October 28, 2025

Caprice Knapp, PhD
Deputy Administrator and Director (Acting)
Center for Medicaid and CHIP Services (CMCS)
7500 Security Boulevard
Room S3-14-07
Baltimore, MD 21244

Re: Medicaid Community Engagement Reporting Requirement

The AIDS Institute, AIDS United, and the Center for HIV Law and Policy Innovation are leading national organizations working to ensure access to care for people living with and vulnerable to HIV. Given the significant health risks and unique nature of HIV, we write to urge you to exempt people with HIV from the Medicaid community engagement requirement included in H.R. 1. We also request to meet with you to discuss how this exemption could be designed to minimize disruptive impact on access to HIV care and treatment.

In 2019, President Trump launched the Initiative to End the HIV Epidemic. His commitment to invest in innovative strategies to bring an end the HIV epidemic in the United States has helped to move our country closer to achieving that goal. Consistent access to health care coverage and treatment for people with HIV is crucial to continuing that progress and Medicaid is a critical source of that coverage.[1] Forty percent of adults living with HIV are covered by Medicaid, compared to just 15% of the general population.[2] Medicaid provides 45% of all federal funding for HIV treatment.[3] But people with HIV make up a very small share of Medicaid enrollees overall – less than one-half of a percent.[4]

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[1] *See* Lindsey Dawson, Priya Chidambaram & Jessica Mathers, *5 Key Facts About Medicaid Coverage for People with HIV*, KAISER FAM. FOUND. (Apr. 1, 2025), https://www.kff.org/medicaid/5-key-facts-about-medicaid-coverage-for-people-with-hiv/.
[2] *Id.*; Lindsey Dawson et al., *Medicaid and People with HIV*, KAISER FAM. FOUND. (Mar. 27, 2023), https://www.kff.org/hiv-aids/medicaid-and-people-with-hiv/.
[3] *Id.*; Lindsey Dawson et al., *Medicaid and People with HIV*, KAISER FAM. FOUND. (Mar. 27, 2023), https://www.kff.org/hiv-aids/medicaid-and-people-with-hiv/.
[4] Lindsey Dawson et al., *5 Key Facts About Medicaid Coverage for People with HIV*, KAISER FAM. FOUND. (Apr. 1, 2025), https://www.kff.org/medicaid/5-key-facts-about-medicaid-coverage-for-people-with-hiv/.

Ensuring access to effective HIV care, treatment, and supports through the Medicaid program is important to the health of people living with HIV and to public health, broadly.[5] When HIV is effectively managed and individuals stay engaged in treatment and virally suppressed, people with HIV can live healthy lives and there is no risk of sexual transmission.[6]

HIV is a serious and complex chronic illness

H.R. 1 requires states to exempt people with "special medical needs" – including people with "serious or complex medical conditions" – from community engagement requirements.[7] HIV is the very definition of a serious and complex medical condition, requiring consistent, continuous, lifelong treatment to prevent advancement to AIDS. Continuous insurance coverage and access to care is critical to enabling people living with HIV to achieve viral suppression and positive health outcomes.[8] But because HIV is infectious, consistent management is also necessary to prevent others from acquiring it and to achieve an end to the epidemic.

As a result, CMS has historically recognized that HIV is a "serious chronic medical condition" warranting special treatment related to Medicaid eligibility and coverage,[9] as have several states.[10] We urge you to cement this recognition of the impact that HIV has on people and

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[5] *See* Dawson, Chidambaram & Mathers, *supra* note 1 (finding that "Medicaid is the primary payer for HIV care and treatment" but in 2022, federal Medicaid spending on HIV still represented less than 2% of total federal Medicaid spending).

[6] *See* Myron S. Cohen et al., *Antiretroviral Therapy for the Prevention of HIV-1 Transmission*, NEJM (2016); Robert W. Eisinger, Carl W. Dieffenbach & Anthony S. Fauci, *HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable*, 321 JAMA 451 (2019).

[7] *See* One Big Beautiful Bill Act, Pub. L. No. 119-21, 139 Stat. 72, 312; HEALTH AND ECONOMIC LIVELIHOOD PARTNERSHIP (HELP) SECTION 1115 DEMONSTRATION WAIVER APPLICATION, MONT. DEP'T PUB. HEALTH & HUM. SERV. 14 (2025) ("*Montana Waiver Proposal*").

[8] Lindsey Dawson and Jennifer Kates, *Insurance Coverage and Viral Suppression Among People with HIV*, 2018, KFF, (Sept. 4, 2020), https://www.kff.org/hiv-aids/insurance-coverage-and-viral-suppression-among-people-with-hiv-2018/.

[9] *E.g.*, Medicaid and Children's Health Insurance Programs: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes, and Premiums and Cost Sharing; Exchanges: Eligibility and Enrollment, 78 Fed. Reg. 42,160, 42,233 (July 15, 2013) ("We agree with the commenters that illnesses such as HIV/AIDS, viral hepatitis, cancer and end stage renal disease are all serious chronic medical conditions."); Medicare and Medicaid Programs; CY 2024 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment and Coverage Policies; Medicare Shared Savings Program Requirements; Medicare Advantage; Medicare and Medicaid Provider and Supplier Enrollment Policies; and Basic Health Program, 88 Fed. Reg. 78,818, 78,938 (Nov. 16, 2023) ("Examples of a serious, high-risk condition/illness/disease include, but are not limited to… HIV/AIDS"); Centers for Medicare & Medicaid Services, CMS Manual System, Pub. 100-04 Medicare Claims Processing, Transmittal 12461 (Jan. 18, 2024) https://www.cms.gov/files/document/r12461cp.pdf ("[I]f the practitioner is furnishing ongoing care related to a patient's single, serious and complex condition, e.g., … HIV, then the add-on code G2211 could be billed. The add-on code G2211 captures the inherent complexity of the visit that is derived from the longitudinal nature of the practitioner and patient relationship.").

[10] *E.g.*, ARIZONA SECTION 1115 WAIVER AMENDMENT REQUEST: AHCCCS WORKS WAIVER, 9 (Dec. 19, 2017), https://www.azahcccs.gov/shared/Downloads/News/AHCCCSWorks1115WaiverAmendmentRequest.pdf (those with HIV/AIDS would be considered "medically frail," qualifying for exemption under proposed work requirement); Indiana State Plan Amendment: IN-15-0025-HIP Plus ABP, ABP 2a (Oct. 29, 2015), https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/IN/IN-15-0025.pdf ("All individuals with an active disability determination by the Social Security Administration *or* a confirmed diagnoses of HIV/AIDS from the Indiana State Department of Health will be confirmed medically frail without having to self report their frail status." (emphasis added)

communities by specifically exempting people with an HIV diagnosis from H.R. 1's community engagement requirement.

Community engagement requirements will disproportionately harm people with HIV

People living with HIV will be disproportionately challenged by the effects of this requirement. HIV can produce symptoms or disabilities that are not visible yet serve as impediments to steady employment.[11] For example, HIV can produce periods of inability to work due to medication side effects, periods of illness, or the need to attend many doctors' appointments; thus, employees with HIV may require flexible work arrangements that can be hard to find or keep.[12] More than half of people living with HIV are age 50 and older,[13] a group that is particularly likely to have difficulty complying with work requirements.[14] For people living with HIV, loss of Medicaid due to arbitrary denials and administrative red tape can lead to care disruptions that can pose enduring, costly, and complex health risks.[15]

We understand that implementing the community engagement requirement and other aspects of H.R. 1 is a complex job that requires balancing many different considerations. We look forward to working with you to ensure that these important decisions do not undermine the goal we share with President Trump: achieving once and for all an end to the HIV epidemic in the United States. Please reach out to Rachel Klein, Deputy Executive Director at The AIDS Institute at rklein@taimail.org or (202) 815-2973 to arrange a time to meet.

Sincerely,

Rachel Klein
Deputy Executive Director
The AIDS Institute

Leslie McGorman
Senior Director of Policy & Strategy
AIDS United

Liz Kaplan
Director of Health Care Access
Center for Health Law & Policy Innovation

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[11] Rachel Garfield, Robin Rudowitz & Anthony Damico, *Understanding the Intersection of Medicaid and Work*, KAISER FAM. FOUND. (Jan. 2018), http://files.kff.org/attachment/Issue-Brief-Understanding-the-Intersection-of-Medicaid-andWork.

[12] Catherine H. Maulsby et al., *A Scoping Review of Employment and HIV*, 24 AIDS BEHAV. 1, 5 (2020) https://pmc.ncbi.nlm.nih.gov/articles/PMC7716244/pdf/nihms-1650652.pdf ("Among employed individuals, those who have workplace accommodations are more likely to be adherent to HIV medications than those without an accommodation.").

[13] HIV.gov, Aging with HIV, (Sept. 8, 2025), https://www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv.

[14] Nari Rhee, Medicaid Cuts—Including Work Documentation Requirements—Harm Older Adults, UC Berkeley Labor Center (June 23, 2025), https://laborcenter.berkeley.edu/medicaid-cuts-including-work-documentation-requirements-harm-older-adults/.

[15] Elizabeth Hamlyn et al., *Plasma HIV Viral Rebound Following Protocol-Indicated Cessation of ART Commenced in Primary and Chronic HIV Infection*, PLOSONE (2012); Gerald Friedland & Ann Williams, *Attaining Higher Goals in HIV Treatment: The Central Importance of Adherence*, 13 AIDS S61 (1999) ("Therefore, potent and continuous suppressive therapy for the duration of viral replicative capability is necessary for therapy to be effective.").