HIV and AIDS in the United States of America (USA)

**KEY POINTS**

- More than one million people are living with HIV in the United States of America (USA); one in seven are unaware of their status.
- The HIV epidemic is driven by sexual contact and is concentrated among certain key populations, in particular gay men and other men who have sex with men.
- African Americans are worse affected by HIV across all key population groups.
- Despite condoms being widely available, use is falling, even among people who are at heightened risk of acquiring HIV.
- The USA is experiencing a public health emergency in the form of an opioid epidemic which is threatening the gains made on reducing HIV among people who use drugs.
- Stigma remains a huge barrier to preventing HIV, and is linked to low testing rates, as well as poor adherence to treatment, particularly among young people.

Explore this page to find out more about the populations most affected by HIV, testing and counselling, prevention programmes, antiretroviral treatment, civil society’s role, barriers to the response, funding and the future of HIV in the USA.

Around 1.1 million people are living with HIV in the United States of America (USA). Nearly one in seven of these people are unaware they have HIV. The size of the epidemic is relatively small compared to the overall population but is heavily concentrated among several key affected populations. In 2017, 66% of annual new HIV infections occurred among gay men and other men who have sex with men (sometimes referred to as MSM) among whom African American/black men are most affected, followed by Latino/Hispanic men. Heterosexual African American/black women, young people and transgender women of all ethnicities are also disproportionately affected.

### USA (2018)

- **1.1m** people living with HIV**\( ^* \)**
- n/a adult HIV prevalence (ages 15-49)*
- **38,500** new HIV infections**\( ^* \)**
- **6,000** AIDS-related deaths
- n/a adults on antiretroviral treatment*
- n/a children on antiretroviral treatment*

*All adults/children living with HIV

Source: UNAIDS, *no data since 2011/12, **CDC 2015
Although the USA is the biggest funder of the global response to HIV its ongoing HIV epidemic saw around 38,700 new infections in 2017.3 Stigma and discrimination continue to hamper people's access to HIV prevention as well as testing and treatment services, which fuels a cycle of new infections.

HIV rates are higher in southern states, which are home to around 45% of all people living with HIV, and account for around half of new diagnoses annually, despite making up roughly one-third (37%) of the population.4

From the beginning of the HIV epidemic until 2016, around 692,790 people died of AIDS-related illnesses.5

President Obama created the country’s first National HIV/AIDS Strategy in 2010. This was updated in 2015, and will run until 2020, and is structured around four core aims: reducing new HIV infections, increasing access to care and improving health outcomes for people living with HIV, reducing HIV-related disparities and health inequities, and achieving a coordinated national response to the epidemic.6

Following the election of President Trump in 2016, concerns have been raised over the administration’s approach to HIV, both globally and domestically. In 2017, the post of Director of National AIDS Policy, which existed to coordinate efforts to implement the National HIV/AIDS Strategy, became vacant and remains so as of June 2019.

By the end of 2017, all members of the Presidential Advisory Council on HIV/AIDS (PACHA), which provides advice on the National HIV/AIDS Strategy, had either resigned or been fired.7 8

In February 2019, President Trump used the State of Union address to pledge to eliminate the USA's HIV epidemic within 10 years. The goal is for a 75% reduction in new HIV infections over the next five years and at least a 90% reduction in the next 10 years.9 A month later, in March 2019 PACHA was
finally re-staffed.10

**Populations most affected by HIV in the USA**

The HIV epidemic in the USA has impacted some groups more than others. These groups, sometimes referred to as key populations, can be grouped by transmission category (for example, men who have sex with men) but also by race and ethnicity, with people of colour having significantly higher rates of HIV infection over white Americans.11

A complex set of economic and socio-economic factors drive risk to these populations, including discrimination, stigma, poverty and a lack of access to care.12 Sexual networks also present a major risk factor as populations at a high risk of HIV tend to have sex with people in their own communities.

**Men who have sex with men (MSM)**

Men who have sex with men (sometimes referred to as MSM) are the group most affected by HIV in the USA, accounting for an estimated 2% of the population, but 66% of new annual HIV infections.13 At the end of 2015, the most recent data available, around 632,300 USA-based men who have sex with men were living with HIV. One in six of these people were unaware they were HIV positive.14

Between 2010 and 2016, new HIV infections among men who have sex with men remained stable at about 26,000 a year.15 However, trends vary greatly by age and ethnicity. For example, new infections among African American/black men who have sex with men remained stable overall, at about 10,000 new infections (around 38% of all new infections among men who have sex with men, which in itself is greatly disproportionate) but they increased by 65% among those aged 25 to 34 (from 2,600 to 4,300). Among Latino and Hispanic men who have sex with men, new infections rose by around 30%, from 6,400 to 8,300. Again, the greatest rise was among 25 to 34-year-olds, where new infections increased by 68%. Among white men who have sex with men, new infections decreased to less than a-fifth overall, from 8,000 to 6,700.16

In 2016, it was estimated that, if current diagnosis rates continued, one in six American men who have sex with men would be diagnosed with HIV in their lifetime. This equates to one in two African American/black men who have sex with men, one in four Hispanic/Latino men who have sex with men and one in 11 white men who have sex with men.17

Every three years, the US Centers for Disease Control and Prevention (CDC) studies sexual risk behaviours among men who have sex with men in selected cities. The latest data from this survey suggests the number of men who have sex with men having anal sex without a condom is increasing. In 2008, 13.7% reported having condomless sex, rising to 15.7% in 2014.18

In 2017, 24% of HIV-positive and 21% of HIV-negative men who have sex with men whose last sexual partner was male reported having condomless anal sex in the three months before the interview.19
African American/black people

In the USA, African American/black people are more affected by HIV than any other ethnic group. This group accounted for 43% of all new HIV infections in 2017 despite only making up around 12% of the population. At the end of 2015, an estimated 468,800 African American/black people were living with HIV. One in seven were unaware of their status.

Among all African American/black people diagnosed with HIV, the largest proportion is among men who have sex with men, who, in 2016, accounted for six out of ten diagnoses.

From 2010 to 2016, HIV diagnoses decreased by 12% among African American/black people overall. However, trends varied for different groups within this population. Over this period, diagnoses among heterosexual African American/black men and women fell by around a quarter. However, rates of new diagnoses are still high compared to heterosexuals from other ethnic groups, with around 4,000 new diagnoses in 2017 among African American/black heterosexual women and around 1,700 diagnoses among African American/black heterosexual men. Among African American/black men who have sex with men, new diagnoses have remained stable overall.

Hispanic/Latino people

HIV also disproportionately affects the Hispanic/Latino community. In 2016, Hispanic/Latino people accounted for 26% of new diagnoses of HIV in the USA, despite only representing around 18% of the population. Hispanic/Latino men account for 22% of the total number of annual new HIV diagnoses, while Hispanic/Latina women accounted for 3%. The vast majority of infections among Hispanic Latino men are the result of condomless sex with men.

At the end of 2015 around 252,400 Hispanic/Latino people were living with HIV. One in six were unaware of their HIV status.
From 2011 to 2015, HIV diagnoses among Hispanic/Latino people remained stable overall. However, diagnoses among Hispanic/Latina women declined steadily by 14% but rose by 13% among Hispanic/Latino men who have sex with men. Among young Hispanic/Latino gay and bisexual men (aged 13-24) HIV diagnoses increased by 19%.\textsuperscript{28}

The Hispanic/Latino community faces a number of challenges to accessing HIV prevention and treatment services. Language, cultural factors and a fear of being deported are all key barriers.\textsuperscript{29}

Transgender people

Around 1 million adults identify as transgender in the USA. From 2009 to 2014, around 2,350 transgender people were diagnosed with HIV, the vast majority of whom (84%) were transgender women. This equates to around 14% of transgender women in the USA living with HIV. Around half of transgender people who received an HIV diagnosis from 2009 to 2014 lived in the Southern states of the USA.\textsuperscript{30}

HIV prevalence is particularly high among African American/black transgender women; 44% are estimated to be living with HIV.\textsuperscript{31}

Transgender people experience high levels of stigma, discrimination, abuse and violence, all of which put them at increased risk of HIV. In addition, often HIV prevention programmes do not adequately address transgender people’s needs.\textsuperscript{32}
You could have been made fun of the entire way to the health provider’s office, and when you get there, you may still face stigma and discrimination. Even in the doctor’s office, you might face incorrect pronoun use, misnaming, hostile waiting rooms, or being asked to use bathrooms that don’t support your gender identity.

– an American transgender woman.33

**Prisoners**

The USA has the largest incarcerated population in the world, with 2.1 million people in prison or other closed settings.34

At the end of 2015, the most recent data available, 17,150 prisoners in the USA were living with HIV, this equates to around 1% of the overall prison population. The vast majority are men, with 15,920 male prisoners living with HIV, compared to 1,220 female prisoners. The number of prisoners living with HIV between 2010 and 2015 fell by 14% among male prisoners and 31% among female prisoners.35

From 2010 to 2015, between four and six people per 100,000 died from AIDS-related illnesses in state prisons.36

Among prison populations, African American/black people are more likely to be diagnosed with HIV than any other ethnicity group. Most prisoners are HIV-positive before they are incarcerated, with one study estimating that one in seven people living with HIV in the USA go through the prison system every year.37 Others acquire HIV while they are in prison – for example, via unprotected sex. A study in the New York area found 13% of incarcerated men and women reported being sexually active in the previous six months.38

**People who inject drugs (PWID)**

It is now widely accepted that the USA is experiencing a nationwide public health emergency in the form of an opioid epidemic.39 40

Heroin use is increasing in the USA among men and women in most age groups and across all income levels, rising by 63% between 2002 and 2013 alone. A study published in 2019 estimated that more than 750,000 people in the USA inject drugs and that this number is rising.41

A huge contributing factor to this is misuse of prescription opioids, which has seen an increasing number of people turn to injecting drug use, particularly in non-urban areas where previously, injecting drugs had not been a significant issue. This has created new HIV prevention challenges as it has placed more people at risk of HIV.

Between 2010 and 2016, new infections among people who inject drugs fell by 30% overall.42 However, there are concerns that the level of new infections may have stagnated or reversed in
recent years due to increased levels of injecting.43 44

Evidence is emerging of increases in hepatitis C infections and new, localised outbreaks of HIV.45 For instance, Scott County in Indiana, with a population of only 23,744, experienced 181 new HIV infections in 2015.46

The impacts of the opioid epidemic are far reaching: the US has experienced the fastest proportional rise of drug-related overdose deaths ever recorded, which rose by 21.4% between 2015-2016 alone.47

Overdose deaths disproportionately affect people living with HIV. A study examining opioid overdose deaths between 2011 and 2015 found the opioid overdose death rate among people with diagnosed HIV to be 42.7% greater in 2015 than in 2011, despite the rate of all deaths among people diagnosed with HIV declining overall by 12.7%.48

In 2016, around 3,425 people in the USA became HIV-positive through injecting drug use, equivalent to 9% of all new HIV diagnoses in the country that year. Around a third of these were due to male-to-male sexual contact and injecting drug use.49

Of the HIV diagnoses attributed people who inject drugs in 2016, 73% were among men, and 27% were among women. When analysed on ethnicity, 43% were among white people, 31% were among African American/black people, and 21% were among Hispanic/Latino people.50

**Young people**

Adolescents and young adults (aged 13-29) account for 41% of new HIV diagnoses in 2017.51 Those aged 13 to 24 accounted for 21%; roughly one in every five new diagnoses.52

Data from 2012 to 2016 shows HIV diagnoses have either stabilised or fallen among the majority of adult population groups, however they increased by 6% among those aged 13 to 29.53 Young ethnic and racial minority men who have sex with men are worse affected. Among young Hispanic/Latino men who have sex with men, HIV diagnoses have risen by 17% over this period and by 9% among young African/American black men who have sex with men. Overall, young racial and ethnic minority men who have sex with men accounted for around six out of every 10 diagnoses among adolescents and young adults in 2017. Young transgender people and young people who inject drugs are also particularly vulnerable to HIV.54

At the end of 2016, an estimated 50,900 13 to 24-year-olds were living with HIV. Of these, 44% were unaware of their status. This age group is the least likely to test for HIV, receive HIV treatment or be virally suppressed.55 56
HIV testing and counselling in the USA

It is estimated that 40% of new HIV infections in the country are transmitted by people who are living with undiagnosed HIV, making increasing access to testing and counselling a fundamental priority for HIV prevention.57

In 2015, the US government expanded Medicare (the national health insurance programme) coverage to include annual HIV testing for everyone aged 15 to 65-years-old, regardless of their risk, as well as pregnant women and people outside of this age range who are at increased risk. This means that people with health insurance – both public and private – have good access to testing, often at no cost. For those without insurance or those wishing not to use their insurance, HIV testing can often be
obtained at little or no cost.\textsuperscript{58}

In July 2012, the first HIV home-testing kit was approved for use in the USA. Between then and 2017, approximately 1.1 million home-testing kits were sold in the country, primarily through private purchase, online and at pharmacies.\textsuperscript{59}

HIV testing is also available in non-clinical or community-based settings. These services typically provide same-day rapid HIV testing and some offer HIV prevention services. Nonclinical testers may also offer outreach and mobile testing to reach people who are particularly marginalised. Settings include churches, bathhouses, parks, shelters, syringe services programmes, health-related shops and people’s homes.\textsuperscript{60}

People from groups most affected by HIV are testing more, although testing coverage among heterosexual people who are at increased risk remains relatively low. In 2014, 71% of men who have sex with men were estimated to have tested for HIV, compared to 63% in 2008. Among people who inject drugs, 58% tested for HIV in 2015, compared to 50% in 2009. Among at-risk heterosexual people, 41% tested in 2016, compared to 34% in 2010.\textsuperscript{61,62}

Despite, the widespread availability of HIV testing, only 54% of Americans have ever tested for HIV, and only 16% had tested in the last year. Testing rates also vary greatly by state, age, and race/ethnicity. For example, people who are African American/black or Latino are more likely to report having been tested for HIV than white people.\textsuperscript{63}

HIV related stigma, socially conservative communities, and low HIV risk perception all serve as barriers to testing.\textsuperscript{64}

In 2017, as part of the \textit{Act Against AIDS} initiative, CDC launched \textit{Doing It}, a national campaign designed to motivate all adults to get tested for HIV and know their status. The campaign aims to normalise HIV testing so that it becomes part of everyone’s regular health routine.\textsuperscript{65}

**HIV prevention programmes in the USA**

In 2017, an estimated 38,700 people became newly infected with HIV.\textsuperscript{66}

In an attempt to advance high-impact HIV prevention across the USA, between 2012 and 2017, CDC created a new prevention fund cycle for US $339 million. Grants were awarded to health departments that could demonstrate they were providing HIV prevention services to those with the greatest need. Services also had to show they used combined behavioural, medical and structural HIV prevention strategies.\textsuperscript{67}

In 2019, CDC announced a new 10-year plan to end the HIV epidemic. The programme aims to reduce new HIV infections by 75% in five years and by 90% in 10 years. It focuses on Washington, D.C., San Juan (Puerto Rico), 48 counties and seven states that have a substantial rural HIV burden. Its key components are described as being ‘diagnose, treat, protect, and respond’; the latter two components relate to HIV prevention. ‘Protect’ relates to using evidence-based prevention interventions, while ‘respond’ relates to detecting and responding to growing HIV clusters to disrupt chains of transmission, thereby preventing new infections.\textsuperscript{68}
Condom availability and use

One of key requirements for health departments receiving previous CDC prevention funding was to establish and maintain condom distribution programmes for people with HIV and people at high risk of acquiring it. Between 2012 and 2014, the most recent data available, these types of programmes distributed over 248 million condoms.69

Despite this, CDC reports a long-term decline in condom use among men who have sex with men from as early as 2005 (see men who have sex with men section above). In 2016, it was reported that the greatest increase in sex without condoms was seen in young men, aged 18 to 24.70

HIV and sex education

The status of sexual health education varies substantially throughout the USA and is insufficient in many areas. In most states, fewer than half of high schools teach all 16 topics CDC recommends for effective sex education. Many also argue that sex education is not starting early enough.71

The percentage of schools in which students are required to receive instruction on HIV prevention is decreasing, from 64% in 2000 to 41% in 2014.72

Conservative support for abstinence-only sex education has also been a major barrier to progress, and has been shown to be associated with increased HIV rates among adolescents.73

President Obama eliminated three-quarters of the budget for abstinence-only sex education in 2009, which had previously received the majority of funding.74 75 However, funding for abstinence-only sex education began to rise again in the following years and stood at US $85 million in 2016.76

In February 2018, this was renewed for two more years at US $75 million annually under the new name of ‘sexual risk avoidance education’.77 As of 2019, 37 states require that information on abstinence be provided, 27 of which require for abstinence to be emphasised, with the 10 remaining states requiring that abstinence is covered. In contrast, only 12 states require discussion of sexual orientation. Of these, nine states require that discussion be inclusive.78

A study by the Guttmacher Institute analysed data on 15 to 19-year-olds from surveys carried out by CDC between 2006 and 2010, and 2011 and 2013. It found the proportion of adolescents receiving formal education about birth control decreased from 70% to 60% among females and from 61% to 55% among males. Overall, between 2011 and 2013, 43% of adolescent females and 57% of adolescent males did not receive information about birth control before they had sex for the first time.79

HIV prevention campaigns

CDC leads on campaigns that aim to take the taboo out of HIV. Specifically, the Act Against AIDS campaign has many strands that target different population groups. The most recent include the Start Talking. Stop HIV campaign, launched in 2014. This seeks to reduce HIV infections among gay men and other men who have sex with men by encouraging open discussion between sex partners and friends about a range of HIV prevention strategies.

The Let’s Stop HIV Together campaign raises awareness about HIV and its impact on the lives of all Americans. It aims to address stigma by showing that people with HIV are mothers, fathers, friends,
brothers, sisters, sons, daughters, partners, wives, husbands, and co-workers. This campaign also runs in Spanish as *Detengamos Juntos el VIH.*80 As of 2019, the campaign's public service announcements have been viewed over 4.3 million times online and over 4.1 billion times on television.81

Preventing mother-to-child transmission (PMTCT)

Mother to child transmission of HIV continues to decline in the USA, but rates remain higher among African American/black women and their infants.

As of 2016, around 11,900 people were living with HIV as a result of mother-to-child transmission. Around 1,800 of these people were children.82]

In 2017, 73 infants acquired HIV at birth, the majority of whom (64%) were African American/black. This reflects a 41% reduction in the rate of mother-to-child transmission between 2012 and 2016.83

CDC recommends HIV testing for all women as part of routine pre-natal care and has developed a framework to guide federal agencies and other organisations in their efforts to reduce the rate of mother-to-child transmission to less than 1% among infants born to women with HIV.84

Harm reduction

Key harm reduction interventions – including needle and syringe programmes (NSP) and opioid substitution therapy (OST) – are available in the USA. Progress on harm reduction has been driven by concerted and persistent pressure from people who use drugs and other HIV, health and human rights activists. However, coverage is inconsistent across the country as a whole and remains substantially below recommended levels.85

As of 2016, 355 NSPs were operating across the country, 91 more than in 2016.86 This increase has been driven by increasing concerns about the spread of HIV in non-urban communities linked to increasing opioid misuse and a partial repeal of the ban on federal funding for this service.87

Strict drug law enforcement acts as a deterrent from accessing NSPs for many people, while also increasing the country's prison population. For example, a national survey of NSPs found half reported their clients experienced police harassment on at least a monthly basis.88

As a result of these barriers, data from 2015 suggests an average of 50 syringes were distributed per person who injects drugs, and only 35% of people who inject drugs used sterile equipment in the past 12 months.89

Around 411,300 people are enrolled in OST in the USA. The number of private, for-profit facilities providing methadone has been increasing, with 64% of people who received methadone in 2012 receiving it from this type of facility.90

In March 2018, President Trump announced a move away from harm reduction in favour of a punitive approach to drug use, even proposing to introduce the death penalty for those found selling drugs.91

Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis (PrEP), where HIV-negative people take treatment before exposure to HIV to prevent infection, has been recommended in the USA since 2012 for people at ongoing substantial
risk of HIV infection. This includes HIV-negative people in a sexual relationship with a person living with HIV, people who inject drugs, and men who have sex with men who do not consistently use condoms.92

The USA is the leading country for PrEP use in the world. Two thirds of the estimated 350,000 people who have ever taken PrEP live in the USA. In 2017, around 61,300 people were actively taking PrEP. Use is highest in New York, where 24% of those eligible are using PrEP, Massachusetts (17%) and Iowa (16%).

In San Francisco, PrEP use and increases in viral suppression among people living with HIV have been linked to a 43% reduction in new HIV diagnoses in the city, from 392 in 2013 to 223 in 2016.93

It is estimated that increasing PrEP coverage in the USA could prevent around 48,000 new infections within five years, and up to 185,000 new infections in the same period if increased coverage were combined with expanded testing and treatment.94 However, a 2015 survey found 34% of primary care doctors and nurses in the USA were unaware of PrEP and so were not offering it to people at risk of HIV.95

In addition, an analysis by CDC of PrEP use between 2014 and 2016 found nearly six times as many white people as black people were being prescribed PrEP, despite black/African American people having a greater need.96

Neither are PrEP services reaching enough at-risk young people. It is estimated that around 700,000 adolescents and young adults could benefit from PrEP, but only 27,330 PrEP prescriptions have been issued to this age group since 2012.97

There are also issues with PrEP adherence. Findings from a study published in 2019 suggests people who are young, African American/black or female stay on PrEP for half as long as the average user, even when their risk of contracting HIV remains the same.98

Increasing PrEP use among transgender people and ethnic or racial minority men who have sex with men

In 2015, the CDC launched a three-year initiative to increase PrEP implementation in the USA. As part of Project PrIDE (PrEP, Implementation, Data2Care, and Evaluation), CDC supported 12 health departments in running PrEP demonstration projects aimed at transgender people and ethnic or racial minority men who have sex with men..99

Initial evaluations from New York and Houston released in 2019 suggest the pilots were successful at reaching African American/black and Hispanic/Latino men who have sex with men but far less successful at reaching transgender people. For instance, in New York the total number of transgender people screened for PrEP was low, despite the fact that community outreach workers came into regular contact with transgender people.

In addition, sexual health clinics reported low numbers of transgender people accessing services overall, although those who did access services were likely to receive PrEP.100 Fuller results are expected to be published in 2019 and 2020.
Antiretroviral treatment availability in the USA

In December 2014, the USA released guidelines recognising the benefits of early treatment for someone living with HIV, as well as the benefits treatment can have on preventing HIV being transmitted to others.101

Despite this, for every 100 people living with HIV in the USA in 2015, only 63 initiated care treatment, 49 were retained in care, and 51 achieved viral suppression.102

More people in HIV care are accessing antiretroviral treatment (ART), increasing from 89% in 2009 to 94% in 2013. However treatment outcomes vary across different ethnic groups. Fewer African American/black people than Hispanics and white people are on ART and fewer have a suppressed viral load. African American/black people are also less likely to have sustained viral suppression over time and to experience longer periods with viral loads at a level that increases their risk of transmitting HIV.103 104

Adolescents and young people also struggle to access effective treatment, with worse outcomes than all other age groups at every stage of the HIV treatment cascade. More than a quarter of adolescents and young adults who test positive for HIV are not receiving care services within a month of diagnosis. Around a quarter of adolescents and young adults who access treatment do not stay on it. Only half of all adolescents and young adults who test positive for HIV achieve viral suppression, while one in three adolescents and young adults who achieve viral suppression do not sustain it.105

A study analysed treatment data on 336 young black men (aged 18 to 24) receiving HIV care between 2009 and 2014. It found 80% were prescribed ART and 73% adhered to treatment, but only 36% were virally suppressed over a prolonged period of time, compared to 68% of people enrolled in HIV care overall.106
To improve retention in care rates, in 2013, the USA launched the HIV care continuum initiative. This aims to help health systems across all states identify individuals who have dropped out of care. In an effort to re-engage these people the initiative will enlist the help of non-traditional care providers such as community based organisations.107

In 2010, thousands of additional people living with HIV (on very low incomes) in the USA were also enrolled in comprehensive health insurance (known as Medicaid) through the implementation of the Affordable Care Act.108 A 2014 study by the Kaiser Family Foundation found many people used the systems established under the Act to find more affordable and comprehensive health insurance coverage.109 In fact, Medicaid was the largest source of insurance coverage for people with HIV in 2014, estimated to cover more than 40% of people with HIV who were accessing care.110

Since coming to power President Trump has taken steps to weaken the Affordable Care Act. As a result, people with long-term chronic conditions such as HIV are likely to see their health insurance costs rise. A number of commentators argue that President Trump’s pledge to end HIV in the USA by 2030, which he made in his 2019 State of the Union address, will not be possible unless Medicaid expansion continues.111 112

Ponce de Leon Center - Atlanta, Georgia

Ponce de Leon in Atlanta, Georgia is one of the largest outpatient HIV clinics in the USA with around 6,000 patients. It serves a community of some of the most vulnerable populations in the country, most of whom live in poverty and are either uninsured or underinsured.113 114

The clinic is leading the way in providing comprehensive co-located services for patients with HIV. It offers financial counselling, support around mental health and substance misuse, as well as nutritional and acute care along with other services. The clinic is able to provide a more holistic approach to supporting patients - not only providing treatment but also helping them to stabilise their lives in other respects too. Michael Sidibe, when he was Executive Director of UNAIDS, described the clinic as having a, ‘best practice approach that is saving lives’.115

In 2016, Ponce de Leon launched REACH, a programme designed to reduce the amount of time it took for patients to become virally suppressed. REACH offers those testing HIV-positive an immediate appointment with a healthworker with the option of starting ART within 72 hours. An evaluation of REACH found it had reduced the average time it took for people to first engage with HIV care from 17 to 5 days, the time to start treatment from 21 to 7 days, and the time to become virally suppressed from 77 to 57 days.116

Civil society’s role in the USA

Freedom of expression in the USA has allowed political activism has been a key part of the country’s HIV response since the very beginning.

In the early days of the response, HIV activism was closely associated with gay communities in the USA (and other industrialised Western nations). To some extent, grassroots activism in many parts of the USA declined as antiretroviral treatment became more available in the late 1980s and the early 1990s. During the early 1990s, activists shifted their focus more into providing HIV prevention and
treatment programmes for people most affected by HIV. However, concerns over the rollback of sexual and reproductive health rights, and rights for people who are lesbian, gay, bisexual, transgender and intersex (LGBTI) under President Trump has seen a resurgence of activism in recent years.

There is a systematic and sinister erasing of LGBTQ protections and policies happening at the hands of this Administration. Now more than ever, it’s vital LGBTQ Americans and marginalised communities raise their voices and tell their stories. The LGBTQ community will not go into hiding, and we will not be silenced.

- Zeke Stokes, Chief Programs Officer at GLAAD.

Barriers to the HIV response in the USA

Stigma and discrimination

Addressing stigma and discrimination around HIV is a major challenge for the USA, including misconceptions about how HIV is transmitted.

In 2013, the Global Network of People living with HIV (GNP+) launched the USA Stigma Index as a way for people living with HIV to document experiences of stigma and discrimination and mobilise communities to act to tackle the issue. As of 2019, only findings from Michigan were published. These found 80% of respondents experienced negative feelings of self-blame and guilt about their positive status, 73% experienced at least one form of social discrimination, and 20% experienced at least one form of institutional discrimination, predominately related to healthcare, housing, and insurance access.

Stigma relating to having a different sexual orientation or gender identity to cisgendered heterosexuals is also an issue. A 2017 survey found 69.5% of LGBT people had experienced discrimination in the past year. Uneven healthcare provision is also a major barrier to effective services, with the quality of HIV prevention and care received varying greatly across the country depending on location and socio-economic group. People of colour in the South experience the worst clinical outcomes after being diagnosed with HIV. Factors that contribute towards this include poverty and poor access to healthcare relative to the rest of the country.

A report by Human Rights Watch found many LGBT people encounter discrimination from health providers or health insurers, or delay or avoid care because of concerns about how they will be treated. Lesbian, gay and bisexual people contributing to the report said they most often encountered discrimination when they disclosed their sexual orientation or mentioned a same-sex partner. Some said they would not disclose these facts to health providers to avoid discrimination.

In 2017, 8% of lesbian, gay, and bisexual people and 29% of transgender people questioned by the Center for American Progress said that a healthcare worker had refused to see them because of their
sexually oriented or gender identity in the past year. Similarly, around a third of the 28,000 transgender people questioned for a 2015 survey reported at least one negative experience with a healthcare provider due to their gender identity in the past year.

They accepted the person at first, but when they found out it was a trans client, the doctor said we don’t see trans clients here. They got in the door, but then got turned away.

- Jessica Shea, a clinical social worker in Memphis

**Legal barriers**

Legislation has contributed to the improvement of the lives of those living with HIV and AIDS in the USA. This culminated in 2010 when President Obama lifted the ban on entry into the country for all HIV-positive people.

As of December 2018, 27 states had HIV criminalisation laws. The United States is the third country in the world to bring the most criminal cases relating to HIV, behind Russia and Belarus.

An analysis by CDC and Department of Justice researchers found that, by 2011, a total of 67 laws explicitly focused on persons living with HIV had been enacted in 33 states. Many of these convictions occurred against people for spitting or biting, despite these not being routes of HIV transmission.

The rollback of certain LGBTI rights that began in 2017, coupled with increasing political conservatism, is also acting as a barrier to the HIV response. For example, The Washington Post reported that the Trump administration is prohibiting officials at CDC from using a list of seven terms in official documents being prepared for the 2019 budget. These include ‘transgender’, ‘foetus’ and ‘evidence-based’.

Language shapes our map of the world. If 'transgender' ceases to exist as a term in official government documents, we, too, begin to vanish. It is easier for a cisgender administrator, who we might hope to have as an ally, to forget about our concerns when the government mandates that we be forgotten ourselves.

- Gabrielle Bellot, writer and transwoman from New York

In early 2018, the Department of Health and Human Services issued a proposed rule that would enable healthcare providers and insurers the right to refuse to provide services to people on moral or
religious grounds. A recent study found the passage of religious refusal laws to be associated with a 46% increase in the proportion of LGBT people reporting mental distress.132

As of June 2018, 37 states no longer prohibited health insurance discrimination based on sexual orientation and gender identity, meaning that uninsured LGBT people may struggle to afford healthcare.133

Young people also have lower rates of health insurance than older individuals, and adolescents under 18 years face regulatory, insurance, and confidentiality challenges to accessing HIV services. For example, in many states, prescribing PrEP to adolescents in the absence of parental or guardian consent is not allowed.134

Funding for the HIV response in the USA

Funding for the HIV response has increased significantly over the course of the epidemic. Primarily, this growth has been driven by increased spending on mandatory domestic care and treatment programmes, as more people are living with HIV in the USA, as well as by greater investments to combat HIV in low and middle-income countries.135

The USA’s domestic HIV budget includes funding for HIV care, housing support, HIV prevention and research.136 In May 2017, President Trump released his first federal budget request for the 2018 financial year, which included an estimated US $32 billion for combined domestic and global HIV efforts. The proposal signalled a decrease in funding for HIV of US $834 million, or 2.5%. Most of the cuts were made to the USA’s global spending for the HIV response (a US $1.2 billion or 18% decline). Domestic discretionary programmes faced a US $789 million or 10% reduction, although mandatory funding was set to increase.137 The budget was rejected by Congress and spending remained at levels similar to the 2017 financial year.138

President Trump’s proposed budget for the 2019 financial year, submitted in February 2018, again suggested spending cuts. This includes cutting US $40 million from CDC’s HIV prevention programme, and US $26 million from a federal housing programme for people living with AIDS. It also includes cutting global HIV programmes by US $1 billion.139 However, this was rejected by Congress.140

In 2019, the US government changed its strategy. President Trump’s proposed 2020 budget requested nearly US $300 million, an increase on 2019 levels.141 However, the budget also contains a 12% reduction in total funding to the Department of Health and Human Services (HHS).142 This includes a US $63 million cut to the Housing Opportunities for Persons with AIDS programme, and a US $27 million cut to the Supportive Housing Programme for Persons with Disabilities. It also included cuts to international funding including US $1.35 billion in cuts to the President’s Emergency Plan for AIDS Relief and US $392 million in cuts to the Global Fund to Fight AIDS, Tuberculosis and Malaria.143

The future of HIV in the USA

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.

- The US National HIV/AIDS Strategy’s mission statement

In order to break the cycle of transmission among key affected populations, increasing the impact of targeted HIV prevention and treatment campaigns towards people in these groups is vital. Expanding access and uptake to HIV testing, and increasing the number of people who are aware of their status and who are using condoms, will also go a long way to controlling the epidemic in the USA.

However, unless the complex set of economic and socio-economic factors that drive these group’s risks to HIV are addressed – including discrimination, stigma and poverty – it is likely that HIV will continue to disproportionately affect men who have sex with men, African Americans/black people, Latino/Hispanic men, transgender women, prisoners and people who use drugs.

In addition, the rollback of certain LGBTI rights and inadequate sex education may support HIV-related stigma, already so damaging to America’s HIV response, grow and thrive.

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