WHILE COVID-19 IMPACTED VIRTUALLY EVERYONE, in some ways, the disruptions caused by the pandemic have been even greater for the HIV community than others. People living with HIV and persons in need of HIV prevention services rely extensively on functioning health systems and a range of social services, including housing and food and nutrition assistance. The pandemic caused many clinics and community-based organizations (CBOs) to close, HIV community health workers were deployed to assist with the emerging crisis, and countless resources were allocated to mount an emergency response. While the impact of the pandemic on people living with and at risk for HIV is not fully understood, we know that services were interrupted, resulting in fewer HIV tests being administered and reduced access to pre-exposure prophylaxis (PrEP), syringe services programs (SSPs), and other HIV prevention and harm reduction services. Gaps and challenges also were experienced by some persons who receive HIV treatment services, raising concerns that people will fall out of HIV care.

We know that the impacts of the pandemic were not equally shared, with marginalized populations facing even poorer health outcomes than others. While many HIV providers and infectious disease experts were trained and able to help lead the COVID-19 response, this impacted the HIV response. In addition to HIV services disruptions, critical HIV research was delayed or stopped, and now significant parts of the HIV workforce remain deployed to the COVID-19 response. These challenges have resulted in immense burnout of the HIV workforce. As we move into a future with growing rates of vaccine protection and improvements in COVID-19 treatments, but still lingering concerns related to future COVID-19 variants, a critical question we must ask is, “How do we make up for lost ground and get back on track toward ending the HIV epidemic in the U.S.?”

COVID-19 HIGHLIGHTS
THE NEED FOR INCREASED HIV FUNDING AND A GREATER FOCUS ON OVERCOMING BARRIERS TO SERVICES

To make up for lost ground in the HIV response, urgent action is needed to:

- Analyze and publish data on HIV transmissions, clinical outcomes, and other key metrics to allow for timely policy responses at the jurisdictional level
- Increase federal discretionary HIV funding to support the successful implementation of the Ending the HIV Epidemic Initiative (EHE) and the National HIV/AIDS Strategy
- Bolster support for the Minority AIDS Initiative (MAI), and re-invest in community-based organization (CBO) capacity building
- Embrace the disruptive innovation brought about by COVID-19 to improve HIV services delivery

Four years ago, the last Administration launched the Ending the HIV Epidemic Initiative (EHE), and the nation set a goal of ending the HIV epidemic in the United States by 2030. This effort had an initial focus on 48 of the more than 3,000 US counties responsible for half of all HIV transmissions, along with seven rural states, the District of Columbia, and San Juan,
Puerto Rico. Achieving the EHE’s goals by 2030 was always ambitious. HIV is heavily concentrated among historically underserved, marginalized, and disadvantaged communities: racial, ethnic, and sexual and gender minorities continue to make up most new HIV infections. Research demonstrates that weakened health systems and reduced access to safe and affordable housing are magnified among communities disproportionately impacted by the syndemics of HIV, sexually transmitted infections (STIs), viral hepatitis, and substance use and mental health disorders. The COVID-19 pandemic has likely amplified these syndemic effects and further challenged efforts to meet the 2030 goals.

By applying lessons from COVID-19 to the HIV response, we can take action to have the biggest impact on communities with the greatest needs. **Focused action in three key areas can move us forward:**

### 1. FROM OBSERVATION TO ANALYSIS: THE IMPACT OF COVID-19 ON HIV

To combat longstanding inequities, more timely data are needed to respond to and allocate resources toward the demographic and geographic groups most vulnerable to COVID-19 and HIV. Early observations and analyses are beginning to demonstrate how COVID-19 has impacted people living with HIV and HIV services delivery, but they do not provide a complete picture. We have incomplete data regarding the breadth of impact from COVID-19. For example, HIV testing declined, yet we do not know whether HIV transmissions rose or fell. The pandemic caused many jurisdictions to scale back or pause essential HIV activities, and HIV services providers reduced their office hours and suffered from decreased provider staff availability.1 While many providers were able to maintain core services (e.g., prescription refilling, diagnostics, and in-person appointments for urgent medical care), others halted walk-in services, in-person counseling, social support groups, and at-home visits.2 Furthermore, many subpopulations heavily impacted by HIV lost income and employment, resulting in increased financial distress while simultaneously needing to navigate complicated and overwhelmed unemployment insurance systems; many individuals also lost or were forced to switch insurance coverage.3 Disruptions in HIV prevention and treatment services were represented in national data, with temporary but significant declines in HIV/STI testing, PrEP initiation, and hepatitis C treatment starts, with some still falling short of pre-pandemic levels.4 COVID-19’s impact on transmission of these infectious diseases, however, is less clear. While the Ryan White HIV/AIDS Program reported increases in viral suppression during the COVID-19 pandemic,5 these data may obscure large variations from place to place and across populations.

**POLICY ACTION: Analyze and publish data on HIV transmission, clinical outcomes, and other key metrics to allow for timely policy responses at the jurisdictional level.**

Using public health data to inform policy is often challenged in two competing ways: 1) key data are either unavailable or incomplete, or 2) so much data are collected that they become difficult to analyze and use in a meaningful way, especially when there is a lack of professionals with the appropriate expertise to analyze the data. An added challenge related to COVID-19 is that as more data about the early experience in the pandemic are becoming available, the experience in 2020 seems increasingly less relevant to 2022. Further, while national data are critically important and can identify trends and patterns that may not be observed from looking at localized data sets, national data alone are insufficient to guide jurisdictional (i.e., local, state, and tribal) resource allocation and policy setting.

Efforts to standardize and improve HIV data collection and reporting have progressed immensely over the past decade through actions such as successive iterations of the National HIV/AIDS Strategy and the launch of the EHE, both of which identified and standardized key metrics; the development of the annual Ryan White HIV/AIDS Program Client-Level Data Report by the Health Resources and Services Administration HIV/AIDS Bureau (HRSA/HAB); the issuance of more timely HIV surveillance data and supplemental HIV surveillance reports with indicators by the Centers for Disease Control and Prevention (CDC), including through NCHHSTP Atlas Plus; and non-governmental efforts, such as AIDSVu. The multi-year investment in the CDC Data Modernization Initiative is also an important effort to re-invest in public health and use technological advances to provide timely and actionable data in many areas.6 Still, most data are collected annually and often released months or years after internal review and updating, and national data are not sufficiently granular for identifying inequities, allocating resources, or comparing performance across jurisdictions.

To accelerate efforts to end the HIV epidemic, jurisdictions need to make planning decisions using the best data available. The impact of COVID-19, however, presents new challenges causing CDC to delay the release of surveillance tables for 2020 and they are not calculating incidence and prevalence estimates for 2020 because they do not believe that these data will produce reliable estimates. CDC will not calculate these estimates until data anomalies are rectified. Data for 2021 also are not yet available; thus, to assist jurisdictions in making the most informed priority setting and resource allocation decisions in the near term, new strategies are needed. Where feasible, provisional federal and state data should be released; and local and state health departments should be encouraged to use their own data when
LIMITED DATA ON THE IMPACT OF COVID-19 ON HIV HINDERS EFFECTIVE JURISDICTIONAL PLANNING

There is a critical need to use data to understand the impact of COVID-19 on HIV services and outcomes, but data gaps often make it difficult to make informed resource allocation decisions. This is some of what we know:

**Dual Burden of HIV and COVID-19 Exists:** Counties hit hardest early in the pandemic also have high HIV incidence/prevalence.[1] In NYC, fewer people with HIV were fully vaccinated compared to the general population.[2]

**In 2020, 50% of jurisdictions reported to CDC that they had scaled back or paused essential HIV services.**[3] CBOs and other public health organizations reported COVID-19 limiting their operations.[4] This may have had a disparate impact on jurisdictions and communities.[5]

**45% fewer CDC-funded HIV tests were performed in 2020 compared to 2019.** HIV testing remained reduced 11-54% after states moved out of initial pandemic shutdowns.[6]

**After COVID-19 stay-at-home orders, weekly STI cases dropped.** At the end of 2020, STI cases surged.[7]

**There was a 22% decrease in the total number of PrEP prescriptions and a 25% decrease in the total number of new PrEP users between March 2020 and March 2021.** Declines in PrEP prescriptions were associated with having commercial insurance and younger age; distribution of vaccines was associated with rebounds in PrEP prescriptions.[8]

**Viral suppression among people with HIV receiving outpatient ambulatory care services through the Ryan White HIV/AIDS Program (RWHAP) increased by 1.3% from 2019 to 2020, however, various municipalities/jurisdictions reported declines.[9]** In San Francisco, the odds of viral non-suppression are now 31% higher than before the pandemic. Black individuals had persistent, unchanged disparities in viral suppression compared with white individuals.[10]

**CDC data show a 31% increase in drug overdose deaths from 2019 to 2020.** The rise in overdoses demonstrates that conditions contributing to the syndemics of substance use disorder, mental health, and HIV may have worsened during the pandemic.[11]

**Emergency rooms reported increases in the number of people with acute HIV who came to ERs believing that they were symptomatic for COVID-19.** Emergency rooms are a site where we often miss the opportunity to diagnose HIV early. The pandemic may have facilitated earlier diagnoses and engagement in care for some populations.[12]

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adjusted national data are not available, although caution is warranted in shifting resources based on data from 2020 and 2021 where cascading effects due to the lockdown and COVID-19 waves likely make these data unreliable. Concurrently, the White House Office of National AIDS Policy (ONAP), the HHS Office of Infectious Disease and HIV/AIDS Policy (OIDP), or CDC and HRSA should convene a diverse group of experts from within and outside government to develop a short-term action plan for jurisdictional planning, including consideration of the use of supplementary data sources such as CDC’s social vulnerability index data.\(^7\)

### 2. ADEQUATELY FUNDING AND SUPPORTING THE HIV RESPONSE

A critical challenge to ending HIV is ensuring sustained and adequate funding. Funds provided for the domestic HIV response now exceed $28 billion per year,\(^8\) an amount that exemplifies the country’s commitment to responding aggressively to HIV. At the same time, this funding has never been sufficient to meet the level of need. There are concerns that as policymakers respond to COVID-19 and other pressing national challenges, the bipartisan commitment to supporting the HIV response could be diminished.\(^9\)

Most HIV funding is provided through mandatory programs, such as Medicaid, Medicare, and the Social Security programs. Policy action is needed in these programs to protect health coverage for persons who received Medicaid during COVID-19 and are at risk of losing eligibility, as well as extending health coverage for low-income uninsured people in Medicaid non-expansion states. As we have previously discussed in a recently released brief on improving the quality of life of people living with HIV,\(^10\) there also is a pressing need to bolster the level of income support provided to people with disabilities receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). The federal discretionary budget, however, may have the biggest impact on tailoring programs to meet the needs of specific communities heavily impacted by HIV, related syndemic conditions, and COVID-19.

**POLICY ACTION:** Increase federal discretionary HIV funding to support the successful implementation of the Ending the HIV Epidemic Initiative (EHE) and the National HIV/AIDS Strategy.

One of the biggest challenges facing the HIV response is inadequate and unstable funding at all levels of government. As the federal government has assumed a greater role in financing public health, however, the focus on federal funding has become the critical determinant of whether it will be possible to reach our HIV prevention and care goals. Since COVID-19 has demonstrably harmed efforts to end the HIV epidemic, new federal funding commitments are needed to ameliorate this impact.

The enactment of the Affordable Care Act (ACA) and its accompanying Medicaid expansion has resulted in substantial gains in insurance coverage for people living with HIV.\(^11\) At the same time, the Ryan White HIV/AIDS Program is often the glue that holds together the HIV health system by providing cost-sharing assistance or supplemental services to insured people with HIV, as well as providing primary health care to uninsured people with HIV. Even with recent funding

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**SOURCE:** Ending the HIV Epidemic (EHE) Funding Tracker, KASER FAMILY FOUND. tbl. 1 (Nov. 12, 2020); Domestic HIV Funding in the White House FY 2023 Budget Request, KASER FAMILY FOUND. tbl.2 (Mar. 30, 2022). Note: FY 2019 funding was re-allocated funds to launch the Initiative, but not appropriated for this purpose. Congress has not yet appropriated funding for FY 2023.
CBOs REMAIN THE BACKBONE OF THE HIV RESPONSE

Part of the legacy of the early HIV response is that people in communities all across America stepped forward to provide critical services and advocacy often in the face of government inaction and failures. Many people with no prior experience filled needs in their communities and formed new organizations, sometimes out of their own homes or their houses of worship.

Over time, we have allowed our network of CBOs to weaken. Ending HIV requires a new commitment to bolstering communities’ responses to HIV and related syndemic conditions.

As efforts have been made to support sustainability, many leading CBOs have become health centers. This is a positive development, but a consequence often has been a weakening of their community roots or a singular focus on addressing HIV prevention and care. More disturbingly, many small Black or racial and ethnic minority-led CBOs, often serving communities that were historically the most marginalized, have closed, leaving critical gaps. For example, more than half of all HIV transmissions occur among Black and Latinx gay and bisexual men, yet very few organizations rooted in these communities still exist throughout the country. Further, many of the communities most impacted by substance use disorders and rising overdose deaths lack easily accessible, trusted CBOs to provide services.

Congress has a critical role to play in re-investing in the HIV CBO infrastructure. Congress and the Administration must consider:

- Are the CBOs adequately supported to be financially viable and effective at meeting community needs?
- Do CBOs led by members of their communities with competence, expertise, and trust exist to serve all priority populations, such as gay men of color, transgender people, people who use drugs, or women of color, etc.?
- Are sufficient capacity building and technical assistance resources available to ensure the sustainability of these essential community resources?

increases for the EHE Initiative, funding for the Ryan White HIV/AIDS Program in FY 2022 is only 10.9% higher than it was in FY2013 and is effectively lower when considering medical inflation.\(^1\) HIV prevention at the CDC has fared better due to increases in funding for the EHE Initiative with its FY 2022 budget 28.4% higher than in FY 2013.\(^2\) Much of this increase, however, was for the EHE, which is focused on specific jurisdictions. CDC’s base HIV prevention program, which serves the whole nation, increased by only 3% compared to a decade earlier.\(^3\) Congress needs to assess the impacts of the COVID-19 pandemic and increase funding for critical HIV programs accordingly.

POLICY ACTION: Bolster support for the Minority AIDS Initiative (MAI), and re-invest in community-based organization (CBO) capacity building.

As we observe disproportionate impacts of COVID-19 that exacerbate longstanding inequities in the HIV response, it is important to ensure that resources at the state and local levels are directed to communities with the greatest needs. Similar to health departments and clinical providers, CBOs also were impacted by the pandemic.\(^4\) Special attention is needed to support CBOs with established trust and led by members of the communities they serve. It was this expertise in public health crisis response during COVID-19 that enabled many of these same CBOs to support COVID-19 testing and vaccination in communities across the U.S.

An important resource to achieve this goal is the Minority AIDS Initiative (MAI). Established in 1998, this program represented a concerted effort by Congress to focus more on the racial and ethnic minority communities heavily impacted by HIV, with a key goal being to build the capacity of trusted, community-based providers to deliver high quality prevention and care services. The program remains essential although reforms should be considered to refocus MAI on its original capacity building purpose and to ensure that the resources are directed to activities that will have the greatest impact. Unfortunately, Congress has not invested adequately in the MAI, and it has never achieved the appropriate prominence in the overall HIV response. While most MAI funding is allocated by agencies such as CDC, HRSA, and SAMHSA, the level of this funding is not readily available. In FY 2022, only $56.9 million was appropriated for the Minority HIV/AIDS Fund (formerly called the Secretary’s Minority AIDS Fund of SMAIF), which is only $6.9 million more than the funding level when the program was established decades ago.\(^5\) Congress should be encouraged to consider ways to strengthen this program, and most importantly, provide the resources necessary to achieve its intended impact.

A related issue is that the nation has not invested sufficient funding and support for CBOs. Because these organizations are led and staffed by people from the most marginalized and underserved jurisdictions and communities, they need ongoing
resources, training, and support to remain viable. Additionally, CBOs are often more known and trusted by their communities and often have culturally competent providers. And although most HIV tests occur in healthcare settings, HIV positivity is higher in non-health care settings. Thus, we need greater investment in programs that bridge non-healthcare settings with HIV primary care. There is often a lack of funding and capacity at the federal and local levels to support enough vibrant and financially sound organizations. While some of the estimated $380 million that Congress provides to state and local health departments annually are re-granted to CBOs, as governmental fiscal pressure collides with increasing demands for core public health functions, CBO funding has suffered. As an illustration of the mismatch in investment for CBOs, the CDC’s budget for FY 2022 provides resources to directly fund fewer than three CBOs per state. Congress and the Administration need to take several steps to buttress the CBO response by increasing funding, streamlining application and reporting requirements, and providing more technical assistance to CBOs and health departments. Importantly, better support for HIV CBOs cannot be achieved solely by HHS operating divisions, such as CDC and HRSA. HHS-level compliance requirements for all grantees of federal funds are often structured for large health systems, and while they appropriately seek to ensure accountability for taxpayer funding, they create large obstacles to small CBOs applying for and successfully competing for grant funds. Congress should examine HHS funding and reporting requirements and streamline such requirements for CBOs to facilitate compliance.

3. EMBRACING THE OPPORTUNITY OF COVID-19 TO DO THINGS DIFFERENTLY

At the beginning of the pandemic, many clinics and providers impressively pivoted and put in place new approaches and models of care to ensure that critical HIV services continued. As we move forward, it is important to assess which innovations and new opportunities were created by the pandemic response that should continue or be adapted to provide a more sustainable future. Among the tools and strategies for HIV services delivery that were either put in place for the first time or gained new prominence are:

- **The use of technology, including through telehealth, to deliver services and address social isolation:** In a previous Big Ideas Brief titled, Integrating Telehealth into HIV Services Systems Can Help to Sustain Improved HIV Outcomes (October 2020), we describe the policy opportunities and challenges that must be overcome to make telehealth services a sustainable part of the HIV response. In many ways, our ability to maintain continuity of critical HIV prevention and treatment services during the pandemic was because clinics and CBOs quickly established telehealth services. Telehealth and telephone and video communication platforms were used to deliver health care services, facilitate participation in peer support groups, and mitigate social isolation. Complex issues remain related to payment, privacy and security protections. Responding to client preferences and tackling the Digital Divide that impedes equitable access to these innovations also remains a work in progress. Nonetheless, because the deployment of these technologies are likely here to stay, a significant portion of increased investment must be dedicated to ensuring that even smaller CBOs have the technology and staff capacity to deliver telehealth services effectively and efficiently.

- **Self-sample collection (e.g., self-testing at home):** Enabling individuals to swab themselves and collect their own samples for HIV and STI screening was a promising practice prior to the pandemic. Research has documented the effectiveness and capacity of different populations to collect their own samples, and many groups express a strong desire to have this option. It can help overcome barriers to screening for persons in rural areas or with transportation barriers, as well as increase privacy and convenience. While regulatory and insurance policy questions remain, COVID-19 has provided a proof of concept that this innovation has a role in a re-designed system.

- **More responsiveness to individual preferences:** Many programs gave grantees and providers greater flexibility to support continuity of care and be responsive to client needs; it is hoped that many of these policies will continue. For example, HRSA removed its requirement to conduct eligibility reviews for clients of Ryan White HIV/AIDS Program services every six months. These modifications, among others, have been a long time coming and are especially welcome. Other actions, such as allowing for more prescriptions to be filled for 90-days instead of 30, also should be integrated into our new normal going forward.

- **Public-private partnerships:** The public-private partnership between the federal government and pharmacies was crucial to improving the breadth and efficiency of the COVID-19 vaccine rollout. These types of partnerships hold great potential for tackling a variety of barriers to services such as for persons in rural areas, for overcoming community misinformation and mistrust, and for tackling other problems.
WINDING DOWN COVID-19 EMERGENCY RESPONSES THREATENS HARM

While we all welcome the end of the immediate COVID-19 crisis, the formal end of the Public Health Emergency (PHE) and the end of exceptional COVID-19 relief could threaten critical services:

HEALTH CARE
The Families First Coronavirus Response Act of 2020 guaranteed that persons receiving Medicaid could not be disenrolled due to a continuing eligibility review until one month after the PHE ends. As the nation enters a new phase with declining COVID-19 cases, it is likely that the PHE will end in the coming months, thus causing millions of people to lose coverage or have eligibility gaps. The American Rescue Plan Act (ARPA) lowered Affordable Care Act (ACA) Marketplace monthly premiums and provided enhanced subsidies amounts, allowing some who were previously ineligible for financial assistance to receive very low premiums and deductibles. If the extended subsidies disappear, premiums will sharply rise and likely make coverage unaffordable for many.

The Coronavirus Aid, Relief, and Economic Security (CARES) Act of 2020 provided $90 million in supplemental funding for the Ryan White HIV/AIDS Program for preventing, preparing for, and responding to COVID-19 for Ryan White Program clients. Funds could be used for expenses related to extended operating hours and increased staffing hours, additional equipment, workforce training, capacity development, and services to support social distancing, such as home delivered meals and transportation. While this was intended to be one-time funding, its loss could lead to services cutbacks or staffing reductions at a time when organizations are already stretched thin.

TELEHEALTH
Modified policies and relaxed HIPAA restrictions granted individuals the ability to access care from anywhere via audio- and video-based platforms, required services to be charged at least at parity to in-person services, and allowed for home delivery of medications. The conclusion of state PHEs and the reinstatement of various policies could create new barriers to receiving quality care.

HOUSING
Early in the pandemic, the CDC took an unprecedented step to use its public health authority to prevent most evictions for non-payment of rent. In August 2021, however, the Supreme Court invalidated this moratorium. It is estimated that 15 million people are now at risk of eviction.

The CARES Act allocated $65 million for the Housing Opportunities for Persons with AIDS (HOPWA) Program. Funding for the HOPWA program has long been insufficient to meet the needs of people living with HIV. Thus, the loss of this emergency assistance puts additional pressure on the program.

POLICY ACTION: Embrace the disruptive innovation brought about by COVID-19 to improve HIV services delivery.
If many or all of the pandemic-related innovations were adopted in the post-pandemic environment, it could result in much more resilient and client-centered systems of care. CDC, HRSA, and other federal agencies should be asked to demonstrate how they will adapt their internal operations and their funding programs to facilitate the aforementioned innovations. This should be guided by a vision of prioritizing patient-centered care, improving equity, and reducing population-level disparities. While recognizing that funding through many federal programs is allocated by legislatively established formulas, agencies still retain significant funding discretion. Given what we have been through and what we now know is possible, how will agencies utilize their discretion for positive and continuously improving change? Similar questions should be asked of health departments, CBOs, and clinics to ensure that we adapt to the COVID-19 pandemic in ways that make our programs more resilient and the HIV response more effective.

THE TIME IS NOW
Although ending HIV and supporting our communities has never been easy, COVID-19 created additional obstacles on the path to ending HIV by 2030. It

also has likely deepened existing inequities while heightening our understanding of the structural barriers that complicate efforts to achieve our goals. As we celebrate the leadership we observed, we also must respond to the lessons learned to continuously improve efforts to reduce new HIV transmissions and better support all people living with HIV.

ENDNOTES


2. Id.


14. Id.


17. Id. at 3 fig 2; Dawson & Kates, supra note 13.


20. See Robin J. MacGowan et al., Effect of Internet-Distributed HIV Self-tests on HIV Diagnosis and Behavioral Outcomes in Men Who Have Sex With Men: A Randomized Clinical Trial, 180 JAMA INTERNAL MED. 117-25 (Jan. 1, 2020).

