Department of Health and Human Services Office of Inspector General

Systemic and Operational Challenges Hinder Efforts to Ensure HIV Care for Medicaid Enrollees

Ann Maxwell

Deputy Inspector General for Evaluation and Inspections September 2024, OEI-05-22-00242



REPORT HIGHLIGHTS



September 2024 | OEI-05-22-00242

Systemic and Operational Challenges Hinder Efforts to Ensure HIV Care for Medicaid Enrollees

Why OIG Did This Review

- People with HIV need ongoing recommended care to improve their health outcomes, reduce HIV-related deaths, and reduce new HIV transmissions.
- The Medicaid program plays a critical role in supporting HIV care as the largest source of insurance for Americans with HIV. Previous OIG work found that one in four Medicaid enrollees with HIV may have not received at least one service critical to HIV care in 2021.
- This report builds on OIG's <u>previous work</u> by interviewing select State Medicaid agencies (States) and comprehensive, risk-based Medicaid managed care plans (Plans) to explore challenges that contribute to gaps in HIV care and potential actions that could improve their ability to ensure that all enrollees with HIV receive needed care.

What OIG Found

States and Plans reported that two systemic issues—unmet health-related social needs and provider shortages—impact enrollees' abilities to maintain their care and limit States' and Plans' abilities to address resulting gaps in care.

States and Plans reported that two operational challenges—**limited access to data** and **insufficient administrative staff**—impact States' and Plans' efforts to monitor enrollees' care needs and take action to connect enrollees to care.

What OIG Recommends

While the identified challenges include systemic issues that no Federal agency can solve alone, <u>CMS</u> has opportunities to further support State and Plan efforts to ensure that Medicaid enrollees with HIV receive needed care—thereby improving health outcomes and preventing new HIV transmissions. OIG recommends that CMS:

- 1. Pursue further actions to help States share knowledge with each other and coordinate internally regarding strategies to ensure needed care for Medicaid enrollees with HIV.
- 2. Take additional steps to help States leverage the State Data Resource Center to access and use Medicare data for dually eligible enrollees with HIV.

CMS concurred with these two recommendations.

TABLE OF CONTENTS

BACKGROUND	1
FINDINGS	5
States and Plans reported that enrollees' unmet health-related social needs contribute to gaps in I care that are difficult to address	
States and Plans reported that shortages of HIV care providers impact enrollees' access to care	10
States and Plans reported challenges accessing data that could help them monitor care and outcomes for enrollees with HIV	12
States and a Plan said that insufficient administrative staffing within their programs and plans imp their abilities to identify and coordinate care needs	
CONCLUSION AND RECOMMENDATIONS	18
Pursue further actions to help States share knowledge with each other and coordinate internally regarding strategies to ensure needed care for Medicaid enrollees with HIV	18
Take additional steps to help States leverage the State Data Resource Center to access and use Medicare data for dually eligible enrollees with HIV	19
AGENCY COMMENTS AND OIG RESPONSE	20
APPENDIX	21
Agency Comments	21
ACKNOWLEDGMENTS AND CONTACT	25
ABOUT THE OFFICE OF INSPECTOR GENERAL	26
ENDNOTES	27

BACKGROUND

OBJECTIVES

- 1. To identify challenges that may contribute to gaps in care among Medicaid enrollees with HIV.
- 2. To provide insight into actions that could help the Centers for Medicare & Medicaid Services (CMS), State Medicaid agencies, and managed care plans better ensure that Medicaid enrollees with HIV receive care that is critical to improving health outcomes and reducing new HIV transmissions.

HIV in the United States

As of 2022, 1.2 million people in the United States were living with HIV, and significant disparities existed in terms of people diagnosed with HIV and rates of new diagnoses. Specifically, Black/African American people made up only 12 percent of the U.S. population in 2022 but accounted for 40 percent of all people living with HIV and 37 percent of the new HIV diagnoses that year. Similarly, Hispanic/Latino people made up 18 percent of the U.S. population but accounted for 26 percent of all people living with HIV and 33 percent of new HIV diagnoses in 2022. Further, the Centers for Disease Control and Prevention (CDC) reported that gay, bisexual, and other men who have sex with men accounted for 67 percent of those new HIV diagnoses that year.

People with HIV need ongoing recommended care to improve their health outcomes, reduce HIV-related deaths, and reduce new HIV transmissions. The ultimate goal of HIV care is to achieve and maintain viral suppression—meaning that the amount of HIV in the body is very low or undetectable in viral load tests.⁵ At the individual level, viral suppression allows people with HIV to stay healthy, enjoy an improved quality of life, and live longer than if they were not virally suppressed. At the population level, viral suppression can prevent transmission of HIV because people with HIV who maintain viral suppression have effectively no risk of passing HIV to others.^{6, 7}

To promote HIV care and reduce HIV infections nationally, HHS agencies take on various roles. For example:

• The Health Resources and Services Administration (HRSA) oversees the Ryan White HIV/AIDS Program, the largest Federal program designed specifically for people with HIV with low incomes, which provides medical care, medications, and essential support services to those without health insurance and fills in gaps in coverage and cost for those with insurance limitations.⁸

- CDC oversees the National HIV Surveillance System, under which CDC funds and assists HIV surveillance programs in collecting HIV-related data, such as HIV diagnosis and viral suppression, and in reporting de-identified data to CDC to monitor HIV trends nationally. 9, 10
- Multiple HHS agencies participate in Ending the HIV Epidemic in the
 United States, a national initiative aimed at reducing new HIV infections
 across the United States by 90 percent by 2030.¹¹ Part of this effort includes
 providing resources and funds to diagnose, treat, prevent, and respond to HIV
 in select jurisdictions with high rates of new HIV diagnosis.^{12, 13}

Medicaid's Role in HIV Care

Under HHS, the Medicaid program also plays a critical role in supporting HIV care as the largest source of insurance for Americans with HIV. In 2018, Medicaid covered 40 percent of all nonelderly adults with HIV in the United States. The program, administered by State Medicaid agencies (States), covers services that are critical for all people with HIV according to HHS guidelines, including medical visits to manage care, lab testing to monitor viral load levels, and anti-retroviral therapy (ART). Medicaid benefits are offered on a fee-for-service basis, through managed care, for through a combination of these delivery systems. To pay for benefits, CMS matches funds on the basis of each States' per capita income and sets requirements for States to participate in the program and receive their matching funds.

Some States also use optional flexibilities to expand eligibility or benefits provided through their programs, within Federal guidelines. Some of these flexibilities include Section 1115 demonstrations and/or Medicaid managed care in lieu of services or settings. The Notably, with these flexibilities, States can provide additional or substitute benefits to help address enrollees' health-related social needs. Health-related social needs are social and economic needs (e.g., employment, stable housing, healthy food) that affect individuals' abilities to maintain their health and well-being. People with HIV who have unmet health-related social needs may struggle to achieve and maintain viral suppression. CMS sets Federal guidelines for States' use of these flexibilities, and reviews and approves individual States' applications for them.

While CDC tracks outcomes for all people with HIV nationally, CMS aims to track viral suppression specifically for those people with HIV enrolled in Medicaid. To facilitate this tracking, States can report viral suppression to CMS for its Adult Core Set, annual measures used to drive improvements of quality of care provided to Medicaid enrollees.^{22, 23} However, reporting the viral load suppression measure is currently voluntary and only 11 States reported it in FY 2022.²⁴

CMS also works with CDC and HRSA on additional initiatives focused on Medicaid enrollees with HIV. These efforts included:

- The **HIV Health Improvement Affinity Group**, a one-year initiative in 2016 that aimed to increase viral suppression and improve health outcomes among people with HIV enrolled in Medicaid through collaborations between state public health departments and States. CMS collaborated with CDC and HRSA on this group and 19 states participated.²⁵
- The Building Capacity to Improve Collecting and Reporting Viral Suppression Data to the Medicaid Adult Core Set, a four-year Ryan White HIV/AIDS Program Part F Special Projects of National Significance initiative launched in 2021 that aims to build capacity among HIV surveillance programs and States for reporting high-quality HIV viral suppression data. HRSA is leading this initiative and nine States are participating.²⁶

Related OIG Work

Given Medicaid's role in HIV care, OIG previously reviewed Medicaid claims data to determine the extent to which enrollees with an HIV diagnosis had evidence of services critical to achieving viral suppression. That review, *One Quarter of Medicaid Enrollees with HIV May Not Have Received Critical Services in 2021* (OEI-05-22-00240), found that about one in four Medicaid enrollees with HIV may have not received at least one service critical to HIV care in 2021.²⁷ Those results provided an understanding of the scale of potential gaps in care among Medicaid enrollees nationally. This report builds on that foundation by exploring challenges that contribute to gaps in HIV care and potential actions that could improve Medicaid's ability to ensure appropriate care for all enrollees with HIV.

Methodology

Scope

This study was designed to describe challenges reported by selected States and managed care plans (Plans)²⁸ that impacted their ability to ensure that Medicaid enrollees with HIV receive needed care, as well as their efforts to address these challenges and potential needs for further CMS support.

Data Sources

We conducted interviews with a purposive sample of States and Plans, as well as officials within CMS.

Sample selection. We selected 13 States (including DC) and 4 Plans²⁹ for interviews in 2 rounds, in August–November 2022 and in July–August 2023. In selecting States and Plans, we considered (1) known initiatives for Medicaid enrollees with HIV (i.e., Section 1115 demonstrations, HIV Health Improvement Affinity Group participation), (2) geographical region, (3) expansion of Medicaid eligibility under the Affordable Care Act, and (4) HIV prevalence in the State. For the second round, we also

considered State-specific results from our previous review of the extent to which enrollees had evidence of critical HIV services. We did not intend for this sample to be representative of all States and Plans, but rather chose to select a mix of States and Plans for a variety of experiences.

State and Plan interviews. We asked States and Plans about (1) challenges that impact their abilities to ensure that Medicaid enrollees with HIV receive care, (2) efforts interviewees used to ensure that enrollees received HIV care, and (3) ideas for Federal support that could help to better ensure HIV care. We also asked States about their experiences with specific Federal HIV initiatives (e.g., HIV Health Improvement Affinity Group, Ryan White HIV/AIDS Program's Building Capacity to Improve Collecting and Reporting Viral Suppression Data to the Medicaid Adult Core Set initiative).

CMS interview. We interviewed CMS officials in June 2023 to learn about CMS's role in supporting State efforts to ensure care for enrollees with HIV, including those who are dually eligible for Medicaid and Medicare.

Data Analysis

We compiled and reviewed all interview data to identify key challenges, strategies, and supports discussed related to the provision of recommended HIV care. To identify themes, we reviewed interviews to identify ideas and topics discussed by more than one State or Plan.

Limitations

Our analysis includes two limitations: (1) We reported State and Plan experiences as they were presented and did not independently verify the information reported; and (2) State and Plan responses reflect specific points in time.

Standards

We conducted this study in accordance with the *Quality Standards for Inspection and Evaluation* issued by the Council of the Inspectors General on Integrity and Efficiency.

FINDINGS

Medicaid covers services that, according to HHS guidelines, are critical for all people with HIV such as medical visits, laboratory testing for viral loads, and ART. The States and Plans that we interviewed also reported voluntary efforts beyond payment for services to better ensure that their enrollees with HIV received needed care. Efforts discussed included care coordination; connections to social services; and monitoring of enrollees' services and outcomes.

However, States and Plans also reported significant challenges to ensuring that their enrollees with HIV receive needed care. This report focuses on the challenges most frequently reported by States and Plans. These challenges included two systemic issues—unmet health-related social needs and provider shortages—that impact enrollees' abilities to maintain their care and limit States and Plans' abilities to address resulting gaps in care. It also included two operational challenges—limited access to data and insufficient administrative staff—that impact States' and Plans' efforts to monitor enrollees' care needs and take action to connect enrollees to care.

States and Plans reported that enrollees' unmet health-related social needs contribute to gaps in HIV care that are difficult to address

All States and Plans that we interviewed reported that unmet health-related social needs, such as housing instability and lack of transportation, impacted enrollees' abilities to maintain their care. States and Plans also reported difficulty addressing gaps in care among enrollees with these unmet needs. While States and Plans reported taking action to minimize unmet healthrelated social needs as barriers to HIV care, including use of both standard Medicaid benefits and program flexibilities, they noted that these efforts were limited. As a promising approach, States also reported connecting enrollees with HIV to their State



States and Plans discussed multiple unmet social and economic needs that affect enrollees with HIV's abilities to maintain their health and well-being, known as health-related social needs. Unmet health-related social needs reported included:

- Housing instability
- Lack of transportation
- Lack of childcare
- Food insecurity
- Lack of internet or phones
- Stigma

and local HRSA Ryan White HIV/AIDS Program recipients (Ryan White Program recipients) to receive services that can address unmet health-related social needs, when those services are not available through Medicaid.

When you're talking about housing and transportation and eating ... [health care] takes a back seat when you know your needs aren't being met. -State Medicaid official

States and Plans most frequently reported lack of stable housing and transportation as barriers to enrollees' abilities to maintain their care

Though States and Plans discussed a variety of unmet health-related social needs impacting enrollees with HIV, they most frequently identified enrollees' lack of access to stable housing and transportation as barriers to enrollees' abilities to maintain care. These barriers may contribute to enrollees with HIV experiencing gaps in critical services needed to achieve and sustain viral suppression.

States and Plans reported that **securing stable and affordable housing was challenging for some enrollees with HIV** and may impact how they engage in care. One State said that in a survey of all enrollees, about 12 percent reported that securing stable housing was a challenge, and that this number may be underreported as enrollees experiencing homelessness were less likely to have completed the survey. A Plan stated that the HIV population can be at particular risk of experiencing housing instability. Further, another State discussed the impact of housing availability and homelessness on how individuals seek out services, noting that "if [enrollees] don't have a roof over their heads, they don't really want to engage in [care]."

Similarly, many States and Plans said that **some enrollees' lack of reliable transportation impacted their abilities to engage in their HIV care**. For example, one State explained that without reliable transportation, enrollees who might otherwise take medication might not be able to due to logistical barriers. Some States also noted that lack of transportation was more of a concern for enrollees who lived in rural areas compared to those in urban areas where public transportation may be available.

...[Enrollees] might need ...a ride to the pharmacy. It's not that they don't
[want to] take their medicine, but they ... just don't get there.
-State Medicaid official

While issues with securing housing and reliable transportation are not unique to enrollees with HIV, they have a significant impact on a person's risk of contracting HIV

and their HIV care outcomes. Specifically, people experiencing homelessness or housing instability have been shown to have higher rates of HIV compared to those with stable housing.³⁰ Further, lack of stable housing and/or transportation can negatively impact people with HIV's adherence to care and as a result, impact their abilities to reach or sustain viral suppression.^{31, 32} States and Plans reported limited abilities to address gaps in care related to enrollees' unmet health-related social needs.

States and Plans reported having difficulty addressing the gaps in care that resulted from enrollees with HIV having unmet health-related social needs. For example, one Plan said that it can be difficult for its staff to reach or locate enrollees with HIV who are experiencing homelessness. Similarly, a State reported that its staff had to physically look for enrollees experiencing homelessness to get them back in care. Because States and Plans also reported challenges with staffing available to coordinate care for members in general, taking extra steps to locate and help enrollees with HIV to address gaps in critical care may not always be possible.

States reported using Medicaid flexibilities and the availability of support outside of Medicaid to support housing for enrollees, but these efforts were limited. For example, one State reported planning to use an approved Section 1115 demonstration to provide housing support but said that the complexities of setting up its project and the associated costs had delayed the launch. Further, Medicaid enrollees with HIV may qualify for Federal housing programs administered by the Department of Housing and Urban Development (HUD), including the Housing Opportunities for Persons with AIDS program that is dedicated to addressing housing needs of people with HIV who have low incomes.³⁸ Two States discussed the availability of HUD housing services for enrollees, but one noted that the waitlists for HUD programs can be long. Another State noted that enrollees who couch surf or stay in others' homes temporarily may not fit specific definitions of homelessness to qualify for Federal housing supports.

Medicaid Flexibilities for Health-Related Social Needs

States may use Medicaid funds for services to address unmet health-related social needs through approved waivers and in lieu of services or settings (ILOSs). For example, as of July 2024, 10 States have approved **Section 1115 demonstration to provide** housing support.³³ States can also use ILOSs authority to allow Plans to pay for alternative services instead of State plancovered services or settings when it is medically appropriate and cost-effective, and in compliance with Federal regulations.³⁴ Though States' reported experiences with using ILOSs were limited, some noted their value to address health-related social needs.

Since our interviews, CMS released guidance on the use of Medicaid flexibilities for health-related social needs. 35, 36 Also, HHS and HUD selected nine States (including DC) using flexibilities for housing-related supports to participate in the *Housing and Services Partnership Accelerator*. For 12 months, the nine States will receive Federal technical assistance and peer-to-peer support to improve coordination and delivery of services. 37

States and Plans also reported using Medicaid benefits to address unmet transportation needs, with some noting limitations. Medicaid programs are required to ensure necessary transportation for enrollees to and from their providers as needed.³⁹ A Plan said that it has a transportation company available for enrollees to schedule a ride and has found it helpful overall in meeting enrollees' needs. Some States, however, said that enrollees may not use transportation benefits due to other barriers such as limited availability of drivers. As of 2023, States have the option to reimburse transportation provider expenses associated with wait times and/or unloaded mileage to support driver retention.⁴⁰ States also use telehealth to deliver Medicaid-covered services, which could help when enrollees lack reliable transportation.⁴¹ Still, States said that this solution can be limited as not all providers

offered telehealth; some services must be rendered in person; and not all enrollees have access to internet or smartphones to participate in telehealth.

States reported connecting to Ryan White Program recipients as a promising approach to address enrollees' unmet health-related social needs

States said that they use their local Ryan White Program recipients to connect enrollees with HIV to social services. These programs provide medical care, medications, and essential support services to people with HIV—including Medicaid enrollees—that meet the programs' eligibility requirements. The support services offered under this program align with many of the unmet health-related social needs that States and Plans reported as barriers to ensuring HIV care—including housing and medical transportation.⁴² When an enrollee receives services from a Ryan White Program recipient, Medicaid pays for the services it covers and the Ryan White Program covers the cost of needed services that are not fully covered by Medicaid or other sources of coverage.⁴³ One State reported that its Medicaid program is integrated with its respective Ryan White Program recipient, such that Medicaid enrollees are automatically enrolled in both programs if they are eligible. Two other States reported regularly collaborating with their Ryan White Program recipients to help with care coordination for enrollees with HIV. States did not report significant challenges with connecting Medicaid enrollees to their Ryan White Program recipients.



Medicaid Enrollee Participation in the Ryan White Program

In 2022, approximately 39 percent of the 537,254 clients served by HRSA's Ryan White HIV/AIDS Program were covered by Medicaid, including those dually enrolled in Medicaid and Medicare.⁴⁴

As Ryan White Program clients lost Medicaid coverage during Medicaid unwinding, they may need Ryan White Program funds to cover the costs of services. HHS has recognized the importance of HRSA's Ryan White Program for Medicaid enrollees with HIV.

Medicaid enrollees who also receive services through the Ryan White Program have been shown to have higher rates of viral suppression than those who do not. 45 Given this benefit, HRSA is working with CMS and Ryan White Program recipients to ensure that enrollees with HIV who lost Medicaid coverage due to the expiration of the COVID-19 Public Health Emergency's continuous

coverage requirements (also known as Medicaid "unwinding") continue receiving care to achieve and maintain viral suppression. 46 CMS also reported that it regularly collaborates with HRSA on efforts related to HIV care, given HRSA's expertise in this area.

States and Plans reported that shortages of HIV care providers impact enrollees' access to care

HIV care providers, who encompass a range of clinical provider types, are providers who are knowledgeable about HIV care and have the role of guiding care and monitoring progress for people with HIV. The care team for a person with HIV should include a primary HIV care provider and other providers who are experts in taking care of people with HIV (i.e., nurses, pharmacists, mental health workers), and may include social service providers (i.e., social workers, case managers, substance use specialists).⁴⁷

However, States and Plans reported insufficient availability of HIV care providers to treat enrollees with HIV, which impacts the quality and timeliness of care that enrollees with HIV receive. States and Plans that discussed HIV provider availability did so generally and in the context of the Medicaid program. For example, one State said that in some areas there is a limited number of providers who offer HIV care, and therefore enrollees with HIV may need to wait 2 to 3 months to get a first appointment. Another State said that HIV care providers can only serve as consultants rather than primary care physicians due to shortages of these providers in some areas. The State further said that without available HIV care providers, it is challenging for enrollees with HIV to receive optimal care.

When we're talking about working to meet an individual's needs ... we're down nurses, we're down physicians, we're down direct care workers. ... getting anybody connected to timely and consistent care services [is] just a struggle.

-State Medicaid official

To help address the impact of provider shortages on HIV care, States and Plans said that they trained and/or offered guidance about caring for patients with HIV, but the impact of these efforts may be limited. For example, one State said that it connects HIV care and primary care providers to ongoing education and training about caring for enrollees with HIV. Another State said that it also offers training to medical providers about caring for people with HIV, but the decision to prioritize efforts focused on people with HIV is up to the discretion of the organization that the providers work for. While training of non-HIV care providers to work with people with HIV could help alleviate the impact of HIV provider shortages, there are also workforce shortages among other provider types such as primary care physicians. Therefore, preparing these providers to work with patients with complex needs such as HIV may also require decreased workloads and additional compensation.⁴⁹

HHS Response to Workforce Shortages

HHS recognizes the need to address general provider shortages through workforce expansion. Specifically, CDC and HRSA currently offer multiple grant opportunities to expand and strengthen public health and health care workforces. 50, 51 CMS has also approved Section 1115 demonstrations to use Medicaid funds for provider student loan repayment and/or training. 52, 53 Though not specific to HIV, these HHS opportunities are relevant to provider types that may be essential to people with HIV's care team, including mental health, substance use, and nursing. Further, a few opportunities may also fill shortages with providers who deliver culturally competent care by focusing on providers from underrepresented groups. 54, 55 Though not all of these efforts are specific to Medicaid, they may reach providers who serve enrollees with HIV.

States and Plans reported challenges accessing data that could help them monitor care and outcomes for enrollees with HIV

States and Plans described challenges in getting access to data that could help them monitor care provided and clinical outcomes for their enrollees with HIV. These data included enrollees' viral load levels, Medicare claims for dually eligible enrollees, and other data currently unavailable in Medicaid claims.

The biggest challenge is just getting... validated data that we can rely upon to [take] actionable steps.
-State Medicaid official

Some States cannot access surveillance data to assess viral suppression for Medicaid enrollees, while others can access these data but reported some limitations

With data on viral suppression for enrollees, Medicaid programs can better gauge if the care needs of enrollees with HIV are being met. Further, more States reporting viral suppression data to CMS as part of the Adult Core Set would allow CMS to better gauge viral suppression among Medicaid enrollees at a national level. 56

Some States reported challenges with measuring viral suppression statuses of enrollees with HIV due to legal and privacy restrictions for sharing data with HIV surveillance programs. As payers, Medicaid programs can generally see that viral load tests were done via enrollees' claims, but they cannot see the results of those tests. HIV surveillance programs, however, are funded by CDC to collect the results of viral load tests from providers and laboratories for each person diagnosed with HIV in their state, and report it to CDC to calculate viral suppression nationally. Therefore, States

must rely on these programs to access viral load data if they want to monitor viral suppression specifically for Medicaid enrollees with HIV. However, one State said that its HIV surveillance program would not agree to share viral suppression data with Medicaid unless the exchange was bidirectional, which was not permitted per the States' policies. Another State noted that regulations for data can vary across agencies within their state in general, making sharing between groups challenging. A third State reported that statewide statute changes were needed to overcome legal barriers, and that these changes enabled the State to receive data from its HIV surveillance program. Previously, HIV surveillance data in this State could only be used for epidemiological monitoring (i.e., counting cases, reporting aggregate information) and notifying sexual partners of HIV exposure. Amendments to the State

statute expanded access to this data within the state for additional purposes, including to direct program needs.⁵⁷

Other States and a Plan reported that they can receive data from their HIV surveillance programs to monitor viral suppression for enrollees with HIV, but some noted limitations in using it. For example, one State said that it regularly sends its Medicaid eligibility files to its HIV surveillance program, which then provides viral suppression information for those enrollees with HIV. The State then sends that data to the enrollees' Plans to conduct outreach and coordinate care. The State also uses viral suppression as one of its incentivized quality measures for Plans. Another State reported that it uses the data it receives from its HIV surveillance program to monitor viral suppression statuses for its enrollees and submit information to CMS as part of the Adult Core Set. However, this State also noted that its HIV surveillance program provides aggregate viral suppression statuses for Medicaid enrollees but does not provide insight into the matching process to guarantee accuracy of these calculations. Additionally, a Plan reported that it received indicators of viral suppression for enrollees but did not receive the actual viral load levels, which would help the Plan prioritize outreach to enrollees most in need.

States also identified ways to promote better collaboration with HIV surveillance programs. For example, one State said that because there can be differences in data management between Medicaid and HIV surveillance programs, a template or crosswalk that decoded some of the data language differences between programs could help with data sharing. HHS has previously acknowledged cross-agency differences between Medicaid and other state agencies and noted a need for shared project objectives to build strong partnerships through learnings from the 2016 HIV Health Improvement Affinity Group. To One State suggested that CMS could bring States together to learn from one another about best practices to overcoming agency differences. States also discussed the general division of efforts and funding across their states, noting that Medicaid may be excluded from planning when HHS funding, such as that provided as part of the *Ending the HIV Epidemic in the United States* initiative, goes to other agencies—despite Medicaid's key role as a payer. Therefore, States said that improving the alignment of HHS opportunities and efforts could help them better support state-level HIV efforts when relevant.

For enrollees with HIV in both Medicaid and Medicare, States reported having access to some, but not all, claims for services paid by Medicare

States reported having only partial access to claims for Medicarecovered services received by enrollees with HIV who are dually enrolled in Medicaid and Medicare (dually eligible enrollees). States typically only have records of the services that Medicaid paid for in enrollees' claims. However, for dually eligible enrollees, Medicare is the primary payer for most covered services. 60 Therefore, States reported that they do not automatically receive records of those Medicare claims except in the case of "cross-over" claims, in which Medicaid is responsible for partial payment of a service covered by Medicare (i.e., to cover deductibles or coinsurance). One State noted that it can also see Medicare claims if enrollees are in aligned managed care plans,



Dually Eligible Enrollees with HIV

When reviewing Medicaid and Medicare claims, OIG previously found that 46 percent of enrollees with HIV were dually eligible for Medicaid and Medicare. These enrollees were more likely to have received critical HIV services than were those with Medicaid only.⁵⁹

Without complete Medicare claims data, States may not be aware of HIV services these enrollees received that were covered by Medicare. As a result, they might allocate resources to care coordination to address gaps that do not exist.

meaning that they are enrolled in the same plan for both programs. Without a complete view of services, States may not be able to accurately target care coordination efforts for enrollees with HIV who experience gaps in care.

CMS helps States access certain additional Medicare data when they are requested through its Medicare-Medicaid Data Sharing Program. Through this program, States can request access to Medicare fee-for-service data files for Parts A and B claims (current and historical), Medicare Part D Event data, and assessment data (i.e., Minimum Data Set, Home Health Outcome and Assessment Information Set). Due to policy restrictions, CMS reported, it cannot provide Medicare Advantage data to States. To request access to available fee-for-service data, States must work with the State Data Resource Center, run by CMS contractors, to complete necessary forms and get approval from CMS before receiving the data—a process that can generally take 2 to 3 months. When States are granted access to data, the frequency and delivery of data varies by data type. For example, States can receive nonfinal, current Part A and Part B data through daily or weekly automatic electronic feeds with a 2-week lag. The other available data files are available through monthly or annual delivery with longer data lags. The State Data Resource Center also provides technical

assistance to help States select and use the available Medicare data to support dually eligible enrollees on the basis of States' priorities.⁶⁵ For example, it has held webinars on using Medicare data to identify areas of needs for interventions focused on specific conditions, such as diabetes.

Despite the availability of this support, States may still experience barriers that prevent them from accessing and using additional Medicare data for their program needs. Currently, 29 States receive Medicare data through the State Data Resource Center. Of the States we interviewed, one said that it had data use agreements set up through the State Data Resource Center but did not yet have the capacity to receive Medicare data. CMS similarly noted that some States cite lack of administrative staff and/or funding available to prioritize Medicare data sharing despite the available support. Moreover, one State that does receive Medicare data reported that the data lag impacted its abilities to provide timely information on Medicare claims to Plans. Another State said that there is a continued need to enhance the ease of accessing Medicare data for States. Since 2017, CMS has made efforts to streamline the data request process through the State Data Resource Center by reducing the average turnaround time for CMS approval of data requests and by developing a data use agreement that allows States to maintain one agreement to access five different data sharing projects.

Some States and a Plan identified additional types of data that could help them monitor the care of enrollees with HIV and take action where needed

Some States and a Plan also reported limited access to other data that could help them better target care. For example, a Plan reported that it does not have data on enrollees' sexual orientation and relevant health-related social needs which could help identify disparities to better reach specific enrollees in culturally sensitive ways. CMS has recognized the importance of this type of data by adding optional sexual orientation and gender identity questions for States to add to their enrollment systems and promoting documentation of health-related social needs in enrollees' electronic health records. Because these efforts occurred during or after our interviews, we did not learn about States and Plans' experiences and/or successes with using them to access additional data.

Additionally, the Plan reported that it had limited view of services that its State Medicaid program paid through fee-for-service (i.e., not as part of its managed care program). Specifically, the Plan said that it does not see uptake of ART because ART is one of the prescription drugs that are paid through fee-for-service Medicaid, not managed care, in its State. The Plan has been able to access prescription information, including for ART, for only the subset of enrollees with HIV that also have Hepatitis C through a statewide initiative for treating Hepatitis C.

States and a Plan said that insufficient administrative staffing within their programs and plans impacts their abilities to identify and coordinate care needs

States and a Plan reported that they experienced staffing shortages within their programs and plans which impacted their abilities to coordinate and monitor care for enrollees. For example, a State and a Plan said that staffing shortages limited their capacity to provide individual care management for all enrollees. By not being able to conduct individual care management, States and Plans may miss opportunities to identify the unique needs of their enrollees with HIV and connect them to needed services to attain viral suppression.

Additionally, States said that limited administrative staffing impacted efforts to access and use data that could help them monitor the care and outcomes of enrollees with HIV. As previously discussed, CMS and a State noted that staffing capacity can impact States' ability to prioritize accessing available Medicare data to view services received by dually eligible enrollees with HIV. States also reported that insufficient administrative staffing prevented them from or limited them in working with their HIV surveillance programs to access viral load data and then use that data to monitor viral suppression and/or report it to CMS as part of the Adult Core Set. For example, a State that participated in the HIV Health Improvement Affinity Group in 2016 said that while it was able to develop a data use agreement to share viral load data, it stopped participating in the group because it did not have the staff or funding available to dedicate the time. Another State said that limited staffing in its Medicaid and HIV surveillance programs prevented sharing and monitoring of viral suppression for enrollees despite the State's having established agreements and working relationships.

Ultimately the goal is to report the [viral suppression] measure to CMS and also to be able to have that information for our own internal monitoring purposes ... the only challenge really is just resources, staffing, and limited time available ... we have the data, we have the data sharing agreement in place, we have a good working relationship ... staff capacity is the biggest issue.

-State Medicaid official

States reported using contractors as workarounds to meet program needs despite staffing shortages. Specifically, States reported funding external staff to work on program evaluations, redesigning their waiver program, and/or working with viral suppression data. For example, a State said it has an external evaluator review enrollees' lab tests and medications to find enrollees in need of support. Another State said that it has access to an epidemiologist as part of HRSA's Ryan White HIV/AIDS Program's Building Capacity to Improve Collecting and Reporting Viral Suppression Data to the Medicaid Adult Core Set initiative, which has helped with

working on viral suppression data reporting.⁷⁰ Though these workarounds do not fill overall staffing shortages, they provide ways for States that are struggling with staffing to be able to continue their efforts to ensure that enrollees with HIV receive care.

CONCLUSION AND RECOMMENDATIONS

As the largest source of insurance for people with HIV in the United States, Medicaid has an opportunity to not only support individual care outcomes but also promote HHS efforts to prevent new HIV transmissions nationally. Medicaid covers services that are critical for all people with HIV to help them achieve and maintain viral suppression. The States and Plans that we interviewed also reported voluntary efforts, beyond payment of services, to ensure that their enrollees with HIV received needed care. However, previous OIG work found that one in four Medicaid enrollees with an HIV diagnosis may have not received services recommended to all people with HIV per HHS guidelines.

All States and Plans that we interviewed reported challenges that impacted their efforts to ensure that enrollees with HIV received needed care. Two of these challenges—unmet health-related social needs and provider shortages—reflect systemic, national problems that no one agency or program can solve alone. However, CMS has opportunities to help States and Plans mitigate the effects of these problems for Medicaid enrollees with HIV. Two other challenges reported by States and Plans—limited access to data and insufficient administrative staff—reflect operational issues in the Medicaid program. As such, CMS can take steps to further assist States in addressing these issues to support better care for Medicaid enrollees with HIV. Specifically, we recommend that CMS:

Pursue further actions to help States share knowledge with each other and coordinate internally regarding strategies to ensure needed care for Medicaid enrollees with HIV

States reported interest in learning from each other to help strengthen their efforts to ensure that Medicaid enrollees with HIV receive needed care. CMS collaborated with HRSA and CDC to promote such learning with the HIV Health Improvement Affinity Group in 2016, and highlighted its success at helping participating States make progress with collecting viral load data. However, many of the State staff that we interviewed had not participated in the Affinity Group due to staff turnover. Further, best practices and opportunities relevant to Medicaid enrollees with HIV may have evolved since 2016.

Therefore, CMS should pursue further actions to facilitate HIV-related knowledge sharing across States that are sustainable and capable of incorporating new information over time. These actions could take a number of forms, such as initiating a new HIV-focused community of practice for States, issuing new guidance that highlights effective State-level practices, and/or providing targeted technical

assistance to States. In doing so, CMS should strive to address frequently reported challenges and opportunities, such as:

- Leveraging Medicaid benefits and flexibilities, as well as the Ryan White Program recipients, to address enrollees' unmet health-related social needs;
- Recruiting and/or training HIV care providers;
- Strengthening relationships with HIV surveillance programs; and
- Accessing data beyond Medicaid claims.

Additionally, the actions CMS pursues should focus on coordination between relevant entities at the State level, including Medicaid agencies, managed care plans, Ryan White Program recipients, and/or HIV surveillance programs. All of these entities play key roles in providing and tracking care for people with HIV, including Medicaid enrollees, and improved coordination could help mitigate systemic and operational challenges to improve outcomes. For example, CMS could explore ways to assist States in automating Ryan White enrollment for eligible Medicaid enrollees with HIV, as one State reported doing, to help address those enrollees' unmet health-related social needs. CMS should continue to collaborate with other Federal agencies and HHS operating divisions, including HRSA and CDC, as part of its efforts.

Take additional steps to help States leverage the State Data Resource Center to access and use Medicare data for dually eligible enrollees with HIV

CMS should work with the State Data Resource Center to identify new opportunities to help States access and use Medicare data to identify gaps in care among dually eligible enrollees with HIV. CMS has taken numerous steps in recent years to streamline the data request and sharing process with the State Data Resource Center, but some States nonetheless reported challenges in accessing and using Medicare data for this purpose. Accordingly, CMS should explore ways to better leverage the State Data Resource Center's technical assistance to support States that may not have staff with experience using Medicare data for HIV-related tracking and analysis. For example, the center could further strengthen available resources and/or individual assistance regarding the data files and types of analysis needed to effectively identify HIV diagnoses and claims related to HIV care for dually eligible enrollees. Such steps could help minimize the level of effort and expertise required for States with limited staffing.

AGENCY COMMENTS AND OIG RESPONSE

CMS concurred with our two recommendations.

In response to our first recommendation, that CMS help States share knowledge and coordinate on strategies, CMS stated that it will take additional action to help facilitate HIV-related knowledge sharing across States. In doing so, CMS said that it will continue to coordinate with Federal partners and will reiterate the importance of continued collaboration and coordination at the state level.

In response to our second recommendation, that CMS help States access and use Medicare data for dually eligible enrollees, CMS stated that it will work to help States better use available Medicare data for dually eligible people with HIV, including by instructing its State Data Resource Center to provide technical assistance on using Medicare data for HIV-related data analyses. CMS described improvements it has made to its process to support States' access to available Medicare data. OIG appreciates these actions and believes that the technical assistance CMS plans to provide will further help States monitor and address gaps in care for dually eligible enrollees with HIV.

For the full text of CMS's comments, see the Agency Comments appendix at the end of the report.

APPENDIX

Agency Comments

Following this page are the official comments from CMS.







Administrator Washington, DC 20201

September 6th, 2024 DATE:

TO: Ann Maxwell

> Deputy Inspector General for Evaluation and Inspections

Chiquita Brooks-LaSure Chiq & LaS FROM:

Centers for Medicare & Medicaid Services

Office of Inspector General (OIG) Draft Report: Systemic and Operational **SUBJECT:**

Challenges Hinder Efforts to Ensure HIV Care for Medicaid Enrollees (OEI-05-

22-00242)

The Centers for Medicare & Medicaid Services (CMS) appreciates the opportunity to review and comment on the Office of Inspector General's (OIG) draft report. In the United States there are more than 1.2 million people with HIV, and Medicaid is the largest source of health coverage for this population. Ensuring that eligible individuals can access covered services is a crucial element of the Medicaid program and a priority for CMS.

As described in the OIG's report, linkage to and retention in HIV care and treatment are crucial to achieving sustained viral suppression, which can result in reduced transmission to others and improved clinical outcomes for people with HIV. However, challenges related to health-related social needs (HRSNs), such as inadequate access to food or housing, often impede the connection and adherence to HIV care and treatment for people with HIV. States have broad flexibility in how they design their Medicaid programs and can choose to adopt various models of care intended to address unmet HRSNs and improve outcomes. For example, states may elect to adopt the optional Medicaid state plan benefit for Health Homes under section 1945 of the Social Security Act (the Act) to cover certain services that can help improve care coordination for people with Medicaid who have chronic conditions. Many of the services included in the statutory definition of section 1945 Health Home services, such as comprehensive care management, health promotion, and referral to community and social support services, are also recommended strategies for improving engagement in care among people with HIV. As of August 2024, 19 states and the District of Columbia have a total of 34 approved section 1945 Medicaid Health Home state plan amendments, including three states that have included HIVinfection among their eligibility criteria.

In addition, states may elect to cover Home and Community Based Services (HCBS) as part of their Medicaid programs. HCBS make it possible for individuals to receive services in their own home or community rather than institutions and can also provide opportunities for states to

Systemic and Operational Challenges Hinder Efforts to Ensure HIV Care for Medicaid Enrollees ÓEI-05-22-00242

¹ Section 1945(h)(4)(B) of the Act; CMS, Health Home Information Resource Center. Accessed at: https://www.medicaid.gov/resources-for-states/medicaid-state-technical-assistance/health-home-informationresource-center/index.html

address unmet HRSNs of people with HIV.² Subject to CMS approval, states have flexibility to determine the types of HCBS they provide and the populations they serve, as well as whether HCBS are offered under the Medicaid state plan or a waiver program. For example, under section 1915(c) HCBS waiver programs, states can cover a range of services that address unmet HRSNs, such as housing and tenancy support, case management, or home-delivered meals. All states currently provide some form of HCBS, and eight states operate HIV-focused section 1915(c) HCBS waiver programs. Through Section 1115 Demonstration authority, states can test innovative approaches for addressing unmet HRSNs in ways that consider local challenges and response capabilities. For example, subject to CMS approval, states can use Section 1115 Demonstration authority to test the effectiveness of providing housing transition and navigation services for individuals experiencing or at risk of experiencing homelessness. States can also request approval from CMS to test coverage for evidence-based nutritional assistance and medically tailored meals for certain individuals where there is a clinical need. As of August 2024, ten states have received approval for Section 1115 Demonstration authority to provide both housing and nutrition interventions and CMS continues to work with additional states that are interested in these opportunities.

People with HIV enrolled in Medicaid may also be able to receive care coordination and other support services through other federal, state, local, or private programs. For example, the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV through grants to states, cities, counties, and local community-based organizations. Coordination between RWHAP recipients, State Medicaid Agencies, and public health departments is a critical and complex undertaking, and, at the federal level, CMS, HRSA, and the Centers for Disease Control and Prevention (CDC) work together to help facilitate this coordination.^{3,4} For example, as noted in the OIG's report, CMS, HRSA, and CDC launched a year-long HIV Health Improvement Affinity Group in 2016 that sought to support collaborations between public health departments and State Medicaid Agencies to improve rates of sustained virologic suppression among people with HIV enrolled in Medicaid.⁵ A total of 19 states participated in the affinity group, where they developed and implemented performance improvement projects designed to establish data linkages, address gaps along the HIV care continuum and improve health outcomes among people with HIV enrolled in Medicaid.

As discussed above, improving rates of viral load suppression among people with HIV is critical to realizing individual, population, and community health improvements, as well as any cost savings associated with them. The Medicaid Adult Core Set includes an HIV Viral Load Suppression measure, which assesses the percentage of Medicaid enrolled adults with HIV that

guidance/downloads/cib11162023.pdf.

² CMS, Coverage of Services and Supports to Address Health-Related Social Needs in Medicaid and the Children's Health Insurance Program. 2023. Accessed at: https://www.medicaid.gov/federal-policy-

³ CMS and HRSA, Coordination between Medicaid and Ryan White HIV/AIDS Programs. 2013. Accessed at: https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-05-01-2013.pdf

⁴ CMS, HRSA, and CDC, Opportunities to Improve HIV Prevention and Care Delivery to Medicaid and CHIP Beneficiaries. 2016. Accessed at: https://www.medicaid.gov/federal-policy-guidance/downloads/cib120116.pdf
⁵ CMS, HRSA, and CDC, Join the HIV Health Improvement Affinity Group. 2016. Accessed at: https://files.hiv.gov/s3fs-public/HIV-Health-Improvement-Affinity-Group.pdf

are virally suppressed in a given measurement year. However, acquiring the data necessary to calculate this measure can pose challenges for state Medicaid programs, and only 11 states voluntarily reported this measure to CMS in 2022. To support states in this area, HRSA and CMS launched the Building Capacity to Improve Collecting and Reporting Viral Suppression Data to the Medicaid Adult Core Set RWHAP Part F Special Projects of National Significance initiative in 2021. Two of the main goals of this initiative are to increase the capacity for participating states to report high-quality HIV viral suppression data to CMS, and to disseminate and promote the replication of findings and lessons learned from the project with other states and stakeholders. This initiative is still ongoing, and HRSA and CMS continue to work closely with participating states.

The OIG's recommendations and CMS's responses are below.

OIG Recommendation

Pursue further actions to help States share knowledge with each other and coordinate internally regarding strategies to ensure needed care for Medicaid enrollees with HIV.

CMS Response

CMS concurs with this recommendation. CMS is committed to improving access to quality and comprehensive health care for all Medicaid enrolled individuals, including people with HIV. As such, CMS will take additional action to help facilitate HIV-related knowledge sharing across states. In doing so, CMS will continue to coordinate with other federal partners and will reiterate the importance of continued collaboration and coordination at the state level.

OIG Recommendation

Take additional steps to help States leverage the State Data Resource Center to access and use Medicare data for dually eligible enrollees with HIV.

CMS Response

CMS concurs with this recommendation. CMS recognizes the importance of providing coordinated health care services to people dually eligible for Medicaid and Medicare, including for people with HIV. As such, CMS and its State Data Resource Center (SDRC) have implemented several process improvements in recent years to increase the ability of State Medicaid Agencies to access Medicare data. For example, CMS and the SDRC worked to reduce the number of actions a state needs to take yearly to maintain its data sharing agreement with CMS. In addition, the SDRC regularly provides technical assistance to states throughout the data request process, including working with states to help assess what CMS data would best suit their needs and assisting with understanding and working with the CMS data upon receipt. CMS will work to help states better use available Medicare data for dually eligible people with HIV, including by instructing the SDRC to provide technical assistance on using Medicare data for HIV-related data analyses.

CMS thanks OIG for its efforts on this issue and looks forward to working with OIG on this and other issues in the future.

ACKNOWLEDGMENTS AND CONTACT

Acknowledgments

Danielle Noriega served as the team leader for this study, and Gabriella Herter served as the lead analyst. Others in the Office of Evaluation and Inspections Chicago Regional Office who conducted the study include Thaddeus Chatto and Relicious Eboh. Office of Evaluation and Inspections headquarters staff who provided support include Sara Bodnar, Lyndsay Hopper, and Sara Swisher.

This report was prepared under the direction of Laura Kordish, Regional Inspector General for Evaluation and Inspections in the Chicago regional office; Adam Freeman, Deputy Regional Inspector General; and Hilary Slover, Assistant Regional Inspector General.

Contact

To obtain additional information concerning this report, contact the Office of Public Affairs at Public.Affairs@oig.hhs.gov. OIG reports and other information can be found on the OIG website at oig.hhs.gov.

Office of Inspector General U.S. Department of Health and Human Services 330 Independence Avenue, SW Washington, DC 20201

ABOUT THE OFFICE OF INSPECTOR GENERAL

Office of Inspector General

https://oig.hhs.gov

The mission of the Office of Inspector General (OIG) is to provide objective oversight to promote the economy, efficiency, effectiveness, and integrity of the Department of Health and Human Services (HHS) programs, as well as the health and welfare of the people they serve. Established by Public Law No. 95-452, as amended, OIG carries out its mission through audits, investigations, and evaluations conducted by the following operating components:

The Office of Audit Services. OAS provides auditing services for HHS, either by conducting audits with its own audit resources or by overseeing audit work done by others. The audits examine the performance of HHS programs, funding recipients, and contractors in carrying out their respective responsibilities and provide independent assessments of HHS programs and operations to reduce waste, abuse, and mismanagement.

The Office of Evaluation and Inspections. OEI's national evaluations provide HHS, Congress, and the public with timely, useful, and reliable information on significant issues. To promote impact, OEI reports also provide practical recommendations for improving program operations.

The Office of Investigations. OI's criminal, civil, and administrative investigations of fraud and misconduct related to HHS programs and operations often lead to criminal convictions, administrative sanctions, and civil monetary penalties. OI's nationwide network of investigators collaborates with the Department of Justice and other Federal, State, and local law enforcement authorities. OI works with public health entities to minimize adverse patient impacts following enforcement operations. OI also provides security and protection for the Secretary and other senior HHS officials.

The Office of Counsel to the Inspector General. OCIG provides legal advice to OIG on HHS programs and OIG's internal operations. The law office also imposes exclusions and civil monetary penalties, monitors Corporate Integrity Agreements, and represents HHS's interests in False Claims Act cases. In addition, OCIG publishes advisory opinions, compliance program guidance documents, fraud alerts, and other resources regarding compliance considerations, the anti-kickback statute, and other OIG enforcement authorities.

ENDNOTES

- ¹ Centers for Disease Control and Prevention (CDC), "Estimated HIV Incidence and Prevalence in the United States, 2018-2022," *HIV Surveillance Supplemental Report*, May 2024, see Prevalence: Persons Aged >= 13 Years Living With Diagnosed or Undiagnosed HIV on page 27. Downloadable document accessed at https://stacks.cdc.gov/view/cdc/156513 on June 24, 2024.
- ² CDC, "Estimated HIV Incidence and Prevalence in the United States, 2018-2022," *HIV Surveillance Supplemental Report*, May 2024, for percentage of U.S. population and HIV incidence see Black/African American on page 12 and for HIV prevalence see HIV Black/African American Persons on page 34. Downloadable document accessed at https://stacks.cdc.gov/view/cdc/156513 on June 24, 2024.
- ³ CDC, "Estimated HIV Incidence and Prevalence in the United States, 2018-2022," HIV Surveillance Supplemental Report, May 2024, for percentage of U.S. population and HIV incidence see Hispanic/Latino on page 12 and for HIV prevalence see Hispanic/Latino Persons on page 35. Downloadable document accessed at https://stacks.cdc.gov/view/cdc/156513 on June 24, 2024.
- ⁴ CDC, "Estimated HIV Incidence and Prevalence in the United States, 2018-2022," HIV Surveillance Supplemental Report, May 2024, see Figure 7 on page 14. Downloadable document accessed at https://stacks.cdc.gov/view/cdc/156513 on June 24, 2024.
- ⁵ CDC, *Understanding the HIV Care Continuum*, July 2019. Accessed at https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf on March 12, 2024. ⁶ Ibid.
- ⁷ CDC, *HIV Treatment as Prevention*, August 9, 2023. Accessed at https://www.cdc.gov/hiv/risk/art/index.html on March 12, 2024.
- ⁸ KFF, *The Ryan White HIV/AIDS Program: The Basics*, November 03, 2022. Accessed at https://www.kff.org/hivaids/fact-sheet/the-ryan-white-hivaids-program-the-basics/ on February 5, 2024.
- ⁹ This report uses "HIV surveillance program" to represent the entity at the state level that collects viral load data for residents with HIV. The specific entity (i.e., health department, public health department, HIV/AIDS program) conducting HIV surveillance efforts varied across the States we interviewed.
- ¹⁰ CDC, National HIV Surveillance System (NHSS), March 4, 2024. Accessed at https://www.cdc.gov/hiv-data/nhss/index.html#cdc survey profile how the information is used-how-nhss-data-are-used on June 10, 2024.
- ¹¹ CDC, Ending the HIV Epidemic in the U.S.: Accomplishments, June 9, 2023. Accessed at https://files.hiv.gov/s3fs-public/2023-07/CDC-EHE-Accomplishments.pdf on February 26, 2024.
- ¹² CDC, *About Ending the HIV Epidemic in the U.S.*, March 20, 2024. Accessed at https://www.cdc.gov/ehe/php/about/ on June 14, 2024.
- ¹³ CDC, *Ending the HIV Epidemic in the US Goals*, March 20, 2024. Accessed at https://www.cdc.gov/ehe/php/about/goals.html on June 14, 2024.
- ¹⁴ KFF, *Medicaid and People with HIV*, March 27, 2023. Accessed at https://www.kff.org/hivaids/issue-brief/medicaid-and-people-with-hiv/ on June 24, 2024; § 1902(a)(10)(A) of the Social Security Act.
- ¹⁵ Managed care is a health care delivery system organized to manage cost, utilization, and quality. Medicaid managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between States and managed care organizations. See CMS, *Managed Care*. Accessed at https://www.medicaid.gov/medicaid/managed-care/index.html on July 19, 2024.
- ¹⁶ KFF, *Medicaid Financing: The Basics*, April 13, 2023. Accessed at https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/ on March 29, 2024.

- ¹⁷ Section 1115 demonstrations allow States to test experimental, pilot, or demonstration projects that are likely to assist in promoting the objectives of the Medicaid program. These demonstrations give States flexibilities to design and improve their programs to better serve Medicaid enrollees. CMS reviews proposals for these projects to determine whether their objectives align with those of Medicaid and whether they are consistent with Federal policies. See CMS, *About Section 1115 Demonstrations*. Accessed at https://www.medicaid.gov/medicaid/section-1115-demonstrations/index.html on April 1, 2024.
- ¹⁸ In lieu of services or settings (ILOSs) are alternative services or settings that are substitutes for covered services or settings under the State plan. Medicaid managed care plans can provide ILOSs when the State determines it is a medically appropriate and cost-effective substitute within 42 CFR §§ 438.2 and 438.3(e)(2).
- ¹⁹ HHS, *Addressing Health-Related Social Needs in Communities Across the Nation*, November 2023. Accessed at https://aspe.hhs.gov/sites/default/files/documents/3e2f6140d0087435cc6832bf8cf32618/hhs-call-to-action-health-related-social-needs.pdf on April 23, 2024.
- ²⁰ CMS, *Addressing Health-Related Social Needs in Section 1115 Demonstrations*, December 6, 2022. Accessed at https://www.medicaid.gov/medicaid/downloads/addrss-hlth-soc-needs-1115-demo-all-st-call-12062022.pdf on March 29, 2024.
- ²¹ Menza, T. W., Hixson, L. K., Lipira, L., & Drach, L., "Social Determinants of Health and Care Outcomes Among People With HIV in the United States," *Open Forum Infectious Diseases*, 8(7), July 2021. Accessed at https://doi.org/10.1093/ofid/ofab330 on March 29, 2024.
- ²² CMS, *Adult Health Care Quality Measures*. Accessed at https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/adult-health-care-quality-measures/index.html on June 21, 2024.
- ²³ CMS, 2024 Core Set of Adult Health Care Quality Measures for Medicaid (Adult Core Set), see CMIT #325 HRSA. Accessed at https://www.medicaid.gov/medicaid/quality-of-care/downloads/2024-adult-core-set.pdf on June 21, 2024.
- ²⁴ CMS, *Quality of Care for Adults in Medicaid: Findings from the 2022 Adult Core Set*, January 2024, see Total for HIV Viral Load Suppression, page 102. Accessed at https://www.medicaid.gov/medicaid/quality-of-care/downloads/2022-adult-chartpack.pdf on June 21, 2024.
- ²⁵ CDC, *HIV Health Improvement Affinity Group: 2019 Evaluation Report*, 2019, see pages 9-12 for outcomes and pages 26-28 for program description. Accessed at https://stacks.cdc.gov/view/cdc/149324 on May 31, 2024.
- ²⁶ National Alliance of State and Territorial Aids Directors (NASTAD), *Building Capacity to Improve HIV Viral Suppression Data in Medicaid*, 2023. Accessed at https://nastad.org/sites/default/files/2023-12/PDF-Medicaid-HIV-SCP-Project-Fact-Sheet-120123.pdf on January 10, 2023. Also see NASTAD, *Reporting Viral Suppression Data in the Medicaid Data Set*. Accessed at https://targethiv.org/spns/medicaid-data-set on July 19, 2024.
- ²⁷ OIG, One Quarter of Medicaid Enrollees with HIV May Not Have Received Critical Services in 2021 (OEI-05-22-00240) August 31, 2023.
- ²⁸ We selected only comprehensive, risk-based managed care plans for interviews. We did not include other types of managed care arrangements in Medicaid, such as Prepaid Inpatient Health Plans (PIHPs), Prepaid Ambulatory Health Plans (PAHPs), or Primary Care Case Management (PCCM).
- ²⁹ We interviewed the following States for this study: Arizona, California, the District of Columbia, Georgia, Iowa, Louisiana, Maine, Mississippi, Nevada, New York, South Carolina, Virginia, and Washington. We also interviewed the following Plans for this study: Absolute Total Care, Healthfirst, Louisiana Healthcare Connections, and Michigan Meridian.
- ³⁰ CDC, *Issue Brief: The Role of Housing in Ending the HIV Epidemic*, 2022. Accessed at https://www.cdc.gov/hiv/policies/data/role-of-housing-in-ending-the-hiv-epidemic.html on May 2, 2024.
- ³¹ CDC, *HIV Outbreaks Among People Experiencing Homelessness and Housing Instability*, April 12, 2023. Accessed at https://www.cdc.gov/nchhstp/director-letters/hiv-among-people-experiencing-

homelessness.html?CDC AAref Val=https://www.cdc.gov/nchhstp/dear colleague/2023/2023-04-hiv-homelessness.html on June 24, 2024.

- ³² Yehia et al., "Barriers and facilitators to patient retention in HIV care," *BMC Infectious Diseases*, 15(246), June 28, 2015. Accessed at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4485864/ on April 26, 2024.
- ³³ KFF, Section 1115 Medicaid Waiver Watch: A Closer Look at Recent Approvals to Address Health-Related Social Needs (HRSN), March 4, 2024, see Appendix table 1. Accessed at https://www.kff.org/medicaid/issue-brief/section-1115-medicaid-waiver-watch-a-closer-look-at-recent-approvals-to-address-health-related-social-needs-hrsn/ on March 5, 2024. CMS reported to OIG that two additional States (Illinois and New Mexico) were approved for Section 1115 demonstrations to provide housing support in July 2024.
- ³⁴ CMS, *Additional Guidance on Use of In Lieu of Services and Settings in Medicaid Managed Care*, January 4, 2023. Accessed at https://www.medicaid.gov/sites/default/files/2023-01/smd23001.pdf on February 26, 2024.
- ³⁵ CMS, Coverage of Health-Related Social Needs (HRSN) Services in Medicaid and the Children's Health Insurance Program (CHIP) Table, November 2023. Accessed at https://www.medicaid.gov/sites/default/files/2023-11/hrsn-coverage-table.pdf on March 20, 2024.
- ³⁶ CMS, Coverage of Services and Supports to Address Health-Related Social Needs in Medicaid and the Children's Health Insurance Program CMCS Informational Bulletin, November 16, 2023. Accessed at https://www.medicaid.gov/sites/default/files/2023-11/cib11162023.pdf on March 20, 2024.
- ³⁷ Housing and Services Resource Center, *Expanding Access to Housing-Related Services and Supports*, February 9, 2024. Accessed at https://acl.gov/HousingAndServices/Accelerator on April 2, 2024.
- ³⁸ HUD, *Housing Opportunities for Persons with AIDS Program*. Accessed at https://www.hud.gov/program_offices/comm_planning/hopwa on April 1, 2024.
- ³⁹ 42 CFR § 431.53.
- ⁴⁰ CMS, Assurance of Transportation: A Medicaid Transportation Coverage Guide, September 28, 2023, see Payment, pages 29-31. Accessed at https://www.medicaid.gov/federal-policy-guidance/downloads/smd23006.pdf on September 6, 2024.
- ⁴¹ CMS, *Telehealth*, May 2023. Accessed at https://www.medicaid.gov/medicaid/benefits/telehealth/index.html on February 26, 2024.
- ⁴² HRSA, *Available Care and Services*, February 2022. Accessed at https://ryanwhite.hrsa.gov/hiv-care/services on February 26, 2024.
- ⁴³ HRSA, Clarifications Regarding Medicaid-Eligible Clients and Coverage of Services by the Ryan White HIV/AIDS Program, December 13, 2013. Accessed at https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/1301-pcn-medicaid-eligible.pdf on April 3, 2024.
- ⁴⁴ HRSA, *Ryan White HIV/AIDS Program Annual Data Report 2022*, December 2023, see Health care coverage in Table 1a. Accessed at https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2022.pdf on March 27, 2024. Note that 566,846 clients were served by the Ryan White Program in 2022. However, the percentage for health care coverage is out of 537,254 due to missing data.
- ⁴⁵ HRSA, *Program Letter*, March 23, 2023. Accessed at https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/medicaid-continious-enrollment-unwinding-program-letter.pdf on April 2, 2024.
- 46 Ibid.
- ⁴⁷ CDC, Treating HIV, April 12, 2024. Accessed at https://www.cdc.gov/hiv/treatment/ on May 29, 2024.
- ⁴⁸ States and Plans did not provide further detail on how HIV provider availability compares for other payers or how this issue related to HIV providers accepting patients with Medicaid.
- ⁴⁹ Wijesinghe, S., & Alexander, J., "Management and Treatment of HIV: are primary care clinicians prepared for their new role?," *BMC Family Practice*, 21(130), July 1, 2020. Accessed at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7330969/ on April 2, 2024.

- ⁵⁰ CDC, CDC Awards More Than \$3 Billion to Improve U.S. Public Health Workforce and Infrastructure, November 29, 2022. Accessed at https://www.cdc.gov/media/releases/2022/p1129-cdc-infrastructure.html on April 2, 2024.
- ⁵¹ HRSA, *Apply for a Health Workforce Grant*, February 2024. Accessed at https://bhw.hrsa.gov/funding/apply-grant on February 26, 2024.
- ⁵² CMS, *MassHealth Medicaid and CHIP Section 1115 Demonstration*, Demonstration Approval, July 15, 2024, Workforce Initiatives, page 11. Accessed at https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ma-masshealth-dmnstn-aprl-atchmt-p.pdf on July 22, 2024.
- ⁵³ CMS, *Medicaid Redesign Team*, Demonstration Approval, January 9, 2024, Strengthen the Workforce, page 6. Accessed at https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ny-medicaid-rdsgn-team-appvl-01092024.pdf on July 22, 2024.
- ⁵⁴ HRSA, *Centers of Excellence Program*, November 2023. Accessed at https://bhw.hrsa.gov/programs/centers-excellence-program-coe on May 29, 2024.
- ⁵⁵ Kaiser Permanente, *Hiring alone won't solve the health care worker shortage*, March 7, 2023. Accessed at https://about.kaiserpermanente.org/news/hiring-alone-wont-solve-health-care-worker-shortage on February 26, 2024.
- ⁵⁶ CMS, 2024 Core Set of Adult Health Care Quality Measures for Medicaid (Adult Core Set), 2024, see CMIT #325 HIV Viral Load Suppression (HVL-AD). Accessed at https://www.medicaid.gov/sites/default/files/2023-08/2024-adult-core-set 0.pdf on June 14, 2024.
- ⁵⁷ Gasner, M. R., Fuld, J., Drobnik, A., & Varma, J. K., "Legal and Policy Barriers to Sharing Data Between Public Health Programs in New York City: A Case Study," *American Journal of Public Health*, 104(6), 993–997, June 2014, see HIV. Accessed at https://doi.org/10.2105/AJPH.2013.301775 on February 26, 2024, N.Y. Pub. Health Law § 2135(c).
- ⁵⁸ CDC, *HIV Health Improvement Affinity Group: 2019 Evaluation Report*, 2019, see Cross-agency differences on page 15. Accessed at https://stacks.cdc.gov/view/cdc/149324 on May 31, 2024.
- ⁵⁹ OIG, One Quarter of Medicaid Enrollees with HIV May Not Have Received Critical Services in 2021 (OEI-05-22-00240) August 31, 2023. Note that percentage is based on 123,186 dual-eligible enrollees (Exhibit 2) out of 265,493 total enrollees with HIV in the study. Accessed at https://oig.hhs.gov/oei/reports/OEI-05-22-00240.asp on April 1, 2024.
- ⁶⁰ CMS, *How Medicare Works with Other Insurance*, page 10. Accessed at https://www.medicare.gov/publications/02179-how-medicare-works-with-other-insurance.pdf on May 31, 2024.
- ⁶¹ State Data Resource Center, Requesting and Using Medicare Data for Medicare-Medicaid Care Coordination and Program Integrity: An Overview, May 2023, see Table 1 on pages 9-10. Accessed at https://assets.website-files.com/62cc437d87d8a35aa080095a/646cef332f00862c69f64557 Requesting-and-Using-Medicare-Data-Overview.pdf on May 9, 2024.
- ⁶² State Data Resource Center, *The SDRC Data Request Process*, June 14, 2023. Accessed at https://assets.website-files.com/62cc437d87d8a35aa080095a/657a202826314d7c0851e038 SDRC-Data-Request-Process-Webinar (4).pdf on May 9, 2024.
- ⁶³ State Data Resource Center, *Medicare-Medicaid Data Sharing Program Data Request Process Timeline*. Accessed at https://assets.website-files.com/62cc437d87d8a35aa080095a/654aad91cfca85b9b36b3622 SDRC-Data-Timeline-Flyer.pdf on May 9, 2024.
- ⁶⁴ State Data Resource Center, *The SDRC Data Request Process*, June 14, 2023, see table on slide 10. Accessed at https://assets.website-files.com/62cc437d87d8a35aa080095a/657a202826314d7c0851e038 SDRC-Data-Request-Process-Webinar (4).pdf on May 9, 2024.
- ⁶⁵ State Data Resource Center, *Who We Are.* Accessed at https://www.statedataresourcecenter.com/about/about-us on May 9, 2024.
- ⁶⁶ State Data Resource Center, Home page, see States Using SDRC To Obtain Data. Accessed at https://www.statedataresourcecenter.com/ on May 9, 2024.

⁶⁷ CMS, New Sexual Orientation and Gender Identity (SOGI) Questions on the Marketplace Application. Accessed at https://www.cms.gov/files/document/sogi-questions-marketplace-application.pdf on March 29, 2024.

⁶⁸ CMS, Using Z Codes: The Social Determinants of Health (SDOH) Data Journey to Better Outcomes, June 2023. Accessed at https://www.cms.gov/files/document/zcodes-infographic.pdf on March 29, 2024.

⁶⁹ Though we interviewed staff from other States that participated in the HIV Health Improvement Affinity Group, many reported that they did not directly participate in the initiative in 2016 and could not share experiences.

⁷⁰ Though we interviewed staff from other States participating in HRSA's Ryan White HIV/AIDS Program's Building Capacity to Improve Collecting and Reporting Viral Suppression Data to the Medicaid Adult Core Set initiative, their reported direct experiences with the program were limited. Therefore, it is unclear if all States in this program have similar success with staffing support.