we have much ground to cover in the South. I have called Memphis, Tennessee, home for almost 40 years. I've been a part of the fight against HIV for the last 15 years, and have served with some great leaders. Will I live to see a time when Memphis is free of HIV?

A Picture of HIV in Memphis

To even entertain the thought of ending AIDS in Memphis, we need to revisit the disease's history here. From 1982 to 2009 there were 21,500 HIV cases in Tennessee. Blacks make up 16% of the population of Tennessee, but 54% of people with HIV. For the last five years, Memphis has had the highest number of HIV cases in the state. So we first have to understand the makeup of the city to begin strategizing how to attack HIV.

The City of Memphis, the urban hub of the region, sits on the Mississippi River in Shelby County, which has a population of over 935,000. Memphis has a poverty rate of 34%, mainly in the African American community, which is linked to poor education, underemployment, and low-wage service jobs. The low level of education directly affects people's ability to process health information and act on it. In addition, the conservative views about HIV of many faith-based organizations are common in Southern Black communities like Memphis.

Blacks make up 63% of Memphis, and the number of new HIV infections among Blacks in Shelby County has been steadily

increasing. In 2008, 85% of all men with HIV in Memphis were Black, as were 92% of positive women. As of December 2010, a total of 7,563 people were living with HIV in the Memphis area. Unfortunately, only 59% of people with HIV in Tennessee are in regular medical care. And that doesn't include people who are aware of their status but have never accessed medical care in the first place.

Examining the data by Shelby County zip codes and listening to community voices, we see that specific issues are linked to HIV risk in heterosexual women and MSM (men who have sex with men) of color: poverty, unemployment, gender roles, dependence on partners, trading sex (for drugs, food, shelter,

When advocates were asked if we could end AIDS with a plan similar to the one being proposed in New York State, each responded affirmatively, but expressed a number of challenges that would have to be addressed.

and protection), limited partner pools, untreated mental health problems, domestic violence, and using sex as self-medication to cope with stigma, racism, and discrimination.

In considering whether Memphis could implement a plan to end AIDS, I believe it is best to hear the voices of the community. When advocates and stakeholders were asked if they believed that we could end AIDS in Memphis with a plan similar to the one being proposed in New York State, each responded affirmatively, but expressed a number of challenges that would have to be addressed for that goal to be accomplished here.

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HIV Testing

Marvell Terry, Executive Director of The Red Door Foundation, said:

I believe targeted testing has increased since the implementation of the National HIV/AIDS Strategy, but we must not let up. Testing should not just be limited to banking hours. How can we offer testing or PEP (see article on page 14) when [someone says] I have just done something that put me at risk for HIV? I may want to get tested Saturday morning before I go to the car wash because I work during the week when most testing services are offered. Where do I go? What do I do? We have to begin to think outside of the box. But with expanded and increased testing we also need more resources and funding to care for more people who know their HIV status.

Similarly, Dr. Martha Ballard, a physician at Complete Healthcare Center, emphasized:

Rather than focusing testing in the areas which have a high incidence of HIV, agencies should focus on making testing available in places where there are large numbers of people. HIV testing should be a part of standard protocol in doctors' offices, and we need increased funding to make testing available at more providers.

To date there are only a handful of agencies funded in Memphis to provide testing in certain zip codes. This creates a skewed view of who is at risk for HIV. Programs should be targeting persons who are sexually active, rather than certain racial demographics. We must also ensure that when epidemiological data are published, they are accurately reported. The public should not be given information that misinterprets the facts or misrepresents the issues.

PrEP in the South

A 2013 survey by Gilead, the maker of Truvada, found that half of all PrEP prescriptions (drugs to prevent HIV – see article on page 14) were for women, and a third were given in the South. But when I asked service providers to name doctors in Memphis who were willing to write PrEP prescriptions, they could only name three. They also had some major concerns about PrEP and PEP and how to integrate their use in the South.

HIV Outreach Specialist Henry Johnson said, “We first need to be able to have a mature conversation about sex in this community. If we can't do that, it'll be very difficult to integrate and promote PrEP. We also need to address substance abuse and mental health in a comprehensive fashion. Last but certainly not least we need to continue to push comprehensive sex education and condoms, and to find resources to address the high cost of PrEP.”

Laronia Hurd-Sawyer, Executive Director of PEAS (Partnership to End AIDS Status) says:

Providers must consider an age-appropriate, continual, and flexible approach to PrEP and PEP. There are major barriers to accessing programs that target youth in Memphis. Most of the rules that govern these programs prohibit working effect-

ively with this population across the board. Currently, there are rules that do not allow youth to access housing, food pantries, and other services, even when they are emancipated. So they end up in relationships with older adults, selling sex for housing or tolerating domestic violence in exchange for housing. We have to develop programs that help them change their behavior instead of focusing on stopping behaviors. We must partner with youth – rather than shoving condoms in their hands, we have to get to the root causes of why they are using sex to handle situations.

According to Marvell Terry:

First, we must educate providers and community-based organizations on what PrEP and PEP are. I hope to accomplish that by being a part of AVAC's PxROAR Program, a program that trains advocates in HIV prevention, research, and advocacy. Secondly, we must get the conversation on the ground and empower high-risk populations to build relationships with their doctors, so they can have an honest conversation about their sexual history. Finally, we must advocate for the expansion of Medicaid in Southern states so that these medicines are affordable.

Entering and Staying in Care

People who test positive need proper treatment. But the advocates I spoke with agreed that people often refuse care because they don't want to have their HIV status disclosed by being seen walking into clinics that only serve people with HIV. Several community members stressed the need to increase the number of providers if clients are to have real access to care.

Dr. Ballard said:

There are numerous barriers to patients accessing and remaining in medical care. HIV stigma continues to play a role, and there are many challenges we face in helping clients adhere to their medications, keep appointments, eat well, exercise, avoid recreational drugs, avoid stress, etc. We as providers must help them take responsibility for their health so they can do what is needed to manage their disease.

Marvell Terry, living with HIV since 2007, added:

One of the barriers to getting people with HIV into care is their fear of what happens after they get their diagnosis. Achieving viral load suppression requires consistency in taking medication. What prevents some clients from achieving this is that they begin to feel better and stop taking the medication. I know this journey all too well.

Helping providers deal with their personal biases and learn the skills necessary to provide quality care and meet the psychosocial needs of their clients will decrease barriers tremendously. We also need to address “clinical inertia”. Providers can become comfortable with patients being nonadherent to their medications or missing appointments – they no longer encourage the patient to do the work needed to stay healthy.

According to HIV Educator Jennifer Warren:

People go to the doctor and they may receive marginal or sometimes poor care. They are usually herded in and out like cattle. There are few providers and very long waits. This causes “fall-outs” with their doctors – yes, people are put out and can be uncooperative, especially if they have mental health issues. Additionally, many people have poor support systems, including a lack of self-empowerment and trouble adjusting to a new life with the virus. Many times, providers and case workers assume that people with HIV understand things because they say “Yes” when questioned or parrot the jargon they’ve heard. In fact, they have a flawed understanding of what is said or what they’re asked.



There can be a great disconnect between doctor and patient. Too often, doctors forget that people grow tired after being in care for a while, so we need to find ways to help them stay in care and continue to make healthy choices over long periods of time. Providers assume that people will do what’s right because it’s good for them. But often that isn’t enough.

Another challenge is mistrust and skepticism of medications and doctors. Many people here have negative perceptions of doctors. They don’t believe doctors have their best interests at heart and so have difficulty listening to their advice. We need to equip clients with the skills they need to select good doctors and to build productive relationships with them. One newly diagnosed client of mine was “not interested in the free government-funded programs” that offer medical care and browsed the provider list looking for a place with a “good name”. The assumption was that “only poor Black gay people go to those Ryan White clinics, and they get substandard care.” She wanted to go to the place she selected or to a private doctor.

Stigma

Stigma plays a big role in HIV care. A study by Vanderbilt University in rural Tennessee found that three main themes emerged regarding HIV stigma:

1. Negative attitudes, fear of people with HIV, and misperceptions regarding HIV transmission
2. Discrimination by families, friends, and medical staff, and in the workplace
3. Self-isolation as a coping mechanism to limit exposure to negative reactions

While Memphis is a large metropolitan area, many people here use the same coping mechanisms. People shy away from care and support services as a way to avoid the stigma associated with AIDS. They may use herbs and vitamins instead of getting traditional care, they may deny their HIV, or they may be in hiding, not to be found until they become sick.

Reaching Men in the South

Community volunteer Kirrik Sanders stated:

We have to be willing to better address the heterosexual Black male if we are going to end AIDS in Memphis. We can’t afford to keep leaving their input out of the plans to end the epidemic. To continue to do this lets them continue to assume they are no longer at risk. We must also consider HIV prevention for those who are incarcerated or recently released. There are so many people in and out of jail. There needs to be a special team brought together to figure out how to increase testing and how to make condoms available for people having sex inside the jails. Waiting for a person to be released and then giving them condoms and an HIV test is way too late.

Many men in the South are raised in homes that follow a religious doctrine that promotes heterosexuality, marriage, and at times promiscuity for men. Men are encouraged to identify themselves by how others see them – usually “strong” or “macho”. Non-heterosexual men often hide their sexual orientation for fear of losing the relationships in their lives.

But many programs in Memphis are designed to reach only gay men and people with HIV. There are no programs targeting straight men. No one is addressing young Black men. There are no interventions that consider the way Southern Black men see the world, themselves, women, or sex. Many programs fail to address the issues that lead to high-risk sex among straight men.

In order to reach men who identify as heterosexual regardless of their sexual behavior, we must dispel the old wives’ tales about sex that permeate Southern culture. We need to address the lack of understanding of human sexuality and pleasure.

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Unfortunately, we have the wrong people on the front lines addressing the issues facing straight Black men in the South. I am aware of only three heterosexual Black men working in HIV prevention in paid positions, all at the same agency. There are several volunteers, advocates, and HIV educators, but they now work in other areas of expertise. The community is saturated with Black MSM educators and peer navigators due to the priorities of the Tennessee DOH and regional community planning group. Paid positions have only been created to reach the Black MSM demographic, using CDC-endorsed interventions. Since high-risk heterosexuals have not been a priority, no programs or staff positions have been funded to target them for many years. Several agencies are trained on interventions to work with heterosexuals, but no funds can be used to serve them.

Additionally, as a result of the shift in priorities to target Black MSM and do “high-impact prevention” the number of agencies funded to do prevention in Memphis has been reduced from nine to four. While the priorities are supported by statewide epidemiologic data, this sharply decreases our ability to address other communities. Having only gay Black men working in the field perpetuates stereotypes and stigma, and limits opportunities to reach heterosexual men.

Also, heterosexual men have to be handled with a sense of “kingship”. Providers must create programs that let them know their lives matter, that they are stakeholders in the fight to end HIV in the South, that they have a say in how we will do the work, and provide opportunities for them to have a place within the work. There needs to be a sense of brotherhood to even get them listening. Straight Black men have to be brought back in as active participants, educators, employees, and leaders. Kingship means their opinions are respected and men are able to speak and do the work needed to end the epidemic.

Latinos

The barriers for Latinos are similar to those faced by others, but are compounded by the language barrier. There is usually only one Spanish-speaking person per agency, which is insufficient to serve the large number of Latinos here. When an agency wants to work in the Latino community, it must partner with the local YWCA or with Latino Memphis (the largest and virtually only Latino health agency in Memphis). But these two agencies are not equipped to handle the needs of our very large documented and undocumented community.

According to bilingual HIV Educator Gabriella Herrada:

There is not enough bilingual staff to do the massive amount of work needed in the Latino community. There is usually one staff member in an entire agency. Usually that person's employment is funded by a grant. When the grant ends, that person is no longer employed there and doesn't stay connected to the community. The work ends up being lost. Additionally, there are no employers supporting programs to enable existing staff to learn Spanish.

Conclusion

Can there be an AIDS-free Memphis? I believe we can do it. But we must be willing to take the time to work honestly and tolerantly

together on the factors that increase risk. We can work to eliminate HIV stigma and discrimination against people with HIV. We can remove the religious overtones from the provision of care and ensure equality in the distribution of funding and resources. Currently, certain agencies receive special preference when new projects and resources are announced, because the funder wants to work with agencies that align with its ideas. Every agency should have an equal chance to apply for new funding opportunities.

Heterosexual men have to be handled with a sense of “kingship”. Providers must create programs that let them know their lives matter, and provide opportunities for them to have a place within the work.

We must hold providers accountable for the way patients are treated and ensure that they help people achieve healthier outcomes. We must become educated about new HIV treatments and trends. We must take advantage of opportunities for professional development and trainings, and we must adequately compensate staff on the front lines so they can remain in the field and maintain their expertise. We must improve care so it addresses clients' needs in a holistic manner. We must grow our provider pool, and we must invest more resources into testing efforts.

Katherine McMullen, Director of AIDS Services for the now defunct Family Services of the Mid-South said:

I do think we can end AIDS in the South. It would have to be an aggressive, multi-discipline approach with input from experts in addiction, medical care, mental health care, housing, sex work, adult education, employment, social service benefits, and children's services. It would need long-term, continuous, and coordinated access to services, along with ongoing monitoring. Such a plan would be expensive, too. It would have to be an innovative project.

We can start by empowering people with HIV with skills to advocate for resources and creative programs. We can work to ensure that funding streams allow providers to tailor services to meet the needs of the people. We can work to eliminate the fear and shame in communities of color around sex and HIV. We can make it okay to talk about what hurts us. We can locate support within our communities, making services available where people live. And we can create safe spaces for people to obtain the care they need without fear of stigma.

We can be AIDS-free by creating partnerships that mutually benefit all interested parties. We can be AIDS-free in Memphis if we just believe in ourselves. ■

Orisha Bowers is an HIV Educator and Linkage to Care Navigator in Memphis.

Racing For The Podium

How many times have you heard someone speak out about the need for resources to fight the AIDS epidemic for their specific community? As the New York State Plan to End AIDS heats up, we've heard it even more often than we have in the past. Nobody wants to be left out. Nobody wants to see another infection occur if it can be prevented. Nobody wants to see inadequate healthcare for those who are in greatest need.

But who determines who has greatest need? What's the criteria? Lobbyists are in overdrive. CEOs and Executive Directors are travelling across the state and going to an extraordinary number of policy and coalition meetings to speak out and demand resources and demand change. A loud voice helps. Many seem to ascribe to ACT UP's slogan: "Silence Equals Death".

But what has been especially fascinating has been how the needs of older adults with HIV have been addressed – or perhaps we should say how they have not been addressed. Almost 50% of people with HIV in the U.S. are aged 50 and older. Think about what that means with regard to need – housing, healthcare, adherence help, care coordination, and clinical guidelines.

By 2020, 70% of people with HIV in the U.S. will be 50 and older.

In a way, this is good news - it speaks to the fact that people with HIV are living longer, and many can expect to have a normal lifespan. It also means that the care of those who are 50 and older will soon be a major issue we need to address. It's time to wake up.

The AIDS epidemic has changed. While continuing to work to prevent new infections, we need to effectively treat existing ones. And the clinical needs of those 50 and older, both newly-infected (10% of new infections) and long term survivors, are different from those of younger individuals. The treatment guidelines that were created for HIV-positive individuals over 20 years ago were for younger adults. Older adults have more

complex health care needs, since they are often dealing with significant comorbidities and multiple psychosocial issues. HIV care guidelines built on the needs of a younger population lose their specificity and their effectiveness.

So what do we need to know? Here are a few places to start:

- Older adults with HIV are developing multiple chronic illnesses 10-20 years earlier than would be expected – these include heart disease, cancers, diabetes, hypertension, kidney and liver disorders, osteoporosis and frailty.
- 80% of older adults with HIV die from of non-HIV related illnesses.
 - Older adults, like their younger peers, are likely to have former and current substance issues, especially with alcohol – we need to address harm reduction for alcohol use and increase alcohol screening.
 - Over 50% of older adults with HIV continue to use tobacco – we need tobacco cessation programs.
 - Older adults exhibit depressive symptoms at five times the rate typically seen in the larger community. – we need to screen for and treat depression.
 - Older adults are more often socially isolated due to the impact of stigma: upwards of 70% live alone with less than 20% having a spouse or partner – we must address their needs in developing stronger social networks.



What needs to be done? Of course, we must continue to try to stop new infections from occurring in our most vulnerable populations. But we also must keep one eye on the horizon – on the long view. The 50% of people living with HIV includes the newly infected, the long term survivor, the virally suppressed, the sexually active, the substance user and abuser, the depressed, the lonely, the homeless, the retired, the male, the female, and the transgender.

As the years progress those 49 and under will move into the 50 and older category, and effective, quality health care addressing their more complex needs has to be ready for them too. People 50 and older is not a health care group of the future. It's a group we need to make sure has quality care now, and any plan to end AIDS must include them front and center. ■

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