FEDERAL AIDS POLICY PARTNERSHIP
HIV HEALTH CARE ACCESS WORK GROUP

May 20, 2026

The Honorable Robert F. Kennedy, Jr.
Secretary, U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dr. Mehmet Oz
Administrator, Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

The Honorable Russell Vought
Director, Office of Management and Budget
725 17th Street, NW
Washington, DC 20503

Re: Medicaid Community Engagement Requirement

Dear Secretary Kennedy, Dr. Oz, and Director Vought:

On behalf of the HIV Health Care Access Working Group (HHCAWG)—comprised of organizations working to advance policies that ensure the millions of people living with HIV have consistent access to comprehensive care and treatment—we write to urge you to adopt a definition of medical frailty or special medical needs that gives full meaning to the category of people with a "serious or complex condition," which should include people living with HIV. Such a definition honors the language and intent of H.R. 1, ensuring that people who rely on Medicaid to manage serious, complex illnesses that do not meet the standard for disability are able to maintain their connection to ongoing medical care.

Medicaid is the cornerstone of President Trump's initiative to End the HIV Epidemic, which he announced in the State of the Union address in 2019. Medicaid is a crucial program for people with HIV, providing 45% of all federal funding for HIV treatment and providing access to care for 40% of all people living with HIV in the United States. In Medicaid expansion states, more than half of people with HIV who are enrolled in Medicaid are in the adult expansion group.

I. "Serious or Complex Medical Condition" Does Not Require a Showing of Disability

The budget reconciliation act of 2025 (P.L. 119-21) or H.R. 1, the One Big Beautiful Bill Act, established for the first time national community engagement requirements for people who

access Medicaid through the expansion pathway. Recognizing the importance of Medicaid to people who are living with chronic illnesses and disabilities—including many people who are enrolled in Medicaid expansion, rather than traditional Medicaid[1]—Congress included a mandatory exemption from the community engagement requirement for people who are "medically frail or otherwise [have] special medical needs."[2] That broad category includes five statutorily mandated subcategories separated by the word "or," indicating that a person who falls into any *one* of the five subcategories qualifies as medically frail or having special medical needs.

Three of the five subcategories of people with special medical needs are people with disabilities: those who are blind or disabled under the Social Security Act definition of disability, those who have a "disabling mental disorder," and those with a "physical, intellectual or developmental disability that significantly impairs their ability to perform 1 or more activities of daily living." The other two subcategories—those with a "serious or complex medical condition" and those with a "substance use disorder"—by their plain terms do not require a showing of disability or inability to work. Had Congress wanted all five subcategories to require a showing of disability or physical or mental inability to work, it could have specified as much (as evidenced by the language that describes the other three categories), but Congress did not do so. The logical interpretation of this omission is that Congress recognized the importance of uninterrupted access to care for people living with serious or complex conditions, including HIV, and for people living with substance use disorders. The Centers for Medicare and Medicaid Services (CMS) should adopt an interpretation of "serious or complex medical condition" that adheres to Congress's plain intent and does not require a showing of disability.

Moreover, the federal government has elsewhere defined a "serious and complex condition" for the purpose of avoiding disruptions in access to health care. This common-sense definition should be applied to the Medicaid community engagement mandatory exemptions, where continuity of access to care is just as critical. At 26 USC § 9818(b)(2), the Internal Revenue Service defines a "serious and complex condition" as one that, in the case of a chronic condition, is "life-threatening, degenerative, potentially disabling, or congenital; and requires specialized medical care over a prolonged period of time." This definition does not require evidence that a person is already disabled; rather, the emphasis is on the potential for life-threatening or disabling consequences and the need for ongoing access to care.

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[1] 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/; Sara Rosenbaum et al., *Implementing Medicaid Work Reporting Requirements: Defining A 'Serious or Complex Medical Condition'*, Health Affairs Forefront (Jan. 12, 2026) https://www.healthaffairs.org/content/forefront/implementing-medicaid-work-reporting-requirements-defining-serious-complex-medical (finding high percentages of adults on Medicaid who are over 50 but under 65 who do not have known limitations in their ability to perform activities of daily living but who have two or more chronic conditions that make uninterrupted access to care critical).

[2] P.L. 119-21 § 71119(a)(9)(A)(ii)(V).

II. HIV is a serious and complex chronic medical condition that qualifies a person for the medically frail or special medical needs exemption under H.R. 1

HIV is a serious and complex medical condition under the H.R. 1 definition because HIV requires consistent, continuous, lifelong treatment to prevent debilitating illness, potential drug resistance, and ultimately, the advancement to AIDS. 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. When HIV is effectively managed and individuals stay engaged in treatment, and achieve and maintain viral suppression, people with HIV can live healthy lives—including engaging in work, education, or other pursuits—and there is no risk of sexual transmission or community spread.[3] These outcomes require continuous access to HIV medications and related care, which in turn require uninterrupted insurance coverage.[4]

We are concerned that requiring people living with HIV to comply with the new work reporting requirements will create administrative barriers that will lead to improper terminations and lost access to crucial healthcare, even for people who are working. For people living with HIV, loss of Medicaid due to erroneous denials and administrative red tape could lead to care disruptions that can pose enduring, costly, and complex health risks such as the development of drug-resistant HIV.[5] Additionally, more than half of people living with HIV are age 50 and older,[6] a group that is particularly likely to have difficulty complying with work requirements due a variety of factors, including comorbidities that often lead to challenges maintaining employment, age discrimination that makes it difficult to find employment, or caregiving responsibilities for spouses, parents, or adult children with disabilities.[7]

Accordingly, the Centers for Medicare and Medicaid Services (CMS) has repeatedly recognized HIV as a "serious chronic medical condition" warranting special treatment related to Medicaid eligibility and coverage.[8] Several states have also recognized people living with HIV as

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[3] 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.

[4] 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/ ("*Insurance Coverage and Viral Suppression*").

[5] 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.

[6] 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.

[7] 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

[8] *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,

"medically frail" under previous work requirement proposals or exemptions to the Medicaid Alternative Benefit Plan rules.[9] Most recently, Nebraska has included HIV on its list of diagnosis codes that will trigger eligibility for the serious or complex condition exemption to the work requirement under H.R. 1.[10] We understand that numerous other states have planned for that, as well.

We therefore urge you to adopt a definition of the "serious or complex medical condition" subcategory of medical frailty or special medical needs that encompasses all people living with HIV. It is a medical condition that lasts for a lifetime and requires consistent, uninterrupted access to care.

III. Many People with HIV Qualify for Medicaid Only Through Medicaid Expansion

Medicaid expansion has been a lifeline for many people living with HIV. Prior to Congress's passage of Medicaid expansion, eligibility for Medicaid was limited to those who met financial eligibility requirements and fell into one of the traditional Medicaid categories, such as people with disabilities, people over the age of 65, children, and pregnant people. Low-income people living with HIV could not qualify for Medicaid unless they met one of the existing eligibility categories or had already developed advanced disease due to HIV. This created a "catch-22" for many people with HIV, whereby they could not access comprehensive health insurance—which could help them stave off severe disease—until after their health had substantially deteriorated.[11] Many people with HIV in states that have not expanded Medicaid remain uninsured for this reason.[12]

Today, 42 percent of people living with HIV who are enrolled in Medicaid access the program through Medicaid expansion.[13] These individuals may not qualify for any of the categorical

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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.").

[9] *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).

[10] Nebraska Medicaid Work Requirements, Medically Frail Exemption Conditions Index, p. 4, https://dhhs.ne.gov/Documents/Nebraska%20Medicaid%20Work%20Requirements%20-%20Medically%20Frail%20and%20SUD%20Conditions.pdf.

[11] Jennifer Kates and Lindsay Dawson, *Insurance Coverage Changes for People with HIV Under the ACA*, KFF (Feb. 14, 2017), https://www.kff.org/affordable-care-act/insurance-coverage-changes-for-people-with-hiv-under-the-aca/.

[12] *See Insurance Coverage and Viral Suppression*, supra note 4.

[13] 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/

eligibility pathways for traditional Medicaid, including eligibility for people who are disabled. That is because Medicaid based on disability generally requires a person to meet the Supplemental Security Income (SSI) definition of disability, which requires significant impairment in an individual's ability to work.[14] Many people living with HIV do not meet this definition *because* the treatment they are able to get through Medicaid keeps them healthy enough to avoid worsening illness or disability. For them, continuous health coverage and access to care is an essential support that helps them maintain their health so that they can continue to work or otherwise participate in their communities.

IV. Allowing Verifiable Self-Attestation of Serious or Complex Chronic Illness is Necessary

Congress recognized the importance of continuous coverage for people living with HIV and other serious or complex conditions when it incorporated the "serious or complex medical condition" exemption subcategory into H.R. 1 *in addition* to people with disabilities and other concerns. We urge the federal government to fully implement this exemption in its forthcoming guidance and to permit verifiable self-attestation as a sufficient basis for the exemption. Because H.R. 1 does not require states to verify exemption status, states can and should accept self-attestation integrated directly into the Medicaid application—without requiring separate forms or affidavits.[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,

Elizabeth Kaplan, Director of Health Care Access, Center for Health Law and Policy Innovation
Rachel Klein, Deputy Executive Director, The AIDS Institute
Dori Molozanov, Senior Manager of Health Systems Integration, NASTAD
Leslie McGorman, Senior Director of Policy and Strategy, AIDS United
Terri Wilder, Manager of Health & Economic Security Policy, SAGE

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[14] MACPAC, *People with disabilities* (July 30, 2025), https://www.macpac.gov/subtopic/people-with-disabilities/.

[15] National Alliance on Mental Illness (NAMI) and Legal Action Center. *Work Reporting Requirements and Mental Health: Recommendations to Protect Individuals with Mental Health Conditions from Losing Medicaid.* November 2025. Available at: https://www.nami.org/wp-content/uploads/2025/11/2025-Work-Reporting-Requirements-and-Mental-Health.pdf.