



March 2, 2015

The Honorable Joseph Pitts
420 Cannon House Office Building
United States House of Representatives
Washington, DC 20515

ActionAIDS
FRIENDS FOR LIFE
www.actionaids.org

RE: Committee on Energy and Commerce
Subcommittee on Health
Hearing: "Examining the 340B Drug Pricing Program"
Thursday, March 5, 2015 at 10:00 AM
Submitted via email to: energycommerce@mail.house.gov

Dear Chairman Pitts and Members of the Committee on Energy and Commerce, Subcommittee on Health;

I am grateful for the opportunity to make comments regarding the 340B Drug Pricing program and to share how the current structure of the program benefits patients served by ActionAIDS. ActionAIDS is one of Pennsylvania's largest AIDS Service organization. We provide a range of services including Medical Case Management, housing services, volunteer Buddy services, and primary medical care to over 3,500 clients every year. These services are provided by 102 full time staff and over 200 volunteers.

As a 340B covered entity, ActionAIDS has been able to realize significant savings on medications for our patients. This savings has increased our ability to serve our clients in a number of ways, including covering deductibles and co-pays for patients who would otherwise be unable to afford them. The program has allowed us to expand our services by hiring additional staff to reach patients in need of primary medical care and medical case management. **These results reflect the legislative intent of the 340B program, to support 340B safety net providers to improve and expand service provision.**

ActionAIDS data demonstrates that our 340B program is successful in increasing access to life saving services for our patients. **Data from our caseload demonstrates that patients enrolled in Medical Case Management and our 340B pharmacy program achieve an undetectable viral load within three to six months of enrolling in our services.** This outcome has a dramatic impact on the individual and the community. For the individual patient, there is a decrease in emergency room visits and hospitalizations, reducing overall health care costs. For the community, achieving an undetectable viral load reduces the community viral load and decreases HIV transmissions.

It is critical that the definition of who a 340B patient does not change and that both uninsured and insured patients are eligible to be part of this program. **Without insured patients in the program, there would be no cost savings to help assist uninsured and underinsured individuals or an opportunity to expand and improve services.** ActionAIDS and many safety net providers across the country depend on the savings from the 340B program to keep their doors open.

Thank you.

Sincerely,


Kevin J. Burns, LCSW
Executive Director

ActionAIDS Center City
1216 Arch Street, 6th Floor
Philadelphia, PA 19107
P 215.981.0088
F 215.864.6930

ActionAIDS Annex
1026 Arch Street
Philadelphia, PA 19107
P 267.940.5500
F 215.207.0640

ActionAIDS West
3901 Market St., Box 1934
Philadelphia, PA 19104
P 215.387.6055
F 215.387.7989

ActionAIDS North
Casa Nueva Vida
2641 North 6th Street
Philadelphia, PA 19133
P 215.291.9700
F 215.291.0626



www.pacsp.org

Today, 340B remains important and relevant to AIDS Service Providers like ActionAIDS in Philadelphia, PA. Reductions in 340B revenue would result in a direct decrease in services available to our patients. Case Manager positions would be eliminated; plans to expand services to offer medical care in West Philadelphia would immediately halt; and alternative funding would need to be found in order to keep up our core services and to support our wide range of activities.

Below are stories of recent ActionAIDS clients who have had long-term success or made significant strides in maintaining their own health and wellbeing with the support and help of their ActionAIDS Case Managers. All patient names have been changed to protect client confidentiality.

Ellie – Long-term Success Through Case Management

In her mid-thirties, Ellie was nearly nine months pregnant with a diagnosis of HIV, schizophrenia, and a history of substance abuse. Just released from the Philadelphia prison system for a drug-related offense, she had no home of her own and faced the likely loss of her baby to a foster care placement. Fortunately for both Ellie and her baby, she came to ActionAIDS, where her Prenatal Program case manager quickly got her health care services and a place to live. On antiretroviral HIV therapy, she gave birth to a healthy, HIV-negative baby. That was 12 years ago.

Today, Ellie's mental health is stable. She's remained drug-free and out of the criminal justice system. She's been successfully raising her daughter, a well adjusted, high-achieving pre-teen. And for the past five years, she's been happily married to a man she met through a spirituality retreat for people with HIV. Although her current case manager at ActionAIDS says that Ellie is "one of the best mothers I've ever met," Ellie's path to health, successful parenting, and marriage was by no means easy. Her case manager explains that it took many, many counseling sessions over a period of years before Ellie fully recognized that for her, "having to take meds is normal." Now, more than a decade after she first came to us, Ellie is on "continuing care" status with ActionAIDS – she still can call us if she feels she needs our help, but she no longer needs our case management services.

Mark – Significant Results Through Case Management

Several years ago, ActionAIDS Executive Director Kevin Burns received an email inquiry from a man named Mark asking for help. Because of his severe obsessive-compulsive disorder and depression, Mark's basement apartment had effectively become his prison. Then about 50 years old, Mark had found ActionAIDS through the Internet, his only social outlet. It had been seven years since he had seen a doctor. Kevin referred Mark to an ActionAIDS case manager, who began an email correspondence that gently coaxed him out of his apartment. Within several weeks, Mark made it to the ActionAIDS offices, but in such poor health that he was immediately hospitalized. Upon his discharge from the hospital, Mark had no insurance and no financial resources. His medical case manager was able to obtain his HIV medications through the ActionAIDS Blue Star partner pharmacy. Mark began meeting weekly with his case manager. A year later, Mark wrote a letter praising his case manager, who he refers to as "my angel," for being "so positive in those first emails." "That gave me the strength," Mark wrote, "to finally come into his office." Today, Mark's health has fully stabilized, and he's returned to work as a moving company supervisor and has bought a house. "I'm overwhelmed with everything granted to me through ActionAIDS from the very first day I walked through the doors."



www.pacsp.org

Priscilla – Long-term Case Management

Priscilla, a mother of six and grandmother of 50, is now in her mid-seventies, and has worked with her current ActionAIDS Case Manager for approximately six years. Priscilla has a bi-polar disorder and can be difficult to work with. Sometimes suffers from anxiety and depression, resulting in hostility and anger. Her son died several years ago, and his death was especially hard for Priscilla. Thanks to the support of her case manager, with whom she developed a strong relationship, she got through that difficult time.

Priscilla's Case Manager makes sure that Priscilla manages her health care appointments and receives the mental health services she needs. Navigating the health care system can be particularly daunting for someone at Priscilla's age and given her health history. Fortunately, her case manager has been able to accompany her to almost all her physician visits. They consulted two surgeons for help, but both considered surgery "too risky." Priscilla also suffers from severe cardiac obstructive pulmonary disease, which reached a life-threatening stage this past year. During a recent hospitalization, and with her case manager's support, she agreed to undergo the medically necessary procedure. Now, three months later, she is back at home with her beloved pets and doing very well. "You saved my life," she tells her case manager.

Joshua's Story—Enabling Services through Case Management

In a recent case, "Joshua" – an HIV-positive client at ActionAIDS – reported to his case manager that his Supplemental Nutrition Assistance Program (food stamps) benefits had been significantly reduced – by approximately 450 percent. The SNAP reduction made it impossible for Joshua to maintain an adequate diet. Joshua, who struggles with depression and fetal alcohol syndrome, was not able to deal with this problem, given his difficulties resulting from recent flooding of his subsidized housing during the heavy summer rains. That issue has since been addressed, but left Joshua feeling overwhelmed in general.

Through ActionAIDS, Joshua has a case manager who determined that the Department of Public Welfare (DPW) had incorrectly calculated his income, thus resulting in the erroneous reduction in benefits. With his case manager's assistance, Joshua appealed the decision but he did not receive a response from DPW. His case manager also contacted on Joshua's behalf DPW but got no response.

Our ActionAIDS case manager discussed Joshua's plight with her supervisor and they planned to take Joshua directly to the local DPW office to resolve the error. Given the case manager's busy schedule with clients, they decided to expedite the visit by having the supervisor accompany Joshua. After waiting five hours to see a DPW case-worker, they were able to resolve the error and restore Joshua's benefits to the correct level. As Joshua said regarding this problem, "There is absolutely no way I could have done this myself." ActionAIDS staff, working as a team, was able to fix the mistake. At this point, Joshua is now considering his own needs for additional emotional support, a very positive step that will likely assure his adherence with taking medication and receiving on-going health care. Our Case Managers, especially our Behavioral Health Specialists provide support counseling and will refer clients to therapists and psychiatrists as needed.



www.pacsp.org

Expanding Access to Services for HIV/AIDS Patients: The 340B Program's Legislative Intent

What are AIDS Service Organizations? Who do they serve?

Every day, AIDS Service Organizations (ASOs) provide a wide range of medical services, assistive services and supports, and other services necessary to help patients with HIV/AIDS. These vulnerable patients often need a wide range of assistance and lack the means or knowledge to obtain them. AIDS Service Organizations fill the gaps and make sure that no patient has to face HIV/AIDS alone. Ryan White HIV/AIDS Program grantees receive Federal funding to provide HIV/AIDS treatment and related services to people living with HIV/AIDS who are uninsured or underinsured.

Streams of Funding

Providing the wide range of services and supports is expensive. While significant, contributions and fundraising cannot provide enough sustainable funding to meet the long-term needs of these populations. Federal, state and local funds are available but in recent years, due to the economic situation, funds for HIV/AIDS service providers has decreased dramatically. Federal sequestration has further restricted funds available for direct service delivery. ASOs are feeling the pinch but remain committed to serving their patients.

One source of stable funding available to certain AIDS Service Organizations who participate in the Ryan White programs comes through the federal discount drug program known as 340B (named for the section of the Public Health Act). Eligible provider groups—including federally qualified health centers; certain public hospitals; and many Ryan White grantees—can be made a “covered entity” which allows them to participate in this program.

Legislative Intent of 340B

The intent of the 340B program is to reduce outpatient drugs costs to health care providers who serve vulnerable patients —such as AIDS Service Organizations—and to allow those providers to expand services, serve more patients, and to improve the service delivery. In the original Committee report after the legislation passed in 1992 (**H.R. REP. 102-384(II)**), Congress made its intent clear:

In giving these "covered entities" access to price reductions the Committee intends to enable these entities to stretch scarce Federal resources as far as possible, reaching more eligible patients and providing more comprehensive services.

The original intent of the program was not to give access to cheaper drugs to poor, underinsured or uninsured patients. It is to expand the capacity of providers to serve people who are poor, underinsured or uninsured.

Certain Ryan White grantees have been participating in the 340b program since the original authorization. Today, AIDS Service Organizations remain true to Congress' intent and provide expanded medical and support services to vulnerable HIV/AIDS patients across the country. 340B funding allows them to keep the doors open; expand services; and provide medical and case management far beyond what they would otherwise be able to do. 340B is literally a lifesaver for these programs and the beneficiaries they serve.



ActionAIDS
FRIENDS FOR LIFE

ActionAIDS
1216 Arch Street, 6th Floor
Philadelphia, PA 19107
Phone: 215-981-0088
Website: www.ActionAIDS.org

Satellite Offices:

ActionAIDS
1026 Arch Street
Philadelphia, PA 19107
Phone: 267-940-5500
Phone: 215-243-2800

ActionAIDS West/Annex West Clinic
3901 Market Street, Box 1934
(Office entrance on Filbert Street)
Philadelphia, PA 19104

ActionAIDS North
Casa Nueva Vida
2641 N. 6th Street
Philadelphia, PA 19133
Phone: 215-291-9700

ActionAIDS Delaware County
2302 Edgemont Avenue
Chester, PA 19013
Phone: 267-428-3510

Contact:
Kevin J. Burns, LCSW
Executive Director
Email: KBurns@ActionAIDS.org
Phone: 215-981-3338



ActionAIDS
FRIENDS FOR LIFE

ORGANIZATIONAL FACTSHEET

FISCAL YEAR 2013 (ENDING JUNE 30, 2013)

ActionAIDS was founded in 1986 by volunteers with a mission statement that simply read: "ActionAIDS believes that **no one should face AIDS alone.**" Since that time, ActionAIDS has grown to become Pennsylvania's largest AIDS service organization. On the reverse, please read our full mission and history.

NONPROFIT STATUS: Section 501(c)(3) public charity, registered with Pennsylvania Bureau of Corporations and Charitable Organizations. Our official registration and financial information may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

MOST RECENT STRATEGIC PLAN: 2011 (for fiscal years 2012-2014)

CURRENT PROGRAMS



Medical Case Management
(with specialties including Behavioral Health,
Prison Linkage, Perinatal, and Family)



Prevention and Testing



Housing

SPECIAL PROJECTS

VOLUNTEER PROGRAM 390 volunteers provided 10,500+ hours of service

IMMEDIATE SEATING Distributed 2,000+ free tickets to persons with HIV/AIDS for shows and events at approximately 80 venues

POSITIVE ACTION Job search skills and related services to 1,156 persons

MICHAEL TAYLOR FUND Emergency grants, including 32 grants averaging \$217 each to keep clients and their families housed

SERVICE AREA GREATER PHILADELPHIA

3,736

Total clients per year

2,747

Total clients in
medical case management



Office Sites

4



Community satellite
staffing locations

35

100

Number of paid staff

21

Number of board members

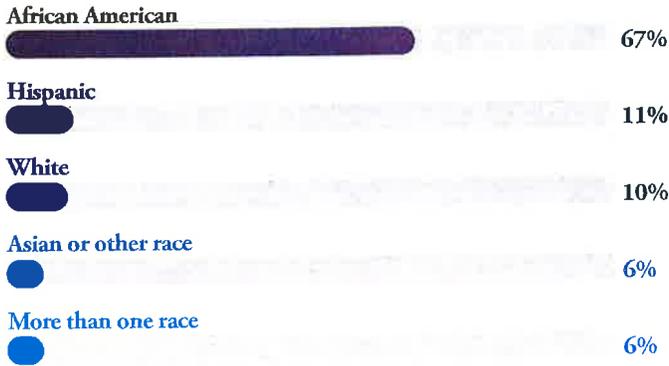
390

Number of volunteers



TOTAL NUMBER OF HIV TESTS: 683

CLIENT RACE/ETHNICITY

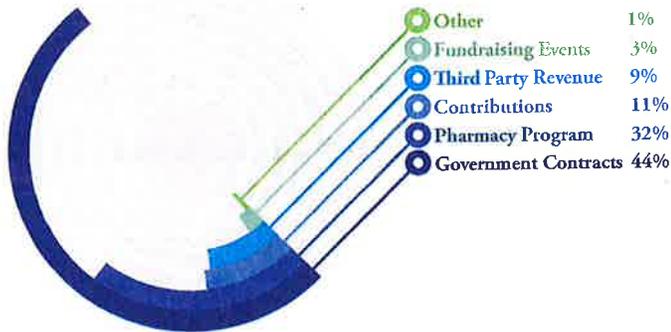


3,736

Total clients per year:

Clients with income below Federal Poverty Guideline: 81%
 Total clients at risk for homelessness: 250
 Number of infants born in Perinatal Program: 36
 Number of Perinatal Program infants born with HIV: 0

TOTAL ANNUAL EXPENSES: \$8,315,169 (FY 2013)



WHERE OUR FUNDING COMES FROM



WHERE IT GOES

OUR MISSION (REVISED 2013)

ActionAIDS is a Philadelphia, Pennsylvania-based organization, committed to creating an AIDS-free generation through a combination of proven strategies. Our services include medical case management, HIV testing, prevention education, supportive housing, HIV treatment as prevention, and volunteer services. Through our work in partnership with people living with HIV/AIDS, we seek to sustain and enhance their quality of life. Our Board of Directors, staff, and volunteers are committed to including and assisting people from our diverse community.

ActionAIDS has a multi-faceted strategy that puts us on the cutting edge of local efforts to defeat HIV/AIDS. Our strategy includes HIV testing and prevention messaging, medical case management services, and provision of supportive housing services. Our testing and prevention services include free, walk-in HIV testing and counseling (including social service and health care referrals) at local community sites. Our medical case management services facilitate access to on-going medical care, which is crucial to enhance and prolong the lives of thousands of our clients. By ensuring continuity of medical care, we also reduce the development of drug-resistant HIV, decrease sexual risk behaviors, and, as our clients in treatment maintain low or non-detectable viral load, we reduce or eliminate the risk of HIV transmission to others. Our housing program addresses the significant need that people with HIV have for adequate, affordable housing.

OUR HISTORY

In September 1986, a group of 84 committed volunteers came together to form a community of care for people with AIDS - the partners, family, and friends of our founding volunteers. Gathering in Center City Philadelphia, these volunteers acted, and ActionAIDS was founded. The mission statement simply read: "ActionAIDS believes that no one should face AIDS alone."

With a budget of \$125,000, and one unfunded staff member, ActionAIDS helped 91 people with AIDS in its first year. Over these many years, thanks to dedicated volunteers, talented staff, generous donors, and ongoing support from City, State, and Federal agencies, ActionAIDS has grown to become Pennsylvania's largest HIV/AIDS medical case management organization.

ActionAIDS typically serves over 4,000 clients and others in the greater Philadelphia area each year through the efforts of over 390 dedicated volunteers and 88 professional staff. Our "Buddy Program" - which is now the largest HIV/AIDS volunteer Buddy service in the United States - provides a model of how peer support can complement and augment the work of medical case management professionals by providing one-on-one emotional support, companionship, and occasional assistance with the tasks of daily living. ActionAIDS staff and volunteers are privileged to be invited into the lives of thousands of men, women, and children who are faced with the challenges of living with HIV disease. ActionAIDS volunteers and staff focus on building relationships one person and one family at a time. Our services are relationship focused, client centered and individualized. ActionAIDS continues to build a strong, diverse, and committed community of caring to make sure that no one faces AIDS alone.

In 2014, as a vital and well-managed organization, the ActionAIDS will undertake a strategic planning process. Our most recent Strategic Plan (FY 2012-2014) was adopted by the board of directors in 2011, and included staff, volunteer, donor, and consumer feedback process and resulted in a comprehensive strengths, weaknesses, opportunities, and threats analysis.

Contact: Kevin J. Burns, LCSW, Executive Director
 kburns@actionaids.org

HIV in the United States: The Stages of Care

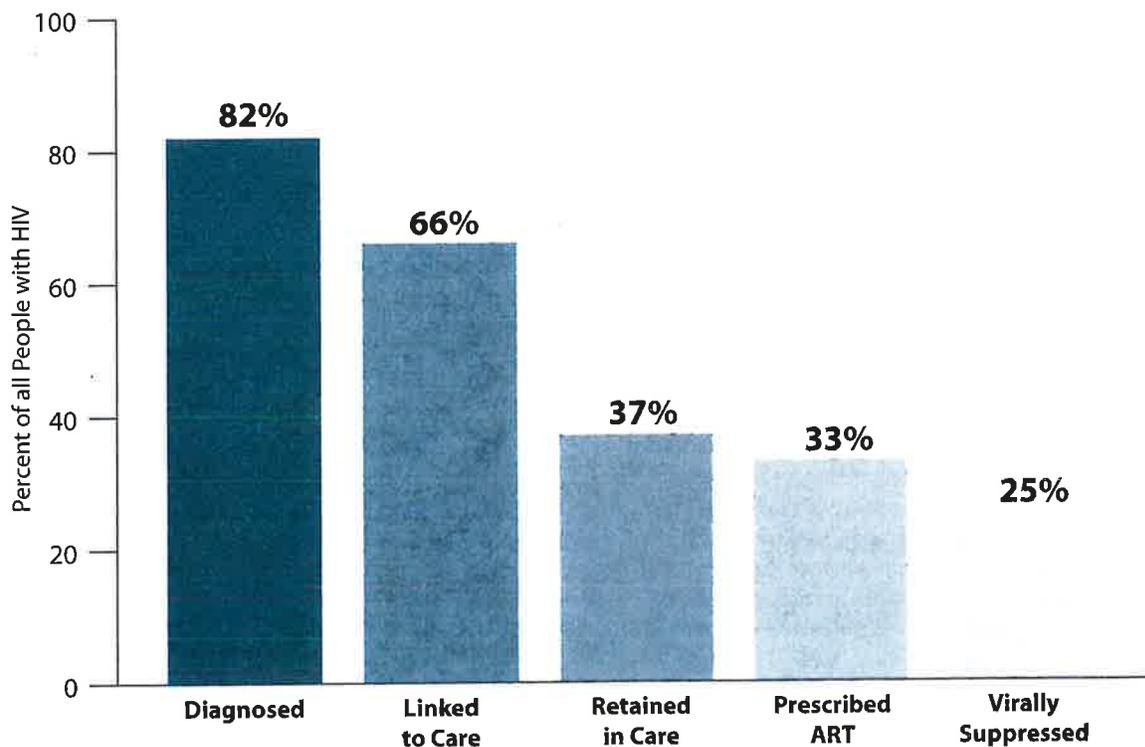
In July 2012, the Centers for Disease Control and Prevention released a comprehensive analysis showing that only one-quarter of the 1.1 million Americans living with HIV have their virus under control — and that African Americans and young people are least likely to receive ongoing care and effective treatment.

The study, based on HIV prevalence data from 2009 and other data sources, includes information on the proportion of people engaged in each of the five main stages of HIV care:

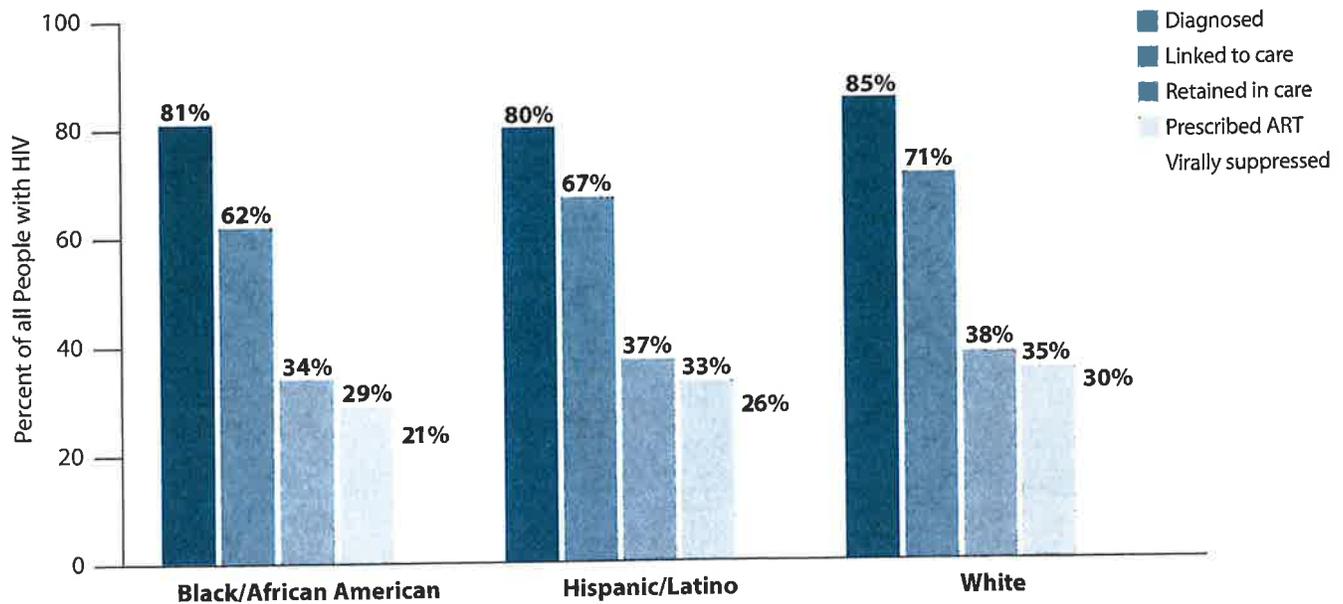
- HIV testing and diagnosis
- Linkage to care for those who test positive
- Retention in care over time
- Provision of antiretroviral therapy
- Achieving “viral suppression,” by using treatment to keep HIV at a level that helps individuals stay healthy and reduces the risk of transmitting the virus to others

The analysis also provides the first-ever look at HIV care by race/ethnicity, age, risk group, and gender. These findings are summarized in the charts below.

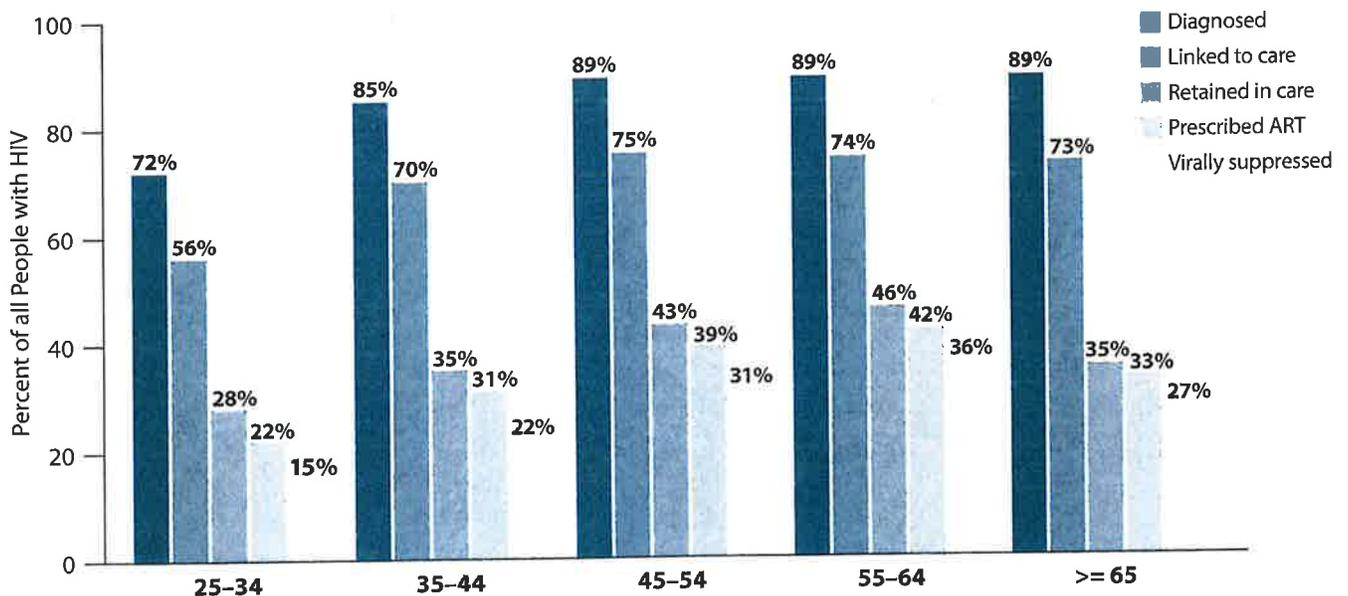
OVERALL: Of the 1.1 million Americans living with HIV, only 25 percent are virally suppressed.



BY RACE/ETHNICITY: African Americans are least likely to be in ongoing care or to have their virus under control.

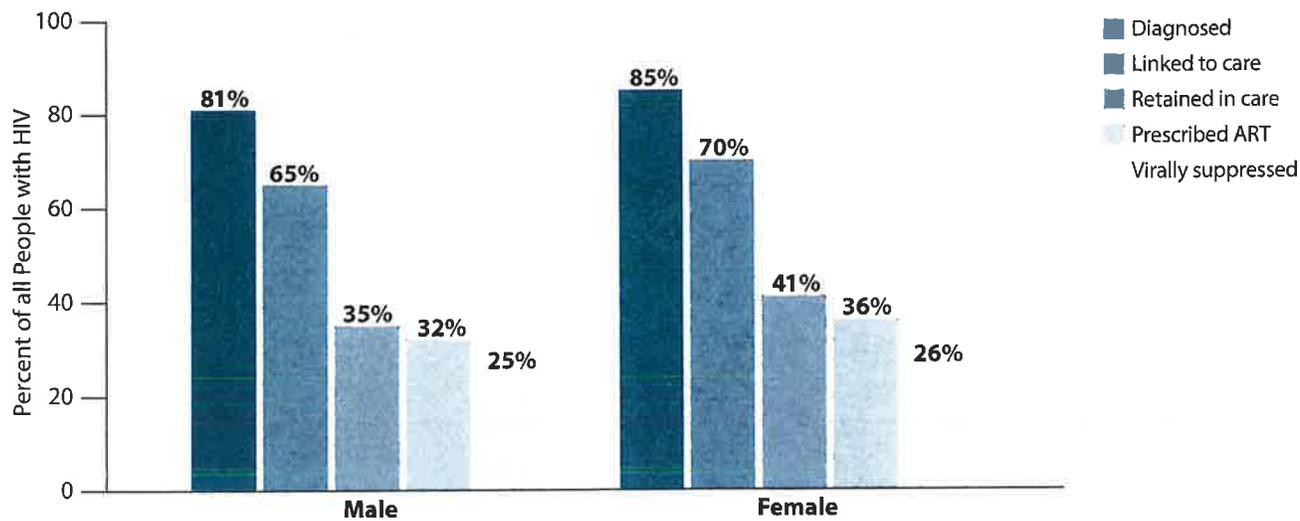


BY AGE: Younger Americans are least likely to be retained in care or have their virus in check; HIV care and viral suppression improve with age, except among those aged 65 and older.

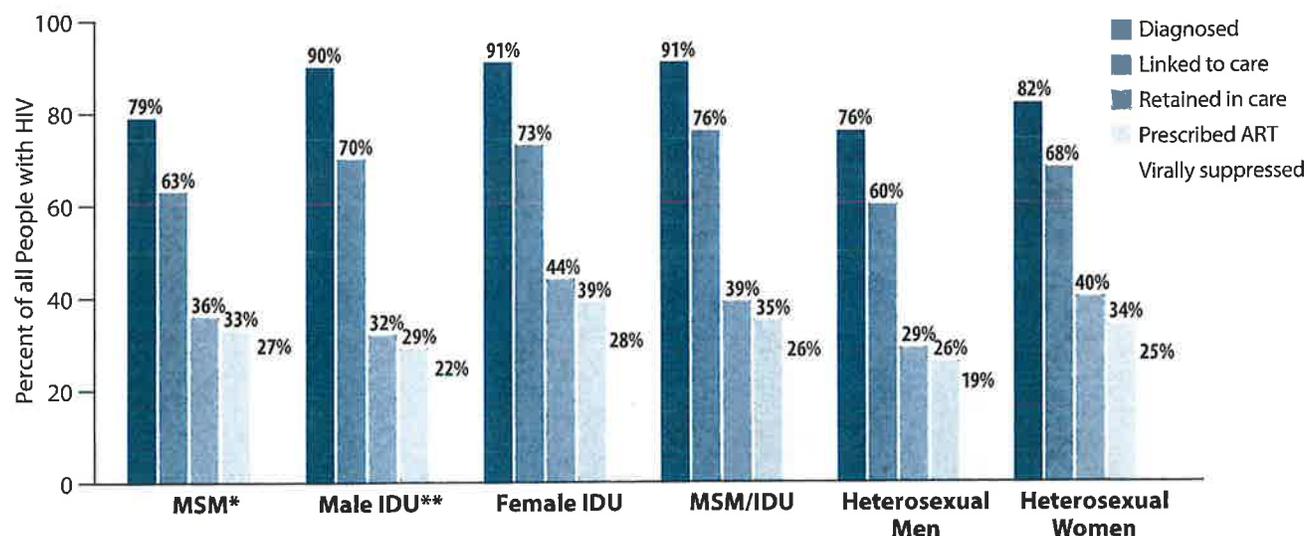


Note: Although national data were not available to provide estimates of viral suppression for those under the age of 25, the data show that 13-24 year-olds are substantially less likely to have been diagnosed with HIV than other age groups (only 41 percent versus more than 70% for all other age groups).

BY GENDER: Although men are less likely to be retained in care, men and women are equally likely to be virally suppressed.



BY RISK GROUP: Across all risk groups, fewer than half are in ongoing care and roughly a quarter have their virus in check.



* The term men who have sex with men (MSM) is used in CDC surveillance systems because it indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality
 ** IDU = Injection drug user

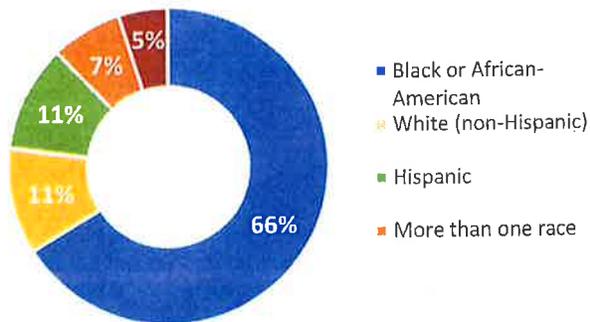
Closing the Gaps

To reduce the impact of HIV in the United States, improvements are needed at each stage of the process with particular efforts to reduce disparities by race and age. HIV testing is a first critical step in HIV prevention, and the only way to identify the nearly one in five — more than 200,000 — Americans with HIV who do not know they are infected. In addition, ensuring that people have access to care, stay in care and remain on treatment will increase the proportion of HIV-infected individuals who achieve and maintain viral suppression, which is critical to improve health and realize the full potential prevention benefits of treatment.

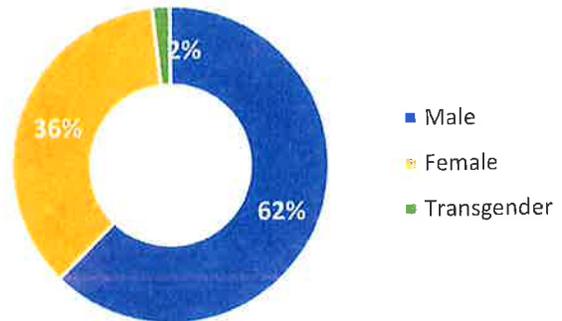
ActionAIDS 2014 Client Facts

All Direct Services Clients Served in 2014

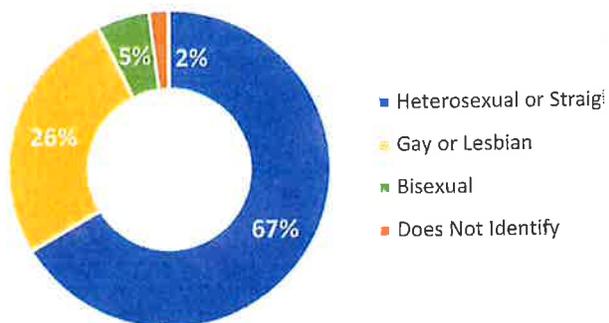
Race & Ethnicity



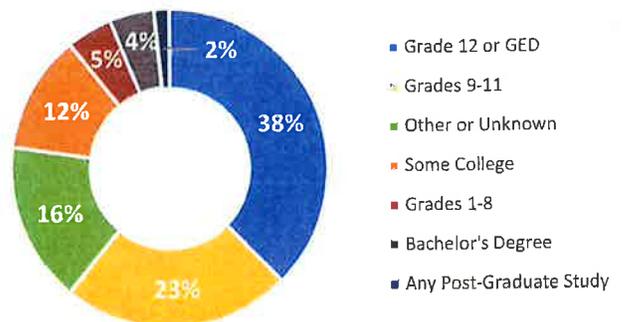
Gender



Sexual Orientation



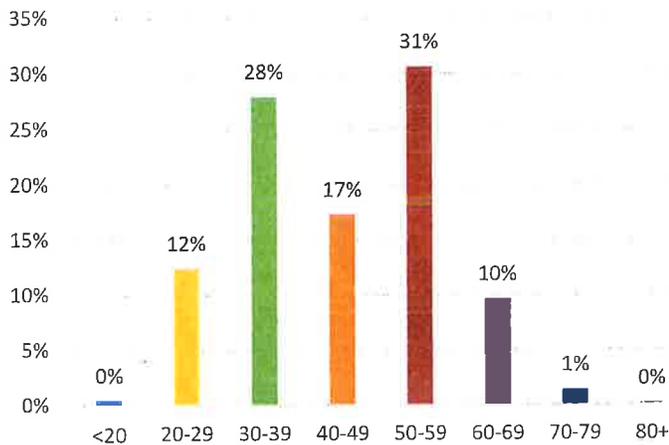
Level of Education



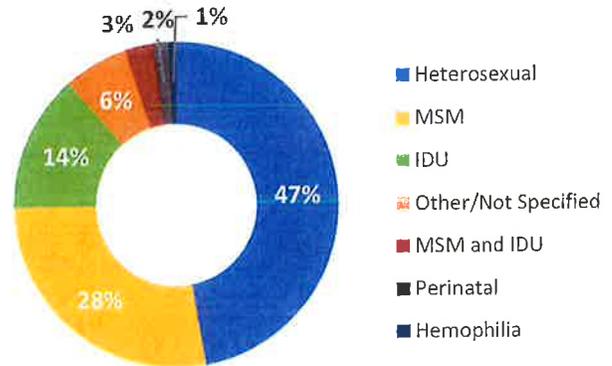
ActionAIDS 2014 Client Facts

All Direct Services Clients Served in 2014

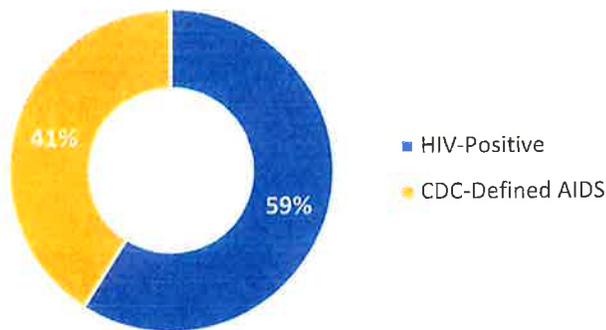
Age



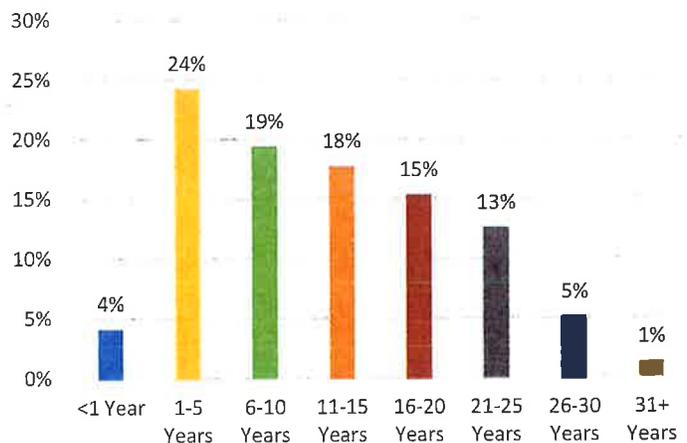
HIV Risk Factor



HIV/AIDS Status



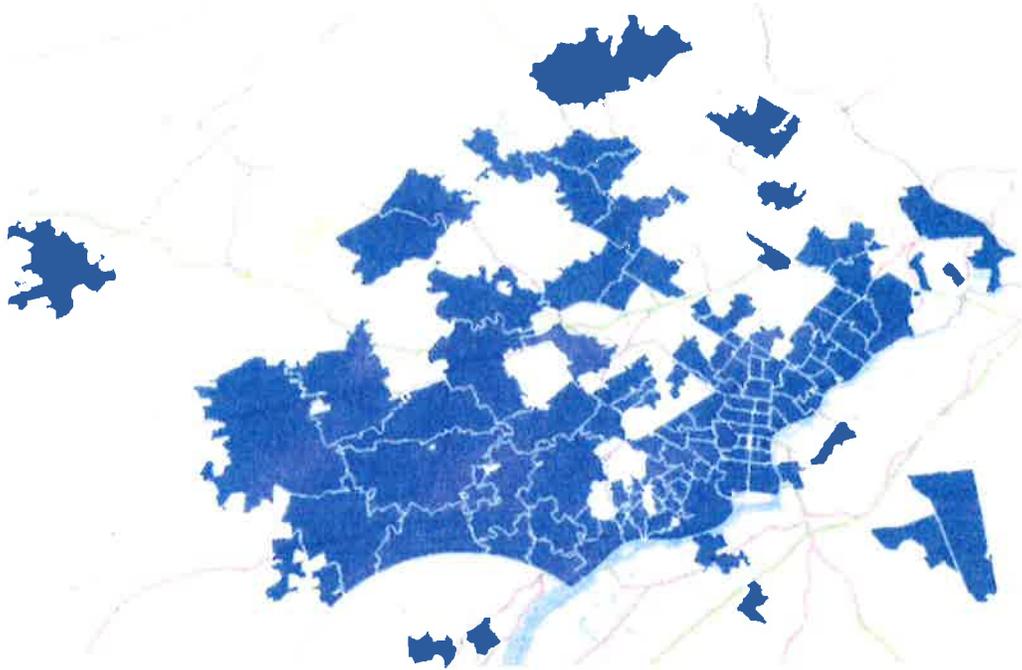
Years Since HIV Diagnosis



ActionAIDS 2014 Client Facts

Zip Codes served:

126



Immigrant Clients served:

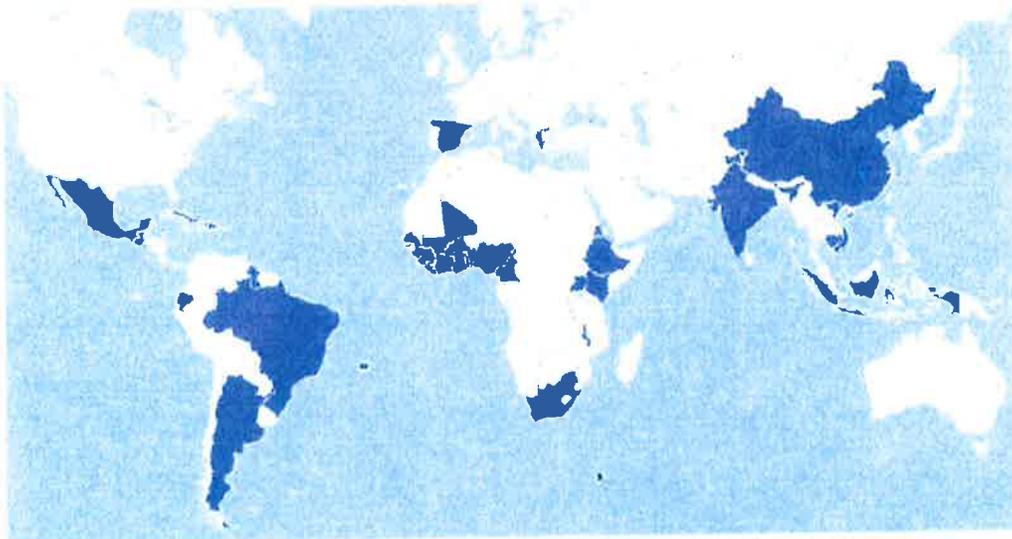
177

Languages Spoken by Clients:

33

Countries of Origin:

38

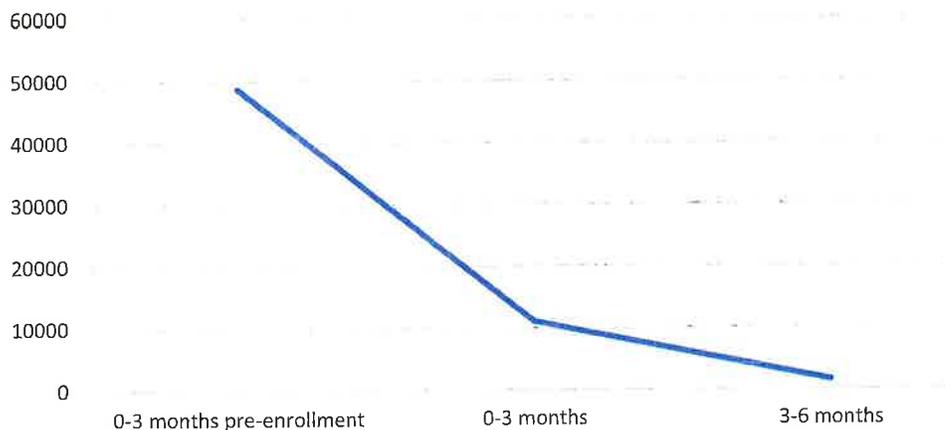


ActionAIDS 2014 Client Facts

Medical Case Management

Medical Case Management clients served	2,343
HIV Medical Visits attended by clients	5,343
Average number of months in Medical Case Management ¹	34
Average reduction in viral load during the first 6 months in Case Management ²	97%

Average Viral Load & Length of Time in Case Management
(Clients Enrolled During 2014)



Perinatal Medical Case Management Program

Babies born to HIV-positive women	38
HIV-positive babies	0

Prison Linkage Program

Clients served	336
Number of completed linkages to medical care	471

¹ Clients who received a service between 1/1/2014 and 12/24/2014.

² Clients enrolled from 1/1/2014 to 12/24/14 who had at least one viral load screening. Calculated difference in average viral load from 0-3 months prior to enrollment in case management, to 3-6 months post-enrollment.

ActionAIDS 2014 Client Facts

Housing Counseling

Housing clients served	471
Total hours of housing services provided	5,635
ActionAIDS' subsidized housing units for people living with HIV/AIDS	70

Prevention Services

HIV tests conducted	311
Percentage of HIV-positive individuals linked to medical care	100%
Percentage of HIV-positive individuals referred to Partner Notification Services	100%

Positive Action Program

Positive Action clients served	128
Number of resume writing sessions	202
Number of group educational sessions	34
Number of clients linked to employment	25

