

COMMUNITIES ADVOCATING
EMERGENCY AIDS RELIEF

CAEAR

COALITION

Advocacy Agenda

2024 and beyond



INTRODUCTION

In 1990, Congress addressed the HIV/AIDS public health emergency with the passage of the Ryan White CARE Act. The resulting system of care and support services is exemplary. The Ryan White HIV/AIDS Program (RWHAP) increases access to HIV-related health services for underserved populations, improves survival, and reduces HIV transmissions. In 2021, 89.7 percent of clients served by RWHAP achieved viral suppression, which is a primary indication the disease is well managed.

The Communities Advocating for Emergency AIDS Relief (CAEAR) Coalition was formed in 1991 in response to the passage of the Ryan White CARE Act. The original CAEAR members were the 16 cities designated as Eligible Metropolitan Areas (EMAs) – areas most disproportionately impacted by HIV and funded by Title I (now referred to as Part A) of the CARE Act.

CAEAR COALITION'S NEW ADVOCACY AGENDA

In 2022, the CAEAR Coalition embarked on a significant strategic planning process to better align its advocacy priorities with the current state of the HIV epidemic in the U.S. That state includes the changing demographics of those who are newly diagnosed, aging population of people with HIV, and biomedical care and prevention advancements that have impacted service delivery models and systems. At this juncture in the HIV epidemic, the key to ending it is a commitment to addressing

VISION

End of new HIV infections and full, healthy lives for all people with HIV.

MISSION

Advocate for robust federal funding and community-based responses to end the HIV epidemic. The CAEAR Coalition is a national membership organization rooted in the Ryan White HIV/AIDS Program. We work to end the HIV epidemic by ensuring equitable access to welcoming, high-quality healthcare and support services.

For over 30 years, the CAEAR Coalition's proactive national leadership has focused on how the components of the RWHAP can best address the service needs and improve the health status of people living with HIV. CAEAR Coalition's members include consumers, grant recipients, and providers of the Ryan White Part A, Part B, and Part C programs, as well as the Part F AIDS Education and Training Centers.

social determinants of health and embracing a syndemic approach to tackle the intersection of HIV, homelessness and housing instability, sexually transmitted infections, hepatitis C, substance use, and mental health.

The CAEAR Coalition advocates for high-quality care and treatment services for all populations impacted by HIV, especially marginalized people faced with institutional and structural challenges and discrimination, including Lesbian, Gay,

Bisexual, Transgender, Queer or Questioning, Intersex, Asexual (LGBTQIA+) people; Black, Indigenous, and People of Color (BIPOC); women; and people who use drugs, experience housing instability/homelessness, and/or mental health concerns. Our goal is to ensure diverse health service access, delivery, and equitable health outcomes.

The CAEAR Coalition's Advocacy Agenda outlined below details the organization's updated priorities and provides a blueprint for its work moving forward. Developed through a community-driven process, the agenda formally expands the Coalition's advocacy efforts to ensure a system of care and services that promotes optimal health for all. Implementation will begin in 2024 and guide the organization's efforts moving forward. Annual assessments will be conducted to gauge success and identify needed adjustments to align with any significant demographic, clinical, or political changes.

The CAEAR Coalition will focus on increasing federal HIV resources and modernizing the Ryan White HIV/AIDS Program. The modernization will include working with HRSA's HIV/AIDS Bureau (HAB) to improve the program's flexibility and address administrative burdens. In addition, CAEAR will work to better integrate federal HIV care and prevention programs including efforts to address sexually transmitted infections, hepatitis C, substance use, and ways to address the housing needs of people living with HIV.

The CAEAR Coalition strongly believes it is neither advised nor prudent to reauthorize the Ryan White CARE Act in the current divisive political environment; therefore, it will not pursue this course of action as it seeks to modernize the RWHAP. If the political landscape improves and the community agrees to such a pursuit, the CAEAR Coalition will engage in its historic role of convening the community to develop a reauthorization plan.

CONDITIONS DRIVING THE CAEAR COALITION'S ADVOCACY

- Racism, HIV stigma, discrimination, sexism, homophobia, transphobia, poverty, and other barriers to health care continue to drive disparities, impacting engagement and retention in care. Key to ending the epidemic in the U.S. is identifying eligible clients, linking and retaining these clients in Ryan White care and services, and increasing the medical and support services to meet the needs of People with HIV (PWH).
- Approximately 1.2 million people in the U.S. have HIV. About 13 percent of them do not know it and need testing.
- In 2021, 32,100 people received an HIV diagnosis in the U.S.
 - » Highest rates of new diagnoses occur in the South (52%).
 - » People aged 13 to 34 accounted for more than half (58%).
 - » Racial and ethnic differences in new HIV diagnoses persist. Forty percent of people with new infections are Black/African American, and 29% are Hispanic/Latino.
- Majority of people living with HIV in the U.S. are over 50 years of age.
- One in four people living with HIV have a housing need, and 40 percent of those are unable to access **any** housing assistance. Twenty-two percent of new HIV infections are due to housing instability.

ADVOCACY PRIORITIES

Priority 1: Ensure the Voice of the Community Remains a Central Component of the Federal Response to the HIV Epidemic in the U.S.

The hallmark of the CAEAR Coalition's advocacy work for the past 30+ years has been its commitment to ensuring the community plays an active role in shaping local and federal HIV/AIDS policy. The Coalition will continue to embrace this responsibility and will work to ensure this is the lens from which all advocacy and policy work will be developed and implemented.

Priority 2: Increase Federal HIV/AIDS Resources

The CAEAR Coalition will advocate to increase appropriations for the Ryan White HIV/AIDS Program (RWHAP) and the End the HIV Epidemic (EHE) Initiative. In addition, CAEAR will seek to expand the EHE Initiative to add the Ryan White Part A jurisdictions that are not currently included. These efforts will ensure RWHAP and EHE services reach more people with HIV, especially people of color and those who are not virally suppressed.

Priority 3: Reduce the Administrative Burdens and Increase Flexibility of the RWHAP and EHE Initiative

Working with the community and Ryan White Part A jurisdictions, the CAEAR Coalition will identify programmatic roadblocks and work directly with HRSA-HAB to increase flexibility and reduce administrative burdens. The CAEAR Coalition will also serve as a liaison with HRSA-HAB to clarify policies and procedures, identify needed technical assistance, and address the need to streamline data systems and processes.

Priority 4: Promote the Integration of Federal HIV Care and Prevention Efforts

Key to ending the HIV epidemic is for individuals with HIV to know their status and to link them to ongoing care and prevention services. This linkage enables longer, healthier lives and reduces the risk of transmission. The CAEAR Coalition believes a more collaborative and integrated relationship is needed between HRSA-HAB (care) and CDC (prevention) to optimize the power of linkage-to-care to end the epidemic. The Coalition will tap its strong relationship with HRSA-HAB and to find ways to improve the integration of its work with the CDC's Division of HIV Prevention (DHP). Key to this effort will be leveraging the Coalition's strategic partnership with the National Association of County and City Health Officials (NACCHO) and NACCHO's strong working relationship with CDC.

Priority 5: Address Homelessness and the Housing Needs of PWH

Research has proven that stable, supportive housing correlates with a much higher likelihood of a person having a suppressed viral load. Even within the RWHAP system of care, PWH who are unstably housed have a viral suppression rate that is 20 percent lower than PWH who are stably housed. The CAEAR Coalition will work with federal housing agencies and national organizations, such as National HIV/AIDS Housing Coalition (NHAHC), to advocate for the housing needs of PWH. The CAEAR Coalition encourages a more collaborative and integrated relationship is needed between HRSA-HAB and the U.S. Department of Housing and Urban Development (HUD)'s Housing Opportunities for Persons with AIDS (HOPWA) Program to maximize the impact of federal housing resources to end homelessness among PWH. The Coalition will work with HRSA-HAB to find ways to improve the integration of its work with HUD's HOPWA administration.

Priority Six: Focus on Social Determinants of Health and Promote a Syndemic Approach

Building on its long history of working in partnership with other national HIV/AIDS organizations and allied associations, the CAEAR Coalition will increase its commitment to address social determinants of health and to promote a syndemic approach are needed to end the epidemic in the U.S. To that end, the CAEAR Coalition will

expand its reach and develop strategic partnerships and/or collaborations with national BIPOC and LGBTQIA+ organizations and national associations focused on harm reduction and overdose prevention, and mental health. The Coalition will actively engage with client-centered to work with client-centered organizations that will help expand its ability to engage constituents.

ADVOCACY ACTIVITIES

Priority 1: Ensure the Voice of the Community Remains a Critical Component of the Federal Response to the HIV Epidemic in the U.S.

Activities:

- Hold quarterly calls with planning councils to foster peer support, gather input to share with federal partners, and provide opportunities to discuss advocacy priorities and concerns.
- Create a webinar series to address issues from the Planning Council Advocacy Survey and to increase consumer engagement in advocacy efforts.
- Organize an event at the National Ryan White Conference on HIV Care & Treatment to convene the community and explore topics of interest.
- Invest in and leverage technology and training to expand the Coalition’s reach, better engage the community, and enhance its advocacy efforts.

Priority 2: Increase Federal HIV/AIDS Resources

Activities:

- Serve as an active member of the Federal AIDS Policy Partnership (FAPP), representing Ryan White Part A Jurisdictions and developing the annual Part A appropriations requests.
- Coordinate Capitol Hill visits two times a year, developing materials and talking points that reflect the Coalition’s priorities.
- Increase involvement in AIDSWatch.
- Establish a webinar series to educate consumers and jurisdictions on how to conduct effective virtual and in-person Hill visits.
- Seek opportunities to engage national HIV advocacy partners to further the Coalition’s advocacy priorities.
- Work to secure 340B Program income as a resource for HIV care and support services.

Priority 3: Reduce the Administrative Burdens and Increase Flexibility of the RWHAP and EHE Initiative

Activities:

- Review the Ryan White legislation to develop a comprehensive list of needed administrative fixes and policy clarifications. Develop a second list of issues to address, if reauthorization is pursued.
- Prepare a definitive list of requests to HRSA-HAB organized by three topic areas: administrative fixes, increase flexibility, and technical assistance. Items for the list will include those identified in the review of the legislation, the Planning Council Advocacy Survey, and calls/discussions from the NACCHO-CAEAR Ryan White Part A Community of Practice.
- Meet quarterly with the leadership of HAB’s Division of Metropolitan HIV/AIDS Programs (DMAP). Communicate recipient and planning council challenges and request administrative changes to remove barriers to optimize implementation of local Ryan White HIV/AIDS Programs.

Priority 4: Promote the Integration of Federal HIV Care and Prevention Efforts

Activities:

- Partner with NACCHO to convene joint HRSA-HAB and CDC meetings to discuss improving inter-departmental collaboration to advance a status-neutral approach to ending the epidemic.
- Work with HRSA-HAB to implement more meaningful inter-departmental collaboration between HRSA-HAB, HUD-HOPWA, CDC, Centers for Medicare & Medicaid Services (CMS), the National Institute of Allergy and Infectious Disease (NIAID), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

Priority 5: Address Homelessness and the Housing Needs of PWH

Activities:

- Partner with the National HIV/AIDS Housing Coalition (NHAHC) to convene joint HRSA-HAB and HUD-HOPWA meetings to discuss improving inter-departmental collaboration to remove barriers to integrate federal funds to house PWH.
- Coordinate advocacy efforts with NHAHC.

Priority Six: Focus on Social Determinants of Health and Promote a Syndemic Approach

Activities:

- Identify national organizations representing the populations most impacted by the current HIV epidemic. Possible BIPOC and LGBTQIA+ organizations include the Asian & Pacific Islander Coalition on HIV/AIDS, Black AIDS Institute, Latino Coalition on AIDS, National Native American AIDS Prevention Center, Positive Women’s Network, and Positively Trans.
- Identify national organizations that focus on the intersection between HIV treatment, harm reduction and overdose prevention, mental health, and the healthcare workforce. Options include, but are not limited to, the National Alliance for HIV Education and Workforce Development, National Alliance on Mental Illness, National Harm Reduction Coalition, and Professional Association of Social Workers in HIV and AIDS.
- Convene calls and/or meetings with individual organizations to work collaboratively to ensure diverse health service access, delivery, and equitable health outcomes. Efforts will include identifying ways to share information, coordinate advocacy efforts, and address the need for culturally and population-focused healthcare providers.