# New York State AIDS Advisory Council
# State Budget Recommendations FY 2014-15/Brief Overview

1. **Challenge:** Fund the essential components to achieve the *End of the AIDS* epidemic in New York State (NYS).

**Solution:** Support the strategies that are necessary to move toward the end of the AIDS epidemic in NYS including enhanced surveillance, aggressive prevention, and linkage to and retention in care.

2. **Challenge:** Access to effective, affordable medications is absolutely critical for New Yorkers living with HIV/AIDS.

**Solution:** Continue to ensure adequate funding for the AIDS Drug Assistance Program (ADAP).

3. **Challenge:** New York State (NYS) has experienced dramatic reductions in federal funding.

**Solution:** Advocate for additional federal resources and fight funding formulas that unfairly penalize NYS.

4. **Challenge:** The health care landscape is undergoing significant changes with NYS Medicaid Redesign (MRT), the launch of Health Homes and implementation of the Affordable Care Act happening simultaneously.

**Solutions:**

- Support funding for the development and delivery of consumer and provider education and funding related to the integration of Health Homes and MRT.
- Prioritize funding for key areas identified by the MRT including: Hepatitis C (HCV) prevention, diagnosis and care; comprehensive harm reduction counseling and services that reduce the incidence of HIV and HCV; supportive housing; and targeted initiatives designed to reduce health disparities.
- Because many downstream Health Home providers are community based former targeted case management agencies without access to Health Efficiency and Affordability Law (HEAL) monies, support funding for infrastructure and information technology (IT) development to ensure the successful participation of these key providers.
- Support the $5 million proposed in the Governor's Executive Budget for health home/criminal justice coordination.

5. **Challenge:** Loss of primary care beds and hospital closures.

**Solution:** The Council encourages a dialogue between lawmakers, the NYS Department of Health (NYSDOH), health care executives and key stakeholders about strategies for ensuring that the health care needs of people with HIV, HCV and other infectious diseases are fully addressed during this time of transition.

6. **Challenge:** Missed opportunities to prevent and treat HIV and HCV in prisons and jails.

**Solution:** Grant $2 million in funding to the NYSDOH AIDS Institute to support legislatively mandated NYSDOH oversight of HIV/HCV in state and local correctional facilities.

7. **Challenge:** Opioid overdoses continue to rise statewide.

**Solution:** Grant $1 million to the NYSDOH AIDS Institute to expand Opioid Overdose Prevention Programs.

8. **Challenge:** Only a fraction of New York's injection drug users (IDUs) have free, confidential access to clean syringes, and service gaps have grown wider in suburban and rural areas.

**Solution:** Grant $1 million to the NYSDOH AIDS Institute to expand syringe exchange programs.

9. **Challenge:** Many New Yorkers remain unaware of their HIV status, which potentially delays diagnosis and access to care, while simultaneously fueling the spread of HIV.

**Solution:** Grant $1 million to the NYSDOH AIDS Institute to support implementation of New York's HIV Testing Law.

10. **Challenge:** Many New Yorkers remain unaware of their HCV status, which potentially delays diagnosis and access to care, while simultaneously fueling the spread of HCV.

**Solution:** Grant $1 million to the NYSDOH AIDS Institute to support HCV Testing law implementation.

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## Background

HIV/AIDS continues to be a significant public health concern. New York State (NYS) remains at the epicenter of the HIV epidemic in the United States, ranking first in terms of the number of persons living with HIV nationally. More than 132,000 New Yorkers are living with HIV or AIDS, with nearly 3,300 new diagnoses of HIV infection in 2012. It is estimated that up to 20,000 persons are infected but are unaware of their status.

Preliminary 2012 NYS data on new HIV diagnoses show several trends of note. The proportion of newly diagnosed infections in men was 78%, as compared to 73% in 2007, continuing a slowly increasing gender imbalance. Blacks and Hispanics continue to be disproportionately affected; together they account for 73% of new diagnoses, down slightly from75% in 2007. An increasing proportion of new diagnoses (52%) is seen in men who have sex with men (MSM); in 2007 they represented 41% of new infections.

The age distribution of newly diagnosed cases among both sexes changed between 2007 and 2012. While the number of diagnoses among persons age 30 and older dropped by 37% during this period, diagnoses among persons under age 30 dropped by only 15.4%. Diagnoses among all age groups decreased in 2012.

Characteristics of persons living with diagnosed HIV infection (PLWDHI) in NYS have remained fairly constant year-to-year. At the end of 2012, 70% were male. Most (60%) had a diagnosis of AIDS; 40% had HIV infection that had not progressed to AIDS. More than three-quarters (78%) were age 40 years and older with 16% age 60 and older. The racial/ethnic distribution included 21% White, 42% Black, 32% Hispanic, 1.3% Asian/Pacific Islander, ≤0.1% Native American and 3.3% of more than one racial group. The distribution of transmission risk among PLWDHI was: 34% MSM, 17% injection drug use (IDU), 2.7% MSM and IDU, 17.3% heterosexual, 11.1% female presumed heterosexual, 16% unknown risk, 2.2% pediatric risk, and 0.2% blood product exposure.

The disease profile of HIV continues to shift the paradigm from an acute to a chronic disease medical model, with patients living longer, healthier lives. There is a need for basic, integrated primary care and preventive services and the availability and accessibility of subspecialty care for disease conditions associated with aging, and long term antiretroviral (ARV) therapy.

At the same time, biomedical advances in prevention, including the FDA's approval of Truvada for pre-exposure prophylaxis (PrEP) offer even more opportunities to build on existing evidence-based prevention strategies to further reduce HIV infection rates in NYS.

For more than 30 years, NYS – and specifically the NYSDOH AIDS Institute - has served as a model for its innovative, impactful, integrative and comprehensive approach to the HIV/AIDS epidemic. The continuum of HIV/AIDS and STD prevention and treatment activities and

services includes disease surveillance, prevention, education, outreach, health care, and a range of support services, as well as access to medications and assistance with insurance continuation (i.e., maintenance of insurance coverage). As we continue into 2014, significant changes in funding formulas, health care financing, service delivery and shifts in the epidemiology of HIV/AIDS present both challenges and opportunities that must be navigated carefully if we are to maintain our historic progress in preserving public health. Those challenges and opportunities are detailed herein.

## 1. Challenge: Fund the essential components to achieve the *End of the AIDS* epidemic in NYS.

The NYS AIDS Advisory Council believes that the end of AIDS in NYS is within our reach. Strategies that are necessary to move toward the end of the AIDS epidemic in NYS include enhanced surveillance, aggressive prevention, and linkage to and retention in care. Funding for HIV/AIDS in NYS has been reduced by more than $60 million in the last few years. An aim to end the AIDS epidemic is not merely a vision but is feasible. However, resources are required in order to work toward this goal.

- **Solution:** The momentum to bring the epidemic to a close in NYS already exists. The effect of ARV treatment in preventing progression to AIDS, improving health and saving lives has long been known. Recent science has shown that treatment is also effective in preventing transmission to others. New York State (NYS) is well positioned to look at the end of AIDS. For example, NYS's comprehensive approach to HIV prevention and care has led to a 40% reduction in newly diagnosed HIV cases in the last decade; a reduction in the proportion of IDUs among newly diagnosed cases from 54% in the 1990s to just 4%; the near elimination of mother-to-child transmission (MTCT), with a drop in the rate of MTCT from 25% to 40% in 1990 to 0.8% -- just three cases -- in 2012; and universal access to HIV medications and care for New Yorkers living with HIV/AIDS through the HIV Uninsured Care Programs (ADAP), which bridge the gap between Medicaid coverage and private insurance.

The "2012 Cascade of HIV Care" ***(see Attachment A)*** is a graphic representation of people accessing HIV testing, linkage to care, retention in care, ARV treatment, and ultimately achieving a suppressed viral load. New York exceeds the nation in terms of the percentage of Persons living with HIV/AIDS (PLWHA) who are in care, retained in care, and virally suppressed. However, significant challenges remain. Improvement is needed in the elements of the cascade.

A focused effort – and the resources needed to support such an effort – will lead to improved viral suppression to the extent that HIV-infected persons no longer progress to AIDS, and additional infections are minimized due to reduced transmission. The NYS AIDS Advisory Council envisions the following key components of a comprehensive plan to end AIDS in NYS:

- **Pre-Exposure Prophylaxis (PrEP) ($1.5 million)** Support provider and public education and access to PrEP for eligible HIV negative individuals.

- **Post-Exposure Prophylaxis (PEP) ($1.5 million)** Support provider and public education and access to PEP to maximize its use to prevent HIV transmission.

- **High-Impact Prevention/Surveillance ($3 million)** Support the high-impact approach to HIV prevention that is designed to achieve the prevention goals of the National HIV/AIDS Strategy and maximize the effectiveness of existing prevention methods. **Surveillance:** An enhanced, updated surveillance system is essential for high-impact prevention and to monitor the epidemic.

- **Linkage to and Retention in Care ($2 million)** Improve individual health outcomes and reduce HIV transmission by supporting innovative initiatives that promote access to treatment and adherence support.

- **Expanded Partner Services ($1 million)** Expanded partner services to identify individuals diagnosed HIV positive and out of care.

- **Evaluation and monitoring ($1 million)** Identify individuals diagnosed HIV positive, in care and not virally suppressed.

These programmatic enhancements that will employ scientific advances and biomedical interventions will pay for themselves as each infection averted saves the system almost $400,000 in lifetime medical costs. The further reduction in new infections brought about by the plan to end the epidemic in NYS could double the savings.

It should be noted that since 1983, the NYSDOH AIDS Institute has led New York in achieving public health results that surpass the progress made by other states. Among the victories are the following:

- **A 93% reduction in new AIDS cases between the years 1993-2011.**
- **An 84% reduction in AIDS-related deaths between the years 1994-2012.**
- **A reduction in mother-to-child HIV transmission from nearly 40% in 1990 to 0.7% in 2010. According to preliminary data, the rate will once again reach less than 1% in 2012.**
- **Reduction in the proportion of IDUs among newly diagnosed cases, from 46% of diagnoses in 1994 to 12% in 2002 and 3% (preliminary) in 2012.**
- **Integration of STD services with HIV/AIDS services to reduce overall transmission.**
- **Integration of HCV screening and treatment in community clinics and neighborhood sites.**
- **Passage of a law that requires the offer of a HCV screening test to every individual born between 1945 and 1965 receiving inpatient hospital care or primary care.**
- **Facilitated the expansion of HIV testing to include people aged 13-64 years old.**
- **Improved the health outcomes for almost 17,000 PLWHA and other chronic conditions through enrollment in the HIV Special Needs Plans (SNPs) in 2013.**

## 2. Challenge: Access to effective, affordable medications is absolutely critical for New Yorkers living with HIV/AIDS.

- **Solution: Continue to ensure adequate funding for the AIDS Drug Assistance Program (ADAP).**
  ADAP serves more than 27,000 uninsured and underinsured New Yorkers living with HIV/AIDS and has played a key role in reducing acute care costs and enhancing the quality of life for people living with HIV. To ensure access to the full spectrum of medications for all persons with HIV and co-morbidities, regardless of insurance coverage or income, the Council strongly recommends the preservation of Medicaid prescription drug coverage and full funding (both federal and State) of ADAP, without any cuts to the formulary.

## 3. Challenge: New York State has experienced dramatic reductions in federal funding.

New York State (NYS) has lost more than $25 million in Ryan White funds, with additional cuts anticipated in 2014, and reauthorization up for debate in 2015. The CDC Cooperative Agreement, which supports HIV prevention, education and support services, has seen a 42% reduction in the current funding cycle; New York has lost more than $13 million in CDC funding since 2012. The NYSDOH AIDS Institute's Enhanced Perinatal Surveillance Cooperative Agreement was terminated in December 2011. New York State (NYS) will likely experience reductions of up to 12% in funding for the National HIV Surveillance System which includes a 48% reduction in HIV incidence surveillance funding in the year ahead when compared to 2012 funding levels.

- **Solution: Advocate for additional federal resources and fight funding formulas that unfairly penalize NYS.**
  New York's state and federal representatives need to make a strong case and become more visible in the fight to ensure than New York gets its fair share of funding and is not penalized for our historic successes in reducing new infections, newly diagnosed AIDS cases and AIDS deaths.

## 4. Challenge: The health care landscape is undergoing significant changes with MRT, the implementation of Health Homes and implementation of the Affordable Care Act happening simultaneously.

As New York continues to re-design Medicaid and make major changes in the delivery of behavioral health care, we are appreciative that the NYSDOH AIDS Institute and its community partners have played a key role in these discussions. If the promise of reduced costs and better access to care is to be fulfilled, state funds should support key transition activities.

- **Solution: Support funding for the development and delivery of consumer and provider education and funding related to the integration of Health Homes and MRT.**

- **Solution: Prioritize funding for key areas identified by the MRT including: HCV prevention, diagnosis and care; comprehensive harm reduction counseling and services that reduce the incidence of HIV and HCV; supportive housing; and targeted initiatives designed to reduce health disparities.**

- **Solution: Many downstream Health Home providers are community based former targeted cased management providers with no access to Health Efficiency and Affordability Law (HEAL) monies. Support funds for infrastructure and IT development for community based Health Homes are necessary to ensure the successful participation of these key providers.**

- **Solution: Develop standards of care as defined within the Affordable Care Act for Federally Qualified Health Centers.**

- **Solution: Provide resources for the monitoring and evaluation of the Health Home implementation.**

- **Solution: Provide resources for the implementation of the Health Homes and criminal justice initiative. Connecting those involved in the criminal justice system to the health care services can result in reduced incarceration, hospitalization and new criminal activity while saving the State significant sums of money. The $5 million proposed in the Governor's Executive Budget will improve linkages between the new Medicaid health homes and the people in the criminal justice system, many of whom have significant medical and behavioral health issues. Uses of the funding may include: Expedited Medicaid coverage if someone is eligible; Health Home liaisons in criminal justice settings to assist in the identification of appropriate patients; support communication mechanisms between criminal justice service providers and health homes; training, technical assistance, and sharing of best practices between health care and criminal justice service providers; and innovative and pilot strategies and approaches to engaging the criminal justice system into health care reform.**

## 5. Challenge: Loss of Primary Care Beds and Hospital Closures.

The Designated AIDS Center (DAC) program was established more than 20 years ago as part of the NYSDOH's first response to the AIDS epidemic. The DACs use a patient-centered program model that can evolve with the needs of the patient in the changing health care environment.

The Council is alarmed by the rapid closure of several hospitals that have historically played a key role in the provision of HIV care. These closures, combined with actual and planned service reductions at other hospitals pose a significant threat to the continuum of care and treatment availability for individuals living with HIV.

Primary care centers, including DAC, are overwhelmed with the demand for medical care, mental health services, addiction management and detoxification services.

- **Solution: The Council encourages a dialogue between lawmakers, the NYSDOH, health care executives and key stakeholders about strategies for ensuring that the health care needs of people with HIV, HCV and other infectious diseases are fully addressed during this time of transition.**

## 6. Challenge: Missed Opportunities to Prevent and Treat HIV and HCV in Prisons and Jails.

It is estimated that about 5% of the 55,000 individuals in NYS prisons are HIV infected. (Since testing is voluntary among inmates, comprehensive information is not available.) The overwhelming majority of those known to be infected are persons of color. The AIDS Advisory Council has long been concerned with disease prevention and health-related services within the State correctional system, issuing reports in the late 1980s and 1990s regarding its findings and recommendations to improve health-related services within Department of Corrections and Community Supervision (DOCCS) facilities.

In FY2012-2013, the AAC conveyed its concerns to the State Health Commissioner, acknowledging some improvement in the medical services within DOCCS facilities and commending those responsible, but also noting continuing concerns regarding the inability of the DOCCS health system to uniformly carry out routine testing for HIV and HCV, and assure consistent treatment. The Council cited estimates that only 50% of the HIV infected population and 70% of those with HCV in prison have been identified. The Council expressed its support for proposed legislation that would require oversight of health services within State and local correctional facilities by the NYSDOH and that legislation was signed into law on September 16, 2009. The implementation of the law did not include any funding to carry out the substantial new mandated responsibilities. The total annual cost to implement this program is estimated at approximately $2.3 million.

- **Solution: Grant $2 million in funding to the NYSDOH AIDS Institute to support legislatively mandated NYSDOH oversight of HIV/HCV in state and local correctional facilities.**
  The recommended funding would provide SDOH with resources to manage and conduct oversight activities relating to the requirements of the enacted legislation in all (58) State and (56) local correctional facilities across the State during State FY 2013-14, the fourth year of implementation. These activities include at a minimum conducting annual reviews, inspecting policies and procedures as well as medical records, interviewing providers and patients, directing DOCCS to implement corrective action plans, and monitoring the implementation of such plans.

## 7. Challenge: Opioid Overdoses Continue to Rise.

The federal Centers for Disease Control and Prevention recently named opioid overdoses one of our nation's most pressing public health problems, due in part to rampant painkiller abuse.

Recent press accounts have detailed the crisis in New York and overdoses are now a leading cause of death in many communities.

In April 2006, the NYSDOH was authorized to approve Opioid Overdose Prevention Programs which are effective in preventing fatal opioid overdoses. In an opioid overdose, the individual becomes sedated and gradually loses the urge to breathe. Most overdoses are not instantaneous and the majority of them are witnessed by others. Many overdose fatalities are preventable, especially if witnesses have had appropriate training and are prepared to respond in a safe and effective manner. Prevention measures include education on risk factors (such as poly-drug use and recent abstinence), recognition of the overdose and an appropriate response. Response includes contacting emergency medical services and providing resuscitation. Resuscitation consists of rescue breathing, and/or administration of an FDA-approved drug (i.e., naloxone) to immediately reverse the effects of an opioid overdose. There are currently over 115 Registered Opioid Overdose Prevention Programs. Program data indicates over 700 "reversals," or lives saved since the program's inception, as well as over 5,000 individuals trained as overdose responders. Given the well-documented heroin/opiate crisis occurring in many areas of the state, particularly Long Island, this program has taken on increased importance in the last year.

- **Solution: Grant $1 million to the NYSDOH AIDS Institute to expand Opioid Overdose Prevention Programs**.
  Funds will support outreach to increase the number of registered programs and fund small contracts with registered providers to pay for program expenses, including professional staffing, naloxone, and supplies such as latex gloves and sharps containers, recordkeeping and data reporting.

## 8. Challenge: Only a fraction of New York's IDUs have free, confidential access to clean syringes and service gaps have grown wider in suburban and rural areas.

The Council notes, in particular, the proven effectiveness of **comprehensive harm reduction services**, which includes risk reduction education regarding drug-using and unsafe sexual behaviors, recovery readiness counseling, provision of and education regarding clean injection equipment and safer injection techniques, condom distribution, as well as direct referrals to supportive services, HIV counseling and testing, partner notification assistance, case management, drug treatment, health care, legal, and housing services. Comprehensive Harm Reduction Services are effective in preventing HCV among IDUs.

**Syringe Exchange Programs (SEPs)** have been the NYSDOH AIDS Institute's most successful prevention programs, reducing HIV transmission among IDUs by over 80% and saving the state hundreds of millions of dollars annually. Improved syringe access and harm reduction education for drug injectors have reduced risk-taking behaviors resulting in profound decreases in HIV transmission. It is estimated that in 2006, more than 4,000 new infections within this population were averted. Given an estimate that the treatment expense that can be avoided by preventing each HIV infection is estimated to be $303,100 (Medical Care, November 2006), the 4,000 infections averted represent an estimated $1.2 billion in savings. Data from the

evaluation of the NYS SEP conducted by researchers from the Baron Edmond de Rothschild Chemical Dependency Institute of Beth Israel Medical Center indicate that by 1994, there was a 50% reduction in HIV transmission, a 75% decrease in the buying or renting of syringes and a 63% decrease in syringe sharing behaviors.

HIV transmission among IDUs in New York has dropped significantly:

- In 1990, it was estimated that 50% of IDUs were infected with HIV;
- In 2012, 3% of new HIV diagnoses were among IDUs.

- **Solution: Grant $1 million of funding to harm reduction and syringe exchange programs to address the current gaps in coverage throughout NYS both for specific population and for distinct regions and locations.**

## 9. Challenge: Many New Yorkers remain unaware of their HIV status, which potentially delays diagnosis and access to care, while simultaneously fueling the spread of HIV.

Effective September 1, 2010, Chapter 308 of the Laws of 2010 authorized significant changes in HIV testing in NYS. This law was enacted to increase HIV testing in the state and promote HIV-positive persons entering into care and treatment. Implementation of Chapter 308 is critical since thousands of HIV-positive New Yorkers are unaware of their infection status and 33% of persons newly identified with HIV are diagnosed so late in their infection that they are found to have AIDS within one year of HIV diagnosis.

Since the law went into effect, a review of multiple public health data sets and other available information indicates that the number of persons being tested in NYS was increasing prior to the law and that this increase appears even greater after the enactment. Linkage to HIV care remains above the national average and persons with HIV can readily access ARV treatment in NYS.

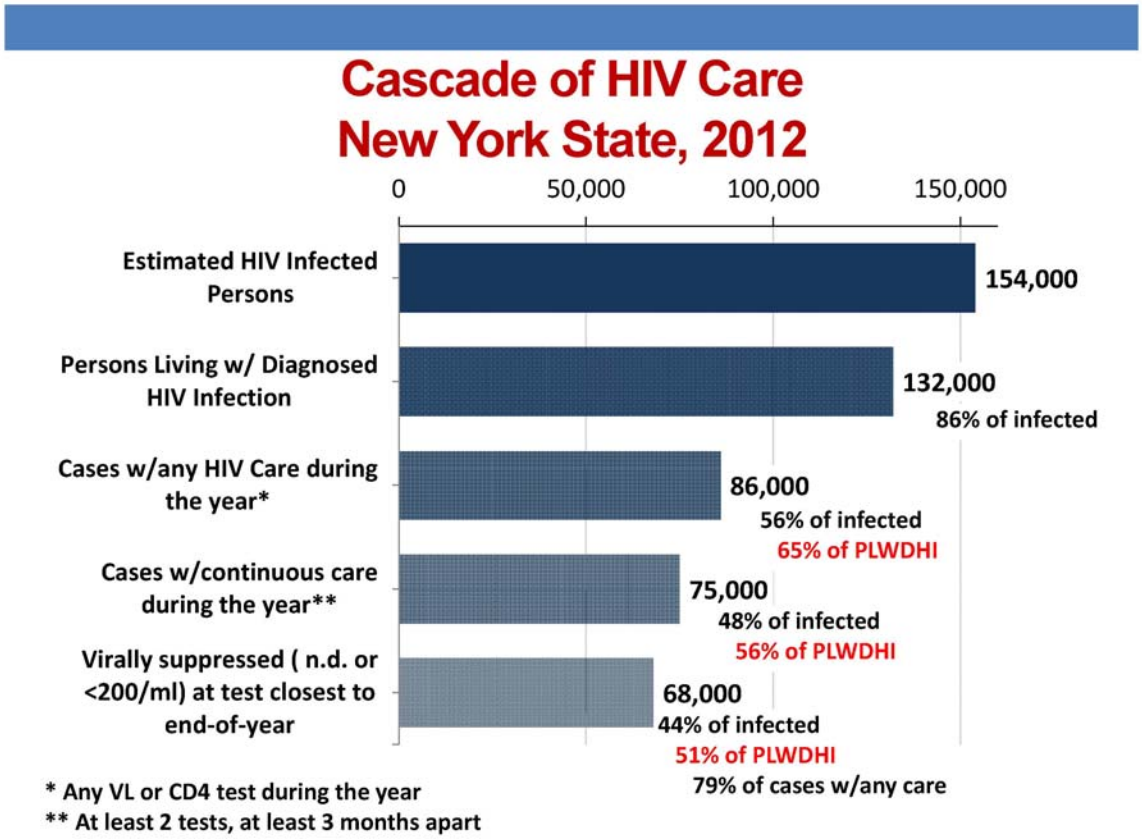
- **Solution: Grant $1 million to the NYSDOH AIDS Institute to support HIV Testing Law Implementation.**
  Passage of New York's historic HIV testing law included no new funding or resources to support implementation. It is an important law and successful implementation will enhance New York's ability to prevent and treat HIV in a timely manner. The requested funding will support the statewide implementation of the law and provide assistance to providers as they alter existing practices to comply with the intent of the legislation, including the state's own monitoring and evaluation activities. Funds will also support consumer education about the benefits associated with HIV testing, information about testing options, risk reduction strategies and linkage to care for those who test positive.

## 10. Challenge: Many New Yorkers remain unaware of their HCV status, which potentially delays diagnosis and access to care, while simultaneously fueling the spread of HCV.

Effective January 1, 2014 is new Section 2171 of the Public Health Law that requires the offering of a HCV screening test to every individual born between 1945 and 1965 receiving inpatient hospital care or primary care. Statewide, an estimated 200,000 New Yorkers are living with HCV infection. Based on estimates of those who are infected not knowing their HCV status, up to 150,000 are unaware of their HCV status. The new law was enacted to increase HCV testing and ensure timely diagnosis and linkage to care. With the advent of new therapies that can stop disease progression and provide a cure in most persons, targeted testing and linkage to care for infected persons in this birth cohort are expected to reduce HCV-related morbidity and mortality.

- **Solution: Grant $1 million to the NYSDOH AIDS Institute to support implementation of the HCV Testing Law as to date no funding has been provided.**

## Attachment A




**Source:** *NYSDOH AIDS Institute Bureau of HIV/AIDS Epidemiology, 2012.*