

UNPACKING THE PROCESS:

HOW TO ENGAGE IN FEDERAL ADMINISTRATIVE ADVOCACY

The executive branch of the federal government can often be a confusing space for both new and experienced advocates. Both the ways to participate in the regulatory process and the agencies making decisions about the lives of people living with HIV are complicated, making the process hard to navigate.

This fact sheet will provide a primer on what the executive branch and administrative agencies do, what the main agencies and policies affecting the lives of people living with HIV are, and what steps advocates can take to influence executive agency decision making.

BACKGROUND: THE EXECUTIVE BRANCH

What does it do?

The executive branch “executes” the laws: putting what Congress passes into action. This includes enforcement.

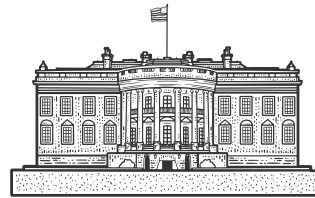
Who’s in charge?

The President is the head of the executive branch and the Vice President (VP) is second in command.

Below the President and VP are the Cabinet officials who serve as advisors to the president and the heads of the 15 main executive (or administrative) agencies. The executive branch is made up of various departments, independent agencies, boards, commissions and committees.

A few administrative agencies that affect HIV policy are the Department of Health and Human Services which is in charge of the Centers for Disease Prevention and Control and the Health and Human Services Administration, which manages the Ryan White HIV/AIDS Program.

President of the U.S.



Vice President of the U.S.



Cabinet (advisors to the President; heads of executive agencies)

- | | |
|---------------------------------------|---|
| Secretary of Agriculture | Secretary of Commerce |
| Secretary of Defense | Secretary of Education |
| Secretary of Energy | Secretary of Health & Human Services |
| Secretary of Homeland Security | Secretary of Housing & Urban Development |
| Secretary of the Interior | Secretary of Labor |
| Secretary of State | Secretary of Transportation |
| Secretary of the Treasury | Secretary of Veterans Affairs |
| Attorney General | |

How do agencies make policies?

Rules

Rules are generally applicable, meaning they apply to everyone, and have a future effect.

They are designed to implement or interpret law or policy.

Orders

Orders are final dispositions in any matter other than rule-making and usually affect individual rights or the rights of very small groups.

They are created by a process called adjudication.

Guidance

Also called “interpretive rules,” these are intended to help the public understand how a rule applies to them.

They may explain how an agency interprets a rule or a law, how a rule may apply in a given instance, and what a person or organization must do to comply.

Guidance cannot set new legal standards or impose new requirements.

HIV AND THE EXECUTIVE BRANCH

White House Domestic Policy Council

Office of National AIDS Policy (ONAP)

This office has provided overall guidance and coordination of the domestic HIV response. ONAP is situated on the White House Domestic Policy Council, which advises the President on all domestic policy matters. ONAP became defunct under the Trump administration, but was reestablished by the Biden administration in 2021. Harold Phillips currently serves as director of ONAP.

Executive agencies that create or influence policies that affect people living with HIV

Department of Health & Human Services

Social Security Administration

Department of Housing and Urban Development

Department of Justice

Department of Agriculture

Advisory bodies

The Presidential Advisory Council on HIV/AIDS (PACHA) and the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHAC) are both governed by a charter.

The charter mandates everything about the advisory body, from who is included on the body (like if people living with HIV must be included) to how many times it meets per year.

PACHA is rechartered by each new presidential administration. At the time of publication of this fact sheet, President Biden has not yet rechartered PACHA.

Presidential Advisory Council on HIV/AIDS (PACHA)

Advises HHS on programs, policies, and research on the treatment, prevention, and cure of HIV, including comment and advice on the EHE and HNSP programs.

- The current PACHA charter specifies a maximum of 25 members who serve for 4-year terms and meet 3 times per fiscal year. There is no requirement that any of these members be people living with HIV.
- For example, following its last meeting in March 2021, PACHA recommended that HHS eliminate administrative barriers to eligibility and recertification process for services that could be creating and perpetuating systemic racism and to examine additional incentives to encourage states that have not expanded Medicaid to do so, among other things.

CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHAC)

Advises HHS, the CDC, and HRSA on objectives, strategies, policies, and priorities for HIV, viral hepatitis, and STD prevention and treatment efforts.

- Comprised of 18 members, at least 4 of which must be people living with HIV, and meets about 2 times per year. As it is currently chartered, members can serve for up to 4 years and can serve for an additional 180 days until their successor takes office. Their terms overlap with one another, so not all members terms will expire at one time.
- For example, CHAC will write letters to the heads of HHS, the CDC, and HRSA, like one it wrote to the Secretary of HHS in June 2020 asking HHS to prioritize young people in the Ending the Epidemic Plan and activities that are known to be linked to prevention of HIV in young people.

Government-wide HIV policies

Ending the HIV Epidemic (EHE): A Plan for America

An operational plan developed by U.S. Department of Health and Human Services (HHS) agencies which aims to end the HIV epidemic by 2030.

It focuses on prevention, diagnosis, treatment, and outbreak response.

Opportunities to influence the implementation of EHE exist at the state & local level, when budgets are being developed, and at PACHA and CHAC meetings.

HIV National Strategic Plan (HNSP)

A road map for ending the HIV epidemic in the United States by 2030.

The current iteration covers 2021-2025.

Opportunities to influence the HNSP implementation exist when budgets are being developed, and at PACHA and CHAC meetings.

Executive agencies, cont.

Department of Health & Human Services

The Office of Assistant Secretary for Health (OASH)

Manages HHS's response to HIV

Minority HIV/AIDS Fund

Funds different programs and activities designed to improve prevention, care, and treatment for racial and ethnic minorities.

Centers for Disease Control and Prevention (CDC)

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

Department of HIV/AIDS Prevention (DHAP)

Focuses on prevention through public health surveillance, scientific research, prevention public education campaigns, programs to prevent and control HIV/AIDS and promoting school-based health and disease prevention among youth.

Office of Infectious Disease and HIV/AIDS Policy (OIDP)

Formerly known as the HIV/AIDS and Infectious Disease Policy (OHAIDP) before it was combined with the National Vaccine Program Office in April 2019.

- Leads EHE project coordination and management;
- Monitors EHE progress;
- Delivers information through hiv.gov.

Office of AIDS Research (OAR)

Coordinates HIV/AIDS research across National Institutes of Health (NIH), which provides the largest public investment in HIV/AIDS research globally.

Health Resources and Services Administration (HRSA)

Health Center Program

- Grant program in which grants are given to health centers which deliver primary health services to low-income and underserved communities
- Health centers often test for and treat HIV and increase access to PrEP and PEP

HIV/AIDS Bureau (HAB)

AIDS Drug Assistance Programs (ADAP)

- Funds are managed by states and territories, but the programs are intended to provide certain approved medications to low-income people living with HIV who have limited or no health coverage from private insurance, Medicaid, or Medicare.
- Funds may also be used to purchase health insurance for clients and for services that enhance access to, adherence to, and monitoring of drug treatments.

Ryan White HIV/AIDS Program

- A funded initiative to provide healthcare, treatment, and related services to people living with HIV. Focuses on linking people living with HIV who are either newly diagnosed or are not in care, to the HIV care, treatment, and support services by granting funds to states, cities, counties, and local community-based organizations.
- Jurisdictional planning councils are supposed to be comprised of at least 33% people living with HIV and decide how to allocate these resources at the local level.

Executive agencies, cont.

Department of Health & Human Services, cont.

Centers for Medicare and Medicaid Services (CMS)

Medicaid

Single largest source of health care for U.S. people living with HIV; represents 30% of all federal spending on HIV care.

It is the second largest source of public financing for HIV care in the U.S.

Medicare

Federal health insurance program for people age 65 and older and younger adults with permanent disabilities.

About ¼ of people living with HIV get their healthcare through Medicare.

The primary pathway to get onto Medicare is through Social Security Disability Insurance (SSDI).

Administration for Children and Families (ACF)

Temporary Assistance for Needy Families (TANF)

Time-limited program that assists families with children when the parents or other guardians cannot provide for the family's basic needs.

Department of Housing and Urban Development

Housing Opportunities for Persons with AIDS (HOPWA)

Grants to local communities, states, and nonprofit organizations for projects that provide housing for low-income persons living with HIV/AIDS and their families.

Social Security Administration

Supplemental Security Income (SSI)

Financial support for people with disabilities and low income and resources.

Social Security Disability Insurance (SSDI)

Provides benefits for people with disabilities, including HIV.

Department of Agriculture

Supplemental Nutrition Assistance Program (SNAP)

Federal program helping low- and no-income people, those receiving public benefits, the elderly or disabled, or unhoused people purchase food.

Department of Justice

Conducts new investigations of HIV/AIDS discrimination under the Barrier-Free Health Care Initiative, the Fair Housing Act, and the Americans with Disabilities Act.

Released the [Best Practices Guide to Reform HIV-Specific Criminal Laws to Align with Scientifically Supported Factors](#) in 2014.

How Do You Make Changes in Administrative Policies?

Join and/or attend the meeting of state or local working groups (Ryan White, Ending the Epidemic, ADAPs).

Join an advisory body, attend the meetings, and submit comments.

[Join Positive Women's Network - USA](#) or another network of people living with HIV.

Disrupt by contacting the media, rallies, direct actions, and demonstrations. You can be creative with how you disrupt the process and different actions are better suited for different issues.

Submit public comments on rules and regulations.

How to find policies and other agency actions

- Rules and Regulations: [FederalRegister.gov](#) OR [Regulations.gov](#)
- Calendar of planned and ongoing rulemaking: [RegInfo.gov](#)

How to Write an Effective Comment

1. Read the Rule or at least the summary.
2. Outline the questions being asked from the agency and other areas where comment will be useful.
3. Give yourself time to write, and to review.
4. Submit comment online by the deadline.

TIPS:

- Share personal stories and/or stories of how the proposed rule will impact you and/or your community.
- Can address all of the proposed rule or only a part.
- Can be as simple as a sentence or as many pages and points as you want to make.
- Constructive comments hold more weight.
- If you have particular expertise because of your work or life experience, make sure to put that up front.
- Support your comment with facts and data if you have it; you may be considered an expert, and your opinion matters.
- If you can think of an alternative to the rule, include it!
- **Form letters:** Many organizations create form letters - if you don't personalize them up front or add your opinion, it is not taken as seriously.

Want to learn more? Or ready to get started?

Go to pwn-usa.org/advocacy-guide

[Claim Your Seat at the Table: A How-To Guide to Advocacy for People Living with HIV](#) has tons of multimedia resources for advocates, from the newest to the most seasoned, to give you the knowledge, skills, tools and templates, and pro tips you need to make a difference for people living with HIV and our communities.

A How-To Guide to Advocacy for People Living with HIV

All PwH USA, we envision a world where those most impacted by policies are the driving voices behind setting priorities and making decisions.

People living with HIV face a kale of all types of government decisions and actions - from education to health care, housing to mass incarceration, employment, to civil rights - and we must participate in crafting and changing policies to ensure that they meet our needs. This multimedia guide is designed to help us make justice for our communities a reality.



Part 1: Getting started in policy advocacy

Part 2: The wide world of advocacy where you can do whatever you like

Part 3: Planning and building your campaign

Part 4: Getting your message out there

DFI Starter Kit: Look here for all things template