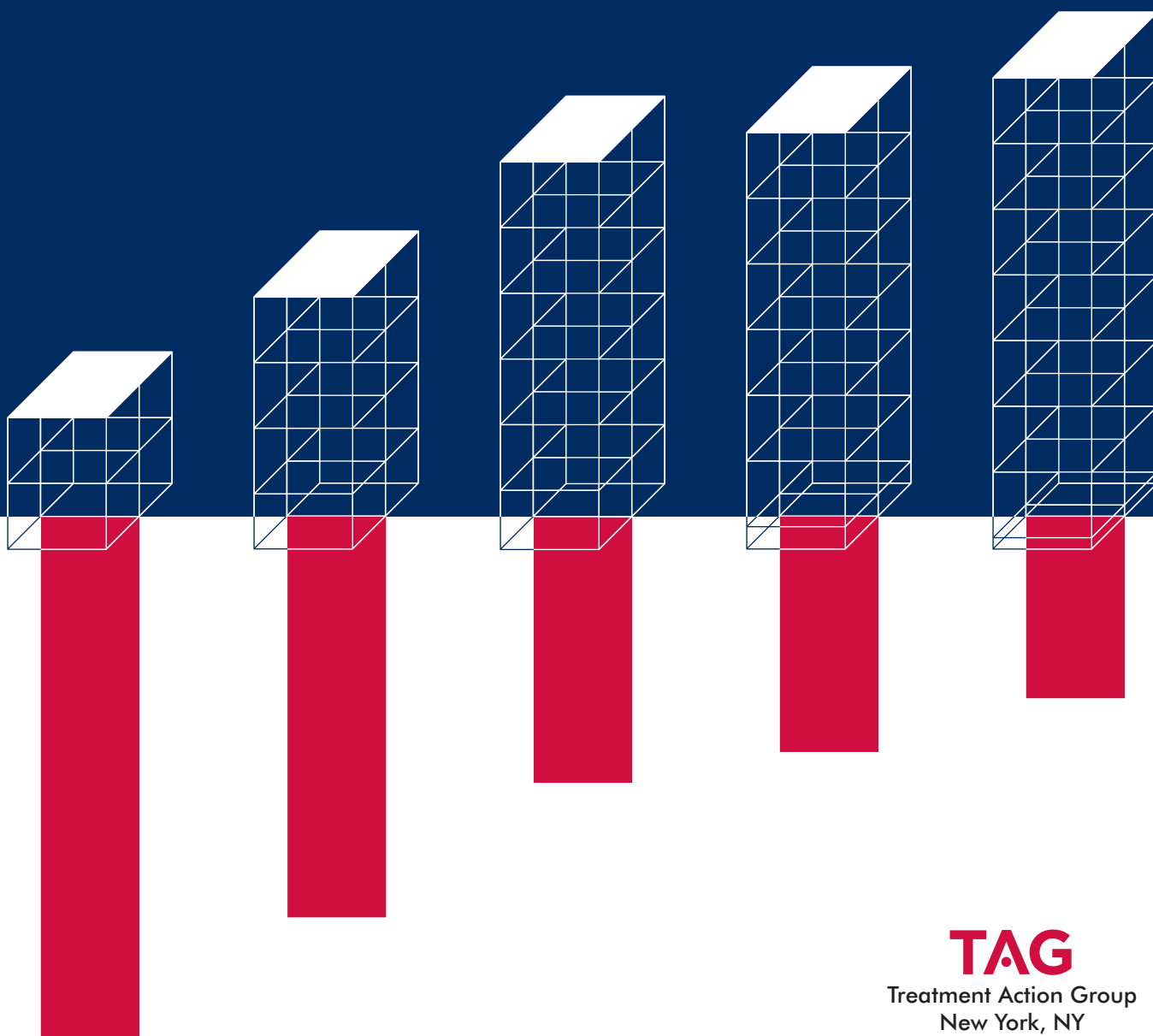


REVITALIZING THE U.S. NATIONAL HIV/AIDS STRATEGY

Action Plan



TAG

Treatment Action Group
New York, NY
April 2013

REVITALIZING THE U.S. NATIONAL HIV/AIDS STRATEGY

Action Plan

This action plan was written by David Barr and Jeff Hoover with assistance from Tim Horn, and edited by Mark Harrington with assistance from Andrea Benzacar.

Treatment Action Group thanks the writer and editors, and especially the Elton John AIDS Foundation for supporting this work.

Treatment Action Group (TAG) is an independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS.

TAG works to ensure that all people with HIV receive lifesaving treatment, care, and information.

We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions.

TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end AIDS.

The logo for Treatment Action Group (TAG) consists of the letters "TAG" in a bold, red, sans-serif font. The letters are closely spaced, with the "A" being slightly smaller than the "T" and "G".

Treatment Action Group

261 Fifth Avenue, Suite 2110

New York, NY 10016-7701

1.212.253.7922 tel

1.212.253.7923 fax

tag@treatmentactiongroup.org

www.treatmentactiongroup.org

ISBN 978-0-9837221-7-5

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.

—White House Office of National AIDS Policy,
*National HIV/AIDS Strategy for the United States*¹

In nine countries, we enrolled 1763 couples in which one partner was HIV-1-positive and the other was HIV-1-negative; 54% of the subjects were from Africa, and 50% of infected partners were men. HIV-1-infected subjects with CD4 counts between 350 and 550 cells per cubic millimeter were randomly assigned in a 1:1 ratio to receive antiretroviral therapy either immediately (early therapy) or after a decline in the CD4 count or the onset of HIV-1-related symptoms (delayed therapy). The primary prevention end point was linked HIV-1 transmission in HIV-1-negative partners. The primary clinical end point was the earliest occurrence of pulmonary tuberculosis, severe bacterial infection, a World Health Organization stage 4 event, or death. RESULTS: As of February 21, 2011, a total of 39 HIV-1 transmissions were observed....Of these, 28 were virologically linked to the infected partner....Of the 28 linked transmissions, only 1 occurred in the early-therapy group (hazard ratio, 0.04; 95% CI, 0.01 to 0.27; $P < 0.001$). Subjects receiving early therapy had fewer treatment end points (hazard ratio, 0.59; 95% CI, 0.40 to 0.88; $P = 0.01$). CONCLUSIONS: The early initiation of antiretroviral therapy reduced rates of sexual transmission of HIV-1 and clinical events, indicating both personal and public health benefits from such therapy.

—Myron S. Cohen et al., *Prevention of HIV-1 Infection with Early Antiretroviral Therapy*²

The fact that treatment of HIV-infected adults is also prevention gives us the wherewithal, even in the absence of an effective vaccine, to begin to control and ultimately end the AIDS pandemic....If one accepts the tenet that science should inform policy, then the scientific data are speaking loud and clear....Major investments in implementation now will save even greater expenditures in the future; and in the meantime, countless lives can be saved.

—Anthony S. Fauci, *AIDS: Let Science Inform Policy*³

Let's Finish the Job and End the HIV Epidemic in the United States

In July 2010—twenty-nine years after the pandemic began—the U.S. government published the first National HIV/AIDS Strategy (NHAS) with the goals of 1) reducing new infections, 2) increasing access to care and improving the health outcomes of people living with HIV, and 3) reducing HIV-related health disparities.

Recent developments on the science, policy, and health care–delivery fronts make it imperative to revitalize the National HIV/AIDS Strategy, using scientific advances and health care expansion to set more ambitious goals and to more broadly engage state, local, and community actors to work together and to bring the epidemic's end into sight.

- Scientific research proves that HIV treatment has a public health benefit and the potential to massively reduce new infections while keeping those living with HIV healthy. Clinical research shows that HIV treatment not only lengthens and improves the lives of people living with HIV, but, when used appropriately, prevents HIV transmission, thus providing a real opportunity to significantly lower HIV incidence in the United States.
- Health care coverage in the United States will expand substantially over the coming decade. The Affordable Care Act (ACA) will increase access to health care for millions of Americans, including many with HIV. Yet its implementation will drastically change the ways in which health care and support services are provided and paid for. The entire system through which people receive HIV prevention, care, and treatment services is undergoing changes that will affect the future of all people with HIV and the organizations that serve them.
- Smarter investments of HIV/AIDS program and health care dollars have the potential to achieve greater impacts. New approaches in determining how best to allocate investments for the HIV response provide important opportunities for improved and cost-effective health outcomes. The vision statement from the recently released *PEPFAR Blueprint: Creating an AIDS-Free Generation* states:⁴

Scientific advances and their successful implementation have brought the world to a tipping point in the fight against AIDS. The United States believes that by making smart investments based on sound science and a shared global responsibility, we can save millions of lives and achieve an AIDS-free generation.

This ambitious vision should apply not only to the global epidemic, but to the epidemic within the United States as well. The U.S. should commit itself to achieving the same dramatic advances here at home as it recommends to partner countries abroad.

The NHAS provides process-related targets but fails to describe the impact expected by fulfilling such targets. The current NHAS expires in 2015. The time to discuss the next iteration of a national AIDS strategy is now.

If we grasp the opportunity these developments offer, there is a chance to bring the end of the U.S. HIV/AIDS epidemic into sight. However, successful realization of these opportunities requires policy and program reconfiguration, activism, resources, and education. The NHAS was released prior to many of these new developments; in any case it expires in 2015. We now have the responsibility to revitalize the NHAS to incorporate these developments and lay out the roadmap to get us closer to the endgame for HIV/AIDS in the United States. A revitalized NHAS must set more ambitious goals and targets and deploy the resources to achieve them.

What Is Needed to Meet the NHAS Goals?

While the *PEPFAR Blueprint* sets ambitious impact and outcome targets, the goals of the original 2010 National HIV/AIDS Strategy are mostly process-based interim ones:

Reducing New HIV Infections

- By 2015, lower the annual number of new infections by 25 percent (from 56,300 to 42,225).
- Reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of people living with HIV, by 30 percent (from 5 persons infected per 100 people with HIV to 3.5 persons infected per 100 people with HIV).
- By 2015, increase from 79 percent to 90 percent the percentage of people living with HIV who know their serostatus (from 948,000 to 1,080,000 people).

Increasing Access to Care and Improving Health Outcomes for People Living with HIV

- By 2015, increase the proportion of newly diagnosed patients linked to clinical care within three months of their HIV diagnosis from 65% to 85% (from 26,824 to 35,078 people).
- By 2015, increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous care (at least 2 visits for routine HIV medical care in 12 months at least 3 months apart) from 73 percent to 80 percent (or 237,924 people in continuous care to 260,739 people in continuous care).
- By 2015, increase the number of Ryan White clients with permanent housing from 82 percent to 86 percent (from 434,000 to 455,800 people). (This serves as a measurable proxy of our efforts to expand access to HUD and other housing supports to all needy people living with HIV.)

Reducing HIV-Related Health Disparities

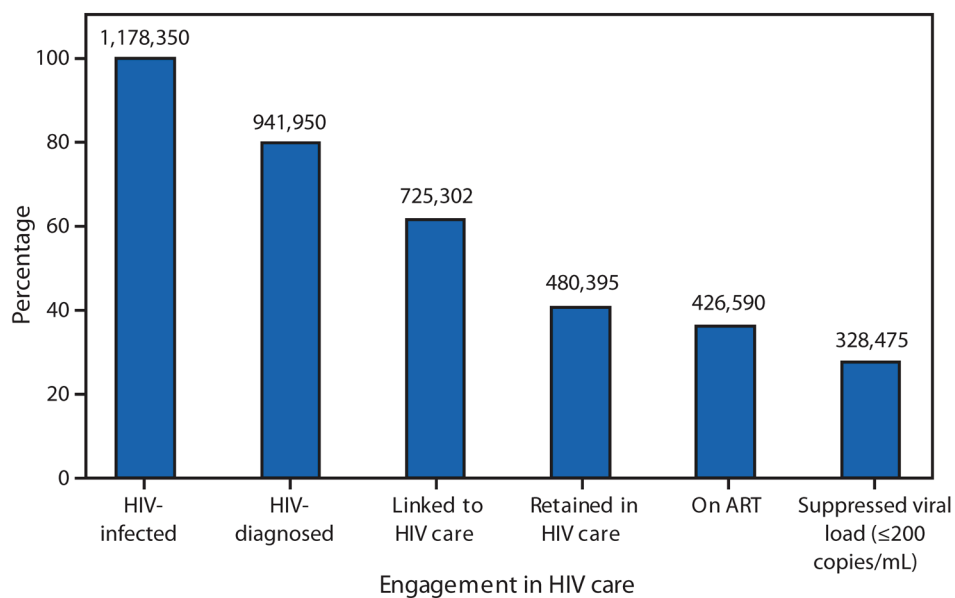
While working to improve access to prevention and care services for all Americans

- By 2015, increase the proportion of HIV diagnosed gay and bisexual men with undetectable viral load by 20 percent.
- By 2015, increase the proportion of HIV diagnosed Blacks with undetectable viral load by 20 percent.
- By 2015, increase the proportion of HIV diagnosed Latinos with undetectable viral load by 20 percent.

Source: White House, Office of National AIDS Policy. National HIV/AIDS strategy: federal implementation plan. Washington, D.C.: White House Office of National AIDS Policy; 2010 July. p. 7. Available from: <http://www.whitehouse.gov/files/documents/nhas-implementation.pdf>.

A recent study by Holtgrave et al. examined the feasibility of reaching the relatively modest NHAS goals.⁵ The authors estimate that an additional \$15.2 billion is needed through 2015 to reach the prevention and treatment targets including support for housing and other essential services. Many—but not all—of these resources will be provided through the ACA implementation and Medicaid expansion, but not all of it. However, the additional investment would ultimately be cost saving, with an estimated \$18 billion saved in medical costs through successful prevention efforts. However, since the release of the NHAS, the CDC total HIV prevention budget has been essentially flat or has gone down slightly once adjusted for inflation. The gaps in meeting treatment needs are clearly demonstrated in this graphic depicting the U.S. HIV/AIDS service continuum of care—more often known as the treatment cascade:

Number and percentage of HIV-infected persons engaged in selected stages of the continuum of HIV care—United States



Source: Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment—United States. MMWR Morb Mortal Wkly Rep. 2011 Dec 2;60(47):1618–23. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm>.

The Holtgrave analysis shows that it could be possible to meet current targets, but only through increased investments starting immediately. To meet the current NHAS goals, the authors concluded:

- Simply waiting for expansion of care services in 2014 and 2015 will not be enough to reach the NHAS goals for incidence- and transmission-rate reduction.
- Greater investment in HIV testing and prevention services for people with HIV—as well as care and housing—would enable us to reach those goals.
- Investing in treatment scale-up without additional resources for prevention interventions will fail to reduce incidence even by the modest levels set by the NHAS. Only through greater investment in additional prevention interventions can these goals be achieved.
- Substantial progress toward investing in these services must be made this year otherwise; the window on achieving the NHAS goals will be closed.

- The cost-effectiveness from HIV investments is usually equal to or better than cost-effectiveness levels in other areas of public health.
- Prevention efforts should focus on identifying who is infected and getting them into ongoing care and treatment as well as focusing on reducing the risks by half for both HIV-positive and HIV-negative people. Biometrical and behavioral interventions used together are needed to significantly reduce transmission.

An Action Plan to Revitalize the NHAS

The following are recommendations for revitalizing the NHAS and developing targets that can lead to ending the HIV epidemic in the U.S. These recommendations were developed at a meeting organized by Treatment Action Group (TAG) and attended by 35 HIV activists, service providers, policy experts, and researchers from around the country. The full report from this meeting, the participant list, and the meeting agenda can be found at: www.treatmentactiongroup.org/hiv/nhas.

I. Develop an HIV Implementation Science Research Agenda

Working with community groups and scientists, the Office of National AIDS Policy (ONAP) should coordinate the development of a domestic HIV implementation science research agenda and assure the resources to carry it out. ONAP should ensure that the Centers for Disease Control and Prevention (CDC), the Center for Medicare and Medicaid Services (CMS), the Food and Drug Administration (FDA), the National Institutes of Health (NIH), the Office of HIV/AIDS Housing in the Department of Housing and Urban Development (HUD), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Department of Veterans Affairs (VA), and other relevant federal agencies are involved in the development of this agenda along with state and city health officials, health care providers, research scientists, service providers, community activists, and people with HIV.

To make greater progress faster, we need much better data on how to optimize the management of HIV prevention and treatment approaches in all the relevant settings and populations. Implementation science can provide important insights into improvements of HIV service delivery through each point in the HIV continuum of care as well as in prevention and supportive services.

Implementation science is the study of methods to promote the integration of research findings and evidence-based interventions into health care policy and practice and thus to improve the quality and effectiveness of health services and care. Examples of HIV-related implementation science research include studies regarding how to optimize service delivery to prevent mother-to-child transmission of HIV, provide voluntary medical male circumcision, distribute clean syringes, assure harm reduction, and treat people with HIV—including gay and other men who have sex with men, women, drug users, and people in the incarceration system.

Ending the AIDS epidemic will require a balanced approach among basic, clinical, and implementation science, the last of which is an emerging field of study. Better coordination between research and program delivery, and among their funders, and greater consensus on scientific research approaches and standards of evidence will be required to fulfill the promise of implementation science as a pillar of the AIDS response.⁶ Initially, the President's Emergency Plan for AIDS Relief (PEPFAR) budget included no funding for evaluation or implementation science research. The Office of the Global AIDS Coordinator realized, however, that research was essential to improving program outcomes. PEPFAR is now supporting an implementation science agenda. Many domestic mechanisms could support this work, but it will require collaboration among disciplines, funding agencies, researchers, and implementers.

Implementation science is a key tool to determining how to fill the gaps in the treatment cascade, implementing combination prevention approaches, and addressing the social determinants that affect the HIV response. Rapid development of this research will align with the ongoing implementation of the ACA and Medicaid expansion and has the potential to be a key tool in advocating for continued resources and critical social services through the Ryan White CARE Act. People with HIV, service providers, and others from affected communities must participate in developing and carrying out the implementation science agenda.

It will be important to better understand how both needs and effective strategies differ in different contexts. Some factors to consider are:

- Disease burden within a community, city, and state;
- Demographics of those affected, including race, gender, age, sexual orientation, geographic location, and incarceration- and immigration status;
- State and local health care delivery and financing structures; and
- Service delivery capacities within the health system and among community providers.

Priority issues to be addressed through implementation science research include:

- Understanding the motivators that increase demand for HIV services and help to retain people in care over the long term;
- Identifying the obstacles that keep people from using HIV counseling and testing services, and ways to overcome them;
- Measuring how comorbidities and social determinants of health affect engagement in HIV care and HIV health outcomes;
- Determining how improved coordination among federal, state, and local agencies and community service providers can improve health systems and the use of those systems by patients;
- Assessing what models, including peer-based approaches, are most effective at supporting engagement in and use of health services;
- Investigating how stigma and discrimination affect gaps in the treatment cascade and in the effective use of prevention interventions, and ways to overcome their negative effects;
- Quantifying the continued value of behavioral interventions and designing studies to measure the optimal integration of behavior and biomedical approaches to prevent HIV transmission and support retention in care; and

- Developing measures of how the structure and selection of health care insurance plans affect health outcomes, and identifying strategies and structures to help people with HIV navigate the changing health- and service-delivery system.

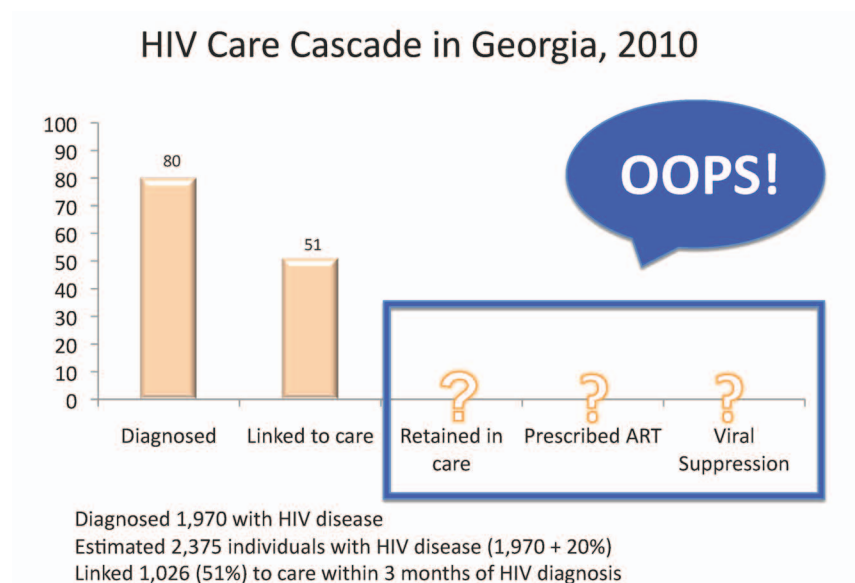
II. Define HIV Prevention and Treatment Targets Using the Continuum of Care/Treatment Cascade

The CDC should support the development of state- and population-level (e.g., people resident in a state correctional system; migrants; other key populations) prevention and treatment cascades to define HIV prevention and treatment targets and monitor progress. ONAP should coordinate the standardization and availability of appropriate data sets and ensure that metrics to define success in each step of the cascade are aligned across all federal, state, local, and other reporting jurisdictions.

The HIV continuum of care/treatment cascade provides a simple approach to understanding the steps in HIV care from testing through treatment sustainability, as well as the level of current success in utilizing these services. The cascade displays a clear and easy-to-grasp picture of the current gaps in care across the spectrum.

However, there are serious questions about the accuracy of the current cascades offered by the CDC and others. Data on which the CDC cascade is built are limited, and in many instances based on models or meta-analyses. Broad estimates about the number of people linked to care are based on very small data sets.

Based on the CDC cascade, Melanie Thompson, MD, of the AIDS Research Consortium of Atlanta attempted to develop a similar model for Georgia. The table below illustrates the lack of complete data that hinders the ability to adequately monitor the use and effectiveness of care delivery.



Source: Thompson M. Creating a Continuum of Care: The HIV Treatment Cascade in the U.S. Paper presented at: Revitalizing the U.S. National HIV/AIDS Strategy Meeting; 2012 December 11–12; Washington, D.C.

At both national and state levels, good data exist, but obtaining access to these data is difficult, and even when access is available, interaction between multiple databases is challenging. Even when integration of databases is possible, information about the numbers of people actually taking ART is incomplete. The cascades have also not yet incorporated current U.S. treatment recommendations into their structures. Based on current U.S. guidelines, the number of people who should be on ART could be as high as the total number of people infected. Systems are needed to collect real and useful data to monitor entry into and retention in care. Data collection needs to be built using one set of reliable, standardized metrics.

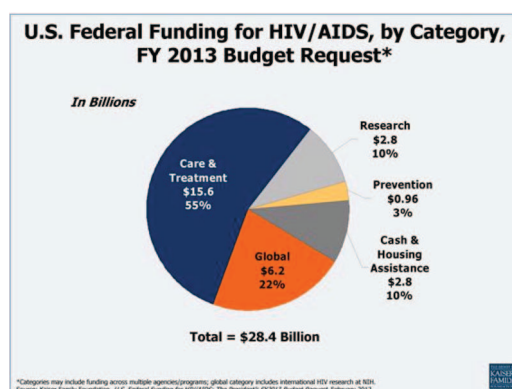
Improving the continuum of care/treatment cascade requires the following steps:

- Developing a continuum of HIV prevention interventions and strategies that can be measured easily and universally across populations and regions
- Harmonizing the definitions and capture times for key indicators
- Measuring the treatment cascade by gender, race, age, region, and risk factor to capture disparities in HIV-related health outcomes and the use of health services
- Describing the treatment cascade at state and local levels, using graphs, to better understand where the gaps in care lie

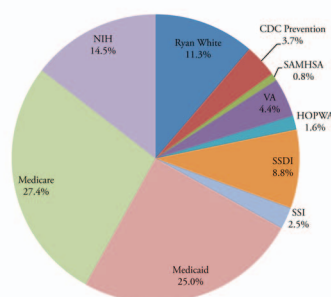
III. Reallocate Investments in HIV Prevention and Care for Better Results

ONAP should immediately review federal and state HIV investments and redirect funding to effective interventions and high-burden communities and populations. Reallocation of resources will produce better health outcomes and reduce costs.

Care and treatment comprise the largest component (55%) of U.S. HIV expenditures, most of which are spent on antiretroviral drugs, which cost substantially more in the U.S. than anywhere else in the world. More than half of U.S. government HIV funding is provided through Medicaid and Medicare (53%). The CDC funds most prevention efforts, a paltry 3% of the overall budget. Critical enabling support services, a small part of the U.S. budget, are provided primarily through Ryan White and SAMHSA, with other agencies providing smaller amounts.

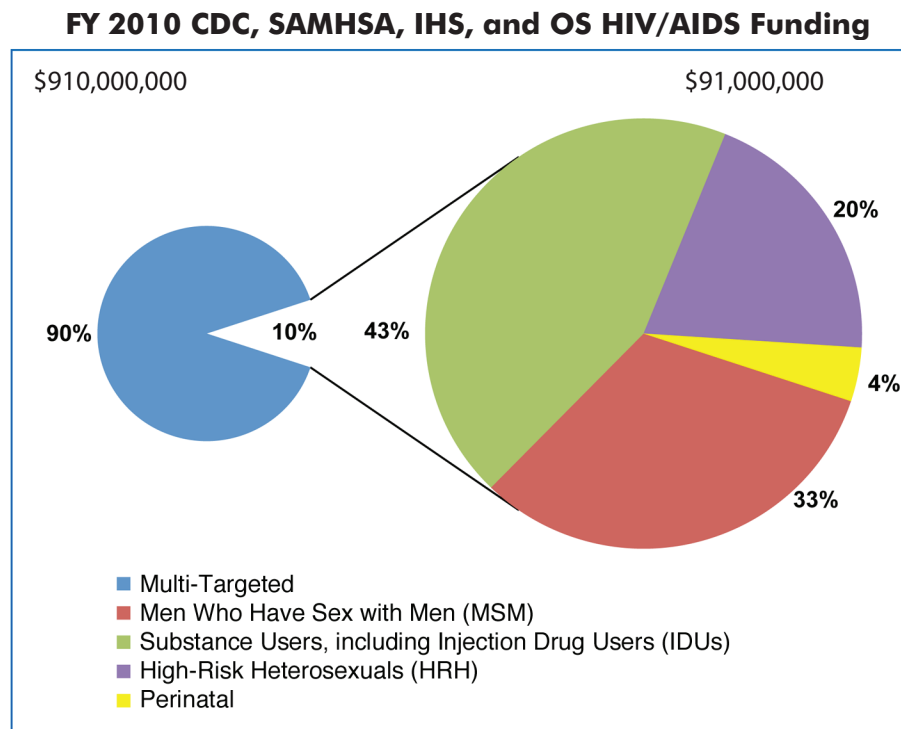


Federal Funding – Domestic HIV/AIDS, FY 2012



Source: Kaiser Family Foundation. U.S. federal funding for HIV/AIDS: The president's FY2013 budget request. 2012 February. Available from: <http://www.kff.org/hiv/aids/upload/7029-08.pdf>.

To achieve the greatest impact, funding must be redirected to the people and places where it is most needed. The slide below illustrates combined allocations targeting key affected populations and indicates the low resources levels targeting the populations with the highest HIV incidence and prevalence in the nation. Funding for HIV prevention makes up only three percent of the total U.S. HIV funding allocations. And, although 50 percent of new infections occur within MSM, only sixteen percent of NIH research funding targets this group. Funding is also geographically disproportionate, with areas of higher incidence and prevalence—primarily the South—often receiving inadequate funding—an inequity made even more damaging by the reluctance of many state governments in the South to contribute substantially to Ryan White, let alone to carry out Medicaid expansion.



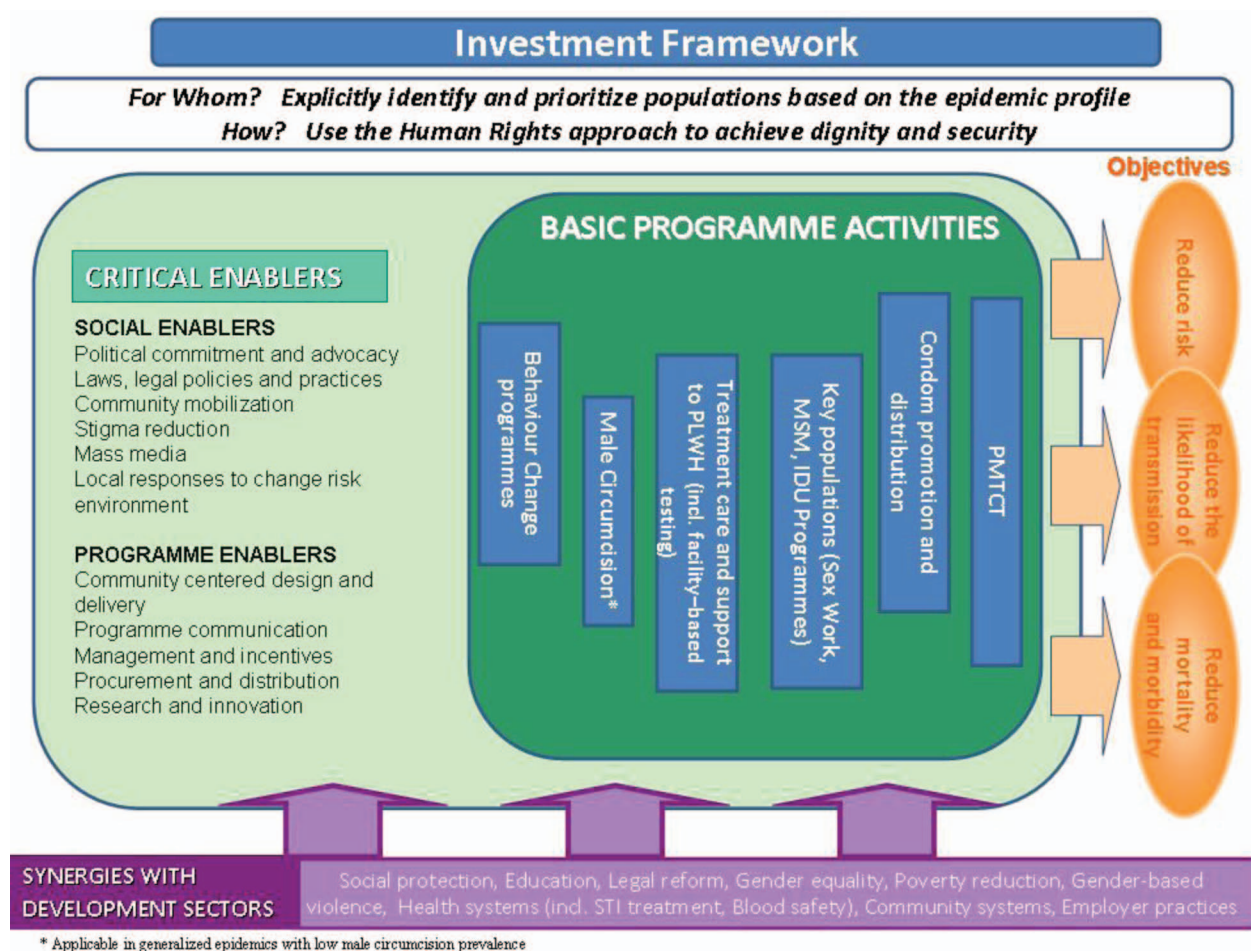
Source: Department of Health and Human Services. HHS operational plan: achieving the vision of the national HIV/AIDS strategy. Washington, D.C.: Department of Health and Human Services; 2011 February. Available from: <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas-operational-plan-hhs.pdf>.

Recent research indicates that prevention programs focusing on gay men, drug users, and prevention for people with HIV have the most potential impact on reducing new infections.⁷ One model from Philadelphia found that testing gay men in non-clinical settings was particularly cost effective, followed by adherence support, and testing in clinical settings. Behavioral modification among those uninfected was the least cost-effective. The overarching message from multiple models and studies is that the most effective course of action would be an increase in funding for prevention targeting gay men and African Americans to focus on scaling up testing, treatment, adherence support and education for people living with HIV.

HIV incidence is falling in several parts of the country, including Massachusetts and San Francisco. The common denominators for this success include: universal access to and expanded utilization of health care; health care provided in ways that is respectful of the needs of affected populations; and support for critical enabling services such as housing, nutrition, transportation, mental health, and

supportive environments. An intriguing feature of the places where the most progress is being made is close communication among public health authorities, researchers, providers, and the HIV community.

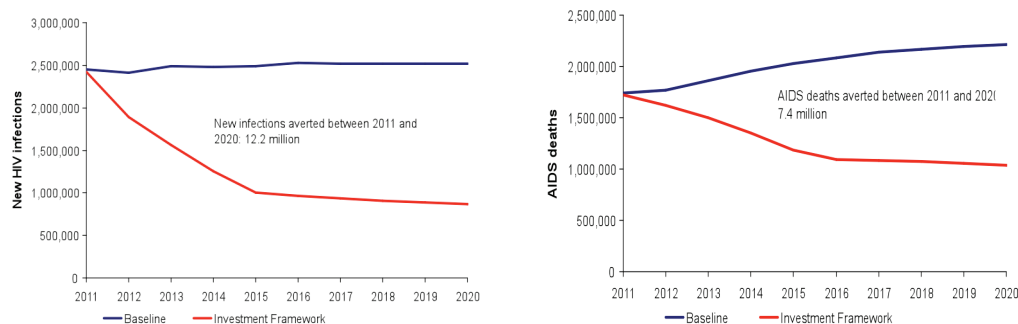
Despite a significant domestic investment in HIV prevention, care, and treatment, there are many opportunities at national, state, and local levels to achieve better health outcomes and reduce infection rates. Reallocation of funding to better target those at greatest risk using evidenced-based interventions, especially treatment scale up, can produce better results and save money. This approach to smarter use of HIV funding was first described in a paper in the *Lancet*, "Towards an improved investment approach for an effective response to HIV/AIDS."⁸ The framework also calls for funding of critical enabling services without which basic services cannot be effectively implemented.



Source: Schwartländer B, Stover J, Hallett T, et al.; Investment Framework Study Group. Towards an improved investment approach for an effective response to HIV/AIDS. *Lancet*. 2011 Jun 11;377(9782):2031–41. doi: 10.1016/S0140-6736(11)60702-2. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/21641026>.

Community mobilization is essential in reaching NHAS goals. Community-driven outreach and engagement activities connect people facing similar issues and engage them in HIV-related interventions. Community-based support activities enhance quality of life, promote treatment literacy and adherence, and provide comprehensive services for people on treatment, engaged in harm reduction or drug treatment services, and using sexual and reproductive health services. Community organizations have

a key role in advocacy, transparency, and accountability efforts at national, state, and local levels to ensure that high-quality health services are available and accessible to all who need them, including the most excluded and vulnerable populations. Finally, the investment framework is rooted in ensuring rights-based approaches to service delivery that require community participation and oversight.



Source: Schwartländer B, Stover J, Hallett T, et al.; Investment Framework Study Group. Towards an improved investment approach for an effective response to HIV/AIDS. *Lancet*. 2011 Jun 11;377(9782):2031–41. doi: 10.1016/S0140-6736(11)60702-2. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/21641026>. (Accessed 2013 March 26)

The investment framework estimates that—globally—a relatively modest yearly increase of resources peaking at 2015 would produce dramatic results as described in the charts above. Conversely, reduced or flat funding would lead to not only increased infection rates and AIDS deaths, but increased costs as well. The most cost-effective steps governments can take now are to invest more in the HIV response and direct the investments to the interventions that work the best. The U.S. government has already adopted many of the values of the investment framework in its global programs. The recently published *PEPFAR Blueprint* shows modeling indicating likely impact on HIV incidence. The strategic investment framework could be adapted for use in the United States.

IV. Implement the ACA and Medicaid Expansion Effectively

CDC, HRSA, SAMHSA, and other relevant federal, state, and local agencies—alongside community-based service providers—should support information dissemination and training to ensure that critical enabling services are supported, that the experience and expertise of community-based organizations are well used, and that navigation is smooth for patients within the new health care and coverage landscape. Continued funding for critical enabling activities and support services should be provided through Ryan White funding and other sources.

The passage of the ACA, Medicaid expansion, and other health reforms will expand access to services for people living with and at risk for HIV.⁹ However, these reforms will drastically change the structures in which HIV care is provided.

The ACA requires coverage for a set of minimum essential health benefits, some of which affect HIV, and many of which are currently covered through Ryan White programs. It remains to be seen if and how Ryan White will continue to provide resources for these essential services. The ACA mandates the development of “medical homes” that will affect HIV care delivery. In a medical home, a provider or group of providers is responsible for coordinating a given patient’s care, with some kind of financial incentive to do so. About 50 percent of state Medicaid programs have initiated some form of medical-home program, which will support case management and other interventions.

However, unlike Ryan White and other CDC- and HRSA-supported programs, the health homes will not necessarily be characterized by expertise or experience in HIV care delivery.

HIV is not the foremost concern of state policy makers, health insurance exchange panels, Medicaid program staff, and insurers. There will be significant variability in state-level coverage, benefits, and payment systems. The HIV community must organize and mobilize to ensure that HIV-positive beneficiaries’ needs are met. Many people with HIV and their family members will need significant help in choosing the insurance plan that best meets their needs.

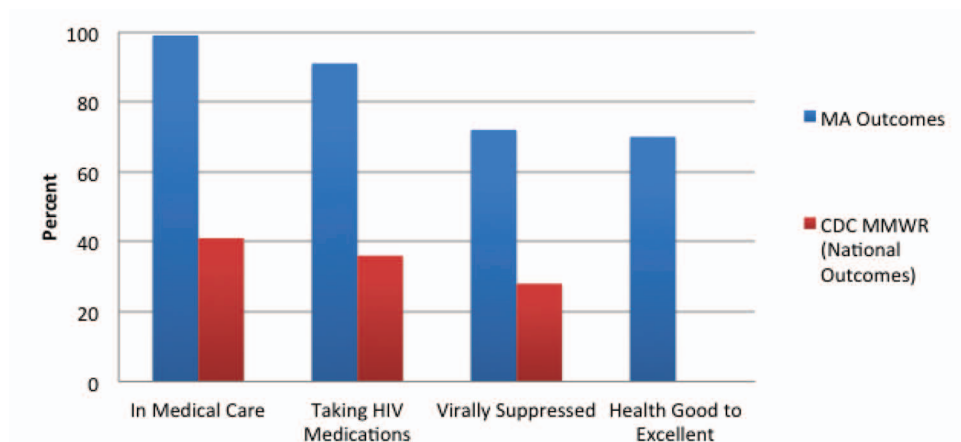
The essential health benefits package for people with HIV will vary considerably geographically and by public- and commercial systems, insured population, insurer, and by service-delivery systems (e.g., fee-for-service or managed care). Managed care service-delivery and payment models are likely to be adopted. Many existing HIV programs and providers are likely to be unfamiliar with these models, may not participate in insurance plans, and may not have staff sufficiently credentialed to serve as providers. HIV clinical and support providers must learn to market their services to ensure they have a role in HIV care delivery.

Reform of the Massachusetts health care system provides an important model for achieving successful HIV outcomes. The reforms included:

- Expanded Medicaid coverage to pre-disabled people living with HIV with an income up to 200 percent of the FPL (2001);
- Enacted private health insurance reform (“Romneycare”) with a heavily subsidized insurance plan for those with an income up to 300 percent of the FPL (2006);
- More ADAP funding spent on insurance than on prescriptions, while maintaining an unrestricted formulary and income eligibility up to 500 percent of the FPL (2006);
- Waiver from the Ryan White Program 75/25 rule supporting the ability to provide necessary services (2007).

These reforms have led to improved health outcomes, surpassing both the national status quo and the NHAS goals:

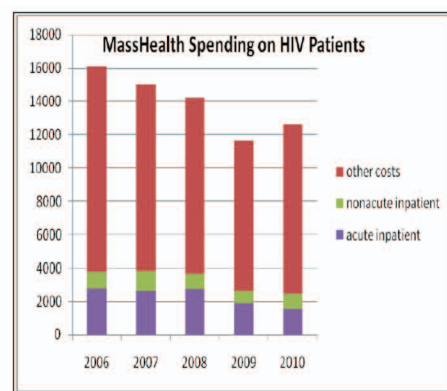
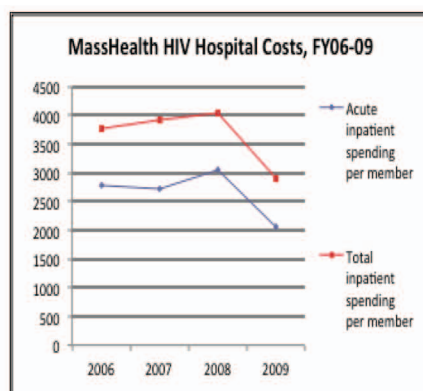
MA Outcomes vs. National Outcomes



Source: JSI Research and Training, Inc. Massachusetts and southern New Hampshire HIV/AIDS consumer study final report. 2011 December.

Source: Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment—United States. MMWR Morb Mortal Wkly Rep. 2011 Dec 2;60(47):1618–23.

- Between 2006 and 2009, Massachusetts's new HIV diagnosis rates fell by 25 percent compared to a two percent national increase;
- Current Massachusetts new HIV diagnosis rates fell by more than 50 percent;
- Between 2002 and 2008, Massachusetts's AIDS mortality rates decreased by 44 percent compared with 33 percent nationally; the Massachusetts cost per Medicaid beneficiary living with HIV has decreased, particularly the amount spent on inpatient hospital care; and
- The Massachusetts Department of Public Health estimates that reforms saved approximately \$1.5 billion in HIV health expenditures.



Source: Massachusetts Office of Medicaid. Data request from Robert Greenwald.

V. Mobilize Communities and Build Coalitions for Health Access and Human Rights

Communities affected by HIV should invest in state- and local coalition-building and advocacy that link the HIV response with advocacy for the right to health, with specific health advocacy efforts, and with social justice movements. Mainstream national LGBT organizations should be challenged to place HIV back on their agendas and devote resources to these efforts.

Today, in the U.S., HIV is about “invisible people” poor people; sexual, ethnic, and racial minorities; women; immigrants; and those who are undocumented, discriminated against, or otherwise marginalized. HIV continues because of this. In the U.S., it’s about people who don’t count. We will never stop HIV unless we address the needs of these people. The HIV movement needs to align with other health and social movements, such as environment, criminal justice, and immigration movements. HIV is affected by a diverse set of social determinants and issues, and HIV affects these issues as well. Human rights abuses continue to plague efforts to prevent and treat HIV. As the primary target population for new and existing HIV infections, gay communities and their organizations and donors have a continued responsibility to address HIV.

A more ambitious NHAS must include expanded opportunities for community mobilization including resources, tools, and strategies. These include:

- Support for community organizations to develop communications tools to describe the potential and positive outcomes that can be achieved through the ACA and Medicaid expansion, including community-friendly and locally specific ACA navigation guides, a policy guidebook for effective community mobilization and monitoring, and creation of a “story bank” of successes and failures based on human rights reporting standards
- Establishment of an ONAP task force on service integration and ACA expansion that also considers the ongoing need for Ryan White CARE Act supportive services
- Development of state- and local-level plans to end AIDS using the continuum of care/treatment cascade and strategic HIV/AIDS investment framework as models
- Formation of alliances with other groups advocating around chronic health issues such as asthma, diabetes, mental health, and others
- Investigation of whether a structure analogous to the NIH Office of AIDS Research (OAR) is needed to coordinate service delivery and reduce inefficiency across federal agencies
- Use of the experience and expertise developed by ASOs over the past 30 years in the development of health homes and exchanges. The HIV experience should be considered a model for other health areas
- Patient navigation, including peer-based approaches, to help people into and through health service systems, access information, and follow through on health decisions
- Training and technical support to build a cadre of community support services that works in partnership with health systems and is able to rapidly incorporate research results into program development
- Inclusion of Education Departments in discussions about and delivery of health literacy services, especially given the high incidence of HIV among young people

Conclusion

The opportunities to end the HIV epidemic in the United States have never been greater. By applying advances in science, health system reform, investment strategies, and community mobilization, the job that began in 1981 by people living with AIDS—to end the AIDS epidemic—can finally be accomplished. Let's work together to plan and implement a strategy to end AIDS in the United States once and for all.

ENDNOTES

1. White House, Office of National AIDS Policy. National HIV/AIDS strategy for the United States. Washington, D.C.: White House Office of National AIDS Policy (preface); 2010 July. Available from: <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf>. (Accessed 2013 March 30)
2. Myron S. Cohen et al. for the HPTN 052 Study Team. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011 Aug 11;365(6):493–505. doi: 10.1056/NEJMoa1105243.
3. Fauci AS. AIDS: let science inform policy. *Science*. 2011 Jul 1;333(6038):13. doi: 10.1126/science.1209751.
4. Department of State, Office of the Global AIDS Coordinator. PEPFAR blueprint: creating an AIDS-free generation. Washington, D.C.: Department of State; 2012 November. Available from: <http://www.pepfar.gov/documents/organization/201386.pdf>. (Accessed 2013 April 1)
5. Holtgrave DR, Hall HI, Wehrmeyer L, Maulsby C. Costs, consequences and feasibility of strategies for achieving the goals of the National HIV/AIDS Strategy in the United States: a closing window for success? *AIDS Behav*. 2012 Aug;16(6):1365–72. doi: 10.1007/s10461-012-0207-0. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/22610372>. (Accessed 2013 March 26)
6. Schackman BR. Implementation science for the prevention and treatment of HIV/AIDS. *J Acquir Immune Defic Syndr*. 2010 Dec;55 Suppl 1:S27–31. doi: 10.1097/QAI.0b013e3181f9c1da.
7. Farnham PG, Holtgrave DR, Sansom SL, et al. Medical costs averted by HIV prevention efforts in the United States, 1991–2006. *J Acquir Immune Defic Syndr*. 2010 Aug;54(5):565–67. doi: 10.1097/QAI.0b013e3181e461b2.
8. Schwartländer B, Stover J, Hallett T, et al.; Investment Framework Study Group. Towards an improved investment approach for an effective response to HIV/AIDS. *Lancet*. 2011 Jun 11;377(9782):2031–41. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/21641026>. (Accessed 2013 March 26)
9. For an in-depth review of the impact of the ACA on HIV service delivery, see Crowley J, Kates J. The Affordable Care Act, the Supreme Court and HIV: what are the implications? Washington, D.C.: Kaiser Family Foundation; 2012 September. Available from: <http://www.kff.org/hiv/aids/upload/8363.pdf>. (Accessed 2013 March 27)

