

TESTIMONY to the New York State Legislature

Joint Legislative Public Hearing on SFY 2015-16 Executive Budget Topic: Health/Medicaid

(Submitted February 9)

Thank you for the opportunity to submit written testimony. My name is Jacquelyn Kilmer, and I am the Chief Executive Officer of Harlem United Community AIDS Center in New York City. On behalf of Harlem United, I am submitting this written testimony on the importance of 1) Expanding Governor Cuomo's Opportunity Agenda by reinvesting in sustainable human and health services 2) Investing in health systems transformations essential to Medicaid Redesign 3) and Ending AIDS in New York State by 2020.

Harlem United is vastly experienced in providing critical health, housing and human service to people with multiple needs. With 625 units of supportive housing, 3,000 primary care visits to our Federally-Qualified Healthcare Center, adult day health services, mental health, harm reduction, community-based outreach and preventive screenings, Harlem United is able to "level the playing field" for more than 15,000 New Yorkers each year. Many of these individuals are among the most economically-disenfranchised individuals in New York City – homeless or unstably housed, living with HIV or AIDS, Hepatitis C, Diabetes, extreme poverty, substance use, and mental illness. We serve the most vulnerable citizens of New York and are, for many, the service provider of last resort.

With a New York City-wide reach and roots in Harlem, we work every day to improve the health and well-being of individuals and communities by providing supportive housing, community-based healthcare, and responsive human service.

We thank the Legislature for recognizing the critical role that nonprofit human and health service agencies, like Harlem United, play in alleviating inequality, for investing in supportive housing through Medicaid Redesign and moving the state further down the road universal payment for quality outcomes in healthcare instead of just reimbursing for services rendered for providing per-member-per-month capitation payment to managed care organizations. We further commend Governor Cuomo, in his SY2015-16 Budget, for taking concrete steps to address some of the underlying causes of poverty in New York State. We believe his Opportunity Agenda is an excellent starting point for

further investment; and we look forward to working with the Legislature and the Governor to create more comprehensive, sustainable delivery of human and healthcare services and a more equitable and just New York.

In your upcoming budget deliberations we urge you to consider the following:

- Expand Governor Cuomo's Opportunity Agenda by reinvesting in sustainable human and health services
- Invest in health systems transformations essential to Medicaid Redesign
- End AIDS in New York State by 2020.

Reinvest in Human and Health Services

In a recent *Albany Times Union* op-ed, then Assemblyman Karim Camara, who has now assumed the position of Executive Director of the Office of Faith-Based Development Services, observed that the state's \$5.4 billion bank settlement represented a golden opportunity for the state to reinvest in human services. In a letter to the editor published January 25th in the Sunday Opinion page (Perspective) of the *Albany Times Union*, I agreed. Healthcare, housing and supportive services are necessary variables in the equation to eradicate poverty. Harlem United endeavors to integrate public health, primary care and housing to improve individual health as well as offer opportunities for independence and economic security and promote wellness in our communities. The Governor's \$50 million proposed investment toward non-profit infrastructure is inadequate and represents little more than 10 percent of the surplus. Harlem United urges that this investment be significantly bolstered to create a non-profit infrastructure, technology and business investment fund that could initially be capitalized from \$500 million of the surplus.¹

Invest in health systems transformations essential to Medicaid Redesign

New York's Medicaid program is experiencing a transformation of mammoth proportions through the implementation of the Delivery System Reform Incentive Payment (DSRIP) program, which represents the state's interest in continuing to do away with fee-for-services Medicaid, emphasizing the quality of outcomes, and paying for value over volume. Harlem United is aligned with six lead Performing Providing Systems (PPS). Harlem United will benefit from this initiative as a community partner. The precise financial benefit is not known, but funding will ideally flow from leads to their partners and projects will be valued according to a highly-technical algorithm established by the state. Community based health partners are a critical part of DSRIP, and the Governor's budget includes over \$1 billion in new funding for health care restructuring. Harlem United is concerned that the allocation will uphold a system of acute care rather than investing in the transformations essential to Medicaid Redesign. **Harlem United urges the Legislature to earmark some of the capital funding in the budget to community health centers and other community-based providers, such as Harlem United.**

As new initiatives like the State Health Innovation Plan emerge, it will be important that Medicaid funding and other public dollars be available for safety-net, community-based providers that serve low-income communities, communities of color and underserved

populations. Harlem United is a proud member of Medicaid Matters New York, and joins with this coalition in its budget and legislative requests.

- **Preserve Provider Prevails:** The budget proposes to eliminate the provision that guarantees that the prescriber of a prescription drug has the ultimate discretion as to the precise drug formula administered by a pharmacist. We urge the Legislature to reverse this and preserve “provider prevails” and thereby preserve choice in prescribing practices.
- **Reject Outpatient Prescription Drug Billing Proposal:** The Executive Budget proposes to require that claims for outpatient prescription drugs submitted to a Medicaid managed care plan by a provider participating in the federal 340B program be billed at the actual acquisition cost (invoice price) minus discounts. Harlem United urges the Legislature to reject this proposal, which would reduce reimbursement and critical revenue to these federally-designated providers, like Harlem United.

End AIDS in New York by 2020

Finally, as a member of the Governor’s *Ending the Epidemic Task Force*, which recently completed its charge to deliver a blueprint to end AIDS in New York State by 2020, Harlem United wholeheartedly endorses the recommendations therein. Harlem United has been integral to this effort since its inception, much prior to the Governor’s announcement and the convening of the Task Force.

Here are just a few of the items we endorse:

The Blueprint recommends that New York State take action to:

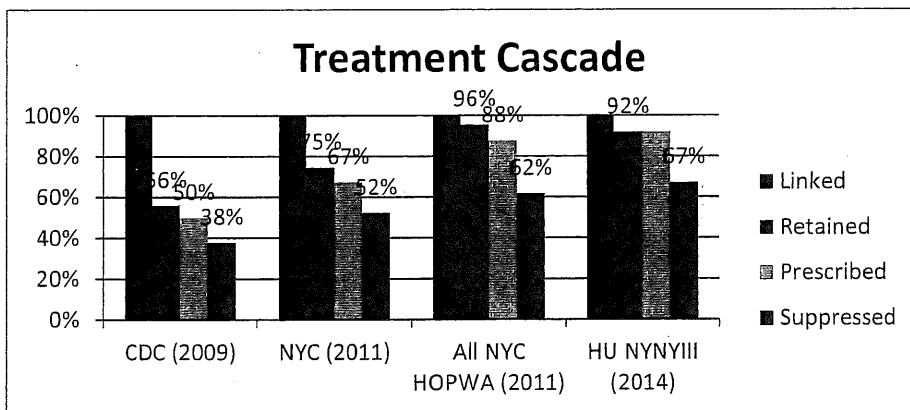
1. **Improve and expand HIV testing:** In the 2014-15 budget, the New York State Department of Health (NYSDOH) removed the requirement for written informed consent, making the mandatory offer of an HIV test for people between the ages of 13-64 years of age much easier in medical settings. However, we need to increase the number of New Yorker’s that know their HIV status through both expanded routine testing and targeted testing-and link those New Yorker’s to care. We applaud the measure in the budget to remove written informed consent for HIV testing in New York State prisons. An additional \$1 million should be added to the NYSDOH AIDS Institute budget for ongoing implementation and enforcement of New York’s testing law.
2. **Stabilize homeless HIV-positive New Yorkers through access to housing and essential services.** Access to affordable housing, food and transportation for low-income people with HIV is essential to enable each person to realize the benefits of HIV treatment and improved health. The greatest unmet need of people living with HIV is access to safe, affordable, stable housing, and transportation and nutrition assistance. Research shows that stably housed individuals are more likely to be retained in medical care and achieve viral suppression.

Essential housing supports for homeless and unstably housed low-income people living with HIV should be expanded throughout New York State to meet the basic survival needs of New Yorker's: 1) The existing NYS HIV Enhanced Rental Assistance Program for people with HIV/AIDS should be updated and expanded statewide and 2) Affordable housing protections, such as the 30% Rent Cap, should be made available statewide to protect rent burdened people with HIV on SSDI and as a bridge to work for low-income people with HIV.

Potential funding sources to fund the expansion of essential housing supports for homeless and unstably housed New Yorker's include:

Supportive housing created through NY/NY IV: A program for supportive housing development financed in large part by the JP Morgan Chase Settlement Fund, there is an opportunity to inform a percentage set-aside for people living with HIV. The previous supportive housing agreement made in 2005, NY/NY III, was seen as a cost-effective tool to increase supportive housing capacity and address the multiple challenges faced by chronically homeless individuals and their families.

Harlem United knows firsthand that supportive housing can reduce the number and length of hospital stays, the number of emergency room visits, and the number of psychiatric hospitalizations. **Housing is healthcare.**



Reaching HIV positive individuals with routine testing, linking and retaining them in care to achieve suppressed viral load – which, in turn, brings health benefits for the individual client and drastically reduces the risk of transmission to others - is referred to as the treatment cascade. NY/NY III has shown tremendous success in improving this cascade. Viral suppression for the clients in NY/NY III from 2011 to 2013 nearly doubled. More than 90 percent of our tenants in NY/NY III in December 2014 were linked to care and 67 percent are virally suppressed. In 2013, 84% of our housing clients had a least one primary care visit every six months. **Supportive housing saves lives.**

A new statewide agreement should be negotiated to provide for 20,000 new supportive housing units over the next ten years, with at least 4,000 of those units targeted to people with HIV with co-occurring behavioral health issues.

Medicaid reimbursement for supportive housing services: Securing Medicaid reimbursement for the services provided in supportive housing programs could generate significant funding for rental assistance and housing operating costs. In New York City, HASA supportive housing contracts fund units at about \$25,000 per year, of which about half goes to supportive services that could be funded through Medicaid.

Medicaid reimbursement for supportive housing services (such as case management), ideally through a bundled managed care rate rather than per-service billing, would free an amount equal to the federal portion of the Medicaid reimbursement which could be used to fund rental assistance and other housing operating costs.

3. **Expand access to HIV prevention treatments.** To effectively end the epidemic New York State must create a PEP and PrEP statewide education campaign, drug assistance program and monitoring, evaluation, and quality improvement program.

One of the key components of the Governor's three point plan is ramping up access to and use of PrEP. The Executive budget calls for the creation of a PrEP Assistance program to assist New Yorker's in accessing and affording PrEP. In addition to a once daily pill, people utilizing PrEP for HIV prevention must also visit their doctor every three months for HIV and STI testing, counseling about safer sex practices and harm reduction and counseling to promote medication adherence.

Currently, there is only \$2,000,000.00 allocated for a PrEP Assistance Program. However, given the fact that PrEP scale up is such a large component of the Governor's three point plan, the high cost of the drug and the medical costs associated with adherence and New York's population size, it is essential that additional funds be dedicated to this program. We do not want to have to create a PrEP Assistance Program waiting list, that will simply deter people from seeking access to PrEP in the future and it will not become as widely utilized as we are aiming for. **An additional \$10 million is needed to fully fund the PrEP Assistance Program for people at high risk of HIV infection, which includes drugs, labs, medical provider visits, as well as funding for patients navigators and outreach workers in clinics and community based organizations.**

PEP and PrEP are fairly new medical advances and much education is needed to both providers, on the uses and benefits of PEP and PrEP, and the general public, on their use and availability. **We urge an additional \$5 million be provided for statewide PEP and PrEP infrastructure, education and media campaigns.**

4. **Adopt 21st-century HIV surveillance strategies and health systems to target interventions where they're most needed.** Last year, the Legislature approved a measure to allow for enhanced use of HIV surveillance data between the NYSDOH AIDS Institute and community health partners so that people who have fallen out of care can be identified and linked to care. This was a wonderful first step in identifying people that have fallen out of care but there is much more to be done to fully engage those who are either unaware of their status or aware of their status but are not engaged in care.
- Acutely infected persons are the most efficient transmitters of HIV when engaging in risky behavior. Providers should have the capacity to screen for acute infection using 4th generation testing and allowing for higher reimbursement for providers using the most sensitive tests.
 - All testing centers should provide referrals for engagement in care for both HIV-positive and HIV-negative individuals.
 - Testing centers should identify what caused someone to delay testing or fall out of care if they were already aware of their status. Connections should also be made to housing and supportive services and behavioral health needs and PrEP programming.
 - Existing HIV special needs plans (SNPs) should be expanded to provide prevention services, such as PEP and PrEP, to eligible high-risk individuals.
5. **Improve retention in care and viral suppression for people with HIV.** Support outreach programs for people with HIV who have fallen out of care, to link them to culturally competent services and treatment, as well as programs to support and incentivize positive health outcomes such as suppressed viral load.
6. **Provide HIV education, prevention, and treatment outreach and access for all New York youth.** Reduce HIV incidence among youth with comprehensive sexual health education in New York State schools, improved access to confidential HIV treatment and prevention, and housing support for homeless youth.
- Pass the *Healthy Teens Act*. Funding should be made available for comprehensive age appropriate sexual health education. We should equip our youth with the knowledge to make informed decisions about their sexual health, but also their physical, emotional, mental and spiritual health. Curriculum should also address condom use, PrEP, substance use, mental health, healthy relationships, sexual orientation and gender identity.
 - Extend the NYS Family Planning Benefits Program (FPBP) to cover all sexual health services such as PrEP, HIV treatment (testing is already covered), Hepatitis C testing and treatment and transgender transition related services.

- Remove the restriction on mature minor's consent to HIV treatment. Currently, minors can consent to HIV testing, but not HIV treatment. Mature minors should be allowed to consent to HIV treatment if they test positive.

Youth are at increased risk for HIV due to a variety of social drivers including lack of support and financial stability. Therefore, stable housing and supportive services for homeless and at risk youth should be greatly expanded. Without these comprehensive services, we will not be able to keep our youth HIV-negative.

- Given the high rates of HIV among LGBT populations and the substantial lack of housing resources, housing options for homeless LGBT youth should be substantially expanded. Services for Runaway and Homeless Youth is current funded at \$2.36 million and it should be increased to \$4.7 million.

7. **Expand healthcare and human rights for transgender New Yorkers.** Pass the Gender Expression Non-Discrimination Act (GENDA) and improve and expand transition-related health care for transgender New Yorkers. The Governor took significant steps throughout this past year to provide access to gender affirming health care in private health insurance plans and Medicaid. However, transgender New Yorker's lack basic civil rights protections in New York, resulting in discrimination in housing, employment and access to healthcare. The Governor did include GENDA as one of the priorities identified in his Opportunity Agenda.

There is a fiscal impact upon the State by failing to pass GENDA and allowing unfettered discrimination against transgender New Yorkers. Discrimination in employment leads to increased use of public assistance programs and decreases in tax revenue for the State. Discrimination in housing increases the amount of state and federal dollars that must be spent on public housing programs, shelter systems and other costs associated with homelessness. Discrimination in both of these areas, leads transgender individuals to be reliant on public assistance programs and accessing healthcare through Medicaid. Transgender identified individuals are fifty times more likely to contract HIV. While significant strides have been made to provide easier access to health care coverage over the past year, we will not achieve a reduction in new HIV infections among the transgender population absent passing GENDA.

- GENDA should be included in the Article VII.
- Given the high rates of HIV among the transgender population and the substantial lack of housing resources, housing options for homeless and unstably housed transgender individuals, these resources should be substantially expanded.

We applaud the NYS Department of Health for taking the crucial step of lifting the exclusions of coverage for transgender-related care in the Medicaid program. The previous exclusions were discriminatory and detrimental to the health of transgender New Yorkers. Studies have shown that transgender people face disproportionate rates of discrimination and face significant difficulties in accessing the healthcare they need. The proposed changes to Medicaid will improve the health and well being of many transgender individuals. We are concerned with a number of the age restrictions identified in the policy proposal.

- The proposal to limit coverage for hormone therapy only to individuals 18 or older, for example, is inconsistent with medical standards of care and would deprive many younger individuals of the care they desperately need. We strongly recommend that the proposal be amended to remove all age restrictions for appropriate care, and that puberty blockers be made available for those under the age of 18.
- The draft regulation unnecessarily spells out specific exclusions for care that have been clearly considered appropriate medical care for the treatment of gender dysphoria. We recommend that the regulation be amended as not to arbitrarily identify specific procedures that would not be covered and instead leave those determinations to the individual and their medical providers.

New York has taken a bold step forward in advancing the medical needs of the transgender population in New York, arbitrary restrictions on that care will only result in significant difficulties for transgender individuals attempting to access care, which will negate the original intent in providing the coverage.

8. Eliminate barriers to clean syringe and condom use

The criminal law allows for condom possession to be used as evidence of prostitution and sex trafficking related crimes which discourages individuals from carrying condoms, and therefore using condoms, for fear of arrest. The Executive budget calls for the end of condoms as evidence in limited misdemeanor crimes. This ban should be expanded, to all prostitution and trafficking related crimes, whether misdemeanor or felony. It is time the criminal law and public health law work in harmony. No individual should be deterred from carrying and using condoms, that is simply bad public health policy.

Injection drug users were once the highest number of people testing positive for HIV, however implementation of syringe exchange programs has resulted in a 90% decrease in the number of new HIV infections attributable to sharing syringes. These programs are an extremely cost efficient way to avert new infections and access should be expanded with no barriers.

- The Executive budget proposes removing limits on the Expanded Syringe Access Program (ESAP) and adding specific language to the Penal Code to allow for ESAP and Syringe Exchange Program (SEP) participants to be exempt from current laws regarding syringe possession. However, this is not enough and allows for far too much room for arrests to continue.

ESAP and SEP participants should never have a reason to be deterred from utilizing clean syringes and equipment. Instead, we should be encouraging injection drug users to access these programs. Therefore, the language should be expanded to allow for decriminalization of syringes in all circumstances.

- Funding should also be expanded to effective syringe exchange program and other harm reduction programs. Syringe exchange programs should be accessible statewide and there are currently significant gaps in coverage across Upstate New York. A 3-year scaled up increase in current funding (including the cost of a pilot project for a safer injection facility) would require an additional \$4 million be added to the AIDS Institute budget for this fiscal year.

9. Provide testing and treatment for Hepatitis C. It is estimated that approximately 15-30% of HIV-positive individuals are also co-infected with Hepatitis C. Hepatitis C leads to sever liver damage and death when not treated appropriately. Co-infected individuals are much more likely to utilize emergency rooms and have longer hospital stays. New York State has already passed a testing law aimed at increasing testing for Hepatitis C. Treatment efforts have substantially improved but the treatment guidelines for Hepatitis C lag behind. While we wait for the treatment guidelines to catch up, we risk the health and lives of thousands of New Yorkers.

- Testing efforts should be increased so that we are identifying people that are Hepatitis C-positive as early as possible.
- Treatment guidelines should be updated to provide for immediate treatment for all co-infected individuals.
- An additional \$2 million should be added to the budget to support NYSDOH oversight and enforcement of HIV/HCV care in correctional facilities.

Thank you. Feel free to contact myself or Kimberleigh Smith, our Vice President for Policy and Advocacy, directly with comments and questions at ksmith@harlemunited.org or 212-803-2890.

¹ Human Services Council, FY16 State Executive Budget Statement: More Substantial Reinvestment Needed