The Audacity of New York's Hope to End AIDS

Can the Empire State end its epidemic by the end of the decade? And what exactly would it mean to do so?

May 1, 2015 By Benjamin Ryan

On a brilliant and warm New York City spring day in late April—one that followed an exceptionally brutal winter—New York State Governor Andrew Cuomo stood before a cheering crowd and became the first leader of a U.S. state to throw his weight behind a plan to end a statewide AIDS epidemic. The stage for the announcement was poignantly symbolic: Cuomo gave his rousing address before the city's Lesbian, Gay, Bisexual & Transgender Community Center in Manhattan's West Village. This is where a seminal group of activists living in the epicenter of the burgeoning AIDS crisis founded ACT UP, back in 1987, and met regularly to chart their way out of the long winter of the pre-antiretroviral (ARV) era.

Watch a recap of the event:

A number of ACT UP veterans were in the audience, having served on the 63-member task force that took the governor's June 2014 call to develop an action plan to vanquish the disease. The task force included a who's who of the administrative, activist, medical, mental health and nonprofit leaders in the state's HIV fight. The group completed what is known as the blueprint to end AIDS in January, but it wasn't until the April 29 event at the LGBT Center that Cuomo officially endorsed and released the plan.

"We're beginning to see a real ray of light in what has been a 35-year nightmare," said Cuomo, who presides over the state with the largest number of people living with HIV, an estimated 154,000 New Yorkers. The second-term governor, a Democrat, acknowledged that when the early sketches of the blueprint were drawn, "people thought it was an outrageous goal." He then asserted that "sometimes what sounds outrageous is exactly what we need to do."

The blueprint is an outgrowth of a larger movement, fast gaining steam in recent years, that seeks to harness the power of ARVs to prevent HIV, both by treating people living with the virus in order reduce their likelihood of infecting others, and with the use of pre-exposure prophylaxis (PrEP) among high-risk HIV-negative people. Through measures intended to drive up statewide rates of HIV testing, treatment and viral suppression, and to increase the use of Truvada

(tenofovir/emtricitabine) as PrEP, the statewide initiative aims to identify more of the estimated 22,000 New Yorkers who are unaware of their infection and to reduce the estimated annual number of HIV transmissions from about 3,000 in 2013 to 750 in 2020.

While the national estimated HIV infection rate remains constant, New York State's HIV incidence has apparently fallen by 40 percent during the past decade. To meet the new target, the state essentially needs to double the overall rate of decline of its HIV incidence. Doing so will require, in particular, tackling head-on the essentially unchanging HIV transmission rate among New York's men who have sex with men, and the rising rate among MSM ages 13 to 29. While anecdotal evidence suggests that PrEP's use is surging among gay New Yorkers, it remains to be seen whether a critical mass of Truvada can be effectively targeted to those who are at the highest risk, in particular young black MSM.

According to the blueprint's definition, "ending AIDS" would mean reaching the target of 750 new infections per year, in addition to tapering annual HIV-related deaths, currently about 600, toward zero and getting people with HIV diagnosed earlier, long before they develop AIDS. The number of people living with HIV in New York State would then eventually start to shrink for the first time.

These are arbitrary distinctions. There is no official scientific definition of what constitutes an AIDS epidemic. Worldwide groups that have set similarly lofty epidemic-ending goals in recent years use an array of different criteria—and sometimes they avoid specific definitions entirely—for what must be achieved before waving a victory flag. These definitions are made all the more murky when the notion of an AIDS epidemic, which is primarily defined by illness and mortality, has become increasingly antiquated in the age of ARVs. The crisis of the past has been supplanted by the more manageable HIV epidemic, as the promise of living a long life with the virus has taken center stage.

The blueprint is a 70-page progressive manifesto that includes a 30-point litany of recommendations for retooling and improving the state's HIV testing, treatment and prevention infrastructure. It also calls for expanded supportive services, such as housing for homeless people with HIV, and for better addressing the needs of transgender New Yorkers, who are at very high risk for contracting the virus.

Mark Harrington, executive director of the Treatment Action Group and a member of Cuomo's task force, spoke after the governor. Wearing the shirt of a friend from ACT UP who died of AIDS-related causes, he noted that implementing the blueprint's recommendations "is going to be an expensive undertaking. It's going to cost millions of dollars to get what we need. But it's going to pay for itself in the long run." He insisted that "the money is not going to be that hard to get."

As for how many millions are needed, no estimate exists.

ACT UP member Terri L. Wilder, MSW, was less cavalier than Harrington, telling POZ, "My big concern is about money. Are we going to be able to fund the things that are in the blueprint? Because it's not so easy to write a check. You have to have legislative support."

Within the already-passed 2015–2016 state budget, the only money for blueprint initiatives is $10 million for New York's AIDS Institute—a figure Harrington told POZ amounts to "a drop in the bucket." But a major boon will come in the form of rebates that the New York State Medicaid director was able to secure from at least four of the six main pharmaceutical manufacturers of ARVs. The price cuts, the amounts of which have not yet been released, should generate huge savings to the state, considering that an estimated half of people living with HIV are Medicaid eligible.

New York State Medicaid director Jason Helgerson is working with other governmental officials to secure an agreement that any Medicaid expenditures effectively saved from averting new HIV infections will be re-routed into supporting the blueprint's plans.

This is where the accounting gets tricky. The blueprint's authors took a recent estimate that averting one case of HIV saves $357,500 in lifetime HIV treatment costs, and then calculated that the cumulative savings of preventing the target of 2,250 averted infections by 2020 would amount to $804 million. This assumes that the blueprint is responsible for the entirety of the drop in new infections, despite the reality that state's HIV incidence rate is already dropping; and the calculations also measure the count of averted infections starting in 2013 rather than the present. In addition, the blueprint glosses over the fact that the near-billion dollar savings would be realized over the average remaining lifespan after someone tests HIV positive—a time of more than 30 years—not in a lump sum. Also, counting on averted-infection funds introduces a catch-22: The money needed to ensure success in lowering infection rates would only come after that success has been achieved.

Internationally, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has stressed that a large financial investment is needed up front in order to achieve the organization's own audacious target of ensuring that, by 2020, 90 percent of HIV-positive people will know their status, 90 percent of those people will be on treatment, and 90 percent of those treated will have a fully suppressed virus. This gargantuan effort, UNAIDS argues, will save money in the long run by bending the curve of the virus's trajectory at what amounts to a crucial tipping point.

Jennifer Flynn, executive director of VOCAL-NY, which advocates for low-income New Yorkers living with HIV, said in an interview, "Legislators have told us that they couldn't put money into a plan they hadn't seen." She is hoping that government officials, now with the plan in hand, will cotton to the call for constructing housing for 12,000 homeless or unstably housed people living with HIV, projected to cost $600 million to $720 million.

Blueprint task force members such as Flynn and Harrington are also hoping the end-AIDS initiative will soon benefit from the billions of dollars in settlements New York is expected to receive from financial institutions the state attorney general has been prosecuting for various forms of malfeasance.

Ultimately, all the finer points of the blueprint's recommendations will likely take years to put in place. This raises the question of how quickly these measures may affect the state's HIV rate and

if, the already falling HIV rate notwithstanding, setting a target of 2020 for a 75 percent cut in new infections is overly aspirational.

“We’re at the beginning of this ambitious project,” State Senator Brad Hoylman told POZ. “And clearly we as advocates and elected officials can’t just deliver the blueprint to the governor and say, ‘Okay, our job is done.’ This is going to be as much or more work than we ever imagined on behalf of the HIV/AIDS community.”

At the apex of his speech, Cuomo said that eventual victory against AIDS in New York State would lead to a repeat of what he characterized as the domino effect the state legislature set off after voting to legalize same-sex marriage in 2011.

“After New York passed that law, every politician in the country was asked a question: Will you do what New York did, and will you pass marriage equality?” the governor said. “And the same thing’s going to happen here. They’re going to put that microphone in the face of congressmen and senators and presidents and governors and say, ‘Will you end the AIDS epidemic in your state?’”

In New York City that fine spring day, there were signs that change was already in the air. Numerous speakers that followed the governor led the crowd in a retooled take on the age-old ACT UP chant:

“Act up, fight back, end AIDS.”

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