HIVAC

Maine HIV/AIDS Advisory Committee
- 2019 Annual Report -

Background

Maine's HIV/AIDS Advisory Committee (HIVAC) is commissioned under Maine statute Title 5 §19202. As part of statutorily mandated requirements we are providing the Joint Committee of the Legislature on Health and Human Services with this annual report.

Membership

HIVAC's membership consists of a diverse range of experience within the landscape of HIV/AIDS in Maine and strives to be representative of the community for which it serves. Currently, the Committee includes HIV-positive individuals, medical providers, social service community-based organizations, as well as members of the Maine Legislature, Maine's Center for Disease Control and Prevention (CDC), Department of Corrections, The Office of MaineCare Services, and Department of Education.

Mission & Function

The core functions of the committee, in accordance with Maine statute Title 5 §19202 continue to be focused on advising the legislature, state agencies and departments as follows:

- A. Advise the Office of the Governor and state, federal and private sector agencies, officials and committees on HIV-related and AIDS-related policy, planning, budget or rules; [2009, c. 203, §2 (NEW); 2009, c. 203, §8 (AFF).]
- B. Make an annual assessment of emerging HIV-related issues and trends; [2009, c. 203, §2 (NEW); 2009, c. 203, §8 (AFF).]
- C. Initiate and respond to legislation, both state and federal; and [2009, c. 203, §2 (NEW); 2009, c. 203, §8 (AFF).]
- D. Prepare and present, in person, an annual report on the status of HIV in the State to the Office of the Governor and the joint standing committee of the Legislature having jurisdiction over health and human services matters by March 1st of each year. [2013, c. 108, §1 (AMD).]

2019 Report

HIVAC's 2019 Report to the Joint Committee of the Legislature on Health and Human Services seeks to provide more personal and direct experiences among persons impacted by HIV/AIDS. In fulfilling this goal, HIVAC conducted interviews in 2019. Direct quotes throughout this report originate from HIV-positive long-term survivors and medical providers from across the state. It is our hope that these experiences offer a unique perspective and valuable resource, which contribute to furthering education, improving service delivery, and reducing stigma. These efforts lead to reducing new HIV infections and improved quality of life among people living with HIV/AIDS (PLWHA) in Maine.

These important voices will also reveal the most current concerns around policy, service delivery, and community, and will focus on concrete steps being taken by the Committee to address barriers to care.

HISTORY AND THE NATIONAL HIV/AIDS STRATEGY UPDATED TO 2020

Resulting from more than three decades of grass-roots HIV/AIDS and healthcare advocacy, federal programs and medical advancements have allowed for the development of comprehensive and integrated services that support improved health outcomes for people living with and at risk for HIV/AIDS, and serve as a model for quality healthcare in the United States. These include, The Ryan White Care Act, Housing Opportunities for Persons with HIV/AIDS (HOPWA) through the US Department of Housing and Urban Development, and The Affordable Care Act.

Developed in 2010 and updated in 2015, The National HIV/AIDS Strategy provides a roadmap in the fight against HIV, and focuses on strategic goals aimed at reducing new infections, increasing access to care and improving health outcomes among PLWHA, addressing HIV-related health disparities, and achieving a more coordinated national response to the HIV/AIDS epidemic.

While these programs and resources have enhanced the health and well-being of PLWHA, more work is needed to address significant gaps in care. The uncertain future of the Affordable Care Act, inequality and discrimination toward the LGBTQ community, and harmful immigration policy all pose a threat to continued progress toward the end of the HIV/AIDS epidemic.

> *"I think sometimes for individuals, HIV isn't their only issue and people have other co-occurring issues such as mental illness and substance abuse and those two are tremendous issues that don't have easy solutions. We do not have good services for the mentally ill or for those who suffer from substance use disorders. Each one of these alone makes it difficult for individuals to adhere to HIV medications. And together can present serious adherence issues. Homelessness, poverty, housing instability are also very significant barriers to finding and or maintaining care."*

MAINE RESOURCES AND THE STATE'S ROLE IN THE NATIONAL STRATEGY

Direct Services

An estimated 1,800 people are living with HIV/AIDS in Maine. People in Maine living with HIV/AIDS may access insurance coverage through Maine's Medicaid program. The State's 1115 Special Benefit Waiver increases this access to 250% FPL, and the administration of The Ryan White HIV/AIDS Program provides private insurance and medication coverage for people ineligible for MaineCare due to immigration status and/or income up to 500% FPL. While this Committee recognizes the impact of Maine's 2019 implementation of Medicaid Expansion, that policy did not significantly increase access for Mainers living with HIV because of the existing 1115 waiver mentioned above. The AIDS Drug Assistance Program, a provision of The Ryan White HIV/AIDS Program, also provides financial assistance for housing, heating, food, medication co-pays, and dental services. Case Management through Ryan White Part B also assists with transportation to and from medical appointments. Ryan White B services, administered by Maine's Department of Health and Human Services, and Section 13 of MaineCare provide support for comprehensive case management services for PLWHA delivered by clinical and community-based organizations throughout the state.

> *"The success of HIV treatment and containment is dependent on patient centered care. The system these days does not allow the primary care doctors to really address all the needs of chronic illness. There are a lot of opportunities to fail in our current approach to care."*

People in Maine living with HIV/AIDS may also be eligible for housing assistance through Maine's three HOPWA grants from the US Dept. of Housing and Urban Development (HUD). This assistance comes in the form of short-term rent, mortgage and utility assistance, assistance with security deposits, transportation to and from medical appointments, case management, and a housing subsidy program similar to Section 8. These federal funds are administered by Maine's Frannie Peabody Center and coordinated by HIV case managers throughout the state.

Program	Number of Mainers enrolled calendar year 2019
Ryan White Part B Program	1113
MaineCare 1115 Waiver	511
HOPWA Subsidy	94
HOPWA Subsidy Waitlist	105

Prevention Services

The Maine CDC contracts with community-based and clinical providers throughout the state to provide free, confidential HIV and Hepatitis C counseling, testing, and referral (CTR) services. These low-barrier services are critical to meeting high-risk populations where they are, and effectively linking people to the care necessary for achieving and sustaining health. While the primary purpose of these CTR services is to diagnose and link people to HIV and Hep C care, it is important to note that testing clients are also screened for need and appropriately referred in the areas of social services and insurance enrollment, and are counseled in a variety of risk-reduction strategies.

> *"There's an arc to care. You know, first you need to get tested. You then need to grapple with the results. You then need to, either have people around, find people to surround you and give you the strength you need in order to find care. Or even, find the door to [an HIV case management program], which will then get you integrated into the actual care you need to survive. And then, once that happens, there's a lot of responsibilities that fall on the individual. Retention to care. All that can be achieved; you can get to that point."*

The provision of disease intervention services ensures people who are diagnosed with HIV and/or Hepatitis C are linked to care, and provides anonymous partner notification. These services are also a key piece of monitoring the spread of HIV and Hepatitis C within the state.

Community-based HIV outreach and education services are provided by CDC-funded agencies, in coordination with the Department of Education and family planning clinics throughout the state. These efforts are widespread and target populations disproportionaely affected by HIV/AIDS including, but not limited to, homeless youth, people struggling with drug misuse, racial minorities, and LGBTQ populations. Activities take place at schools, shelters, recovery centers, and community venues.

> *"I do, however, think that the number of people infected is going to continue to rise. I think that's mainly because of this lack of knowledge and education. And a lot of people just think, oh it's just this population or that population and so I don't need to worry."*

COMMUNITY CONCERNS

Stigma

Stigma remains one of the most significant barriers to care and risk factors for HIV/AIDS. It manifests and infiltrates communities, cultures, family structures and support systems, fuels discrimination and isolation, halts awareness and acts as one of the most harmful agents in the fight against HIV/AIDS both nationally and globally.

> *"When we don't talk about HIV, and we assume everybody's got what they need, and we allow these assumptions to fill the voids of ignorance,what happens is we don't see it for what it is. If we don't solve stigma issues; if we don't start talking about this. When and if that day ever comes, we're gonna be so ill-equipped to deal with it. It creates a real issue moving forward."*

Drug Misuse and Risk-Reduction Services

As the Opioid Epidemic and drug misuse rages in the United States and particularly in Maine, increased awareness, and recovery and risk-reduction services are critical to supporting sustained health with HIV, and preventing future infections. Expanded resources are needed to build on the efforts of the Maine Harm Reduction Alliance and Opioid Task Forces in implementing critical strategies such as Medication Assisted Therapy (MAT), syringe exchange programs (SEP), and Naloxone.

Drug misuse can be both a risk factor for HIV infection and a side-effect of living with HIV/AIDS. When resources and linkage to care are not adequately available, HIV infection rates increase.

> *"I could get on my phone right now; it's easy in Augusta. Right now, here in Portland, I know I could get on my phone and in a matter of fifteen minutes I could find somebody who has crystal meth."*

Rural Healthcare

As a rural state, medical care is already scarce in many regions. Maine has lower HIV-infection rates as compared to others states in the country, exacerbating the challenges associated with accessing care in rural areas, especially when coupled with HIV-related stigma. Both direct and prevention services become more limited, increasing the risk of HIV being undiagnosed and untreated. As federal funding for critical services shifts to regions of the country most affected by HIV/AIDS, the limited capacity of organizations to reach populations at risk poses a threat to minimizing the spread of HIV. Additionally, a lack of social support resources throughout the state further contributes to stigma and isolation.

> *"When we can have our gathering to encourage people to first come out [as HIV-positive]; they're just finding out they got diagnosed. We go around the room, and we'll say, 'who has been positive for at least five years?' And people will stand up. And then you get to the—like, I'm one of the last ones to stand up. So, there's guilt there, but it helps people when you say thirty-five years."*

Housing Instability

According to the National AIDS Housing Coalition, housing stability is one of the strongest contributors to medication adherence and subsequent viral load suppression, significantly reduces avoidable emergency and acute healthcare, and reduces mortality among PLWHA.

HOPWA assistance is accessible to those living with HIV/AIDS in Maine, but HUD restrictions, the rising cost of living, and low-vacancy rates in areas surrounding healthcare and social service settings make it more difficult to obtain and maintain stable housing.

Over the past year, clients experienced a growing number of financial requirements from landlords including, first and last months' rent, security deposit, background and credit checks. Many clients stably housed on Maine's HOPWA subsidy program face eviction because landlords and management companies make upgrades to units that are then priced above HOPWA subsidy guidelines. As clients move farther from medical and social service centers, transportation assistance may be accessed to and from medical appointments, but limited options are available for transportation to employment and education opportunities.

In September of 2019, HUD fair market rental rates dropped in areas outside of Greater Portland, forcing housing stability even further out of reach. Currently, approximately 94 Mainers living with HIV/AIDS access the states HOPWA subsidy program, and about 105 are on the waitlist. Many people who obtain HOPWA subsidy notifications are unable to find a housing unit within the required 120 days.

Access to Medication

The aformentioned ADAP within the state's Ryan White services provides support for medication access, but policy implemented by private health insurers may limit that access as HIV medication costs remain incredibly high.

> *"The insurance company spent between $45,000 and $50,000 just for my medication. That was not any other care, that was just for the medication for me to stay alive. And that was only two different pills."*

The emergence of private insurance mandated mail-order pharmacies have had devastating effects on access and adherence to HIV medications, particularly for people who are chronically housing unstable and/or experience severe stigma.

> *"We had clients whose medications ended up buried in snowbanks, and individuals forced to receive medication mailed to a building without a secure mailbox. Or in the case that someone lives with a roommate or family member and fears their status will be revealed when a package is opened. These are real experiences that, when faced with that decision, people may rather stop filling prescriptions than risk their status be disclosed. It can be the difference between life and death. All because the insurance company can save money on those meds by using a pharmacy benefit manager."*

Emerging Policy Within MaineCare

Maine's implementation of the Opioid and Behavioral Health Home programs offered an opportunity for increased access to comprehensive services, but are considered duplicative of HIV case managment services

under section 13 of MaineCare by the [Federal] Centers for Medicare and Medicaid Services (CMS). Community-based and clinical providers work diligently to maximize resources and work collaboratively to serve those in need and prevent duplication of services. Isolating eligibility to these services significantly reduces agencies' capacity to serve clients and/or forces PLWHA to choose between programs that may be equally critical to their sustained health.

ADDRESSING GAPS IN CARE AND HIVAC'S 2020 OUTLOOK

With a diverse membership and audience reach, HIVAC is prioritizing unified and comprehensive messaging to increase HIV awareness, fight stigma, and promote quality care. Collaboration between providers, advocates, businesses, lawmakers and community members is critical to furthering Maine's role in turning the tide of HIV/AIDS. Among these strategic areas of focus is "Undetectable Equals Untransmittable" or U=U. This important label is widely accepted by national HIV advocacy organizations, Centers for Disease Control and Prevention, The National Institute of Health, and public health agencies. It also serves as a clear and succinct tool in educating the public on viral load suppression and treatment as prevention. As we look toward 2020, HIVAC will serve as a leader in the effort to coordinate this messaging across key statewide agencies.

Additionally, expanded access and understanding of pre-exposure prophylaxis, or PrEP, is a crucial component of HIV prevention. PrEP reduces the risk of HIV infection through sexual transmission by about 99% when taken daily. Among those who inject drugs, daily PrEP reduces the risk of becoming infected with HIV by at least 74%. Truvada, an HIV treatment medication, was approved by the FDA in 2012 as an effective preventative intervention, and Descovy received similar approval in 2019. Much work is needed to educate providers and the public on the proper use and accessibility of these medications as well as advocating for expanded access, so individuals feel supported in making informed decisions regarding the prevention strategy that is best for them.

HIVAC is also working collaboratively with legislators to address gaps in care, especially in the areas of medication access, risk reduction and MaineCare policy. The recent passage of comprehensive prescription drug reform may significantly impact the future of HIV medication access, and place Maine at the forefront of the addressing the urgency of medication affordability.

As HIV-related stigma and isolation continue to raise challenges and barriers to care, HIVAC has made it a priority to advocate and coordinate opportunities for PLWHA to build supportive networks which contribute to a sense of community and positive health outcomes.

Recommendations for the Legislature

Among other things the HIV Advisory Committee exists in statute to "Advise the Office of the Governor and State, federal, and private sector agencies, officials, and committees on HIV-related and AIDS-related policy, planning, budgets, or rules."

Based on the above report the Committee recommends the following in order to meaningfully move Maine towards the dream of ending HIV. This includes recommendations to prevent the continued spread of the virus, enhancing care for people living with HIV, and addressing HIV stigma.

HIV Prevention:

- Establish standardized and inclusive sexual health education curricula to be implemented throughout all Maine public middle and high schools.
- Increase public funding for community-based outreach and HIV testing services to restore Maine's

network of HIV prevention services.
- Intentionally address gaps in the network of HIV prevention services throughout Maine through support for establishing infrastructure and capacity building.

Care for People Living with HIV and HIV Stigma:

- Support continuing medical education on HIV for medical providers throughout Maine, including an emphasis on aging with HIV.
- Support regular conferences/gatherings for people living with HIV to congregate in a safe, affirming, and educational environment.
- Embrace and support the U=U (undetectable equals unstransmissable) campaign and encourage the adoption and amplification of the campaign among medical providers, hospitals, health care networks, and public health providers throughout Maine.

Laying the Foundation for the Future:

- Support the strengthening of the HIV Advisory Committee, including the appointment of a publicly funded 'Coordinator' role to support HIVAC efforts and initiatives.
- Support the development of a 'Plan to End HIV', engaging stakeholders throughout Maine, including people living with HIV and those communities most impacted by HIV, to the pursuit and allocation of funds, the development of programs and services, and other state-level initiatives moving forwards.

CONCLUSION

The historical progress and current efforts are not possible without the dedication and collaborative commitment between PLWHA, medical and social service providers, state and local agencies, advocates, and a compassionate community. We must remain steadfast and committed to address ongoing challenges; ensuring PLWHA can maintain health stability, well-being, and prevent future infections. This can only be acheived when we have quality care systems in place and have opportunities to foster supportive connections within the PLWHA community.

> *"I'm hoping, after the last eight years, that there's going to be improvement. I'm hoping that there's going to be fast-tracking people to make sure that they're being taken care of. That there is hopefully a Winter Gathering [for PLWHA], or something to that effect. It is important. People came when it was possible. They listened and related to others and found support. I think it gives them hope. If people don't have hope, they slide into that spot, that you might not be able to get them back from."*

All data featured below originates from Maine Center for Disease Control and Prevention's 2018 HIV Surveillance Report

HIV

Maine Surveillance Report | 2018

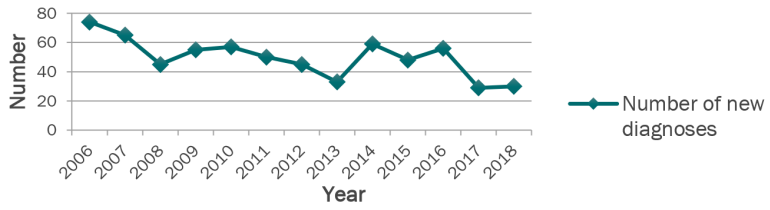
Case Information:

30
Patients diagnosed with HIV

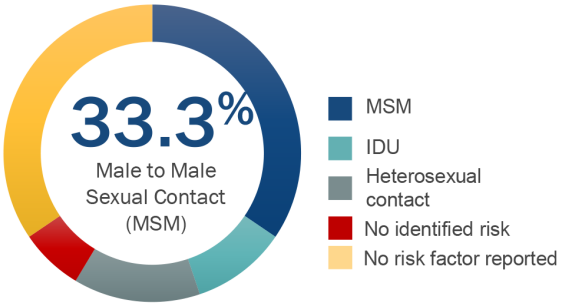
2.2
Cases per 100,000 people

3.4%
increase since 2017

Number of New Diagnoses



Transmission Category:



10%
Reported adult injection drug use (IDU)

37%
Reported no risk factor reported

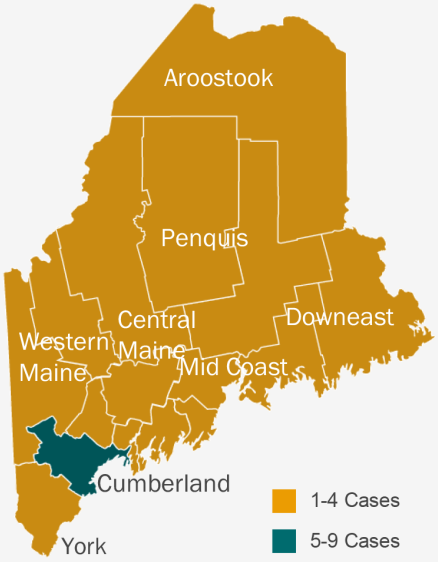
Prevention:

- Proper condom use
- PrEP for those at risk
- Treatment for those who are HIV positive/maintaining viral suppression
- Regular HIV testing by providers
- Clean injecting equipment

Demographics:

77% of new cases were male
37% ages 24-34
70% Not Hispanic, White
17% Not Hispanic, Black

Geography (Public Health District):



For more information visit:

http://www.maine.gov/dhhs/mecdc/infectious-disease/hiv-std/data/hiv.shtml

https://www.cdc.gov/hiv/default.html

https://www.cdc.gov/hiv/basics/prep.html

https://www.maine.gov/dhhs/mecdc/infectious-disease/hiv-std/services/hiv-testing-sites.shtml

People Living with HIV in Maine:

1,724

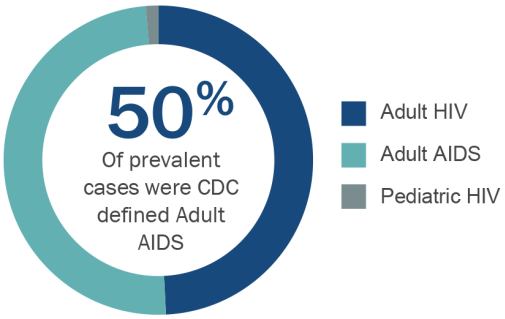
Estimated number of people living with HIV in Maine

128.8

Cases per 100,000 people

Age	# Cases	% Cases
<20	24	1.38
20-24	19	1.10
25-29	52	3.02
30-34	79	4.58
35-39	140	8.12
40-44	149	8.64
45-49	194	11.25
50-54	307	17.81
55-59	304	17.63
60-64	222	12.88
>= 65	234	13.57

Diagnostic Status:



Characteristics of People Living with HIV (PLWH) in Maine:

21%

of PLWH in Maine were diagnosed with AIDS simultaneously

75%

of PLWH in Maine were born in the United States

55%

of PLWH in Maine identified as men who have sex with men (MSM)

Understanding HIV:

- HIV health care providers help patients determine which HIV medications are best for their individual needs (ARTs).
- PLWH who take their medication as prescribed can reduce the amount of HIV in their body (viral load), keeping them healthy.
- People with undetectable viral loads are not able to transmit their HIV to another person through sex or syringe sharing (treatment as prevention).
- If you or someone you know is concerned that they may have been in contact with HIV, get tested. Everyone between the ages of 13-64 should be tested at least once in their lifetime, and if you are at higher-risk as your doctor to be tested.

For more information visit:

https://www.maine.gov/dhhs/mecdc/infectious-disease/hiv-std/services/hiv-testing-sites.shtml

https://www.cdc.gov/hiv/basics/livingwithhiv/index.html

https://www.cdc.gov/hiv/basics/livingwithhiv/treatment.html

https://www.cdc.gov/hiv/basics/livingwithhiv/understanding-care.html