What Will It Take?

by Corey Johnson

During a routine physical exam 12 years ago, I received news that changed my life forever: I was HIV positive. I was young, scared, and unsure of what my options were and what my future would hold.

Only in my early 20s at the time, I was forced to navigate our complicated healthcare system both at times when I had insurance and when I was uninsured. Like so many New Yorkers, I had to manage my healthcare proactively while working full time and trying to keep up with our city’s rising cost of living.

The road has not been easy, but I am extremely fortunate that, because of extraordinary medical breakthroughs, an HIV diagnosis is no longer considered the death sentence that it once was. Today, with proper treatment, people with HIV can live long, healthy lives. New prevention options like PrEP promise to reduce the number of new infections dramatically. And as the search for a cure continues, research advances are bringing us tantalizingly close to a breakthrough.

New York State will end the epidemic here by the end of 2020, but we’ve got a long way to go before we do.

Medical advancements need to be matched with progressive, compassionate housing and healthcare policies that ensure that all low-income HIV-positive New Yorkers are in a position to manage their care.

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The bottom line is this: Housing is healthcare.

I can safely say that if I did not have stable housing while seeking treatment, particularly in the earliest days of my diagnosis, I would not be where I am today.

When HIV-positive people have adequate housing, we see that they end up with increased rates of viral suppression and reduced mortality rates. Importantly, their communities see lower HIV infection rates as well.

On the other side of that coin, we have seen that homelessness has a direct and staggering impact on people’s health. A large body of research demonstrates that homelessness and unstable housing are strongly associated with a greater risk of HIV, inadequate HIV health care, poor health outcomes, and early death.

At the City Council, I’m proud to have sponsored “HASA for All” legislation that would expand lifesaving benefits to all low-income New Yorkers with HIV. HASA (the HIV/AIDS Services Administration) is a program that currently provides critical shelter, food, and transportation assistance to people in the direst health circumstances – those who have an AIDS diagnosis, a CD4 count of 200 or less, or two opportunistic infections.

Certainly these individuals need this assistance, but when we wait for people to become sicker before we lend a helping hand, we do them, and ourselves, a great disservice.

Currently, thousands upon thousands of people with HIV – including the 800 or more who reside in NYC shelters on any given night – remain medically ineligible for the publicly funded HIV-specific non-shelter housing assistance, case management, and transportation allowances that HASA provides for people with symptomatic HIV. Homeless people with asymptomatic HIV are often forced into the Hobson’s choice of initiating treatment and remaining homeless or delaying treatment until they qualify for rental assistance or supportive housing.
It’s time to reach these people while we have a chance to change the course of their illness. It’s time to usher in HASA for All. I look forward to working with my fellow elected officials and so many incredible advocates to make this goal a reality. Indeed, I’ve been greatly encouraged by my colleagues in the City Council, who have joined in the effort to end the epidemic in a number of crucial ways.

Together we’re working to channel modern scientific breakthroughs in ways that have a profound impact on HIV-positive New Yorkers. Last year, City Council Speaker Melissa Mark-Viverito and I announced a new $6.6 million City Council initiative that will fund new prevention and support services, as well as the largest PrEP and PEP access program in the nation.

This funding will allow us to make sure our health care professionals are fully trained on these treatments so they can offer their clients the most effective care possible. It will support education and training for those who work with high-risk clients, and it will support expanded PrEP and PEP access for young people of color. This initiative will help us reach out to those who exhibit the highest risk for HIV, and it will allow us to get them the education, testing, and medical assistance they need to stay HIV-free.

Governor Cuomo has provided game-changing leadership on this front as well. With his announcement last year that he will seek an additional $200 million for supportive housing and health care programs for people with HIV, he is solidifying New York State’s place as a national leader on this issue.

Similarly, Mayor de Blasio’s commitment of $23 million toward new prevention and health care programs for people with HIV, he is solidifying New York State’s place as a national leader on this issue.

We’re on track to prevail against HIV, but we cannot let up. We need to continue with unabated determination, using every tool at our disposal. If we stay focused and keep fighting, I have no doubt whatsoever that we can and will end the epidemic once and for all.

Corey Johnson represents the 3rd District in the New York City Council, covering neighborhoods on the West Side of Manhattan, including Hell’s Kitchen, Chelsea, Greenwich Village, Hudson Square, and parts of SoHo and the Upper West Side. He also serves as Chair of the Committee on Health.

Homeless people with asymptomatic HIV are often forced into the Hobson’s choice of initiating treatment and remaining homeless or delaying treatment until they qualify for rental assistance or supportive housing.
Sex Education Can Help End The Epidemic!

by Sara Flowers, DrPH, Deborah Levine, LCSW, and Mia Ragozino

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.

– World Health Organization

In the field of public health, there has been an important shift away from blaming people for any negative health outcomes they may experience. Instead, the field acknowledges the ways in which different influences (social, political, and economic) contribute to individual and community health.

Sexual health outcomes, including unintended pregnancy, HIV, and other STIs, are very much included in this shift, for many reasons. First, high-quality, comprehensive sexuality education goes beyond helping students learn how to use condoms correctly or gain access to reliable contraception (though these remain critical components of the work). Truly comprehensive sexuality education is sex-positive, includes all gender identities and sexual orientations, and empowers youth to build their knowledge and skills.

The research is clear: youth experience negative sexual health outcomes at rates higher than adults. One in four adolescents will contract a viral or bacterial sexually transmitted infection (STI). The number rises to one in two by age 25. According to the 2011 Youth Risk Behavior Survey (YRBS):

• 61% of New York State high school students reported they had sexual intercourse by 12th grade. Over 20% had sexual intercourse by 9th grade.

Youth experience negative sexual health outcomes at rates higher than adults. One in four adolescents will contract a viral or bacterial sexually transmitted infection. The number rises to one in two by age 25.

• 13% of students did not use any method to prevent pregnancy during their last sexual intercourse.
• Only 11% of sexually active students used both a condom plus another birth control method (recommended to address both pregnancy and STI/HIV prevention) during their last sexual intercourse.
• Youth with special circumstances, such as youth in foster care, have significantly higher rates of sexual activity and pregnancy. Nearly a third of young women in foster care reported that they had been pregnant at least once by age 17.

Reproductive and sexual health issues are key for adolescents and young adults, and the one-sized-fits-all approach is missing the mark – especially for those who are most vulnerable, namely youth of color and those who identify as lesbian, gay, bisexual, transgender, or questioning (LGBTQ). Love Heals, Inc. believes that young people who are provided age-appropriate, medically accurate information will develop the knowledge and skills they need to stay healthy, while learning the advocacy skills they need to tackle the larger systemic issues that contribute to their sexual health.

Social Drivers, Youth, and HIV
Systemic factors are major drivers of the HIV epidemic. When risk-taking behaviors are otherwise equal, factors such as poverty, poor health care, systemic inequality, and location elevate risk for HIV transmission. As a result, youth of color and young men who have sex with men continue to have a higher risk for HIV infection than their peers.

Living in poverty increases the likelihood that a young person has limited or no access to quality health care. As a result, they may delay HIV and STI testing, or not be tested at all, increasing their time without treatment if they are infected. Improving access to youth-friendly clinical care could increase the number of young people who have access to condoms, HIV and STI testing, and treatment. This could help decrease transmission in two ways: through the consistent use of condoms, and by adherence to HIV medications, which reduces viral load.

Systemic inequality perpetuates HIV transmission in numerous ways. First, racist and discriminatory police practices, such as Stop-And-Frisk and increased surveillance in schools (part of the “School-to-Prison Pipeline”), target youth of color and those who identify as LGBTQ. These are the same young people who are more likely to live in unstable housing or poor neighborhoods, to experience homelessness, or to be victims of harassment and bullying. They are more likely to be arrested, subjected to frequent and harsher disciplinary action, and experience overall marginalization at rates much higher than youth who are white and/or heterosexual.

Stop-and-Frisk policies target youth of color and LGBTQ youth, resulting in arrests for prostitution if condoms are found. By criminalizing condom possession, law enforcement actually increases the risk of HIV transmission in those who are trying to prevent it. Youth exposed to the criminal justice system often experience social isolation due to homophobia and transphobia, and often receive little support from adults. This increases their risk for HIV infection by maintaining the status quo of unjust school rules and law enforcement practices.

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In order to combat these practices and decrease HIV transmission, larger strides need to be taken so that social systems promote fairness rather than impeding it. Enacting legislation can help spark systemic change. By working to change NYC police leadership and enacting an anti-racial-profiling bill, Mayor Bill de Blasio’s administration is attempting to dismantle the School-to-Prison Pipeline, end Stop-and-Frisk, and decriminalize condom possession, which collectively can shift the impact those policies have on HIV transmission.

Bolster HIV Prevention Education in Schools

The National HIV/AIDS Strategy (NHAS) states that everyone needs to be educated about how to prevent HIV. It follows that HIV education should be a part of health education nationwide. Aligned with the NHAS, New York State mandates that HIV prevention be taught in grades K-12. As a result, the NYC Department of Education recommends that young people receive sexual health education for one semester in both middle and high school.

However, this sex ed requirement is neither funded nor enforced during curriculum design and planning for middle and high school students. For those reasons, more could be done to bolster prevention efforts across the state and to help meet the objectives outlined in Governor Cuomo’s End the Epidemic (ETE) Blueprint.

Of all age groups, young adults aged 20 to 29 had the most HIV diagnoses (36%) in 2014. The Northeastern U.S. had the second highest HIV rate: 14.2 per 100,000 people. The only region experiencing higher HIV rates was the South, at 18.5 per 100,000 people. The only region experiencing higher HIV rates was the South, at 18.5 per 100,000 people.

In addition to the steps described in the ETE, Love Heals suggests the following ways to help decrease HIV transmission rates in youth, which will in turn bring HIV diagnoses down to the goal of 750 per year in NYS.

Teach Sexual Health Education

There are many ways in which schools and youth-serving community-based organizations (CBOs) work around systems that perpetuate health inequality, including risk for HIV. One of the most important ways to prevent HIV transmission is to strengthen the methods by which young people develop the knowledge, skills, and abilities needed to navigate their schools, neighborhoods, and communities. Providing quality comprehensive sexuality education is one way to help bolster this skill set.

By mandating comprehensive sexuality education for all public school students in grades K-12, New York State could establish a strong foundation of health-based knowledge, skills, and behavior.

Quality sex education is age-appropriate, clear, concise, medically accurate, skills-based, includes all gender identities and sexual orientations, and teaches both consent and pleasure. The ETE recognizes that this is a cost-effective way to prevent HIV transmission. By mandating comprehensive sexuality education for all public school students in grades K-12, as outlined in the National Sexuality Education Standards (NSES), New York State could establish a strong foundation of health-based knowledge, skills, and behavior. This would set the stage for HIV prevention and sexuality education nationwide. Healthy sexual development is a lifelong process, so expanding sex education to the elementary level will position students in New York City to:

• Avoid unintended health outcomes, including reducing HIV, STIs, and unintended pregnancy.
• Learn to communicate effectively about sexuality and sexual health with family, friends, partners, and clinicians.
• Develop a sense of autonomy over their own bodies and learn to respect the autonomy of others.
• Understand and practice consent.
• Develop a sense of dignity and respect for all people, regardless of sexual orientation or gender identity, and speak and behave inclusively.

Quality comprehensive sexuality education should be taught by professionally trained, culturally similar sexuality health educators.

In New York State, there are over 2.6 million public school students in grades K-12. Of these, 25% are Latino and 18% are African American. Culturally appropriate sex education is tailored to the students’ values, beliefs, traditions, and lifestyles. Sexuality is inherently rooted in an individual’s own culture. Therefore, an understanding of that culture – its norms and expectations – will help ensure that the teacher meets students where they are, and increases the chance that the skills being taught match their community values.

Engage Youth in Prevention Activities

Youth-Adult Partnerships, a team-based approach in which young people and adults collaborate as equal partners, is a driving force of youth development and civic engagement. The World Health Organization suggests that such partnerships are critical components of HIV education and reproductive health programs, stating “Youth should be involved from the start as full and active partners in all stages, from conceptualization, design, implementation, feedback, and follow-up.” Partnerships that mobilize young people and adults in the fight against HIV need to be put into practice more widely, particularly when working to lower HIV infection rates in youth of color and LGBTQ youth.
Condom Distribution is Effective

Worldwide, community-based condom distribution efforts are recognized to be a cost-effective HIV prevention method. Youth-led condom projects, such as the one led annually since 2009 by alumni of Love Heals’ Leadership Empowerment and Awareness Program (LEAP) for Girls, integrates a youth-adult partnership model with proven intervention approaches to make female and male condoms and lubricant widely available to youth and adults alike.

It’s important to note that youth-led condom distribution efforts have a positive impact both on the youth doing the outreach and on the community they serve. The initiative makes condoms available and acceptable in the community, while helping young people develop health knowledge and leadership skills as they talk with community members of all ages. Youth in Love Heals’ condom distribution projects say the experience had a positive impact in numerous ways: They grew as individuals, learning to initiate conversations about the importance of consistent condom use, while providing members of their community with HIV prevention tools they might otherwise have gone without.

Through youth-adult partnerships, Love Heals’ Youth Advisory Council has developed a series of projects aimed at spreading awareness about PrEP. From handing out educational pamphlets and safer sex kits to performing at the Brooklyn Museum’s LGBTQ Teen Night, YAC members have used their knowledge of historic social justice struggles and their public speaking skills to advocate for change.

Youth Are The Experts

In order to achieve the ETE’s objectives, educators, policy makers, and researchers need to clearly embrace the notion that young people know best. Young people know best how to communicate with other young people – including what language to use and which modes of social media to engage with. They know best the specific barriers young people face when using protection or getting tested. They know best the stigma facing young people who are LGBTQ or who have HIV.

Young people understand that they are cornerstones in their communities. With adult support and guidance, their efforts to make positive change will be successful. As Common says in his song, “Glory”, “No one can win the war individually. It takes the wisdom of the elders, and young people’s energy.” By listening to youth, and giving them the opportunity to use their voices and implement their ideas, we will find new insights about how best to achieve Governor Cuomo’s objectives and finally End the Epidemic.

Sara Flowers is Director of Love Heals’ Youth Initiative, Mia Ragozino is Manager of its Youth Advisory Council, and Deborah Levine is Executive Director.
I Choose To Not Be Silent

by Kalvin Leveille

It’s early Friday morning on a warm Spring day in early June. I’m standing in front of a class filled with about 30 teenage girls from all racial backgrounds, at the Young Women’s Leadership School in Queens. As I begin to speak, I immediately have their attention. I can hear a pin drop. As I move through my presentation, they cling to their seats. They follow each word with anticipation, as I share an emotional story about a dear friend:

“A few years ago, a longtime friend went missing for about five days. His name was Orlando. No one heard from him. He was not answering phone calls, replying to texts, or posting any messages on Facebook. So my other friends and I began reaching out to his family. None of us thought his disappearance was life-threatening, but we were concerned nonetheless. Through further investigation, we learned that he had committed suicide a few days earlier. We were all heartbroken. But naturally, our next response was to try to figure out what caused him to end his life. His mother told us that Orlando had discovered he was HIV positive a few weeks ago. He became depressed and didn’t know how to live with it. That was the moment when my heart really sank. It was another life-changing moment for me.”

Had I been brave enough to tell him that I was HIV positive, he would probably still be alive. I still believe that to this day. We could have supported each other. We could have gone to the doctor together. We could have spoken about the challenges of taking our meds. But just like him, I was too scared to tell anyone about my status. I didn’t know how to stand in my own truth. I kept my HIV diagnosis a secret for six months after finding out. I didn’t tell a soul. It wasn’t until Orlando died that I decided it was time for me to be brave. I didn’t want any more of my friends who might be suffering to feel alone.

Since joining Love Heals’ Speakers Bureau as a Freelance Health Educator many years ago, I’ve had the privilege of traveling throughout New York City to tell my personal story about living with HIV to college and high school students, similar to the school mentioned above. In addition to sharing my own story, I’ve also educated young people about ways to prevent HIV, and raised awareness about this epidemic that continues to affect us locally, nationally, and globally. Although my goal is to ultimately decrease HIV infections among young people, I also aim to provide contextual insight, share preventive tools, and reintroduce the element of humanity that is so often excluded from the HIV prevention narrative.

There is an amazing quote by Brené Brown, “Every time you tell your story, you make it easy for someone else to tell theirs.” I agree with that, and I have continued to experience it time and time again.

As an HIV-positive speaker, I have shared my story with over 25,000 youth throughout the metropolitan area. As a result, I’ve noticed that I have inspired young people to share their own stories. After seeing the girls’ reaction to me disclosing my status, I began to pay closer attention to how my audience responded to my story. I became more aware of and in tune with the different ways that audience members process
and respond to the information I provide. I realized that telling my story inspired them to share their own stories. There is an amazing quote by a researcher named Brené Brown, “Every time you tell your story, you make it easy for someone else to tell theirs.” I agree with that, and I have continued to experience it time and time again.

Since I have been telling my story at schools and CBOs, some young audience members have requested counseling for past sexual abuse trauma. Others have disclosed their HIV status to me, and for many of those young people, that was their first time doing so. Last year, a 15-year old girl from Long Island approached me in tears, completely distressed and desperate for help because she was more than four months pregnant and had not told anyone. These are just some examples of how sharing my own story helped others share theirs.

The common thread that remains clear and consistent with every single presentation I give is that many young people have stories locked within them that need to be told. Due to fear of judgment, stigma, lack of acceptance and validation, endless ridicule, projected shame, lack of compassion, and disapproval, young people choose to conceal their stories and wear masks instead of asking for help.

How can we expect young people to demand that others recognize the value of their bodies if they don’t acknowledge it themselves? How can we teach about HIV when we so often forget that the H stands for “human”? How can we expect youth to ask for help if they have been taught to conceal their pain?

I have always said young people are truly the most resilient people alive. They are growing so fast. They’re literally on the brink of adulthood, and in this digital age they have access to so much information at the tap of their finger.

So telling my story is about much more than just HIV education and awareness. It is the first step for many toward healing and addressing an epidemic of silence. As we continue to address HIV prevention, I hope we can remember the humanity that links us all, regardless of our HIV status. We all want to be seen, and we all deserve to be seen, flaws and all. The moment we start talking to each other about what’s really happening in our lives – without fear, shame, and judgment – is the moment we can start healing and see the value in ourselves and each other, making better informed and healthier decisions.
A key component of New York’s Plan to End the AIDS Epidemic (ETE) is to lower new infections, and one strategy for that is increasing access to PrEP. While the use of PrEP has increased since it was approved in 2012, its use in the communities where it is most needed remains low. What can we do to change this?

Where We Are Now

The number of new HIV diagnoses is falling – the CDC reported a 19% decline from 2005 to 2014. In New York State, they declined from 5,712 in 2000 (the first year HIV infections were reported) to 3,512 in 2013, a 38% reduction. In New York City, they declined from 4,619 in 2000 to 2,615 in 2013, a 43% reduction. Clearly we are making progress.

But these declines don’t hold true across the board. In fact, the CDC reports that the number of new infections is actually rising among Latino men who have sex with men (MSM) – their rates are up 24%. Black MSM, women of color, and transgender women also have higher rates of infection than other groups.

The numbers are staggering. Without effective interventions to stop this trend, half of all Black MSM and 25% of Latino MSM will be diagnosed with HIV in their lifetimes. These communities, along with women of color, transgender women, and intravenous drug users, are the populations most in need of prevention tools like PrEP.

Prevention and the ETE Plan

Prevention of HIV infection is critical to achieving the goals of the Ending the Epidemic Plan, and it calls for more access to PrEP. It recommends focusing on four primary areas:

1. Statewide education and awareness campaigns
2. Measures to address affordability and cost
3. Enhanced availability
4. Expansion of pilot programs in settings most likely to reach people at greatest risk

PrEP is a once-daily pill, Truvada, that can reduce a person’s risk of getting HIV by over 90%, and possibly as high as 99%. With such high effectiveness, PrEP should be the “easy” solution to achieving fewer infections for all groups. Unfortunately, it’s not as simple as that.

First, before being prescribed 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. Along with taking a pill every day, being on PrEP requires HIV, STI, and kidney function testing every three months, counseling about the use of condoms to prevent STIs, education about harm reduction, and counseling to stay adherent. Side effects are few, which is a plus. The main drawback is that PrEP must be taken every day for maximum effectiveness, which can be an issue for a number of reasons. Other factors can also pose barriers to access.

The ETE Plan recognizes that a “one size fits all” strategy for increasing access to PrEP won’t work. The Task Force that authored the Plan cautioned that, in order to be effective, the Plan must continuously study the key groups most affected by the epidemic, at continuing risk for new infection, and most disadvantaged by the health, economic, and racial inequalities that lead to new infections.

We are still gathering data on PrEP use, both in NYS and on a national level. But even at this stage, the data show that the increased use of PrEP since 2012 has been primarily among white gay and bisexual men.
With respect to PrEP, the Plan recommends that special care be taken to ensure that MSM of color are reached through education campaigns that resonate with them, because PrEP is likely to have the most impact in that group. The Plan also recognizes that lack of stable housing and stigma are two very important factors that, unless addressed, will continue to contribute to poor health outcomes, including new HIV infections.

**Progress So Far**

We are still in the early stages of gathering data on PrEP use, both in NYS and on a national level. But even at this stage, the data show that the increased use of PrEP since 2012 has been primarily among white gay and bisexual men.

Findings from a New York City Department of Health study showed a substantial increase in PrEP prescriptions in NYC outpatient care practices from 2012 to 2014. The largest increase was found in primary care practices in the Chelsea/Village area. So, although the number of prescriptions is increasing overall, it isn’t going up in the communities that are at highest risk for infection.

Gilead, the manufacturer of Truvada, reported in June 2016 that there are broad racial differences in the use of PrEP, White MSM are using it more, despite the fact that Black and Latino MSM have higher rates of HIV. Based on CDC data, only 5% of people engaging in high-risk behaviors have used PrEP since it was approved in 2012.

Our own experience at Harlem United reflects what the data show. In our health and wellness centers, where some 90% of our clients are Black and Latino, we see first-hand how slow the uptake of PrEP has been. Dr. Keith Joseph, our Chief Medical Officer, cites several factors as contributing to this, including lack of information about PrEP, the cost of Truvada and the required follow-up care, lack of access to health insurance, and difficulty in navigating the insurance system.

But these challenges are actually the easier ones to address. The more difficult challenges that we see, and which were recognized by the ETE Task Force, are those that arise from the social determinants of health so deeply imbedded in the communities most at risk for HIV: poverty and the lack of basic needs like housing and food. These take priority over health care and limit focus on the future.

Dr. Joseph points out, “You really can’t expect someone to take medication if they are starving or worrying about where they are going to sleep tonight.” Stigma and shame around sexuality, sexual orientation, and gender identity are also major barriers to addressing either HIV or PrEP. In addition, as a result of past human rights violations rights in clinical trials such as the Tuskegee syphilis experiment, many people in communities of color distrust the medical profession as a whole. This distrust is another barrier to accessing health care and any form of HIV prevention, including PrEP. We also know that mental health and substance use issues compound the already significant barriers for many people who might otherwise be prime candidates for PrEP.

**Swallow This**

Despite the challenges, in the past couple of years substantial progress has been made in getting the word out about PrEP and making it more available. Education and awareness campaigns have increased and are showing effectiveness.

Harlem United’s “Swallow This” campaign (harlemunited.org/PrEP) is one of a growing number of campaigns raising awareness and increasing education about PrEP. Now in its second year, it specifically targets HIV-negative Black and Latino MSM living in Harlem, the South Bronx, and Washington Heights. It features print ads in bars and at bus stops and bodegas, digital outreach on dating
When we first rolled out “Swallow This”, some of our clients were embarrassed by it. Others thought it was cool. Regardless of their reaction, it got people’s attention and got them talking.

is a sex-positive campaign that is plastered across the city’s transit system and online. It promotes the city’s PlaySure kits – pouches that can hold the user’s choice of prevention tools, such as condoms, lubes, PrEP, etc. The campaign also promotes the city’s message of combination prevention to end HIV as an epidemic.

Another information campaign launched in New York is the Department of Health’s PrEPforSEX campaign (preppforsex.org). The campaign has had widespread coverage throughout the State in bus shelter ads, billboards, convenience store ads, and ads on dating sites and on other social media designed to reach target audiences.

PrEP Stigma

In addition to promoting education and awareness about PrEP, these campaigns can help normalize the conversation about sex and sexuality and reduce some of the stigma that surrounds these topics. The more these campaigns become a part of daily life, the easier it can be for someone to have a conversation with a provider or partner. These campaigns can also help to combat the disinformation campaign that started shortly after PrEP became available. PrEP was called a “party drug” by some, with warnings that it would lead to promiscuous sex. Even though the initial backlash against PrEP has died down, we still hear from some clients that it just makes it easier for people to have sex without being accountable. This attitude creates fear and stigma around starting PrEP.

Educating the medical community about PrEP is as important as educating potential users. NYS has undertaken many clinical education initiatives, with both in-person and online trainings, including training about payment. In addition to understanding the clinical aspects of PrEP, our own experience tells us that some providers who have not worked in the world of HIV are not comfortable asking the questions needed to determine if someone would benefit from PrEP. And if providers aren’t comfortable starting these conversations, their patients are not likely to be comfortable asking their own questions. An important chance to talk about HIV can be wasted.
Access
Options to help with cost are improving. Medicaid and most insurance plans cover the cost of PrEP, which runs about $1,400 a month. The required lab tests and primary care office visits required for PrEP may not be covered, however, or may come with co-pays. On January 1, 2015, the State rolled out PrEP-AP to provide access to PrEP for under- and uninsured people (800-542-2437). It provides reimbursement for medical care for HIV-negative people who need PrEP, but does not cover medication costs. For that, Gilead also has a program that provides Truvada for those who meet the income requirements (855-330-5479).

The State is increasing access to PrEP by offering it at STD clinics, including PrEP starter packs, insurance connections, and navigation to primary care providers. A pilot program is in process for syringe exchange programs, which serve large numbers of people who are eligible for PrEP, to implement PrEP linkage and navigation. NYC DOHMH is working with 70 community-based clinics to start providing PrEP in underserved areas in the city. The more available PrEP is, and the more it is imbedded in clinics and locations that serve the communities most in need, the more successful we will be in reaching them.

More of the activities that the State has undertaken to implement the Plan’s recommendations can be found in the Ending the Epidemic 2015-2016 Activity Report (health.ny.gov/ete).

Where Do We Go From Here?
We are making progress. The State and City, working with community-based health and social service organizations, are attacking PrEP from a variety of angles, but there is still much work to be done.

Addressing culture-based stigma around sex and sexuality is essential. For many, even going to a doctor is not a cultural norm. Providers must understand and help combat this stigma. Making PrEP and other HIV prevention strategies a part of routine primary care will help to normalize and reduce stigma. Using peers to guide and support people through this process can be useful, but this requires training and must be funded. Integrating PrEP care into settings that promote sex-positive approaches, including community-based primary care and other non-HIV clinical settings will also help. Stigma may also be addressed by partnering with nontraditional, community venues like churches, faith-based organizations, and family planning centers.

We need more public health campaigns targeted to Black and Latino MSM, women of color, and the transgender community with accurate information about the risks and benefits of PrEP. We need culturally competent social marketing campaigns aimed at those most in need.

We must continue and expand provider education efforts to ensure they are addressing PrEP in culturally competent ways. Providers must proactively address sexuality, sexual health, substance use, and other behaviors that put their patients at risk. This means they must be comfortable addressing these issues with their patients and must create a welcoming environment for patients to discuss them. Education of this type should be part of the curriculum in all medical schools. Providers must also recognize and be willing to address the distrust of the medical profession that some of their patients may experience based on historical abuses in medical care and research.

Taking steps to make the PrEP process more user-friendly will make it easier to access. One way is to combine PrEP specialists with primary care services to help patients navigate insurance and services. These navigation services must be reimbursable.

New medication delivery systems, including monthly or quarterly injectable meds, may help with adherence issues. Adherence can also be addressed by taking advantage of easy-to-use technologies like text messages, phone apps, and other electronic reminders.

All of these strategies must be accompanied by funding: Cash-strapped CBOs, which are most likely to make the greatest impact, cannot take on new initiatives without adequate funding.

Making PrEP services available at the locations and times convenient to the communities most in need will also help increase PrEP uptake. Harlem United is partnering with New York Presbyterian/Columbia University to provide services in our mobile medical unit for extended hours, and one of our focuses is providing PrEP services. Harlem United will take advantage of NYP/Columbia’s navigators, with hours that are convenient to reach young MSM of color.

All of these strategies must be accompanied by funding in order to be successful. Cash-strapped community-based organizations, which are most likely to make the greatest impact, cannot take on new initiatives without adequate funding.

Conclusion
Reducing new HIV infections in New York State to 750 by 2020 is an ambitious but achievable goal. The reduction must happen across all populations, however, not just in select communities. We cannot address the slow uptake of PrEP in communities of color – the very communities most at risk for HIV – in a vacuum.

The most complicated barriers to access and adherence are the social determinants of health. Many Harlem United clients are focused only on making it through today and worrying about where they are going to sleep tonight, not on taking ownership of their health. And our experience is not unique. Creating social media campaigns and educating providers are important activities, but in order to make real and lasting change, we must address the systemic issues facing the communities most at risk for new infections. Poverty, homelessness, mental health, substance use – we must prioritize all of these in order to achieve our goal.

Jacquelyn Kilmer is Chief Executive Officer at Harlem United Community AIDS Center, Inc.
Among my friends, I am known as the “HIV guy”. This has nothing to do with my HIV status, but rather is due to my job: I work as an HIV Educator. Unfortunately, despite many advances in treatment and social issues, anything related to HIV is still considered a “big secret” by many in my community. When it comes to the people I know, the ones most likely to open up about their HIV status, or even just talk about HIV, are white. In the Latino community, you simply do not talk about it. I also have very few HIV-positive Latino friends who have come out of the “HIV closet” compared to my white friends. The biggest obstacle to PrEP in my community is HIV Stigma!

Many people who tell me that PrEP is too toxic expose themselves to nicotine, alcohol, and recreational drugs, and never think twice about the impact of those substances on their overall health.

PrEP first became available back in 2012. Yes, it’s been around for that long, but it seems that only now are people in my community finally talking about it. I have very few friends on PrEP, and some are embarrassed to talk openly about it for fear of being judged. This issue in particular does a great disadvantage to my community – if we don’t talk about it or share our real-life experiences, people will just continue to believe everything they read about it online.

My friends who have decided not to consider PrEP have many reasons:

“It’s too toxic.”
“It doesn’t work.”
“I have a partner.”
“I don’t sleep with many guys.”
“I screen my sexual partners.”
“I’m a top, and tops don’t get HIV.”

Toxicity seems to be the most popular reason people I know decide not to consider PrEP, but many of the same people who tell me that PrEP is too toxic expose themselves to nicotine, alcohol, other medications, and recreational drugs, and never think twice about the impact of those substances on their overall health.

Another issue I find is that many people I know decline PrEP because they are in relationships and consider themselves to be at very low risk for HIV. But I know many of them have sex outside those relationships and don’t always use condoms when they do. I know this is a bigger issue that goes well beyond PrEP. I wish our community would begin to talk about the fact that some people may not consider sex with only one partner for the rest of their life an ideal.

Some of my friends decided to start PrEP with the idea that they would no longer use condoms. To them, PrEP was the answer for condomless sex. They felt a sense of freedom – a rebirth of the sexual revolution after decades of having condoms as their only protection against HIV. But one of them got gonorrhea twice and syphilis once since starting PrEP a year ago, and is now rethinking his sexual freedom.

I’ve been in situations where I’m ready to put on a condom but have been told, “You don’t need to – I’m on PrEP.” But I wonder: if they’re ready to have anal sex with me without a condom, does that mean they’re doing it with others? My answer is always the
same: I use a condom because PrEP does not protect me against other STIs.

Many people forget that PrEP is not 100% effective – it’s supposed to be used with condoms. Birth control pills are also not 100% effective and have a long list of potential side effects, and some women become pregnant while taking them. But society accepts these facts. We have seen just two cases of people getting HIV while on PrEP, and people are already losing faith in its efficacy.

If we had a pill that protected against chlamydia and gonorrhea, people would be more than willing to take it. I have tons of friends taking medications to suppress herpes without any concerns or fear of stigma. Why? Because herpes does not carry the same stigma as HIV. A herpes diagnosis is something common that can happen to anyone, but HIV stigma is so strong in my community that an HIV diagnosis is seen as something that only happens to “certain people”.

It’s much easier for people to just ignore the problem. Many do not even want to think about HIV at all, much less take a daily pill to prevent it. Wrong, outdated messages continue to damage our community – their perception of risk is shaped by how attractive or sexy a person looks. The amount of misinformation I hear from friends, and even social service professionals, is remarkable. Many of these myths come from the ’80s and continue to haunt people today. One in particular that comes to mind is, “If I had HIV I would know it.” Why would you take a pill to prevent HIV if you thought your risk for it did not exist? Many gay Latino men lack a clear perception of risk, leading them to make health decisions based on myths, not science.

I was recently talking about PrEP to another gay Latino friend at the gym. He clearly expressed his dislike for it, saying that PrEP was only for people with many partners, and that long-term side effects were a big problem. He said he would never use it. He added that he was able to tell if someone was HIV positive by looking, and would never have any kind of sex with someone who had HIV. To him even a kiss would be too risky. As we continued to talk, I tried to educate him about basic HIV risk, but he wasn’t interested in any other point of view. The conversation about PrEP ended, and his final advice to me was to try steroids to increase my muscle size! Clearly, we have a huge disconnect in our communities as to what is socially acceptable and what is not. The use of performance-enhancing drugs has been linked to severe negative health outcomes but is not stigmatized by many.

I was recently talking about PrEP to another gay Latino friend at the gym. He said he would never use it. He added that he was able to tell if someone was HIV positive by looking, and would never have any kind of sex with someone who had HIV.

We are asking people to take a pill to prevent HIV when many of them are unable to even ask for an HIV test for fear of being outed as gay. How can we expect our community to embrace PrEP when people are afraid to be seen taking an HIV med, even though it’s just for prevention?

I think many of the prevention messages in my community are misunderstood. Messages like “Undetectable = Uninfectious” are being disseminated by word of mouth and not by medical providers or community educators. Once again, we see stigma in action – many people are more comfortable Googling in private than visiting a community-based organization and running the risk of being seen. If we can’t even talk openly about HIV, how are we going to talk about medications to prevent HIV?

But the Latino gay community in New York is resilient. I am confident that through community efforts, targeted outreach, and proper social messages, we as Latinos will soon come together and embrace the possibility that HIV is not “the monster”, and that any sexually active person – no matter what age or gender – may be at risk for HIV.
“People don’t think about transgender people in the picture of AIDS. In the Village, for years, for decades, there were transsexuals, male to female, which is what I’d like to talk about – the Village has always had tons of them. Basically on every block lived one or a few of them. Slowly, the AIDS epidemic came up, and it engulfed everyone. I can tell you that now that I’ve been living here; there is nothing, there is hardly anything.”

AIDS in the Transgender Community

These words were written by Nora Molina in 1996 and are still true today, over 20 years later. Nora was an out, HIV-positive, transgender Latina – a former sex worker and peer educator at the Gender Identity Project (GIP) at NYC’s LGBT Community Center. The epidemic eventually claimed her life in 2009.

I had the good fortune to work with and learn from Nora in 1998 and 1999, when we both worked as peer educators at The Center. Together, we conducted outreach to transgender clubs and street sex workers. Nora was rarely seen without her bicycle and was always the only one with a helmet in the clubs we visited. She was a formidable and inspiring sight on the street.

Building the Movement

Leaders like Nora were the roots of today’s transgender movement and helped build the GIP. It was the first transgender-driven, peer counseling and empowerment HIV prevention program in NYS and has been a flagship program for transgender and gender non-conforming (TGNC) people for more than 26 years. It began in 1989, led by transgender activists Riki Anne Wilchins and Christian O’Neal, who founded Survivors of Transsexuality Anonymous (STA). In 1991, they worked with Dr. Barbara Warren to create the GIP. The Center took the lead on numerous other TGNC firsts in the 1990s, including partnering with Callen-Lorde to create the first transgender medical clinic in NYC. The Center also produced “Safe-T-Lessons: HIV Prevention for the Transgender Community” (a transgender education and HIV prevention film), brought providers and community members together in the first Transgender & Transexual Health Empowerment Conference, and partnered to help create the first NYC transgender HIV needs assessment. This early needs assessment documented many issues TGNC people still confront, including provider prejudice and insensitivity, lack of knowledge of TGNC-issues, economic obstacles, and so forth.

Major strides have been made since the turn of the century. In 2002, after three years of advocacy by the GIP and others, New York City added discrimination protections based on gender identity and expression to the City’s Human Rights Law. In 2006, after two years of advocacy by The Center and other partners, the NYC Department of Homeless Services released its groundbreaking Transgender and Intersex Policy, to help TGNC people get equal access to housing. In 2012, after two years of negotiation by The Center and other key partners, the NYPD revised its Patrol Guide

I shared my critique of the failure of current HIV prevention approaches to address TGNC people and my concerns that measures such as PrEP would fail to successfully affect HIV with TGNC New Yorkers.
to help ensure that police officers treat TGNC people with dignity and respect. And this year, The Center partnered with six other trans-driven programs and NYC Councilman Ritchie Torres to open the Bronx Trans Collective – the city’s first multiservice center dedicated to transgender people.

Creating an Advisory Group

The GIP’s peer-driven model also amplified the voice of the TGNC community. In July 2015, after seventeen years working to address HIV in trans communities, I delivered the keynote address at the Transgender Health Symposium of the NYS AIDS Institute’s “LGBT Health: Beyond the Epidemic” conference. I shared my critique of the failure of current HIV prevention approaches to address TGNC people and my concerns that measures such as PrEP would fail to successfully affect HIV with TGNC New Yorkers.

In response, and in face of the minimal inclusion of TGNC people in the process that created the Blueprint for Ending the Epidemic in NYS, the AIDS Institute asked me to help convene a TGNC Advisory Group. The purpose of this diverse group was to advise on specific actions that should be taken to address HIV in TGNC communities.

We worked with Carmen Vasquez, the Director of the LGBT Health & Human Services Unit for the NYS AIDS Institute, and Associate Director Kraig Pannell. Group members included Erin Alexander, Nicole Bowles, Jonovia Chase, Sean Coleman, Lyndon Cudlitz, Carrie Davis, Cecilia Gentili, Juli Grey-Owens, Cristina Herrera, Nathan Levitt, Kierra St. James, Levi Solimine, Gabby Santos, and Rev. Moonhawk River Stone.

We first met in Albany in November, 2015. Though AI staff provided ongoing support, the Advisory Group crafted the recommendations on our own to help ensure that the final product was reflective of community needs. We met for six months and developed a comprehensive set of recommendations that will soon be made public and reviewed for potential implementation.

TGNC Health

Some of the health needs of trans people are well documented, as is the fact that they are more likely to experience certain health concerns than are heterosexual and gender-conforming people. The U.S. Department of Health & Human Services’ Healthy People 2020 includes a chapter on LGBT Health, noting that TGNC people are more likely to face “a high prevalence of HIV/STDs, victimization, mental health issues, and suicide and are less likely to have health insurance than heterosexual or LGB individuals.” Transgender people also experience significant substance abuse problems, while trans youth experience homelessness and self-harm at higher rates than non-trans youth. TGNC people of color are even more affected by these concerns.

Of all of these, HIV has attracted the most attention, for good reason. Transgender women of color are the highest HIV risk group in New York City, and in the world. A recent analysis of worldwide data found that transgender women are nearly 50 times more likely to have HIV than other adults. The New York Transgender Project also found a 50% HIV infection rate among transgender Latina women, and a 48% infection rate among Black transgender women in the study.

As a result, focusing on HIV has become a seductive way to address the health of TGNC people. Simple solutions are attractive, and HIV treatment and PrEP appear, at first glance, to offer that solution. Despite that, a 2015 study of PrEP in 339 transgender women found that it did not reduce their risk of HIV infection. The authors wrote:

continued on next page
PrEP seems to be effective in preventing HIV acquisition in transgender women when taken, but there seem to be barriers to adherence, particularly among those at the most risk. Population effectiveness hinges on the development of widespread PrEP education programs, and structural and legislative reforms to eliminate barriers to health care and HIV prevention services. Provider, policy, and public health interventions that reduce housing instability, improve employment opportunities, mitigate distrust of the medical community, and establish and enforce universal non-discrimination laws that include gender identity and expression are needed.

Transgender people have long understood the importance of looking beyond HIV. When asked about their main concerns, many TGNC New Yorkers often do not even mention HIV. Instead, they focus on employment, access to quality health care, homelessness, immigration issues, criminalization, and incarceration. They also speak of being desperately poor and are almost twice as likely as non-trans people in to have very low incomes.

“I am not a ‘high-risk’ person. I am a member of a community that is put at high risk.” The forces that put us at risk for HIV must be addressed to end the epidemic in the TGNC community.

Looking at the Larger Picture
This complex matrix of psychological, legal, social, and physical hardships disproportionately affect TGNC New Yorkers. Marcela Romero, Coordinator of REDLACTRANS, a Latin American and Caribbean transgender network, noted, “I am not a ‘high-risk’ person. I am a member of a community that is put at high risk.” Clearly, the larger forces that put us at risk for HIV must be addressed in order to end the epidemic in the TGNC community.

Healthy People 2020 identified five social determinants of health: economic stability, education, community context, health care, and neighborhood environment. The CDC notes that “health disparities in HIV, viral hepatitis, STDs, and TB are inextricably linked to a complex blend of social determinants that influence which populations are most severely affected by these diseases.”

This might be visualized as a TGNC Wellness Cascade. Many transgender people experience social and developmental disruptions and have difficulties with educational attainment, economic productivity, and, eventually, mental and physical health. It is critical to note that few, if any, public resources are currently devoted to the two middle tiers of this cascade (education and economic). In addition, the persistently high HIV infection rate among trans women of color powerfully shows the ineffectiveness of most prevention and treatment approaches.

In this way, the social determinants of health are both indicators of and the driving forces behind the many problems TGNC people face as they seek to live healthy and successful lives. While these determinants have generally been overlooked in HIV prevention, they should be considered primary factors when developing interventions that address the HIV, health, and social needs of transgender people.

Addressing the social determinants of health also offers an opportunity to address the individual and community health needs of TGNC people. Importantly, the majority of resources required to address the complex needs of TGNC people in New York State already exist, but are often inaccessible to those who need them most for a variety of reasons, including provider prejudice and insensitivity, lack of knowledge of TGNC-specific issues, difficulty in obtaining identity documents, fear of disclosing a transgender identity or history, racism, and so forth.

Recommendations
The current commitment to a medical prevention model devours nearly all the resources dedicated to transgender health and well-being. More importantly, it is at its core primarily committed to making trans people less infectious or infectable. This is not high on the list that our community has prioritized. Recognizing this, the TGNC Advisory Group focused on the larger forces that put transgender people at risk of HIV.

Over a six-month period, the group produced a set of recommendations to guide the AIDS Institute in planning and implementing the Blueprint for Ending the Epidemic in TGNC communities. They are meant for transgender women and men, as well as transgender youth and elders, and gender non-conforming people of all ages. They also address regional concerns.

1. Employment: TGNC individuals need access to employment that provides opportunities for advancement, competitive wages and benefits, and environments free of discrimination and harassment.
2. Education: TGNC individuals need educational opportunities that provide gender-affirming environments and relevant curricula (such as trans-inclusive sexual health and TGNC history). This includes, but is not limited to, K-12 schools, colleges, certificate programs, and job training programs.
3. Healthcare: TGNC individuals need access to physical, sexual, mental, and behavioral health care that is regionally accessible, affordable, and delivered by staff that are both skilled in trans-specific care and able to provide services in a trans-affirming manner.
4. Law enforcement: TGNC individuals interacting with law enforcement, the Department of Corrections and Community Supervision, and the Department of Justice need to be treated respectfully by professionals knowledgeable about TGNC people. They need to be free from bias profiling, and to have access to safe and gender-affirming housing and services in jails, prisons, and detention centers of all kinds, including immigrant detention centers.
5. **Housing:** TGNC individuals need access to safe and gender-affirming housing that is not exclusively dependent on HIV status. This includes, but is not limited to, transitional living, long-term housing, and various sheltering services.

6. **Community-based organizations:** TGNC individuals need access to Community-Based Organizations (including AIDS Service Organizations and LGBTQ nonprofits) that provide services and programs relevant to TGNC communities, designed and delivered under the leadership of TGNC people, and located in safe environments where all staff, board, and volunteers understand the needs and identities of TGNC communities.

7. **Immigration:** TGNC individuals of immigrants experience need access to all of the aforementioned priority areas in their first languages, as well as the ability to seek asylum from anti-transgender persecution.

8. **NYS Department of Health:** The DOH must reflect the needs of TGNC communities and its commitment to TGNC health in its data collection, hiring practices, training of staff, grant oversight, and funding priorities.

Something has to change if trans New Yorkers are to take their rightful place as whole, healthy, successful, and self-sufficient leaders in the next generation of the LGBT community.

It is important to note that few, if any, of the above recommendations can be accomplished solely by the NYS DOH. Addressing the persistently high rates of HIV among TGNC people requires collaborative solutions that engage a wide range of stakeholders, including many State agencies: Labor, Education, Corrections, etc., as well as local governments, private enterprise, community-based organizations, and the transgender community itself. New York offers numerous strengths that can and must be leveraged to improve the health and well-being of its TGNC residents, including a robust educational, economic and health safety net, as well as notable private sector protections and role model opportunities, a strong, progressive public environment, and a diverse and visible TGNC community with an expanding network of culturally relevant providers.

**A Vision for the Future**

An authentic vision for TGNC people can’t be based merely on reducing risk of HIV infection. Instead, it must acknowledge the importance of creating opportunities for trans people that include meaningful connections and safe, healthy, stable places to live, learn, and work. Despite the sincere and long-held beliefs of the many public and private institutions that fund our work, focusing exclusively on reducing HIV, violence, or stigma has not moved trans people significantly closer to this vision.

A lot has happened in the nearly 20 years since I began working in the field of HIV and LGBT health. That period has seen many changes in the way transgender people perceive themselves and the way others perceive them, in the U.S. and even globally. While there have been many successes, TGNC people still struggle in ways we had hoped would have become part of our collective history by now. Something has to change if trans New Yorkers are to take their rightful place as whole, healthy, successful, and self-sufficient leaders in the next generation of the LGBT community.

We can start by retooling our work with trans people toward the outcomes that trans people themselves prioritize, rather than those decided for them. Addressing these concerns for transgender people is sustainable and cost-effective, and will reduce negative health consequences such as HIV and other STDs, suicide, and homelessness, as well as their significant costs.

If TGNC people, in particular transgender people of color, are identified and engaged in a network of trans-led support services that directly improve their economic, educational, social, and health status, and related concerns, they will be healthier and more likely to make a successful transition to self-sufficiency. They will also become change agents and contributors to a healthy, thriving community. That is the vision that TNGC people see for themselves.

**Carrie Davis** is a health and human services leader and the former Chief Programs & Policy Officer at The Center.
Maybe you didn’t know.

Maybe you were listening but didn’t really hear an important but often overlooked fact about the HIV epidemic.

Half of all people with HIV in New York State are over 50 years old. That’s also the case nationally.

And it’s estimated that number will rise to 70% by 2020. In addition, one in every six new HIV diagnoses in New York occurs in older adults.

There’s another important fact about people over 50: the older they get the less likely they are to be offered an HIV test. And older adults are more often likely to be diagnosed with AIDS at the same time they first find out they have HIV. This “contemporary diagnosis” highlights the lack of testing efforts targeting older adults, since people often take ten years or more to develop AIDS once they have HIV.

Unfortunately, studies also show that condom use drops significantly in people over 50, while sexual activity (and HIV and STD risk) continues into their 80s and beyond. Still, most doctors don’t talk to their older adult patients about their sex lives. One reason is discomfort with the subject, and another is the myth that older adults just don’t have sex.

“An important issue raised was the gap between the beginning age for accessing aging services, which is 60, and the 50+ HIV-positive population – a ten year service gap. So even if we educate aging service providers and encourage older people with HIV to use aging services, those aged 50 to 60 are unable to.

Also, aging service providers are not asking about sexual orientation and gender identity, and though they ask about every other health issue under the sun in case management services, they do not ask about HIV.”

– Tom Weber, SAGE Advisory Group Member

The needs of older adults should have been an important part of New York State’s Plan to End the Epidemic (ETE) by 2020. But if you look at the “Blueprint to End the Epidemic” – a document of 30 recommendations the ETE Task Force created in 2015 – you won’t find a single reference to older adults. In the original 44 Blueprint recommendations (distilled from over 300 community recommendations) older adults were mentioned four times, but the final document included only...
30 of those recommendations, and all mention of older adults disappeared. If there’s one thing we know about advocating for scarce funding it’s that if you aren’t named you don’t get the resources.

**Addressing the Needs of Older Adults**

During the six months after the Blueprint was accepted by Governor Cuomo in April 2015, ACRIA and other community-based organizations that focus on HIV and aging got to work to change this. The NYS Department of Health AIDS Institute responded to concerns about the impact of the epidemic on older adults. In December, they helped ACRIA establish an “Older Adults and HIV Advisory Group”, to write a report on strategies that would make the Blueprint relevant to older adults. It was essential that their needs not be forgotten in the ETE planning and implementation process. Older adults would be named!

The Advisory Group started as a handful of organizations led by ACRIA, including SAGE, LiveOnNY, AARP NYS, NYS Office of the Aging, Housing Works, the NYC Department of Health, and the AIDS Institute, but quickly grew to over 70 people representing HIV, aging, faith, and community-based organizations, along with community members from across the state.

The group was divided into Core and Full groups, with Core members agreeing to do the majority of the work, to meet monthly in Albany and NYC, and to write a report within six months. The Core group made decisions by consensus, and brought in outside experts to address knowledge gaps in areas like the Delivery System Reform Incentive Program, how to work with current and former inmates, and how to address the needs of older transgender adults.

Their report, *Older Adult Implementation Strategies*, was presented to the NYS AIDS Advisory Council ETE Subcommittee on August 12, and was approved by the full Council on October 7.

**Key Elements**

The Report is broken down into 67 strategies specifically for older adults. Let’s look at four areas where these strategies have already begun:

**Education**

The report included a number of strategies to offer providers training on older adult issues such as:
- Sexual health
- Initial HIV infection
- HIV treatment and prevention
- Chronic disease self-management
- PEP and PrEP
- Use of multiple medications
- Transgender issues

Training HIV providers about aging issues, and training aging providers about HIV issues, is also key since one often doesn’t know much about the other’s issues. Other service providers who have been left out of the HIV and aging loop also need to be targeted for training: correctional facilities and re-entry programs, long-term care facilities, care coordination programs, senior centers, faith-based and community based organizations, and “Health Homes” providers.

ACRIA has provided HIV and aging education, training, technical assistance, and capacity building to NYC HIV and aging providers for the last nine years, with funding from the NYC Council. The programs help organizations through HIV treatment and prevention education, along with social media campaigns, such as the “Age Is Not a Condom” campaign, in high-risk neighborhoods. ACRIA also provides direct services to older adults through HIV testing and education.

In 2008, AARP sponsored the SAGE National Conference on LGBT Aging to send a message to the LGBT community and to show that AARP was paying attention. Since then, AARP and SAGE have worked to deepen this partnership. SAGE is providing online training to AARP State Offices on subjects including:
- Introduction to LGBT Aging
- Embracing LGBT Older Adults of Color
- Transgender Aging: What Service Providers Need (and Don’t Need!) to Know
- Respected and Whole: Preventing Anti-LGBT Bias Between Constituents, Staff, and Across Aging Services
- Asking Demographic Questions about Sexual Orientation and Gender Identity

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AARP publications such as AARP Bulletin and AARP The Magazine now include LGBT voices in their mix of 50+ people and stories, and their website features an LGBT section (aarp.org/pride).

**Targeted Testing**

Another strategy that has had success is testing and prevention tailored to the needs of older adults. SAGE currently offers case management, caregiver support, bereavement support, friendly visiting, and E-LINC, which provides comprehensive health services to LGBT individuals over 50.

65 organizations, New York State is finally in the process of lifting the age limits mandated for routine HIV testing, changing them from age 13 to 64, to 13 and up. The bill has been passed by both legislative houses and is currently waiting to be delivered to the Governor for his signature.

**Data and Needs Assessment**

A needs assessment tool is critical to create the evidence base of data to develop targeted interventions (such as getting people linked to care, on treatment, and virally suppressed) that older adults with HIV need. Recognizing this over a decade ago, ACRIA launched its seminal Research on Older Adults with HIV (ROAH) study in 2006. ROAH was the first, largest, and most comprehensive study of its kind and remains so to this day. Over a year ago, ACRIA began an update entitled ROAH 2.0. Its goal is to improve the services provided to older adults with HIV. The study directly coincides with the ETE plan and the Advisory Group’s report.

ROAH 2.0 plans to study three groups in New York: 500 older adults with HIV from NYC whose responses will be paired with their clinical records from Weill Cornell Medical College; 500 older adults with HIV recruited from NYC community-based organizations; and an upstate/rural sample of 450 older adults with HIV. Given the lack of focus on upstate and rural areas, this last sample has significant importance.

ACRIA also plans to establish a long-term cohort with data collected every few years. This will enable the study to monitor participants as they age into their 70s and 80s. ACRIA has raised funds for the first two groups, and data collection has begun. Funding for the upstate/rural sample is still pending.

**Targeted PrEP**

At present little emphasis is placed on offering PrEP to older adults. The Report’s introduction states five reasons to change this:

1. Half of men over 40 have erectile dysfunction, making condom use problematic.
2. Research shows that few older men or women use condoms, and use decreases with age.
3. Providers are not discussing sexual health with the majority of their older patients.
4. Older women may have difficulty negotiating condom use, which could lead to abuse. PrEP allows older women to be empowered about their sexual health.
5. HIV testing rates among adults over 50 are very low. Encouraging PrEP will increase HIV testing, since regular testing is an important part of PrEP.

The AIDS Institute ran a social marketing campaign titled “HIV Prevention Just Got Easier” in 2015 that did include older men. It targeted Black and Latino transgender and men who have sex with men, and, significantly, two of its 13 models were older adults. These bus shelter and transit ads were also placed in Rochester, Albany, Buffalo, Hudson Valley, and Long Island – targeting high prevalence counties outside of New York City.

**Where Do We Go From Here?**

How will the Older Adults and HIV Advisory Group be used, and by whom? What will happen to the Group’s members now that their initial task is completed? The answers involve public health policy and the politics of advocating for scarce resources. The ultimate goal is that the report will be taken by the AIDS Institute and used as a template for ETE work with older adults throughout New York State and the U.S. From the beginning, ACRIA believed this would be an
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...evolving process that extended into the future, and would include current and future members of the Advisory Group. ACRIA believes the Report should serve as a tool for advocacy and education, and should be distributed at conferences. It’s essential that its recommendations lead to change and are not simply left on the shelf to gather dust.

Action needs to be taken to make sure there is follow-through – to ensure that policy makers, providers, and leadership continue to listen and to hear the needs of older adults at risk for and living with HIV.

One action is the evolution of the Older Adults and HIV Advisory Group into a statewide Older Adults and HIV Coalition. This coalition could then advocate for both the implementation of the Report and the implementation of high-priority strategies.

Another strategy is to address areas outside of New York City with high HIV rates, such as Westchester, Dutchess, Nassau, Suffolk, Erie, Monroe, and Albany counties, where resources for older adults are limited.

We must also address depression and social isolation. Older adults with HIV report depressive symptoms at five times the rate of the larger community and HIV-positive older adults are often socially isolated due to stigma (homophobia, racism, AIDS-phobia, ageism, etc.). Over 70% live alone, and fewer than 20% have a spouse or partner, with many estranged from their families. Screening to identify these conditions and interventions to address them as the population continues to age is critical.

The second action – and a priority task of the new coalition – is sending the Report to HIV, aging, faith, and community-based organizations across the state and the U.S. This low-cost action will:

• Raise awareness of the needs of older adults at risk for and living with HIV.
• Educate them on strategies to address these needs.
• Develop collaborations in programs, advocacy, and applications for funding.

Conclusion
We must remember that more than 65,000 New Yorkers with HIV are over 50. We’re optimistic that the steps discussed in this article will contribute to the ETE Blueprint goal of achieving fewer than 750 new infections per year by 2020. But we are also aware that much remains to be done. The needs of older adults aging with HIV are present in the here and now. They are dealing with issues of treatment and prevention, multiple illnesses, depression and isolation, too many pills, and a sometimes lower quality of life. Any plan to end the epidemic must include their concerns.

Leo Asen is AARP NYS President and a member of AARP Board’s National Policy Council. Joe Lunievicz is Deputy Executive Director for Programs at ACRIA.
IV testing is essential to the Governor’s three-point plan to end the AIDS epidemic in New York State by 2020. Testing is a gateway to health care, and knowing your status is the first step in getting linked to care and HIV prevention services.

But ensuring that all New York City residents have access to a voluntary HIV test is no easy task. So, since 2008 the NYC Health Department has partnered with community agencies, including hospitals, health centers, community organizations, elected officials, faith-based organizations, and businesses, through large-scale borough-wide HIV testing initiatives, known as Bronx Knows and Brooklyn Knows.

New York Knows, an expansion of these previous successful initiatives, has grown into the largest HIV testing initiative in the nation. New York Knows aims to help all NYC residents learn their HIV status and facilitate access to the city’s HIV care and prevention services. On World AIDS Day, December 1, 2014, the Health Department officially launched New York Knows and introduced #beHIVsure, a public education and social marketing campaign encouraging all New Yorkers to get tested.

Through community partnerships, New York Knows works to:

- Provide a voluntary HIV test to every NYC resident who has never been tested. (Testing is done at Health Department clinics, partnering hospitals, community-based organizations, and universities.)
- Make HIV testing a routine part of health care in NYC.
- Identify undiagnosed HIV-positive people in NYC and link them to medical care.
- Connect at-risk people who test HIV-negative to prevention services, including PrEP.

To reach these objectives, New York Knows uses collective impact, a framework in which cross-sector partnerships collaborate to achieve lasting social change in making HIV testing routine in NYC. New York Knows activities include:

- Developing borough-wide steering committees which meet monthly and guide the initiative

Borough-specific HIV testing goals are based on the residents who have never been tested for HIV. To date, over 230 New York Knows partners have conducted over 2.9 million HIV tests, identified 7,295 people newly diagnosed with HIV and linked 79% of those to care. This work would not have been possible without the dedication and support of community partners.

Community engagement and collaboration does not occur in a vacuum and requires constant communication, passion, and commitment. As Henry Ford has said, “Coming together is a beginning. Keeping together is progress. Working together is success.” The success of New York Knows relies on the work and support of its partners, which can be challenging due to varying agency capacities, resources, and funding.
To continue moving the needle forward, it is critical that New York Knows partners regularly participate in steering committee and subcommittee meetings, submit quarterly testing data, coordinate events, and most importantly work to grow the initiative by being New York Knows advocates. HIV testing is a vital step in ending the epidemic, and an “all hands on deck” endeavor as we work to end AIDS in New York.

New York Knows is aligned with the following Blueprint Recommendations:

“Identify persons with HIV who remain undiagnosed and link them to healthcare”

BP 1: Make routine HIV testing truly routine
BP 2: Expand targeted testing
BP 3: Address acute HIV infection
BP 4: Improve referral and engagement
BP 29: Expand & enhance the use of data to track and report progress

“Link and retain persons diagnosed with HIV in care to maximize virus suppression so they remain healthy and prevent further transmission”

BP 9: Provide enhanced services for patients within correctional and other institutions and specific programming for patients returning home from corrections or other institutional
BP 10: Maximize opportunities through the Delivery System Reform Incentive Payment (DSRIP) process to support programs to achieve goals related to linkage, retention and viral suppression

“Provide access to PrEP for high-risk persons to keep them HIV-negative”

BP 11: Undertake a statewide education campaign on PrEP and PEP
BP 12: Include a variety of statewide programs for distribution and increased access to PrEP and PEP
BP 13: Create a coordinated statewide mechanism for persons to access PrEP and PEP and prevention-focused care
BP 4: Improve referral and engagement
BP 29: Expand & enhance the use of data to track and report progress

Goals and Accomplishments
Looking forward to 2017 and reflecting on 2016’s accomplishments, New York Knows partners have done amazing work to bend the curve in reducing new HIV infections. The goal of the Ending the Epidemic plan – to reduce the annual number of new HIV infections in New York State to 750 and those in NYC to 600 – is a tremendous undertaking. (The graph below shows estimates of how we might achieve that.)

The mission of New York Knows in 2017 continues with getting people tested and linked to care or prevention services. New York Knows must continue to evaluate its efforts and reflect on the changing landscape of HIV prevention that will end the epidemic.

Routine Testing
Making HIV testing routine is key. Patients receive routine labs for many medical conditions, and HIV testing should be no different. The NYS HIV testing Law (27-F) has been amended over the past several years to reflect the changes in HIV prevention, care, and treatment. But new changes continue to support efforts to streamline and routinize testing. Here are some important recent changes to NYS HIV testing law:

• NYS requires that an HIV test be offered to every individual age 13 years and older in healthcare settings, including inpatient wards or emergency departments of a general hospital, outpatient departments of hospitals offering primary care, and free-standing diagnostic and treatment centers offering primary care.

• Written consent for an HIV test is no longer required. A provider only needs to advise the patient that an HIV test will be provided and give the 7 points of information about the test either orally or in writing.

All of these provisions have been put in place to streamline HIV testing and increase the number of people getting tested. NYC clinical sites that offer lab-based testing can adopt the following steps for streamlined HIV testing:

1. Notify the patient that testing will occur, and document this in the patient’s record
2. Provide required pieces of information, either orally or in writing, and answer any questions
3. Perform the test
4. Provide the results to the patient

If the patient has a non-reactive (negative) test, they must be given the result by
email, mail, or phone, as well as information about PrEP and PEP, and the risk of infection. If an HIV test is reactive (positive), the same counseling requirements remain, but the provider or site staff must arrange for a follow-up medical appointment if the patient consents to care. The case must be reported using the provider reporting form and domestic violence screening must be done. Partner services from the Health Department should also be considered. Questions regarding Provider Report Forms and Partner Services can be answered at 212-442-3388 and 212-693-1419, respectively.

The NYS HIV testing law can be difficult to understand at times and challenging for larger institutions to implement at first, but making testing routine can help reduce new infections and assist in connecting those in need to appropriate care.

**Combination Prevention**

The “New HIV Neutral Continuum of Care” helps to reduce the stigma associated with HIV. This theoretical Neutral Continuum of Care proposes the idea that treatment is treatment, treatment is prevention, and prevention is treatment. This not only reduces stigma, but also supports the importance of routine healthcare by recognizing that HIV care and prevention are equal in ending the epidemic.

People who test positive should be linked to HIV medical care, start antiretroviral therapy, and be supported to stay in care. This will not only improve their health outcomes but also help prevent further transmission. Studies show that HIV treatment leads to a 96% reduction of sexual transmission of HIV in serodiscordant couples. People who engage in high-risk behavior and test negative should be connected to medical care and introduced to PrEP to keep them HIV-negative. Current research indicates that if PrEP is taken daily, the risk of HIV through sexual contact is reduced by up to 99%.

**Increasing Access to PrEP and PEP**

HIV testing needs to go beyond just giving a result by connecting those at higher risk to care and treatment. PrEP is a daily pill taken by people who are HIV negative to protect them against HIV. PEP is emergency medication that can prevent HIV infection if started as soon as possible after exposure to HIV, ideally within 36 hours, but within no more than 72 hours of exposure.

PrEP and PEP are effective medical interventions that have the potential to bend the curve of the epidemic. To increase their use among New Yorkers who would benefit the most, providers must embrace these interventions. Agencies need to increase PrEP awareness, patient assessments, and should have the resources to provide referrals to prescribing providers.

**Next Steps**

Ending the epidemic is a shared responsibility that goes beyond HIV service organizations and advocacy groups. We need to approach the end of the epidemic through a social justice and health equity lens. Working together in NYC, we must continue to adapt our strategies and grow by ensuring policies are up-to-date and adequately implemented. We must use combination prevention messages to help reduce the stigma around HIV. And we must increase the use and awareness of medical interventions like PrEP and PEP.

For more information regarding New York Knows, or how to get involved, please email NewYorkKnows@health.nyc.gov.

*New York Knows continued from previous page*

![The New HIV Neutral Continuum of Care](chart.png)

**New York Knows**

Amanda Phi is the Manhattan Liaison for New York Knows. Paul Santos is the Queens Liaison for New York Knows.
One of the most important tools we have to “bend the curve” of the HIV epidemic in New York State is retaining people with HIV in medical care. This has been shown to increase positive health outcomes and to suppress HIV to undetectable levels. And there is now evidence-based confirmation that the risk of HIV transmission is dramatically lowered when a person with HIV is on treatment and undetectable for at least six months.

Retention in care as a way to improve both individual and public health is a critical part of Governor Cuomo’s Plan to End the Epidemic (ETE). The plan’s “three pillars” are:
1. Identify people with HIV who are undiagnosed.
2. Link and retain people with HIV to health care and get them on HIV treatment, both to maximize HIV suppression so they remain healthy and to prevent further transmission.
3. Increase access to PrEP and PEP.

The plan seeks to drive down new infections from 3,000 per year in 2014 to 750 or fewer by 2020. Another benchmark is to reduce the percentage of New Yorkers who test HIV positive and receive an AIDS diagnosis within two years, from 10% to 5%. Finally, the Plan hopes that at least 80% of people with HIV will have an undetectable viral load.

**How Does The ETE Plan Address Retention in Care?**

In the Blueprint to End AIDS, four of its 30 blueprint recommendations (BP) address retention in care:

**BP 5:** Continuously act to monitor and improve rates of viral suppression.
**BP 7:** Use client-level data to identify and assist patients lost to care or not virally suppressed.
**BP 8:** Enhance and streamline services to support the non-medical needs of all persons with HIV.
**BP 29:** Expand and enhance the use of data to trace and report progress.

New York State’s Cascade of HIV Care has been a driving force in framing the need for retention in care. It outlines the stages of HIV medical care that people go through, from diagnosis to viral suppression.

The model comes from Dr. Edward Gardner and colleagues who observed in 2011 that, for people with HIV to fully benefit from HIV treatment, “they need to know that they are HIV infected, be engaged in regular HIV care, and receive and adhere to effective antiretroviral therapy.” They acknowledged, however, that various obstacles contribute to poor engagement in HIV care, limiting efforts to improve health outcomes and to reduce new transmissions.

It’s estimated that only 77,000 of the approximately 129,000 persons known to have HIV are virally suppressed – leaving as many as 52,000 possibly receiving suboptimal care.

Staying In Care: Key To Ending The Epidemic

*by Kimberleigh Joy Smith, MPA*
According to 2014 data from the NYS AIDS Institute, it’s estimated that only 77,000 of the approximately 129,000 persons known to have HIV are virally suppressed – leaving as many as 52,000 possibly receiving suboptimal care.

The CDC estimates that only 8% of HIV transmissions in the U.S. are from people who are in ongoing care. That’s the good news. The bad news is that almost half of all people with HIV are not in regular HIV care, and they account for roughly 70% of HIV transmissions. According to the ETE Blueprint:

“A key approach to preventing more infections is to identify people living with HIV as soon as possible and link these individuals to care. Ensuring access to continuous care and achieving viral load suppression is critical for reducing mobility and mortality, thereby reducing the number of new infections in New York State.”

Treatment cascades are a great way to measure our success in getting all people with HIV to learn their status and benefit from treatment. The U.S. health system does a fairly good job of serving many people with HIV once they find an HIV care provider. The problem, however, is that too many of these people are not retained in HIV care, which drives the cycle of HIV transmission that results in roughly 50,000 new infections each year.

So, how can we keep people retained in care and how do we measure our success?

For much of the first 15 years of the AIDS epidemic, many providers criticized the “medicalization of HIV” – perhaps because there were not yet effective treatments, and because stigma and confidentiality issues bred skepticism of a medical approach to HIV. But when combination HIV treatment became available in 1996, health outcomes dramatically improved for people with HIV. And in 2015, the START Study showed strong health benefits for people with HIV who began treatment as soon as possible after diagnosis. Other studies provided strong evidence that early treatment reduced the risk of HIV transmission and that treatment interruptions increased the risk of death sixteen-fold. Thus the need to get people on treatment early, and to help them stay adherent and in regular care, is clear.

So, what is retention in care and how is it measured? The U.S. Health Resources Services Administration (HRSA) defines “in care” as receiving at least two HIV care visits per year, at least 90 days apart. In studies, patient retention is measured in three different ways: appointments kept or missed, medical visits at regular intervals, and a combination of those methods focusing on use of the health care system. Measures for linkage to care and viral suppression are a bit more straightforward. If people are diagnosed with HIV, they are deemed “linked to care” if they have a medical visit within 30 days. Similarly, viral suppression is marked by a lab test.

New York Links

“We all know how important retention in care is, but how do you measure it?” asks Steven Sawicki, the lead for the state’s New York Links program. NY Links focuses on improving linkage to care and retention in care, and supports timely and effective care for people with HIV in NYS. It works to bridge the gaps between various HIV-related services to achieve better outcomes. Originally created through HRSA Special Projects of National Significance (SPNS), NY Links has been under the ETE Initiative since September 2015 through the AIDS Institute.

The NY Links program fits well with the Governor’s Plan, and helps community-based health clinics address the issues people face staying engaged in care. It also works to strengthen systems to support them. Sawicki says monitoring retention in care has evolved. It used to have nothing to do with how well

Providers and clinicians play a critical role in helping to close the gaps faced by people who test HIV positive, enabling them to establish care, start treatment, stay adherent, and remain in care.
people were actually doing. Patients either checked in with their primary doctors at regular intervals or they did not. It was hard to know who had fallen out of care and for what reasons, what support helped them stay in care, and who might have been mislabeled as out of care.

NY Links uses a “two-year retention measure,” which, according to Sawicki, “In and of itself … doesn’t tell you the whole story.” The two-year retention measure holds that a visit should happen once every six months in these two years. Further, there is a 60-day period that must exist between visits in order to rule out visits happening due to an acute issue.

But data “drives improvement”, says Sawicki. Providers can determine what barriers to care patients face and set about to eliminate them. NY Links encourages facilities to develop their own care cascades to help highlight gaps and study the barriers that create those gaps.

The program organizes the state into regions. Each region conducts its own analysis and plan its own interventions. Sawicki’s role is to provide technical assistance, data analysis, and training. In addition, NY Links has designed five interventions to support patient retention. “We as a system have all the tools we need to turn HIV around,” says Sawicki. “The primary issues are networking, communicating, and fine tuning.”

Innovative models are emerging. One clinic, Erie County Medical Center in Buffalo, created its own care cascade, using measures provided by the “in+care” campaign for retention of patients and frequency of medical visits. The Center improved the rate of “patients newly enrolled with a medical provider” from 57% to 89% between August 2012 and June 2013. It also maintained a very high two-year retention rate (87% in April 2014) among patients.

Another program, also in Western New York, identified more than 40 barriers to retention and then measured community viral loads for each barrier, in order to find interventions that could be tailored to each issue. One example was domestic violence.

Now fully under the ETE, NY Links is building a set of new interventions that are informed by regional data, the involvement of people with HIV, and providers sharing their best practices and models with one another.

**Callen-Lorde: Retention in Practice**

Callen-Lorde participates in one of two Manhattan NY Links networks. We mainly serve the LGBT community and are the largest New York community-based provider of HIV care, seeing about 4,100 clients with HIV. In 2015, our clinic saw nearly 17,000 patients, with 100,000 visits. As a federally qualified health center, we champion a medical model of HIV care with supportive and enabling services. Providers and clinicians play a critical role in helping to close the gaps faced by people who test HIV positive, enabling them to establish care, start treatment, stay adherent, and remain in care.

This requires a robust network of services beyond clinical care: case management, insurance enrollment, patient navigation, psychosocial supports, an onsite pharmacy, and referrals to housing and nutrition assistance. These services are primar-
and Adherence Program”. RAP recently implemented a rapid-start-to-treatment program called RAPIDTx. It’s modeled on San Francisco’s “test-and-treat” model, which was first tried at San Francisco General Hospital and is now being rolled out there citywide. The model combines multiple stages of the continuum of care – HIV testing, diagnosis, first clinic visit, first primary care provider visit, and starting treatment – into a single day. It has been recognized in the public health world as a success.

Any patient starting HIV care at Callen-Lorde sits with a RAP case manager to assess housing needs, finances, insurance issues, etc. “The faster we get people virally suppressed and connected to the services they need, the better,” Bush said. “That leads to people feeling like they’re doing something. You’ve changed the game.” Callen-Lorde received support from the NYS DOH to pilot RAPIDTx. Sixteen patients have gone through the pilot since August of 2016. Ten are virally suppressed, with an average time to viral suppression of 40 days.

Even with such notable success, differences between groups still emerge in our efforts to keep patients in care and virally suppressed. Data on our patients with HIV in 2015, for example, found significant differences in viral suppression rates between transgender and non-transgender women. A high percentage of transgender women prescribed HIV treatment had detectable viral loads, indicating adherence issues or drug interactions that lower efficacy.

Further, while data systems have come a long way in the last few years, there is not a “be-all and end-all” electronic health record system. Meacher says “Five years ago, I wouldn’t have had any idea who had fallen out of care. New systems can generate lists and we can proactively follow up with patients.” But some systems are better than others and, at times, clinics can feel isolated and stifled by their chosen system. “It’s frustrating when we don’t get the data we were promised.” Meacher said.

Programs like “NYC Reach” in New York City, which allows providers to call a city number to find out the care status of patients, are promising. And NYS is set to roll out a web-based prototype that will allow communication statewide.

**A Call to Action**

We’re more than three years away from the target date to end the HIV epidemic in New York. The Affordable Care Act and shifts in health care delivery create new opportunities for progress. With this progress comes the need for ongoing investments and smart regulatory and legislative change to increase patient retention. Recommendations include:

**Enhance Data Sharing:** The “End AIDS New York 2020 Coalition” recommends that New York State amend its Public Health Law to empower providers to be able to share important patient data with other providers. Advocates are working to ensure that Care Coordinators can access and share patient data. In addition, the AIDS Institute should be able to access and match data from Qualified Health Plans with HIV surveillance data, for the purpose of identifying people with HIV who have dropped out of care. This will allow providers to reach out to them and provide referrals, making data-sharing efforts more robust and seamless.

**Invest $5 million in Data Analytic Capacity:** We must invest in the state’s capacity to measure our progress in the ETE Plan. Blueprint #29 recommends expanding and enhancing the use of data to track progress on ETE objectives. Funding is needed to collect, integrate, and disseminate data on prevention, quality of care, and social determinant indicators. HIV quality metrics that affect provider and plan reimbursement need to be adopted to ensure improved performance is incentivized.

Further, NYS health plans and health purchasers should take action to improve monitoring, engagement in care, and viral suppression.

**Continue to develop, fund, and measure innovative models:** Retention in care extends beyond the clinic. Identifying which patients are at risk for falling out of care, and why, is important. Care coordination and support services can help lower that risk. Addressing other barriers to care should be a top priority, including housing, food, transportation, mental health, childcare, employment, health literacy, patient navigation, and more.

**Conclusion**

Retaining people with HIV in medical care and providing wrap-around services are critical parts of the ETE plan. Furthering retention in care will require improving metrics, investing in new models and research, and advancing regulatory and policy change. The promise and vision to end AIDS – for individual New Yorkers and the state at large – can be truly realized only when retention in care efforts are amplified.

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Kimberleigh Joy Smith, MPA, is Senior Director for Community Health Planning and Policy at Callen-Lorde.
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