

GAY MEN'S HEALTH CRISIS

# STATE POLICY AGENDA

2009



GMHC

# EXECUTIVE SUMMARY

The year 2008 ushered in significant changes in political leadership both in New York and throughout the country. We have a new Governor, new leadership in the State Senate, and a new President. Amidst the excitement for change, we must remain diligent in creating sound public policy in the fight against HIV/AIDS. HIV infections continue to rise and affect underserved communities. Our new leadership must push for evidence-based policies that prevent the spread of HIV and care for those already infected.

GMHC's State Policy Agenda is a reflection of our mission and the needs of the people we serve, as well as the communities most affected by HIV/AIDS. These 2009 public policy recommendations advocate for change in areas where there continue to be clear and demonstrated unmet needs.

Gay Men's Health Crisis, the world's oldest HIV/AIDS organization, puts forth the following policy priorities for 2009:

- Expand outreach for HIV testing, while maintaining written informed consent;
- Promote comprehensive sex education in New York's schools;
- Increase funding for public assistance and a strengthening of the safety net for New York's most vulnerable residents, including Medicaid Managed Care;
- Invest in a statewide HIV research initiative to attract federal research funding to New York State;

Twenty-eight years into the AIDS epidemic, HIV continues to increase among gay and bisexual men in New York City, especially among young men of color. As the epidemic rages on, racial disparities increasingly define the epidemic. Black men in New York City are six times more likely to die of AIDS than white men, and black women are nine times more likely to die of AIDS than white women. Nationally, black women are 20 times as likely to get HIV as white women, and gay and bisexual men are 20 times as likely to get HIV as heterosexual men. In New York State over 115,000 people are living with HIV/AIDS, while an estimated 30,000 remain undiagnosed.

Last August the Centers for Disease Control & Prevention (CDC) reported that the number of annual new infections nationwide is 40% greater than previously thought. This means that more people are getting infected with HIV and living with HIV/AIDS. The recent sharp cuts in state and city funding for HIV/AIDS prevention and care services must be understood in this context of sharply increased need for services.

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New York and the nation are in the midst of a fiscal crisis. Funding for a wide array of social services has been cut back, and HIV/AIDS organizations are being asked to do more with less. New Yorkers living with HIV/AIDS now face burdens from every direction. Enacting the following policy recommendations will help to alleviate those burdens.

GMHC will continue to steadfastly advocate for the healthcare needs and civil rights of all people living with HIV/AIDS. The prevention of HIV transmission, access to affordable, quality healthcare, and the full realization of civil rights for all are the cornerstones of our recommendations.

# TOP PRIORITIES

## Expand HIV Testing

**GMHC supports efforts to increase access to voluntary HIV testing and counseling and to remove any barriers to testing utilization.** Such efforts include making HIV testing and counseling a routine component of medical care. Routine offering of HIV testing in diagnostic settings should include the dissemination of critical information and pre- and post-test counseling so patients can make voluntary informed decisions upon taking an HIV test.

We believe strongly that testing must include meaningful **written informed consent**, with information on what exactly HIV testing means, along with linkages to counseling, care and prevention for both those who test positive and negative. The routine offering of an HIV test to most individuals seeking healthcare will make significant inroads to finding the one in four people infected with HIV who are unaware of their status. Such routinization will also serve to decrease the stigma associated with HIV/AIDS by making it a regular component of healthcare.

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Recent efforts by certain hospitals and clinics to offer testing to more patients clearly demonstrate that effective HIV testing procedures can be accomplished within existing laws and requirements. Public hospitals in New York City have been able to more than double HIV/AIDS testing simply by making it a routine part of medical care.

There is no data to support the notion that eliminating written informed consent would result in a substantial increase in testing. Stigma continues to pervade a positive HIV diagnosis. By maintaining basic consent guidelines, New York State can protect the civil liberties of all New Yorkers and effectively decrease stigma associated with HIV/AIDS. Additionally, while expanding HIV testing is important, it is also critical that we gather data on risk behaviors.

In particular, targeted outreach to immigrant communities in New York is needed. Immigrants in New York City are one third more likely than native-born residents to be diagnosed with both HIV and AIDS. This means they are being diagnosed late. Making testing a routine aspect of medical care will tremendously and positively impact the public health of these communities.

GMHC supports legislation designed to increase HIV testing throughout the state, while maintaining **written informed consent**. We support legislation proposed by Department of Health Commissioner Daines, Assembly Member Gottfried and State Senators Duane and Hannon that would mandate the offering of an HIV test in most diagnostic settings.

We oppose legislative efforts that would eliminate written informed consent from the testing process. We also oppose efforts to eliminate pre- and post-test counseling regardless of HIV status. GMHC favors streamlined counseling, when appropriate, and the creation of a general consent form, with a dedicated portion for HIV test consent.

**GMHC opposes mandatory HIV testing legislation.** GMHC strongly opposes legislation that seeks to mandate HIV testing for any New Yorker. GMHC urges the State to consider the advice of public health experts, scientists, and AIDS organizations before considering involuntary testing legislation. Testing the source patient as a means of gathering one's HIV status is severely flawed and does not properly address the health of those involved.

Mandating HIV testing runs counter to our goal of making HIV testing a routine procedure for everyone wishing to know their status, as well as raises a number of civil liberties issues. Additionally, studies have shown that people who test voluntarily are more likely to seek care following a positive result, as well as to adhere to subsequent treatment. GMHC firmly opposes any such measures.

## Promote Comprehensive Sex Education

**GMHC supports passage of the Healthy Teens Act.** New York State currently has no dedicated funding stream to provide comprehensive sex education to young people. Comprehensive sex education programs provide information about contraception and disease prevention, and teach abstinence. Such programs do not increase sexual activity or sexual risk behaviors. Research shows that comprehensive sex education helps to delay the onset of sexual intercourse, increase condom and contraception use, and decrease the number of sexual partners of program participants.<sup>1,2,3</sup> The Healthy Teens Act would create a competitive grant program to fund age-appropriate, medically accurate sex education in New York State. This investment will save public health dollars in the medium term.

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In the absence of a cure or preventive vaccine for HIV/AIDS, our best hope of stemming the epidemic lies in preventing new HIV infections. GMHC strongly supports comprehensive sex education, a vital tool in helping to stop the spread of HIV, other sexually transmitted infections, as well as unintended pregnancies.

The need for such education among our state's youth is evident. Studies by the CDC have shown that one in four girls age 14 to 19 either have HPV or Chlamydia, while that rate is nearly double among black adolescent women.

Further, less than one-third of girls age 15 to 17 reported getting tested for a sexually transmitted infection. Additionally, while the rate of condom use had increasingly risen through the 1990s, it has remained virtually level since 2001.

GMHC thanks Assembly Member Gottfried for his work to pass this legislation and look forward to working with a Senate sponsor in this legislative session.

## Increase Public Assistance, Strengthen Healthcare Safety Net, and Preserve HIV Exemption in Medicaid Managed Care Enrollment

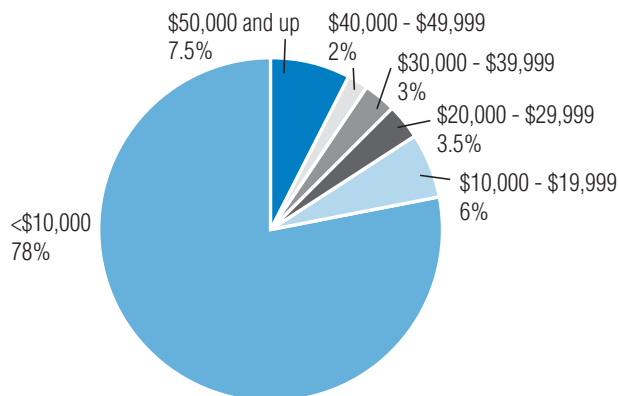
**GMHC calls on the State to standardize New York City HIV/AIDS Services Administration (HASA) benefit calculations to be consistent with federal Department of Housing and Urban Development policy, specifying that clients pay 30% of their income towards rent.** GMHC recognizes the crucial role of stable housing to the ongoing health and well-being of people living with HIV/AIDS. Housing benefits, such as those provided by New York City's HIV/AIDS Services Administration (HASA), help clients reduce high-risk behaviors and adhere to HIV treatment.

Currently, clients receiving benefits from HASA who also have other forms of income—including SSI, SSDI, veteran's benefits or work—are forced to pay all but \$330 of their monthly income towards their rent. This leaves these clients with an unlivable budget of \$11 a day. A cap on the share of rent for low-income people living with HIV/AIDS at 30% of their income should be put in place. GMHC supports legislation by Assembly Member Glick and Senator Duane which would accomplish this goal.

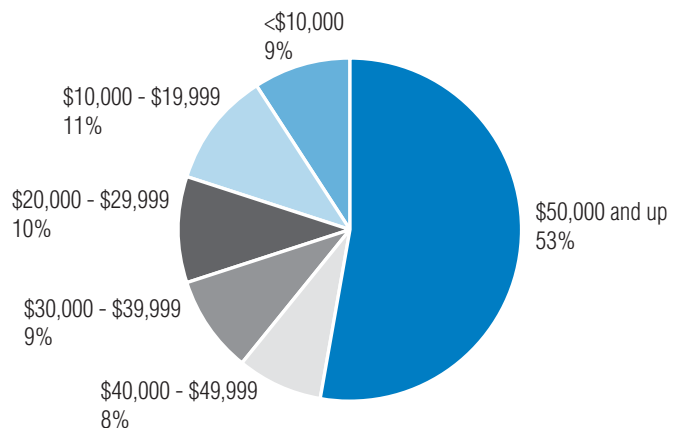
Further, because Public Assistance and Emergency Shelter Grants have been flat funded since 1986, clients receiving cash assistance from HASA have been expected to live on \$330 per month without increase for nearly a quarter century. An increase is long overdue. The cost of living has risen dramatically in New York City. According to the Consumer Price Index inflation calculator, \$330 in 1986 is the equivalent of just \$167 today. Put another way, to have the same purchasing power today as \$330 in 1986, one would need over \$652.

### Quick Stats:

**GMHC Annual Client Income**



**New York State Residents' Income**



**GMHC strongly urges the State to preserve the mandatory managed care HIV exemption.** For the last couple of years HIV beneficiaries have been voluntarily enrolling in Medicaid managed care and HIV Special Needs Plans (SNPs). However, New York State may soon mandate that all Medicaid recipients join a managed care plan, including people living with HIV and AIDS. GMHC has strong concerns about the use of managed care as a universal approach for the delivery of care for all Medicaid beneficiaries, especially for those with complex healthcare needs. We are opposed to any measures that would limit the choice for people living with HIV and AIDS to stay in traditional Medicaid fee-

**We are opposed to any measures that would limit the choice for people living with HIV and AIDS to stay in traditional Medicaid fee-for-service plans, join a managed care plan, or join a HIV SNP.**

for-service plans, join a managed care plan or join a HIV SNP. Before any attempt is made to implement mandatory managed care enrollment, we ask for the establishment of a taskforce—comprised of various community stakeholders, including people living with HIV/AIDS—to gauge health outcomes and assess the quality of care provided to people living with HIV/AIDS who are currently enrolled in managed care.

GMHC is concerned that mandating enrollment will cause confusion among HIV-positive Medicaid recipients as they will have to become accustomed to a managed care system of healthcare delivery. They will face challenges of care network choice limitations and have to obtain referrals to see specialists. They will face confusion in regard to managed care plan case managers who might appear duplicative of COBRA case management, treatment case managers and other care coordinators. While some of the same challenges exist for many Medicaid managed care consumers, it is especially egregious for HIV-positive Medicaid recipients who may also be afflicted with mental health and/or substance abuse. And others, who for reasons associated with stigma/discrimination and/or unstable housing, will find greater challenges in seeking out medical care from a provider located in a place which is accessible, confidential, and welcoming.

GMHC believes that HIV-positive individuals should be allowed to easily change plans or move into a SNP from mainstream or regular managed care plans at anytime without any lock-in period. GMHC urges the state to carefully consider all of the ramifications of mandatory enrollment prior to making such a significant impact to healthcare delivery.

## Invest in Research

**GMHC supports the establishment of an HIV/AIDS research initiative.** A greater investment in research will not only help in the fight against HIV/AIDS, but also serve as an economic stimulus for the state, creating many new jobs. Such an initiative will cultivate New York-trained and practicing scientists, as well as fulfill a 1983 law to create an AIDS Research Council, ignored by all over the last 25 years.

New York State, long an incubus of ideas for the rest of the nation, should be a leader in research and policy development. Public health policies must be informed by knowledge gained from rigorous scientific research. Such research will greatly benefit the state and become a model for private/public partnerships.

In the 1980s three states – California, Massachusetts, and New York – committed to investing in a substantive research infrastructure. However, New York failed to provide the necessary resources to benefit from such an initiative. The other two states have successfully garnered millions of federal research dollars with minimal state investment. For every dollar California invests in AIDS research, it receives \$7 in federal research dollars into the state, thereby significantly leveraging state funds. Massachusetts, with one third the population of New York, receives more federal research dollars (e.g., National Institutes of Health) than New York.

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Additionally, a newly created research program would not only serve as a link between the healthcare system and universities, but would serve as a tremendous stimulus to the economy by creating numerous jobs in a variety of industries. GMHC supports efforts by Assembly Member Gottfried and Senator Duane to fund such an initiative.

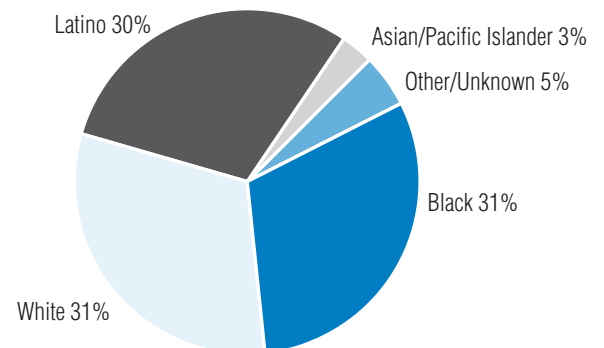
## ADDITIONAL PRIORITIES

### Prevention

**GMHC supports universal access to post-exposure prophylactic (PEP) treatment for all those potentially exposed to HIV.** PEP, a regimen of antiretroviral drugs taken to reduce the risk of becoming HIV-positive, has proven highly effective if started within 72 hours of exposure. Every hospital, emergency room, clinic, and police station in New York should have PEP treatment on hand to ensure that every New Yorker who is potentially exposed to HIV will be able to access the treatment needed so he or she does not seroconvert.

GMHC supports legislation by Assembly Member Jaffee and Senator Morahan that works toward this goal and would make PEP treatment universally affordable to all victims of sexual assault, while maintaining full confidentiality of the victim.

### Quick Stats: GMHC Clients by Race/Ethnicity



## GMHC supports permanent continuation of the Expanded Syringe Access Program (ESAP).

New York's ESAP program has been one of the most effective HIV prevention initiatives ever undertaken.

In 2007, ESAP was continued for four additional years by then-Governor Eliot Spitzer and the State Legislature. New York's ESAP program has been one of the most effective HIV prevention initiatives ever undertaken by the state, with infection rates dropping by 78% among injection drug users in just a few years since its inception.<sup>4</sup> GMHC urges the State to go beyond the previous

extension of the program and permanently continue ESAP.

## Access to Affordable, Quality Healthcare

### Healthcare Benefits

Gay Men's Health Crisis has long recognized the importance of universal, comprehensive, accessible and high-quality health coverage for all. We welcome the introduction of universal healthcare proposals that expand access to Medicaid and Medicare to ensure universal access to HIV prevention, treatment and care services for all New Yorkers. GMHC strongly supports the protection and expansion of the healthcare safety net. We support the concept of universal health coverage and are encouraged by legislation introduced by Assembly Member Gottfried and Senator Schneiderman. We look forward to reviewing the continued efforts of Governor Paterson as he seeks to provide affordable healthcare for all New Yorkers.

**GMHC continues to support access to life-saving medications for persons with HIV/AIDS.** GMHC supports pooling Medicaid, Elderly Pharmaceutical Insurance Coverage (EPIC), public employee health plans, and other state agencies' drug purchasing. Pooling is a positive step toward lowering drug prices for our clients and other New Yorkers in need of access to life-saving medications. We encourage the State to work through any barriers that may exist to implement this much-needed program.

**GMHC calls for the exemption of antidepressants from the Preferred Drug Program (PDP).** The Governor has called for the expansion of the preferred drug program (PDP) and the clinical drug review program (CDRP). These programs, designed to lower drug costs, are not a suitable solution for the drugs needed by people living with HIV/AIDS. Expanding the PDP and CDRP is an illusory gain, as whatever cost-savings are achieved are at the expense of consumer access to needed medications. The complexities of the epidemic require that physicians have unfettered ability to prescribe drugs to fit the changing medical needs of patients living with HIV/AIDS. It is not enough that antiretrovirals remain exempt and that the "provider prevails" provisions have been maintained. People living with HIV/AIDS suffer from high rates of mental health disorders, including depression, and their drug regimens must be carefully and constantly balanced. Additionally, removing antidepressants from existing exempted categories, while dangerous in and of itself, sets a bad precedent regarding the future vulnerability of other exempted classes of drugs. For these reasons, GMHC urges the legislature to reject efforts to remove the exemption for antidepressants from the PDP.

**GMHC calls for the elimination of co-pays for low-income New Yorkers.** Three years after the rollout of Medicare Part D, prescription drug cost-sharing remains an issue for many GMHC clients who are dually eligible for Medicaid and Medicare. High cost sharing associated with Medicare's Part D prescription drug program places many life-sustaining

prescription drugs out of reach. Prescription drug co-pays, even if nominal, are substantial for many of our clients who take upwards of 10 to 20 prescription drugs per day. This speaks directly to the more than three out of four GMHC clients living on an annual income of less than \$10,000. GMHC supports legislation by Assembly Member Gottfried (A. 884) that would cap prescription co-pays for dual eligibles at \$200 a year, but we can go further. GMHC calls for the elimination of co-pays because no matter how modest, any required co-pay puts basic healthcare out of reach for many New Yorkers.

**GMHC opposes efforts requiring individuals to undergo "step therapy" as a part of their drug regimen.** This policy forces patients to take a generic form of a prescribed drug to determine its effectiveness prior to taking the name brand medication. This can significantly hinder the effectiveness of drug therapy. In particular, people living with HIV/AIDS often take dozens of different medications that often require different schedules and combinations. Requiring "step therapy" for people on HIV medications will disrupt critical drug regimens and threaten the health of people living with HIV/AIDS.

**GMHC calls for the expansion of the Elderly Pharmaceutical Insurance Coverage (EPIC) program.** For several years GMHC has been fighting to extend the Elderly Pharmaceutical Insurance Coverage Program to low-income adults with chronic illnesses and/or disabilities under the age of 65. Many chronically ill or disabled people under the age of 65 live on marginal incomes and do not qualify for Medicaid. As a result they must often choose between buying crucial medications and paying rent or buying food. For people with HIV and AIDS—as for people with other chronic illnesses—such medical rationing can be life threatening. Fifteen states, including Connecticut and New Jersey, have implemented prescription drug benefit programs that cover non-elderly adults with disabilities. GMHC supports legislation to expand EPIC to low-income disabled New Yorkers under the age of 65.

**GMHC supports full access to primary care for all New Yorkers regardless of immigration status.** GMHC supports universal access to healthcare coverage for all New York State residents, and firmly opposes any denial of medical care and treatment to immigrants. Immigrants make up a disproportionate share of New York's uninsured population. However, the reality is that access to and utilization of primary healthcare remains a major obstacle for a significant number of immigrants. Language barriers due to inadequate translation and communication assistance services are a key contributor to low levels of public insurance enrollment and primary care utilization among immigrants. GMHC supports legislation to enable hospitals to receive a Medicaid reimbursement for providing interpretation and translation services to limited English-speaking patients.

In addition to linguistic barriers, foreign-born individuals face HIV-related health disparities. According to the New York City Department of Health and Mental Hygiene, foreign-born individuals are more likely (32%) to be dually diagnosed with both HIV and AIDS than their native born counterparts (24%), a marker of late diagnosis. Further, results from the NYC Community

### Quick Stats: GMHC Clients by Gender

76%	Male
23%	Female
1%	Transgender

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