



LOS ANGELES COUNTY
COMMISSION ON HIV



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Consumer Caucus Virtual Meeting

Be a part of the HIV movement

Thursday, September 9, 2021
3:00-4:30PM (PST)

Agenda and meeting materials will be posted on
<http://hiv.lacounty.gov/Meetings>

REGISTRATION NOT REQUIRED + SIMULTANEOUS TRANSLATION IN SPANISH AND OTHER LANGUAGES NOW AVAILABLE VIA CLOSED CAPTION FEATURE WHEN JOINING VIA WEBEX. CLICK [HERE](#) FOR MORE INFO.

TO JOIN BY COMPUTER: **registration is not required*

<https://tinyurl.com/2y4awhrr>

Meeting password: CAUCUS

TO JOIN BY PHONE:

+1-213-306-3065

Access Code/Event #: 2599 284 1022

For a brief tutorial on how to use WebEx, please check out this video: <https://www.youtube.com/watch?v=iQSSJYcrglk>

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Apply to become a Commissioner at <http://tinyurl.com/HIVCommApplication>

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REGISTRATION NOT REQUIRED + SIMULTANEOUS TRANSLATION IN SPANISH AND OTHER LANGUAGES NOW AVAILABLE VIA CLOSED CAPTION FEATURE WHEN JOINING VIA WEBEX. CLICK [HERE](#) FOR MORE INFO.

CONSUMER CAUCUS (CC) VIRTUAL MEETING AGENDA

**THURSDAY, SEPTEMBER 9, 2021
3:00 PM – 4:30 PM**

TO JOIN BY COMPUTER

<https://lacountyboardofsupervisors.webex.com/lacountyboardofsupervisors/j.php?MTID=m8551fe19b9fb159555cfbb6566aaa839>

MEETING PASSWORD: CAUCUS

TO JOIN BY PHONE: +1-213-306-3065 MEETING #/ACCESS CODE: 2599 284 1022

- | | | |
|------|---|-----------------|
| I. | Welcome & Introductions (Co-Chairs) | 3:00pm - 3:05pm |
| II. | COH Meeting Debrief | 3:05pm – 3:20pm |
| III. | Staff Report/Commission Updates | 3:20pm - 3:30pm |
| IV. | Co-Chair Report | |
| | • 2021 Priorities/Workplan | |
| | ○ Recenter & Streamline Activities for Planning Effectiveness | 3:30pm - 3:40pm |
| | • NMAC Building Leaders of Color (BLOC) Training (Sept 13-17) | |
| V. | Discussion: | |
| | • Commission's Response to STD Crisis in Los Angeles County (STD Letter) | 3:40pm – 4:30pm |
| | ○ Supporting/Championing Commission Initiatives via Public Comment and Other Outreach Efforts in Your Communities | |
| VI. | Announcements | 4:25pm-4:30pm |
| VII. | Adjourn | 4:30pm |



Consumer Caucus Workplan 2021 (September 9, 2021)

PURPOSE OF THIS DOCUMENT: To identify activities and priorities the Consumer Caucus will lead and advance throughout 2021.

PRIORITIZATION CRITERIA: Select activities that 1) represent the core functions of the COH and Caucus, 2) advance the goals of the local Ending the HIV (EHE) Plan, and 3) align with COH staff and member capacities and time commitment.

CAUCUS RESPONSIBILITIES: 1) Facilitate dialogue among caucus members, 2) develop caucus voice at the Commission and in the community, 3) provide the caucus perspective on various Commission issues, and 4) cultivate leadership within the caucus membership and consumer community.

#	Activities & Lead/Champion(s)	Priority Level (High, Medium, Low)	Approach/Comments/Target Deadline
1	Foster and nurture consumer (both PLWH and HIV-negative) leadership and empowerment in COH and community	High	<ul style="list-style-type: none"> • Trainings, meeting debriefs and Q&As to be determined by Consumer Caucus and weaved into Consumer Caucus meetings. ➤ NMAC BLOC training confirmed for September 13-17.
2	Increase consumer participation at Consumer Caucus/COH meetings, especially individuals from the Black/African American, Latinx, youth, and indigenous communities.	High	<ul style="list-style-type: none"> • Work with community advisory boards. Explore follow-up opportunities to the CAB conference held in 2019. • Use testimonials from members and use in social media-based recruitment. Staff emailed Commissioners on 2/2/21 to solicit testimonials. No replies received as of 2/18/21. • Encourage consumers to attend caucuses and task forces first as those meetings may be less intimidating than full body or Committee level meetings. • Develop outreach tracking form that Commissioners will use to what events they attended to promote the COH and consumer participation. C. Moreno to share draft template for consideration. ➤ Partner with the Operations Committee to develop strategies and best practices to engage and retain consumer members.
3	Increase integration of consumer voice into all COH Committees	High	<ul style="list-style-type: none"> • Encourage consumers (including non-COH members) to attend COH Committee meetings. Attendance at meetings may incite consumers to apply to the COH or as Committee members. <i>Ask Committee and other subgroups to attend Consumer Caucus meetings.</i> • Encourage at least two consumers attend each Committee and subordinate work group meetings as champions and representatives for CC and report back to CC. • Encourage more consumers to apply to the COH. • Consumer voices should drive the COH agenda. • Provide feedback on updated membership application to create a more

			<p>consumer friendly format and use as a recruitment tool for consumers</p> <ul style="list-style-type: none"> • Encourage providers to support and promote consumer participation at COH meetings. ➤ Develop list of consumer-focused priorities/recommendation for Commission consideration/implementation - ongoing.
4	<p>Support/partner with Black/African American Community Task Force (BAAC TF), Women’s Caucus, Transgender Caucus and Aging Task Force to develop a more coordinated and collaborative planning agenda for consumers from all priority communities on the COH.</p>	Low	<ul style="list-style-type: none"> • Host an “all Caucus/Task Force” meeting to combine planning efforts for consumers from all priority communities. <ul style="list-style-type: none"> ○ Schedule an “all Co-Chair” meeting to brainstorm and develop agenda. Meeting took place on March 9. Follow up/next steps to be determined. • Help implement BAAC TF, WC and ATF recommendations. • Work with ATF <i>and Women’s Caucus</i> to coordinate an activity for Long Term Survivors Day (June 5); activity can be leveraged to build consumer-led coalitions. ➤ “All Caucus” Co-Chairs met and determined that “All Caucus” efforts be placed on hold until LAC Human Relations Commission training has concluded



Greetings from NMAC's Building Leaders of Color (BLOC) Program. It is our privilege to announce that we have the opportunity to partner with the Los Angeles (LA) County Commission on HIV to provide a BLOC Bootcamp training in September 2021. Through the BLOC Program we train people of color and allies living with HIV to be full, active, and engaged participants on planning bodies, medical and support care teams, boards of directors, and other efforts to address the goals of the National HIV/AIDS Strategy. The BLOC Program also provides participants with leadership skills to empower you to advocate for yourself and your communities, while providing opportunities where you can apply these skills on a local, state or national platform.

The purpose of this intensive virtual four-day BLOC Bootcamp training is to increase awareness and competency as well as fine-tune the leadership capacity of up-and-coming leaders from the People of Color and allies living with HIV community. Through the BLOC Bootcamp training, participants will learn how to become more formally engaged in the planning, implementation, and evaluation of HIV-related services. Our belief is that together with community, we can work towards ending disparities and ending the HIV/AIDS epidemic in America. The BLOC Bootcamp training learning objectives include:

- **Introduce and define leadership including traits and characteristics of leaders**
- **Introduce forms of stigmas including enacted and layered stigma**
- **Introduce health numeracy, measurement tools, and patient support**
- **Build skills for calculation, data analysis, and performance measurement**
- **Increase knowledge of the Ryan White HIV/AIDS Program and opportunities for involvement**
- **Develop individualized goals and goal statements for seeking leadership opportunities**

"By far the best training I've ever experienced. I've been to numerous trainings and never felt more connected and engaged in my life." – 2019 Participant Quote



In order to apply, you must be a person of color or ally living with HIV living in **LA County, CA** area with intermediate leadership skills. The BLOC Bootcamp training group will be a mix of diverse backgrounds and identities. Applicants with experience working alongside various populations around HIV disparities are highly encouraged to apply. Applicants should have basic knowledge and skills relate to HIV disease management and consumer involvement experience (participation in speakers' bureaus, consumer or community advisory boards, support groups, etc.). After completion of the BLOC Bootcamp training, participants are encouraged to participate in activities related to program planning for PLWH in the community.

Due to the turnaround time for the training, the applications for the BLOC Bootcamp training are due by **8/30/2021**. Spacing is limited to 30 participants for the LA County BLOC Bootcamp training. Selected applicants who are accepted into the LA County BLOC Bootcamp training will be contacted by email with acceptance by **9/1/2021**.

We will be hosting our LA County Bootcamp training on 9/13/2021-9/16/2021 virtually. A mandatory orientation webinar is scheduled for **1:00 PM PST on 9/10/2021** where we will discuss the BLOC program overview including the training expectations, agenda, and trainer introductions.

Please use the link below to apply:

[BLOC Bootcamp Training Application - LA County](#)

For questions related to the BLOC Bootcamp training, please. Contact Lauren Miller at lmiller@nmac.org or for further details.

Thank you,

Lauren Miller

NMAC's Center to End the Epidemics

Health Equity Coordinator

Cell 202.997.0951

lmiller@nmac.org

1000 Vermont NW, Suite 200, Washington, DC 20005 > nmac.org





LOS ANGELES COUNTY COMMISSION ON HIV



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August 3, 2021
Board of Supervisors
Los Angeles County
313 N. Figueroa Street, Room 806
Los Angeles, CA 90012

Dear Board of Supervisors:

Los Angeles County is in an ongoing STD crisis that has seen rates explode over the last six years. As the Board of Supervisor's designated HIV and sexually transmitted diseases (STD) prevention and care planning council for Los Angeles, the Commission on HIV (Commission) is extremely concerned about the sharp increase in STD rates in the last three years, especially the startling increase of syphilis and congenital syphilis cases¹, and the ability of the County's existing STD programs and resources to respond to this crisis.

While we sincerely appreciate that the COVID-19 pandemic necessitated an immediate and acute public health response, the effects of compounded public health crises are evident in the most recent surveillance data and what providers and community see on the ground. As the County entered lockdown, a new syndemic of HIV, STDs, and COVID-19 emerged, exacerbating the STD crisis and laying bare gaps in our local public health system. The data speaks for itself, and the voices of the community must be heard even louder – **we need to act now to prevent the STD crisis from getting worse**. We are calling on the Board and Alliance for Health Integration (AHI) leadership to immediately take bold, concrete actions to expand resources and build public health infrastructure so that we can end this crisis.

The Commission first raised the alarm in 2018 and over the last three years has continued to express our dismay as the STD crisis grows. We have examined annual surveillance data and reports, held forums and discussions to mobilize at the community level, supported concerns raised at a provider meeting with DPH leadership in February 2020, and have monitored the Board and DPH's engagement with this crisis through the November 2018 Board Motion and subsequent Quarterly STD reports. It is evident that there is a clear pattern of additional factors contributing to the crisis including and not limited to methamphetamine use, undiagnosed and untreated mental illness, little to no access to prenatal care, homelessness as well as a devastating lack of concise and consistent public understanding regarding this overwhelming and preventable crisis. Three years later, the Commission and the broader STD and HIV

¹ DHSP surveillance data shows a 450% increase of syphilis among females and 235% increase among males in the last decade (2009-2019), with 113 congenital syphilis cases in 2020.

advocacy community feel that there has been little movement in combatting this crisis, we have done everything we can and advocated with leadership at all levels, but have been met with silence all around.

Our concern has only grown as the COVID-19 pandemic exacerbated gaps in an already overstressed public health system that was not prepared for the pandemic. With the onset of the COVID-19 pandemic, HIV and STD testing and treatment rates sharply declined while new transmissions continued. Particularly concerning is, the same communities disproportionately impacted by STDs, including men who have sex with men (MSM), transgender individuals, women, communities of color, and now youth, have also been disproportionately impacted by COVID-19, exacerbating existing health and social inequities.

Moreover, in our County, an already understaffed and under-resourced STD response was made worse by the redeployment of nearly all staff to COVID-19 work. As reflected in DPH's Quarterly STD reports over the last year, staff had to quickly pivot to address the overwhelming demands of COVID-19 work with the existing STD crisis, and the majority of County and community programming for STDs was severely reduced in capacity or entirely put on hold. The diversion of most staff to COVID-19 work resulted in a significant reduction in the timely surveillance work necessary to identify clusters and outbreaks, missed opportunities to treat individuals and their partners because County clinics were closed or at reduced capacity, and overburdened public health staff with a large COVID-19 caseload on top of their STD caseload. The service capacity of public and private sector partners was also impacted, as providers had to close or reduce STD services to focus on COVID-19.

Even before the COVID-19 pandemic began, the County faced significant challenges that have made it difficult to combat exploding STD rates, including inadequate infrastructure, suboptimal access to a fragmented local system of care, and decades of limited resources. Combatting the STD crisis requires a robust infrastructure for County-funded services with a fully-staffed surveillance team, comprehensive and up-to-date public health lab capacity, adequate contact tracers and disease intervention specialists (DIS), timely partner services, a strong network of County and community providers who offer access to culturally competent STD testing and treatment, and adequate resources to support all of this programming. Yet the County's resources to support STD public health infrastructure remain woefully inadequate, this fact continues compounding the crisis for decades to come.

As noted in 2018, STD resources have been impacted by a 40% decrease in purchasing power caused by federal STD allocations remaining level since 2003 and the minimal annual support received from the State. In 2018 the Division of HIV and STD Programs (DHSP) estimated that an additional baseline investment of \$30 million annually is necessary to support adequate programming and access to STD prevention, testing, and treatment, and as STD morbidity has increased in the last three years, that estimated resource need has also increased significantly.

While the Commission thanks the Board for the \$5 million allocation for STDs in 2018, we remain steadfast in our belief that an annual investment based on DHSP's estimated need is vital to effectively control and treat STDs in LA County. While one-time funding sources are helpful, having to advocate for piecemeal allocations each year at every single level, allows the

STD crisis to continue to grow uncontained. We are encouraged that this year's State budget will include an additional \$4 million ongoing investment for STDs, and a large investment in public health infrastructure in 2022, some of which must be directed to STDs. However, since years of fierce advocacy nationwide has not secured truly adequate federal and State resources, the County must recognize that it has to step up to identify a long-term, sustainable funding source commensurate to the magnitude of the county's STD crisis.

The COVID-19 pandemic has highlighted the core function of public health departments and how they are able to mobilize when given adequate resources. The Board of Supervisors and AHI leaders can make a real impact and be champions in combatting our STD crisis, as they have demonstrated in their strong efforts to combat the COVID-19 pandemic in our County. DHSP, with support from the Commission, has developed and implemented responsive and innovative programs to curb the HIV epidemic, and these efforts are well supported with federal, state, and local resources proportional to the magnitude of the HIV epidemic in Los Angeles. Yet the County lacks a comparable, robust infrastructure to address the STD crisis. Our policies and resource allocations reflect our values and priorities; with strengthened support and a revitalized commitment to ending HIV, we must respond with comparable urgency and resources to curb the STD epidemic and successfully end HIV by 2030. The Commission requests the following actions from the Board of Supervisors and the Directors of Public Health, Health Services, and Mental Health:

Board of Supervisors

- Allocate additional tobacco settlement funds to strengthen the County's STD public health infrastructure and DPH-funded STD services provided by community partners and mandate a minimum annual allocation to address the STD crisis.
- Increase DPH's STD net county cost (NCC) annual allocation to support the additional staff necessary to expand surveillance capacity.
- Re-engage with AHI leaders on program, policy, and resource issues highlighted in the Quarterly STD reports. Request a timeline to complete key activities.
- Work with the Health Officer to declare the STD crisis a local public health crisis and direct the Health Officer to work with other counties to request that the Governor declare a statewide STD public health crisis.
- Work with DPH and community partners to develop short and long-term policy, structural, and community engagement interventions to alleviate the crisis, including advocating for STD-related legislative and budget proposals and exploring changes to the County's healthcare system that facilitate access to STD testing, community education and treatment.
- In alignment with the Board's Anti-Racism, Diversity and Inclusion Initiative, we request the Board to support strategies aimed at uplifting the health and wellness of the Black community such as, but not limited to:
 - 1) provide technical assistance to aid Black agencies in obtaining funds for culturally sensitive services;

- 2) provide cultural sensitivity and education training to include addressing implicit bias and medical mistrust within the Black community for all County-contracted providers and adopt cultural humility into the local HIV/STD provider service delivery framework; and
- 3) provide resources to Community-Based Organizations (CBOs) to develop, implement and evaluate primary prevention interventions which are culturally appropriate and relevant to needs and strengths of the Black community.

Departments of Public Health, Health Services, and Mental Health (AHI)

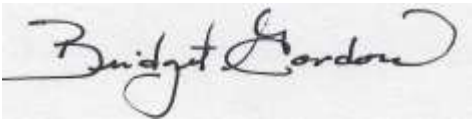
- Identify a concrete timeline to end the County's STD crisis, including key immediate and long-term activities, and approximate funding allocations necessary to achieve activities.
- Develop clear action steps for collaboration between departments and leverage resources to efficiently and effectively marshal a coordinated and synchronized response to the local STD crisis.
- Implement additional action steps to combat the STD crisis which have been clearly outlined in documents including STD Quarterly Reports, responses to federal Requests for Information (RFI), presentations at the Commission, and the provider meeting with DPH leadership, and ensure the response is conducted through a health equity lens.
- Clearly identify all existing funding streams and allocations at all levels for STDs and explore other local health funding streams to identify areas with unspent funds that can be shifted to the STD response. Explore how to better align with other public health programs and resources where issues overlap with STDs (SAPC, etc.).
- Identify all unused COVID-19 public health financial and human resources that can be immediately mobilized and reinvested in competing public health crises, including STDs.
- Call on California's STD Control Branch (CDPH) and the Department of Health and Human Services (DHHS) to advocate with the Governor, and appeal to the federal HHS, for additional federal and state resources to combat the STD crisis, mirroring the County's advocacy efforts that successfully secured additional support for COVID-19.
- Reinvest in existing and establish new partnerships with community health centers (CHCs) and other agencies to expand capacity for community outreach, education, STD testing, and treatment. Collaborate with CHCs, hospitals, and other clinics, including in non-traditional settings, to integrate and routinize STD testing and care for clients.
- Create a public-facing STD data dashboard to track in real-time the County's progress towards reducing the crisis. Establish performance metrics.
- Release all available DPH staff from their COVID-19 assignments to refocus efforts on the uncontrolled STD crisis in Los Angeles County.

We kindly request a meeting with Board representatives and DPH, DHS, and DMH leadership within the next 30 days (or at the earliest possible opportunity given the need to respond to COVID-19) to discuss the concerns and opportunities outlined in this letter. Community engagement and collaboration are critical components of a healthy and well-functioning public health system. We urge leadership in DPH, DHS, and DMH to be transparent in their

communication process with the community and to work with Commissioners and other key stakeholders to identify solutions to our common concerns around STDs and HIV.

The Board of Supervisors must seize the opportunity to show leadership and a very public commitment to ending the *decades long* crisis of the (HIV/STD epidemics) that continues to *severely traumatize our communities* and impact the health and well-being of tens of thousands of Angelenos and *their families*. With the scientific advances in HIV and STD treatment, we truly have a chance at ending HIV and curbing the STD epidemic. Let us not waste this opportunity of a lifetime by remaining inactive and ignoring community voices and strengths and focus instead on transparency, investment and authentic collaboration. We look forward to coordinating a meeting shortly and ensuring an immediate response to our concerns. Thank you.

Sincerely,



Bridget Gordon and David Lee,
Co-Chairs, Commission on HIV

cc:

Health Deputies

Barbara Ferrer, PhD, MPH, M.Ed.

Christina Ghaly, MD

Jonathan Sherin, MD, PhD

Muntu Davis, MD, MPH

Rita Singhal, MD, MPH

Mario Perez, MPH

Celia Zavala

End the Epidemics Coalition

Essential Access Health

Community Clinic Association of Los Angeles County (CCALAC)

Coachman Moore & Associates (We Can Stop STDs LA)

Connect to Protect LA (C2PLA)



LOS ANGELES COUNTY COMMISSION ON HIV



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STD CRISIS PUBLIC COMMENT TALKING POINTS

***** COMMISSIONERS MAY SELECT EXCERPTS AND PERSONALIZE PUBLIC COMMENTS. *****

Hello Honorable Board of Supervisors. My name is _____ and I here today to express my concern about the worsening STD crisis in Los Angeles County. I am member of the HIV Commission and also appealing to you as a concerned member of the community. My public comment is supports the letter sent by Commission on HIV Co-Chairs to you and your Health Deputies on **(July 30)**.

Sexually transmitted diseases (STDs) continue to rise in Los Angeles County. In 2019, there were a total of 98,427 cases of STDs reported to the LAC Department of Public Health. The majority of reported cases (66%) were chlamydia followed by gonorrhea (25%) and syphilis (9%). Sixty five percent of the syphilis cases were early syphilis. 2 Data do not include Long Beach and Pasadena due to reporting delays.

In 2019, the number of congenital syphilis cases continued to rise (N=88) with an increase of 60% since 2018. Since 2012, the number of reported congenital syphilis cases has increased over 1,300%. Latinx (57%) females represented the majority of mothers of infants with congenital syphilis.

We must act now to prevent the STD crisis from getting worse. Our concern has only grown as the COVID-19 pandemic exacerbated gaps in an already overstressed public health system that was not prepared for the pandemic. With the onset of the COVID-19 pandemic, HIV and STD testing and treatment rates sharply declined while new transmissions continued. Particularly concerning, some of the same communities disproportionately impacted by STDs, including men who have sex with men (MSM), transgender individuals, women of color, and youth, have also been disproportionately impacted by COVID-19, exacerbating existing health and social inequities.

***** COORDINATE WHICH ACTIONS WILL ACTIONS WILL BE READ BY COMMISSIONERS. *****

The Commission requests the following actions from the Board of Supervisors and the Directors of Public Health, Health Services, and Mental Health:

Board of Supervisors

- Allocate additional tobacco settlement funds to strengthen the County's STD public health infrastructure and DPH-funded STD services provided by community partners and mandate a minimum annual allocation to address the STD crisis.

- Increase DPH's STD net county cost (NCC) annual allocation to support the additional staff necessary to expand surveillance capacity.
- Re-engage with AHI leaders on program, policy, and resource issues highlighted in the Quarterly STD reports. Request a timeline to complete key activities.
- Work with the Health Officer to declare the STD crisis a local public health crisis and direct the Health Officer to work with other counties to request that the Governor declare a statewide STD public health crisis.
- Work with DPH and community partners to develop short and long-term policy, structural, and community engagement interventions to alleviate the crisis, including advocating for STD-related legislative and budget proposals and exploring changes to the County's healthcare system that facilitate access to STD testing and treatment.

Departments of Public Health, Health Services, and Mental Health (AHI)

- Identify a concrete timeline to end the County's STD crisis, including key immediate and long-term activities, and approximate funding allocations necessary to achieve activities.
- Develop clear action steps for collaboration between departments and leverage resources to marshal a coordinated and synchronized response to the local STD crisis.
- Implement additional action steps to combat the STD crisis which have been clearly outlined in documents including STD Quarterly Reports, responses to federal Requests for Information (RFI), presentations at the Commission, and the provider meeting with DPH leadership, and ensure the response is conducted through a health equity lens.
- Clearly identify all existing funding streams and allocations at all levels for STDs and explore other local health funding streams to identify areas with unspent funds that can be shifted to the STD response. Explore how to better align with other public health programs and resources where issues overlap with STDs (SAPC, etc.).
- Identify all unused COVID-19 public health financial and human resources that can be immediately mobilized and reinvested in competing public health crises, including STDs.
- Call on California's STD Control Branch (CDPH) and the Department of Health and Human Services (DHHS) to advocate with the Governor, and appeal to the federal HHS, for additional federal and state resources to combat the STD crisis, mirroring the County's advocacy efforts that successfully secured additional support for COVID-19.
- Reinvest in existing and establish new partnerships with community health centers (CHCs) and other agencies to expand capacity for community outreach, education, STD testing, and treatment. Collaborate with CHCs, hospitals, and other clinics, including in non-traditional settings, to integrate and routinize STD testing and care for clients.
- Create a public-facing STD data dashboard to track in real-time the County's progress towards reducing the crisis. Establish performance metrics.
- Release all available DPH staff from their COVID-19 assignments to refocus efforts on the uncontrolled STD crisis in Los Angeles County.

Thank you for your time and I implore you to help us respond to the STD crises with the same energy, attention and resources as we have put on COVID. *****COMMISSIONERS MAY PERSONALIZE CLOSING STATEMENT.*****

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.

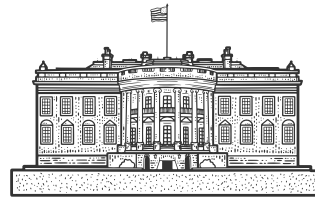
Who’s in charge?

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

DIY Starter Kit: Look here for all things template