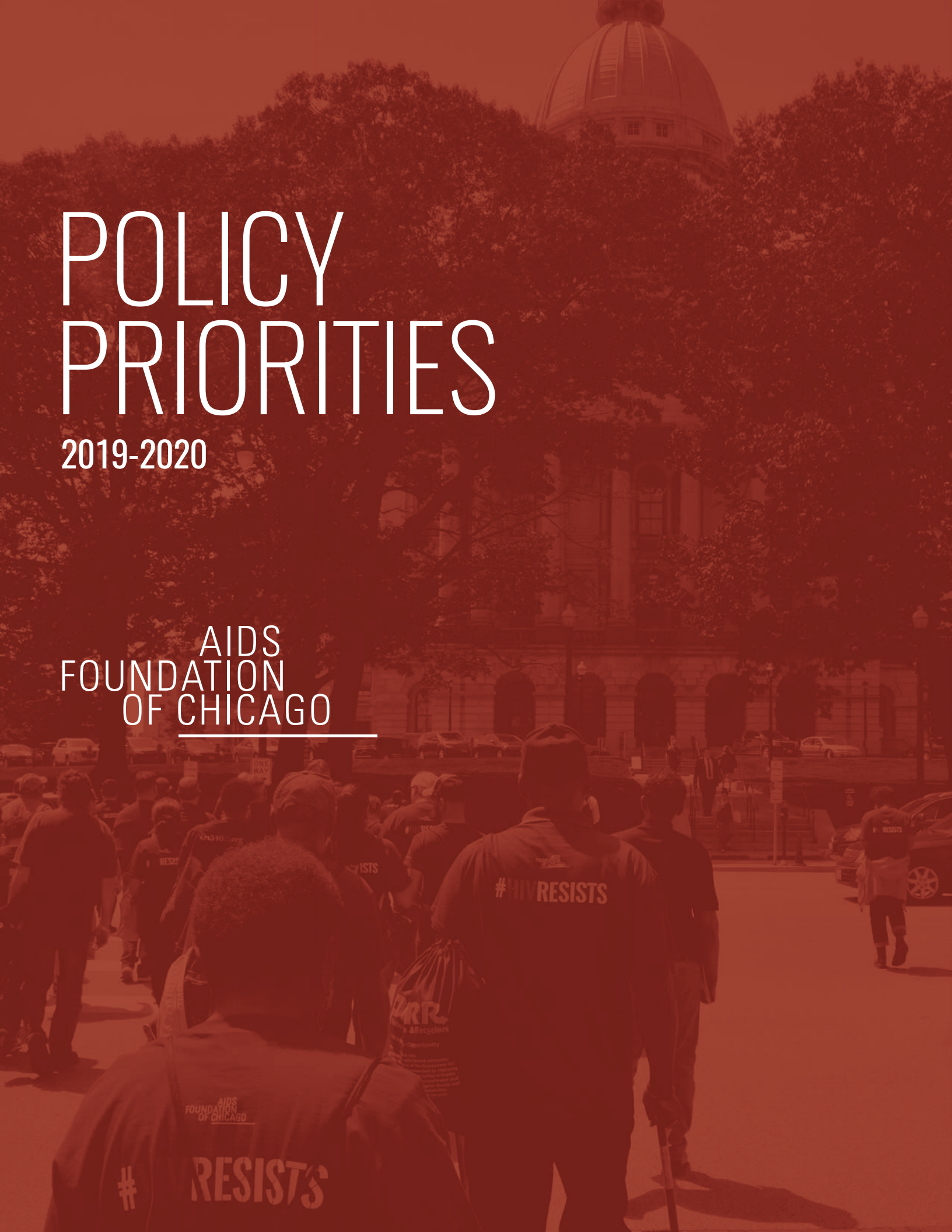


POLICY PRIORITIES

2019-2020

AIDS
FOUNDATION
OF CHICAGO



A time of transition for state and national HIV and AIDS efforts

The year 2019 ushers in a new paradigm in both Illinois and at the national level. With the election of Governor J.B. Pritzker, Illinois is once again one-party, Democratic-controlled at the state government level. Though U.S. President Donald Trump (R) remains the head of the federal executive branch, the Congressional chambers have become divided with the Democratic party gaining control of the House of Representatives and the Republican Party retaining control of the Senate.

In the midst of these changes, the AIDS Foundation of Chicago (AFC) remains committed to continuing, creating and advocating for sound HIV, health care and housing policy.

How we developed the 2019-20 Policy Priorities

During the summer and fall of 2018, AFC staff created and disseminated a community engagement survey to gather input from community members throughout the state on various policy initiatives. AFC received over 50 responses from all over Illinois via our community survey and in community meetings held throughout the state. AFC compiled these results to identify the most crucial items. With limited resources, we cannot address every issue, but we believe this document represents a comprehensive agenda for improving HIV health outcomes. AFC is grateful for the input from all participants. We also note AFC will work on issues that are not identified in this agenda if unforeseen opportunities emerge to impact the HIV epidemic.

AFC's policy priorities are a reflection of our mission and the needs of people impacted by or living with HIV. These policy and legislative recommendations identify needed change in areas where there continue to be proven unmet needs, specifically the HIV continuum of care and to meet the goal of achieving zero new HIV

transmissions in Illinois by 2030. AFC puts forth the following recommendations in these areas:

Getting to Zero Illinois

HIV and STI prevention services

Improve access to health care

Federal-level priorities

State budget priorities

Links to HIV/AIDS care

Remove structural barriers to equity

HIV/AIDS by the numbers

Of new HIV cases in Illinois, nearly 70% are within the African American and Latinx community, 30% are among young people aged 20-29, and 1 in 2 young gay Black men will become HIV-positive by age 40 if trends continue¹. Women of color, people who use drugs and people who live in poverty remain disproportionately impacted by HIV. Structural barriers such as poverty, incarceration, homophobia and unemployment continue to impact vulnerable populations and interrupt the work needed to reduce HIV infections and reach viral load suppression for those living with HIV.

In 2017, it is estimated that 44,842 people (accounting for those undiagnosed) were living with HIV in Illinois, 23,835 of whom lived in the City of Chicago². Of these individuals, fewer than two-thirds were engaged in care during the previous 12 months, and fewer than half were virally suppressed. Among people living with HIV in 2017, a majority were male, Black and over 40.

The Undetectable = Untransmittable (U=U) campaign is accepted science; people with HIV who achieve viral suppression cannot sexually transmit the virus to others. The campaign has been rapidly gathering momentum, having been endorsed by more than 400 organizations from 60 different countries since its launch, including the Illinois and Chicago Departments of Public Health. In 2017, the U.S. Centers for Disease Control and Prevention (CDC) joined the movement by endorsing the science. AFC is committed to the goal of increasing viral suppression to achieve the goals in the Getting to Zero Illinois plan.

Also in 2017, it is estimated that 1,375 people were diagnosed with HIV in Illinois, 752 of whom lived in the City of Chicago³. Of these individuals, more than 80% of newly diagnosed people were linked to HIV-related medical care within 30 days of diagnosis. Among newly diagnosed persons, the majority were male, Black and between the ages of 20-39. Despite significant progress in reducing new HIV cases, dramatic and damaging health disparities remain. Gay, bisexual, and other men who have sex with men (MSM) comprised a majority of people living with HIV in 2017 and newly diagnosed people. Black men comprise a majority of new diagnoses in this population. Among heterosexual women, Black women account for more than 73% of HIV cases⁴ and new infections. Among gay, bisexual, and other MSM, new diagnoses have remained steady while rates in other populations have declined. Coinfection with other sexually transmitted infections are also on the rise. A majority of primary and secondary syphilis cases diagnosed in 2017 were among men — most of whom reported being gay, bisexual and other MSM. Of these men, nearly half were co-infected with HIV.

1 GTZ-IL Draft Plan (n.d.). Retrieved from <https://gtzillinois.hiv/>

2 Ibid.

3 Ibid.

4 Ibid.

Getting to Zero Illinois

In July 2016, a small group of HIV stakeholders met to explore what it would take to radically change the course of the epidemic in Illinois. This group released a framework in 2017 that outlines a path toward a day when there are no new HIV transmissions in Illinois. Through extensive statewide collaboration, the Getting to Zero Illinois plan was released in draft form in December 2018; the final plan will be available in the spring of 2019.

To achieve the goal of ending the HIV epidemic in Illinois by 2030, we must transition our system to one that more effectively serves the entire population of people living with HIV and all who are vulnerable to contracting HIV. We must use strategies that lead to the most effective outcomes possible – specifically HIV treatment and pre-exposure prophylaxis (PrEP) both of which must increase in usage by 20 percentage points in order to achieve “functional zero” by 2030.

Getting to Zero Illinois is prioritized throughout AFC’s Policy Priorities.

State Budget Priorities

AFC calls on Illinois to protect and increase existing funding for HIV prevention and care services and to fully invest state resources into the GTZ-IL plan. After years without a state budget in place and former Gov. Bruce Rauner administration’s failure to prioritize HIV services in proposed budgets, the HIV care sector is in dire need of sustainable, reliable funding from the state. AFC calls on the state to increase funding of the HIV Lump Sum, the state’s main HIV funding account, by \$1 million to \$26.4 million and the Minority HIV service line by \$1 million to \$2.2 million in service of the GTZ-IL plan.



Additionally, to achieve functional zero by 2030, Illinois must meaningfully and fully invest its resources in viral load suppression among those with HIV and increased PrEP uptake among those vulnerable to HIV. Fully investing in prevention and treatment will result in fewer new HIV transmissions and

decrease health care costs for the state. Every new case of HIV costs over \$466,000 in lifetime medical care, and most of that will be paid by the state⁵.

⁵ HIV Cost-effectiveness (2015, September 23). Retrieved from <http://www.cdc.gov/programresources/guidance/costeffectiveness/index.html>

AFC strongly supports funding programs aimed at HIV prevention, treatment, and services in populations most strongly affected by HIV, including Black and Latinx gay/bisexual men, transgender women of color, and Black women living in high-incidence areas. Funding in this area will be crucial in the fight to get to zero by 2030.

AFC supports the creation of dedicated state funding to combat sexually transmitted infections (STIs). STIs other than HIV cause serious and long-term health consequences for individuals and increase likelihood of infection with HIV. STIs continue to plague Illinoisans, and the state should begin a robust effort to invest in combatting their transmission and treating those affected by STIs.

AFC supports an Illinois constitutional amendment to create a fair tax structure in Illinois. Illinois' constitution mandates that every Illinoisan pay the same percentage of their income in taxes, no matter how much they earn. This is called a "flat tax" and is extremely harmful to low-income people. Illinois is one of a handful of states that have a flat income tax. Moving to a fair tax (the way federal and most other state income taxes are managed) would alleviate fiscal strain on those with lower incomes. A constitutional amendment is needed to implement this change.

Strengthen Links to HIV/AIDS Care and Retention in Illinois

Improving the health of people living with HIV and reducing the number of new infections in Illinois will require increased access to HIV medical care and the elimination of barriers that impact the ability of individuals to remain in care. To advance these goals, AFC supports the following initiatives:

AFC supports state funding to increase access to prevention services including PrEP. HIV awareness relies on community-based testing, routine HIV screening in health care settings and navigators to connect people who want to take PrEP or who are HIV-positive to culturally-competent health care providers. The state maintains a website (PrEP4Illinois.com) to educate people about PrEP, and limited funding is available to assist individuals to afford PrEP. The power of PrEP creates the opportunity for convergence of the HIV prevention and care systems. As importantly, HIV treatment improves the health of individuals who are living with HIV and almost completely protects partners from HIV.

AFC supports legislation that clarifies existing law to make clear adolescents can access PrEP without parental approval. The U.S. Food and Drug Administration in 2018 approved PrEP for adolescents.⁶ AFC will work to make sure that all Illinoisans 12 or

⁶HIV/AIDS. (2018, November 01). Retrieved from <http://www.cdc.gov/hiv/risk/prep/index.html>

older for whom this treatment is appropriate are able to access these treatments without parental approval. This will ensure youth are able to access life-saving preventive services in consultation with their health care provider.

AFC supports efforts to increase access to housing for people with HIV and chronic conditions. The first step to improved health is a roof over one's head, particularly for people who are homeless. Stable housing allows people living with HIV, chronic conditions, and behavioral health needs to access comprehensive health care and address their medical needs. AFC supports increased funding for housing in state and federal budgets and will fight for continued funding of supportive housing, rental subsidies, and other housing programs. AFC will work with supportive housing and behavioral health advocates in implementing Illinois' 1115 waiver to secure Medicaid funding for housing services, including case management provided to housing program participants, and promote flexibility for Medicaid managed care plans to invest in housing for their members.

AFC will focus attention on HIV care outcomes in Medicaid and private insurance. AFC will support policy changes that will require Medicaid health plans and private insurance to report on the quality of HIV care provided by collecting data from health plans on HIV viral load suppression. In 2017 there were 23,748 people living with HIV/AIDS who were enrolled in Medicaid, making it the largest provider of health care for the HIV community in Illinois.⁷ If Medicaid monitored the viral loads of these enrollees, Illinois could begin to better engage those who are not virally suppressed into care, which would move Illinois closer to the goals outlined in the Getting to Zero Illinois plan.

Improving Access to Health Care for All Illinoisans

In the 2019-20 legislative session, AFC will continue to focus on prevention, engagement and care for key affected populations in the epidemic, such as men of color who are gay or MSM, women of color, transgender women, people living with mental illness and substance use and justice-involved individuals.

AFC will oppose any cuts to the Medicaid program. Medicaid is an essential source of health care coverage for people living with HIV in Illinois. Medicaid has become the number one provider of health care for people living with HIV here since the expansion of Medicaid by the legislature in 2013. As an organization that cares deeply about health care access for vulnerable populations, particularly those living with HIV, AFC believes that Illinois must ensure efficient and effective operation of the Medicaid program with renewed robust investment in the program.

AFC will protect Medicaid and the health insurance Marketplace from harmful federal cuts. Through the Protect Our Care Illinois (POC-IL) coalition, AFC has fought myriad proposals coming out of Washington that sought to dismantle the Affordable Care Act (ACA), also known as Obamacare, remove protections for those with preexisting conditions, and decrease protections that ensure that an insurance plan must meet certain standards. AFC and POC-IL will continue to push back against any policy proposals from the federal government that impair and diminish health care benefits and protections in the Medicaid program and the private insurance marketplace.

⁷ Illinois HFS, FOIA request received by AFC June 2019.

AFC opposes federal rules that would allow for Association Health Plans to be created without clear and defined association sponsors existing and without state regulation.

AFC urges the Illinois Department of Insurance (DOI) to move swiftly to implement the 2018 state law that regulates short-term, limited duration health plans, provides warnings to consumers on what exactly the coverage purchased includes, and limits plans to 6 months (P.A. 100-1118).

AFC supports proposals that would stabilize the individual health insurance market. Rising health care costs, especially health insurance premiums, continue to be a concern for consumers.

AFC believes Illinois should consider a Marketplace reinsurance program in Illinois; research and state experience shows reinsurance brings down premiums for consumers.

The state should also explore a state-based individual mandate that would bring more people into the Marketplace by requiring that people who can afford coverage will obtain coverage.

AFC supports a Medicaid Buy-In program to bring down consumer costs and move towards a system of universal health care. Allowing higher income Illinoisans to enroll in Medicaid through a buy-in program provides the opportunity to control insurance costs, stabilize health insurance markets and provide consumers with more coverage options.

The ACA mandates that plans sold on the insurance marketplace must include essential health benefits (EHB), a set of 10 categories of services like prescription drugs and hospital care. If anything were to change at the federal level, Illinois does not have protections in place to keep EHBs. AFC believes Illinois should consider codifying them in Illinois state statute.

The medical loss ratio (MLR) is the percent of the premium dollar that health insurers spend on medical care and quality improvement activities as opposed to overhead costs. AFC advocates that Illinois should establish its own minimum MLR ensuring that more money is spent on care and less on insurance company profits and overhead.

AFC will protect Illinoisans living with pre-existing conditions. The Trump administration is allowing enormous “state flexibility” on the consumer protections provided by the ACA. Illinois has an opportunity to strengthen its own state laws on key ACA protections. While Illinois has a law that protects people with pre-existing conditions, the state does NOT have community rating (which prevents health insurers from varying premiums within a geographic area based on age, gender, health status or other factors) or guaranteed issue (a requirement that health plans must permit an individual to enroll regardless of health status, age, gender, or other factors). Right now, those are protected under the federal ACA; however, the state should explore how to strengthen those guardrails for Illinois health care consumers.

AFC calls on Illinois to modernize the Medicaid eligibility and renewal/redetermination process. In 2012, Illinois implemented legislation that aimed to remove ineligible people from the Medicaid rolls. In the process, the state incorrectly cut off tens of thousands of people who in fact belonged in the program. This Medicaid eligibility redetermination process is inefficient, burdensome and costly. It has resulted in unnecessary and erroneous denials of coverage, causing interruptions in life-saving treatment and forcing community-based organizations such as AFC to research, advocate for, and rectify these mistakes in Medicaid’s client eligibility

status. AFC supports efforts to overhaul the eligibility redetermination process to dramatically reduce the number of people whose eligibility is incorrectly terminated.

AFC calls on the state to provide access for transgender services for Illinoisans through Medicaid. AFC applauds the Pritzker administration for taking the critical first step of announcing upcoming changes to IL's Medicaid rules regarding coverage of transgender services. AFC calls on the state to ensure full access to comprehensive, gender-affirming services when the Medicaid rule changes are finalized. Illinois must allow access to all medically necessary health care services to allow those experiencing gender dysphoria to live their true gender identity. AFC will continue to work with the state, health plans, and all those involved to ensure that no Illinoisans' health care decisions are discriminated against based on gender identity.

AFC condemns the use of co-pay accumulators that drive up costs of people living with chronic diseases. Some Illinois insurance companies are implementing policies that do not count pharmaceutical manufacturer co-pay cards toward patient deductibles or out-of-pocket maximums. This in effect serves as a double dip from insurance companies and will drive patients away from receiving life-saving medical interventions due to cost. AFC supports legislation that would require insurance companies to promptly notify members when co-pay accumulators are used and limit or ban their use.

AFC supports fully funding mental health and substance-use treatment programs and services. The convergence of HIV, substance use and mental illness are a distinct



barrier to people with HIV accessing services. Research demonstrates that people living with HIV have dramatically elevated rates of mental illness and substance abuse. Thus, AFC will advocate for adequate funding for mental health and substance use services through Medicaid and other state programs.

AFC continues to support HIV testing, prevention and treatment services for

people in prison and jail and re-entering society. Good prison health is essential to good community health. Although incarceration is devastating for individuals and communities, people behind bars have a unique opportunity to receive voluntary HIV testing, learn their status, and be linked to care if needed. Programs such as the HIV Community Reentry Project (of which AFC and many organizations across Illinois are a part) support HIV-positive people returning to the community from prison or jail. The program provides housing, intensive case management, linkage to care and treatment, and other supportive services. AFC will work to maintain or increase funding for this program in all budget proposals.

AFC also supports implementing STI/HIV education and prevention programs in correctional settings, including the distribution of condoms. Adopting such a program will help stop the spread of HIV, hepatitis C, and other STIs from inmates to other inmates.

Removing Structural Barriers to Health Equity in Illinois

Due to social disparities and individual and structural barriers such as poverty, incarceration and unemployment, vulnerable people experience barriers to fully engaging in care. We must aim to reduce health disparities and remove barriers to care for the most vulnerable individuals and populations in our communities.

AFC supports efforts surrounding changes to the HIV criminalization statute in Illinois. The stigmatizing law in Illinois statute that makes it a felony to intend to transmit HIV to a partner, regardless of whether it was actually transmitted, must be addressed by the Illinois legislature, either by full repeal or amendment. No person should live in fear of being prosecuted in Illinois simply for being HIV-positive. AFC is committed to working with community members and partners to determine how this law should be changed.

AFC supports legislation that would fight the public health crisis of gun violence. The similarities in the geographic patterns of new HIV transmissions and gun violence in racially segregated Chicago is astounding. AFC recognizes that gun violence is a public health crisis that requires community-informed, life-affirming action immediately. People living with or vulnerable to HIV are traumatized when friends and family are shot or murdered. Gun violence infuses neighborhoods with fear that deters residents from seeking help for HIV testing, care or other services.

AFC supports modernizing the existing sexual health education laws to be more culturally competent and medically and scientifically accurate as it relates to LGBTQ individuals and HIV prevention, testing, and treatment. Current sex education law is not written to be inclusive to all gender identities or sexual orientations. This alienates LGBT youth, who are most vulnerable to HIV and STIs. Moreover, districts are not required to offer sexual health education classes.

AFC supports legislation that would create more gender-neutral restrooms throughout the state. Transgender Illinoisans face discrimination on many fronts, but among those where the public discourse has become overly incensed is dictating which gendered bathroom people are allowed to use. AFC supports legislation that would single-stall restrooms to be gender-neutral. This would remove one form of transgender discrimination and alleviate stigmatizing mandates.

Federal Issues

AFC continues to be deeply engaged in national HIV and health care policy issues. To achieve this goal, the Policy and Advocacy Department will work with advocates and coalition partners to carry out a positive and aggressive policy, legislative and advocacy agenda. AFC pledges to:

Prevent the repeal of the Affordable Care Act (ACA), block disastrous changes to Medicaid, and protect and expand access to high-quality, affordable health care. We will continue to educate and mobilize AFC's networks of health care advocates, providers, consumers, and workers, joining together to support bipartisan efforts to stabilize the ACA health insurance marketplaces; fight administrative policies or regulations that weaken the ACA; advocate against systemic barriers to care in Medicaid like work requirements and other arbitrary restrictions; work with the federal government to take affirmative steps to enhance access to HIV treatment and medications such as those endorsed in the HIV treatment guidelines, including promotion of biomedical interventions like PrEP; prohibiting high out-of-pocket cost for HIV medications that have no generic equivalent; ban changes to medication coverage and cost after someone has enrolled into an insurance plan; and take decisive action to illuminate and stop any discriminatory practices that will discourage people living with HIV from enrolling into insurance coverage.

Secure increased federal funding for critical HIV prevention, care and housing services. AFC, working alongside local and national partners, will fight for robust funding for HIV prevention, treatment, education and housing programs. We will strengthen the Ryan White HIV/AIDS Program, the Housing Opportunities for People with AIDS (HOPWA) program, Medicare, 340 b Drug Pricing Program and other programs that will advance GTZ-IL and the National HIV/AIDS Strategy. In addition, AFC will push for Congressional budget agreement(s) that lift or repeal the sequestration spending caps in the Budget Control Act, as amended, with parity between spending cap increases for defense and non-defense programs. Further, AFC will oppose any large, disproportionate spending cuts to domestic non-discretionary programs and to health and safety net entitlement programs.

Educate lawmakers on the role the ACA and Ryan White HIV/AIDS Program plays in advancing the goal of Getting to Zero. We support a reauthorization of the Ryan White HIV/AIDS Program, which provides life-saving medical and supportive services for low-income people living with HIV who are uninsured or under-insured. AFC will join with local and national partners to secure a reauthorization of the program that, taken together with health care reform, will help us achieve an AIDS-free generation.



Work in coalition to advocates against the Trump Administration's public charge proposed rule. AFC is strongly opposed to the changes regarding "public charge," published in the Federal Register on Oct. 10, 2018. DHS must protect the health of all people living in the United States and has not explained why the proposed changes are needed. The proposed rule would cause major harm to immigrants and their families, including people living with and vulnerable to HIV, service providers and communities. We urge that the rule be withdrawn in its entirety and that long-standing principles clarified in the 1999 field guidance remain in effect.

Mobilizing the HIV/AIDS Advocacy Community

AFC will seek to educate and engage the HIV community in the 2020 state and federal elections. The 2020 presidential election presents a great opportunity to advance health equity in the U.S., and down-ballot elections at the congressional, state and local levels can make a difference in the lives of Illinoisans. AFC will work to make sure HIV advocates are aware of the issues and make GTZ-IL and HIV issues a part of the campaigns.

AFC will engage people living with and vulnerable to HIV, health care and service providers and advocates in advocacy. People with lived experience – and the providers that help them day in and out – are the best messengers for sound HIV and health care policy. Engaging those individuals to bring the message and agenda directly to policy makers is one way AFC is a bold voice for change.

AFC will continue to utilize text messaging and social media tools to engage our advocates. AFC's text messaging advocacy service allows AFC to directly reach our advocates at times when quick action is needed. AFC will continue to use and expand on this service to make sure advocates are engaged and active. Text "AFC" to 40649 to sign up for our occasional, timely calls to action. Our newest newsletter, The Debrief, offers a monthly recap of state and federal actions and updates that impact the HIV community. Go to aidschicago.com/advocate to sign up to receive The Debrief as well as occasional Online Action Bulletins!

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