Getting To Zero

A Framework to Eliminate HIV in Illinois

Getting to Zero Exploratory Workgroup

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What will get Illinois to Zero?

Now is the time for Illinois to build on the state's tremendous progress in the fight against HIV. In the City of Chicago, there have been fewer than 1,000 new HIV cases annually since 2013, the fewest cases reported annually since 1990. New HIV cases in Illinois dropped by nearly 28% over the decade from 2006-2015, and Illinois has nearly eliminated mother-to-child HIV transmission.

Although the future of the Affordable Care Act is uncertain, the insurance marketplace and Medicaid expansion in Illinois have resulted in 12,000 people with HIV getting healthcare coverage, or one-third of people with HIV in the state. At this moment, nearly everyone in Illinois vulnerable to or living with HIV has access to comprehensive, more affordable insurance that can meet their healthcare and prevention needs. The power of pre-exposure prophylaxis (PrEP) – a prevention pill and program that is up to 99% effective at preventing HIV infection when utilized consistently and correctly – creates the opportunity for convergence of the HIV prevention and care systems. As importantly, HIV treatment improves the health of individuals who are HIV-positive and almost completely protects partners from HIV. People living with HIV on successful antiretroviral treatment – meaning their viral load is undetectable for at least six months – are not capable of transmitting HIV sexually to their HIV-negative partners.

These factors – the Affordable Care Act, PrEP, and HIV treatment – give us a new opportunity to take what's working and expand it for every population living with and vulnerable to HIV in our state. It's also a time to take stock of the state's portfolio of programs – targeted for people vulnerable to and living with HIV or for general populations – and optimize them for today's epidemic. Most importantly, it's imperative that we eradicate health disparities so everyone – regardless of HIV status – can thrive.

That's why it's time for an Illinois Getting to Zero plan. In July 2016, a small group of HIV stakeholders met to explore what it would take to radically change the course of the epidemic. A basic framework was developed, which evolved into this document. The exploratory group aims to convene a larger group of leaders during 2017-18 to develop a ten-year plan to dramatically impact the HIV epidemic. These leaders – including city and state governments, health system stakeholders, elected officials, community-based organizations, consumers, and others – will recommend strategies in the HIV sector and beyond to ensure our collective efforts are as effective as possible. They will also be tasked with bringing additional resources to the table.

Across America, states and local governments have launched similar plans to end the HIV epidemic. These plans build on effective programs and services and set ambitious, yet attainable goals for reducing new HIV infections. From 2014 to 2015, San Francisco cut new HIV cases by 17% and ensured 93% of people living with HIV were diagnosed. In Washington State, the Seattle area reached the ambitious 90/90/90 goal of having 90%

of people with HIV diagnosed, 90% of those diagnosed linked to care, and 90% of those in care virally suppressed. New York State's "Ending the Epidemic" initiative aims to cut new HIV cases from an estimated 3,000 in 2013 to 750 in 2020.

What does "Getting to Zero" mean?

It is critical to define what "Getting to Zero" means. In this context, it refers to both HIV prevention and care goals:

- *Zero new HIV infections.*
- *Zero people living with HIV who are not receiving treatment.*

While the HIV epidemic has been altered thanks to advanced medications and medical care, dedicated social services, and so much more, **HIV remains a serious and communicable disease.** As the 2015 HIV outbreak in rural Indiana shows, abandoning evidence-based prevention methods is devastating and costly to taxpayers. [1]

Illinois must act now to protect the health of its citizens and the taxpayer against needless spending. HIV is completely preventable, but every new case of HIV costs over $350,000 in lifetime medical care.[2] Moreover, an estimated 21,000 people with HIV in Illinois are not receiving medical care[3], and the State risks paying millions of dollars annually in medical care that could have been averted with early intervention.

Current State

While the state has made great progress in the prevention of new cases and care for those living with HIV, there remain significant challenges and inequities.

People living with HIV – In 2015, it is estimated that 38,314 people were living with HIV in Illinois, 20,422 of which lived in the City of Chicago. Of these individuals, less than two-thirds were engaged in care during the previous 12 months (IL: 39%; Chicago: 58%), and less than half were virally suppressed (IL: 44%; Chicago: 48%). Among people living with HIV in 2015, a majority were male (IL: 80%; Chicago: 81%), Black (IL: 47%; Chicago: 50%), and over 40 (IL: 70%; Chicago: 69%).

[1] Philip J. Peters and others, "HIV Infection Linked to Injection Use of Oxymorphone in Indiana, 2014-2015," N Engl J Med 2016; 375:229-239, July 21, 2016.
[2] B.R. Schackman, The lifetime medical cost savings from preventing HIV in the United States. Med Care. 2015 Apr;53(4):293-301. doi: 10.1097/MLR.0000000000000308.
[3] IDPH Integrated HIV Prevention and Care Plan, 63

New HIV Infections – In 2015, it is estimated that 1,565 persons were diagnosed with HIV in Illinois, 927 of which lived in the City of Chicago. Of these individuals, more than three-quarters of newly diagnosed persons were linked to HIV-related medical care with 30 days of diagnosis (IL: 89%; Chicago: 78%). Among newly diagnosed persons, the majority were male (IL: 84%; Chicago: 85%), Black (IL: 51%; Chicago: 53%), and between the ages of 20-39 (IL: 66%; Chicago: 67%).

Despite significant progress in reducing new HIV cases, dramatic and damaging health disparities remain.

Disparities – Despite significant progress in reducing new HIV cases, dramatic and damaging health disparities remain. Gay, bisexual, and other men who have sex with men (MSM) comprised a majority of persons living with HIV in 2015 (IL: 63%; Chicago: 67%) and newly diagnosed persons (IL: 77%; Chicago: 79%). Non-Hispanic Black men comprise a majority of new diagnoses in this population (IL: 46%; Chicago: 46%). Among heterosexual women, non-Hispanic Black women account for more than three-quarters of HIV cases and new infections.

Among certain groups like gay, bisexual, and other MSM, new diagnoses continue to increase, as do co-infections with other sexually transmitted infections. A majority of primary and secondary syphilis cases diagnosed in 2015 were among men (IL: 92%; Chicago: 92%). Among these men, a majority reported being gay, bisexual, and other MSM (IL: 85%; Chicago: 82%). Of these men, nearly half were co-infected with HIV (IL: 46%; Chicago: 54%).

PrEP – While more people than ever are utilizing PrEP to prevent new infections, it is estimated only a small percentage of vulnerable HIV-negative people have a prescription for PrEP. In 2015, approximately 30,000 Illinoisans were eligible for PrEP, but estimates indicate less than 3,000 had a prescription for it.[4] Many vulnerable populations continue to face significant challenges to accessing this important prevention tool.

In order to get to zero new HIV infections, it is imperative to set achievable yet demanding goals that focus on treatment and PrEP coverage. For example, if Illinois increases current rates of PrEP use and treatment by 20% (PrEP uptake among most vulnerable populations from 10% to 30% and treatment among those living with HIV from 50% to 70%), we would expect fewer than 100 cases per year by 2026.[5] Less than 100 cases per year is a point where the HIV epidemic can no longer sustain itself, or "functional zero." Maintaining current efforts alone

[4] Livak B, Michaels S, Green K, Nelson C, Westbrook M, Simpson Y, Prachand N, Benbow N, Schneider JA. Estimating the number of young Black men who have sex with men (YBMSM) on the south side of Chicago: Towards HIV elimination within US urban communities. Journal of Urban Health. 2013 Dec; 90(6): 1205-1213. PMCID: PMC3853168

[5] This assumes that populations with highest rates of HIV acquisition and transmission in Chicago are engaged the most and that implementation of these interventions is effective immediately. (BARS modeling team Khanna, Schneider et al. University of Chicago).

will not get Illinois to functional zero and will cost the state more than $250 million in avoidable healthcare costs.[6]

To achieve our goal of zero new infections, we must transition our system to one that more effectively serves the entire population of people living with HIV, and all who are vulnerable to infection. We must use strategies that lead to the most effective outcomes possible – specifically HIV treatment and PrEP. We must forge new working relationships with other system leaders to maximize our resources in order to achieve a healthier Illinois.

Response to the HIV Epidemic in Illinois - Outcomes

In order to support our goal of Getting to Zero new HIV infections, **we will focus on outcomes that provide the greatest potential and impact for reducing HIV transmission.** We will focus on two outcomes that are rooted in the successful use of anti-retroviral (ARV) medications: HIV treatment and PrEP.

- **Aim: Suppress viral load in the population of persons living with HIV, leading to "zero people with HIV not receiving treatment" –** *Treatment of HIV with ARV medications is the foundation of individual-level HIV care. Identification, linkage, and successful treatment have led to dramatic declines in mortality and improved quality of life. Treatment-as-prevention significantly reduces the likelihood that HIV is transmitted from people living with HIV to their HIV-negative partners.*

- **Aim: Increase utilization of PrEP and other emerging biomedical technologies among populations vulnerable to HIV infection, leading to "zero new HIV infections" –** *PrEP is an HIV prevention method in which HIV-negative people take ARV medication to reduce their risk of becoming infected. When taken consistently, ARV medication use shows a dramatic decrease in the likelihood of HIV infection among vulnerable HIV-negative persons. Other bio-medical technologies are on the horizon. As these demonstrate effectiveness, we must bring usage to scale.*

Regardless of HIV status, individuals must walk through a set of common steps in order to be prescribed and successfully use ARV medications for PrEP and HIV treatment.

- **Outreach/education/marketing** – *People need to know that help is free, available, and that it can bring value to their lives. People need to feel motivated and empowered to seek help.*

[6] The Lifetime Medical Cost Savings from Preventing HIV in the United States
2015 Schackman et al.

- **Testing** – *HIV testing is a necessary step in people's journey to healthcare. Through testing, individuals become aware of their HIV status.*
- **Linkage to care** – *Once HIV status is known, people need to reach healthcare in order to receive services that support use of ARV medications, as well as other services that lead to other health and wellness benefits.*
- **Retention/engagement in care** – *After connecting with healthcare, people need support staying connected. Staying connected helps individuals use ARV medications correctly.*
- **ARV prescription and use** – *Successful use of ARV medications leads to viral suppression among persons living with HIV and protection among persons vulnerable to HIV.*
- **Support services** – *People have varying needs, so supportive services must be available to meet these needs so individuals stay engaged. Supportive services include housing, financial assistance, behavioral healthcare, services addressing drug-user health, and many others.*

Each of these steps must be implemented in ways that are non-coercive, trauma-informed, and respectful of people's choices and lived experiences. Programs, services, and activities that support these steps must be culturally appropriate and work toward health equity.

In addition to HIV treatment and PrEP, we must continue to support other activities that reduce HIV transmission – condoms, non-occupational post-exposure prophylaxis, screening and treatment for gonorrhea and syphilis, access to clean needles and syringes, and prevention of mother-to-child transmission.

How will Illinois Get to Zero?

For Illinois, the path to zero new HIV infections is not a mystery. It will take sustained investments in HIV prevention, treatment, care, and supportive services. It will take focused attention on the structural drivers of the epidemic, including HIV stigma and homophobia. Without a doubt, it will take increased funding, at least in the short-term, with a focus on programs that have the highest impact.

The State of Illinois has a deep financial stake in Getting to Zero. While the Chicago and Illinois Departments of Public Health are traditionally seen as responsible for HIV in Illinois, other agencies spend far more on HIV care and services but with less deliberate planning or oversight. For example, in 2016, 55% of people with HIV were enrolled in Medicaid, and their care cost an estimated $403 million per year. Yet, Medicaid data is limited with respect to tracking the most reliable HIV health outcomes.[7] Illinois state prisons housed 344 people with HIV in March 2017, and the state pays the full cost of their medical care.[8] Department of Human Services programs are vital for providing behavioral healthcare for people living with and vulnerable to HIV. Focused policy and programmatic changes that help synergize these investments with sound public health approaches can dramatically change the course of the HIV epidemic and more effectively spend public dollars.

Getting to Zero requires a thoughtful, well-researched plan that leverages public-private partnerships and brings people and agencies together that don't always focus on HIV. We ask Governor Rauner and Mayor Emanuel to appoint a year-long task force that will develop a blueprint for dramatically reducing new HIV infections, and oversee implementation of the plan. The task force should, at a minimum, include the following:

- **Elected officials**
- **State agencies:** *Public Health, Medicaid, Human Services, Insurance, Corrections, Aging, Education*
- **Key governmental stakeholders***: Illinois Department of Public Health, Chicago Department of Public Health, Cook County Public Health, Cook County Health and Hospitals System, Department of Family and Support Services, and other relevant Chicago government agencies*
- **Private sector leaders with a direct stake in a thriving workforce**
- **Large health systems, hospitals, private insurance, Medicaid plans, and behavioral health providers**
- **Safety-net health care providers, including Federally Qualified Health Centers (FQHCs)**
- **Community-based organizations that focus on HIV among communities of color**
- **People living with and vulnerable to HIV, including Black and Latino gay, bisexual, and other MSM; Women of color, and transgender women of all races**
- **Healthcare providers with expertise in HIV and healthcare delivery for vulnerable populations**
- **Organizations knowledgeable about addressing the social determinants of health, including housing instability**

[7] AFC calculation based on 2013 Medicaid cost data and 2016 enrollment data from HFS.
[8] IDPH, March 2017

- **Researchers with expertise in youth; aging; gay, bisexual, and transgender communities; and other special populations**
- **Schools of Medicine and Nursing and other allied health training programs**
- **Others as appropriate**

Timeline and getting involved

The AIDS Foundation of Chicago (AFC) is staffing the Getting to Zero planning process, with support from Jolie Holliman (jolie_holliman@msn.com), consultant and John Peller, President/CEO. Contact Jolie to learn more or get involved.

- **July 2017**: *Beginning of one-year period of planning to result in formalized Getting to Zero plan. AFC to hire 1.0 FTE Project Manager to facilitate planning activities, coordinate partnerships and support drafting the plan. Establish Getting to Zero task force consisting of at least 30 diverse public and private stakeholders.*
- **August 2017**: *AFC to facilitate Getting to Zero kick-off summit, consisting of a day of dialogue and initial ideation with task force members. AFC will initiate data collection around broad plan concepts.*
- *October 2017: Task force members engage in second meeting to begin preparing Getting to Zero plan. Planning workgroups are established.*
- **November 2017 - April 2018**: *Planning workgroups engage in periodic meetings and/or focus groups.*
- *April 2018: AFC to begin implementation of robust communications strategy for Getting to Zero, including website launch and social media marketing.*
- **May 2018**: *First draft of Getting to Zero plan reviewed; initial concerns and challenges addressed.*
- **June 2018**: *Getting to Zero plan ready for approval and implementation.*

What do we need from you?

We are sharing this framework to gather feedback and to garner buy-in and support for Getting to Zero. We encourage you to read the framework, ask questions about it, and provide us with constructive suggestions to improve it. You can provide feedback in these ways:

- *Attend in-person community input sessions. Information about these sessions can be found HERE.*
- *Participate in upcoming webinars. Information about webinars can be found HERE.*
- *Send an email with your feedback to Jolie Holliman (jolie_holliman@msn.com).*

Feedback will be compiled and released as a supplemental report in late summer 2017.

The following organizational partners participated in the development of the framework:

- *AIDS Foundation of Chicago*
- *Alexian Brothers Housing and Health Alliance*
- *Center on Halsted*
- *Chicago Black Gay Men's Caucus*
- *Chicago Department of Public Health*
- *Howard Brown Health*
- *Illinois Department of Public Health*
- *Illinois Public Health Association*
- *Lake County Health Department*
- *Northwestern University*
- *Ruth M. Rothstein CORE Center*
- *University of Chicago*

Additional Sources for epi data:

Illinois Department of Public Health, HIV Section, Surveillance Unit. Data as of December 2016.
Illinois Department of Public Health, STD Section, Surveillance Unit. Data as of December 2016.
Chicago Department of Public Health, Surveillance, Epidemiology and Research Division. Data as of December 2016.
Note that Illinois statistics include Chicago HIV cases.
National HIV surveillance data, HIV counseling and testing risk data, and 2015 U.S. Pharmacy Survey