FEDERAL AIDS POLICY PARTNERSHIP
HIV HEALTH CARE ACCESS WORK GROUP

July 31, 2026

Submitted via www.regulations.gov

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2454-IFC

Re: File Code CMS-2454-IFC – Interim Final Rule with Comment Period, "Medicaid Program; Community Engagement Requirement for Certain Individuals" (91 FR 33348) [42 CFR §§ 435.550–435.563]

To Whom It May Concern:

The undersigned organizations write on behalf of the HIV Health Care Access Working Group (HHCAWG) in opposition to the Centers for Medicare & Medicaid Services (CMS) Interim Final Rule with Comment Period (IFR or rule) titled "Medicaid Program; Community Engagement Requirement for Certain Individuals" (File Code CMS-2454-IFC). HHCAWG is a coalition of national and community-based organizations representing HIV medical providers, public health professionals, advocates, and people living with HIV who are all committed to ensuring access to critical HIV health care and support services. We are deeply concerned that the IFR will worsen the impact of work requirements on people living with HIV, causing more people to lose coverage, creating life-threatening barriers to care, and thwarting national efforts to end the domestic HIV epidemic. The IFR will also be administratively unworkable and conflicts with the language of H.R. 1 codifying Medicaid work requirements.

With access to regular antiretroviral treatment and care, people living with HIV can achieve viral suppression, maintain their health, and prevent transmission to others.[1] However, interruptions in health care access can jeopardize viral suppression–sometimes within as few as three to six days of stopping treatment–and can lead to medication resistance and other serious health complications.[2]

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[1] See, e.g., *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV: Antiretroviral Therapy to Prevent Sexual Transmission of HIV (Treatment as Prevention),* HIV.gov (Sept. 25, 2025), https://perma.cc/VSE4-4NWL, HIV.gov; *HIV Treatment as Prevention*, HIV.gov, https://perma.cc/RNB8-98QQ (accessed July 25, 2026); *HIV Undetectable=Untransmittable (U=U), or Treatment as Prevention*, NIAID, https://www.niaid.nih.gov/diseases-conditions/treatment-prevention (accessed July 25, 2026).

[2] *Antiretroviral Therapy to Prevent Sexual Transmission of HIV (Treatment as Prevention)*, HIV.gov; UNAIDS, *Q&A on the impact of the interruption of treatment for people living with HIV* (May 15, 2025), https://www.unaids.org/sites/default/files/2025-05/20250520_QA-ART-Interruption_0.pdf.

To maintain viral suppression, people living with HIV must have uninterrupted health coverage, and Medicaid plays a critical role in this access. Medicaid provides coverage for more than 40% of people living with HIV and contributes 45% of all federal funding for domestic HIV care and treatment.[3] Medicaid expansion is especially important, covering 60% of Medicaid enrollees with HIV in expansion states,[4] and offering these individuals full scope health insurance without having to wait until they have become disabled due to advanced HIV.[5] Medicaid work requirements threaten to interrupt coverage for people living with HIV, especially for the many who may face added barriers to complying with these new rules, such as adults ages 50 and older (a large and growing segment of people living with HIV in the U.S.)[6] and people who are homeless or without stable housing.[7]

During the debate over H.R. 1, Congress promised people with serious medical conditions such as HIV that they would be protected from the new Medicaid community engagement requirement. The IFR breaks that promise. Its interpretation of the "medically frail or otherwise has special medical needs" exclusion is invasive, subjective, unworkable, and contrary to the statute. As written, the IFR threatens essential health coverage for people living with HIV and others whom Congress intended to protect, jeopardizing their health and continuity of care. We urge CMS to withdraw the rule and revise it to conform with the statute before it takes effect.

I. The requirement that people with special medical needs be "significantly impaired" departs from the statute and will harm Medicaid enrollees living with HIV (§ 435.554(c))

a. The statute does not condition the "medically frail" or having "special medical needs" exclusion on proof of functional impairment

Congress excluded from Medicaid work requirements people who are "medically frail or otherwise [have] special medical needs," and defined that category by five conditions joined by "or": a disability as defined under the Social Security Act; a substance use disorder (SUD); a disabling mental disorder; a physical, intellectual, or developmental disability that significantly impairs activities of daily living; or a "serious or complex medical condition."[8] Nothing in the

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[3] Lindsey Dawson, Jennifer Kates, et al., *Medicaid and People with HIV*, KFF, (Mar. 27, 2023), https://www.kff.org/hivaids/issue-brief/medicaid-and-people-with-hiv/.

[4] Lindsey Dawson, Jennifer Tolbert, *Medical Frailty and Medicaid Work Requirements: Challenges for People with HIV*, KFF (July 1, 2026), https://www.kff.org/medicaid/medical-frailty-and-medicaid-work-requirements-challenges-for-people-with-hiv/ (**attached**).

[5] Jennifer Kates, Lindsey Dawson, *Insurance Coverage Changes for People with HIV Under the ACA*, KFF, (Feb. 14, 2017), https://www.kff.org/affordable-care-act/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/#footnote-209018-4.

[6] *Aging with HIV*, HIV.gov, https://perma.cc/Z93N-P7H3 (accessed July 28, 2026) (more than half of people with HIV in the U.S. are ages 50 and older).

[7] Centers for Disease Control and Prevention, *Behavioral and Clinical Characteristics of Persons with Diagnosed HIV Infection–Medical Monitoring Project, United States, 2023 Cycle (June 2023–May 2024)* (March 16, 2026) (accessed July 25, 2026), https://www.cdc.gov/hiv-data/mmp/behavioral-clinical-characteristics-pwh.html (in 2023, 20% of people living with HIV reported unstable housing or homelessness).

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

statute authorizes limiting the exclusion to a person with a condition that impairs their ability to work.

The IFR adds that condition anyway, requiring that a qualifying "serious or complex" condition or substance use disorder also "significantly impair" the ability to meet the requirement–so that someone able to complete 80 hours per month of work or similar activities would not qualify. In the statute's text, three of the five subcategories of "medically frail" or having "special medical needs" are framed in terms of disability, while "serious or complex medical condition" and "substance use disorder" are not. Had Congress wanted to impose a disability standard on all five subcategories, it would have done so. By demanding proof of *impairment* for conditions like HIV–which may cause no functional limitations when well managed with continuous access to care, but can have severe consequences when care is interrupted–the IFR makes the exclusion unavailable precisely to the people Congress intended to protect.

The IFR is simultaneously vague, as it offers no instructions to states as to how to define or implement the "significantly impairs" test. The predictable result will be inconsistency and error: different states applying different standards, eligibility workers being overburdened and potentially tasked with making clinical assessments they are not trained to make, and people who should be entitled to an exclusion under the statute nonetheless losing coverage because they could not navigate the process. Depending on how it is interpreted, the rule may also raise privacy concerns. For example, Medicaid enrollees may need to disclose private medical information (beyond what already appears in their Medicaid claims) to eligibility workers to prove they are "sick enough" to qualify for the exclusion. People with HIV should not have to disclose additional details about their health status to justify their need for uninterrupted coverage under a program for which they are already eligible.

CMS' own preamble commentary illustrates the uncertainty created by the IFR's vague "significantly impairs" test. In discussing HIV, CMS identifies "acuity" as relevant to functional impairment, but does not explain why this is an appropriate basis for that determination or how states should define or weigh it against other relevant considerations. CMS suggests that a person with lower "acuity" HIV is "less likely" to be functionally impaired, but does not explain what this means, or how it interacts with important factors such as the demands of ongoing treatment, comorbid mental health and other conditions, stigma-related barriers to care or employment, and other circumstances that could meaningfully affect a person with HIV's ability to comply with community engagement requirements. We recognize that the IFR does not *prohibit* states from considering these factors when assessing the "functional impairment" prong of the two-part test. However, the absence of a prohibition is not a substitute for a reasoned standard. Thus, even assuming, without conceding, that the "significantly impairs" test may be lawfully applied at all, we are concerned that the IFR as written is ambiguous and vague, and will lead to confusion, arbitrary denials, and inconsistent determinations across states.

Under similar work-requirement programs, exemption and accommodation processes for people with disabilities have failed at high rates. For example, Arkansas' medically frail exemption reached only 11% of beneficiaries subject to the work requirement, even though

nearly 30% of those without an exemption who weren't working reported at least one serious health limitation.[9] Georgia's Pathways to Coverage program requires an eight-step accommodation process (the State has not reported data on how many people successfully use this process but experts have noted its complexity);[10] and hundreds of thousands of SNAP enrollees with disabilities have remained subject to that program's work requirement despite their disability.[11]

The IFR also departs from CMS' own past recognition of HIV as a serious and complex condition. CMS has recognized that HIV is a "serious chronic medical condition" warranting special treatment related to Medicaid eligibility and coverage,[12] and a "serious, high-risk" condition for which patient navigation services may be reasonable and necessary in the Medicare context.[13] States such as Nebraska, Arizona, and Indiana have also recognized the need to exempt people living with HIV from prior work requirement proposals and alternative benefit plan (ABP) requirements.[14] The IFR does not consider any of these positions, nor does it address evidence provided to CMS during the past year regarding the need to exempt people living with HIV from work requirements.[15]

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[9] *Medicaid Work Requirements Don't Protect People With Disabilities*, Center on Budget & Policy Priorities (Nov. 14, 2018), https://www.cbpp.org/research/health/medicaid-work-requirements-dont-protect-people-with-disabilities.

[10] *How Medicaid Work Requirements Hurt People with Disabilities*, National Health Law Program (Dec. 2024), https://healthlaw.org/wp-content/uploads/2025/01/Machledt_NHeLP_WorkRequirementsandPeoplewithDisabilities_January-Update.pdf.

[11] *Id*.

[12] 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.").

[13] 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) ("[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.").

[14] Nebraska Medicaid Work Requirements, Medically Frail Exemption Conditions Index, 4 https://perma.cc/T3TJ-49AV; Arizona Section 1115 Waiver Amendment Request: AHCCCS Works Waiver, 9 (Dec. 19, 2017), https://perma.cc/7A5M-RTV2 (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).

[15] *See* Letter from HHCAWG to Secretary Kennedy et al., May 20, 2026 (**attached**); Letter from The AIDS Institute, AIDS United, and the Center for Health Law and Policy Innovation to Caprice Knapp, October 28, 2025 (**attached**).

HHCAWG is also concerned about the impact of the IFR on people living with and in recovery from SUD, which disproportionately impacts people living with HIV.[16] SUD can contribute to the transmission of HIV, and, for people living with HIV, can create barriers to good HIV health outcomes.[17] Ending the HIV epidemic in the U.S. therefore requires effectively and humanely addressing the SUD epidemic, including by providing people with SUD continuous access to evidence-based treatment such as medications and behavioral counseling and therapies.[18] The IFR, however, unlawfully and unfairly applies the "significantly impairs" test to people who should be excluded from work requirements based on SUD alone. Additionally, it arbitrarily ends the exclusion after five years of "stable recovery," even though SUD is a chronic health condition that can be effectively treated but requires ongoing access to care.[19]

Denying people living with HIV access to the medical needs exclusion unless they are significantly impaired will likely lead to dire consequences for these individuals and for national efforts to end the HIV epidemic. HIV is a serious and complex condition that requires lifelong, uninterrupted treatment. When people with HIV stay in care, they can maintain viral suppression, preserve their health and well-being, and keep working or otherwise engaging with their community. Sustained viral suppression also prevents transmission of HIV. Requiring people with HIV to prove that their condition prevents them from working gets it backwards: it puts coverage at risk for people whose health depends on continuous access to care, and a gap of even a few weeks can cause lasting harm, including development of drug resistance. CMS should eliminate the "significantly impairs" test that the IFR unlawfully incorporates into the definition of medically frail or special medical needs.

II. The rule's exclusion verification processes demonstrate the unworkability of the "significantly impairs" test and will cause eligible people to lose coverage (§ 435.557)

a. The rule arbitrarily limits self-attestation for the special medical needs exclusion, making implementation unworkable (§ 435.557(f)(ii))

The IFR requires a state to use "reliable information" that it has available to try to assess whether someone qualifies for an exclusion or exception before it asks that person for information. This requirement adheres to the language of H.R. 1 and will help protect individuals who should be excluded or excepted from work requirements from losing coverage due to administrative barriers.[20] However, as discussed, the IFR fails to define what it means for someone to be significantly impaired in their ability to comply with work requirements such that they may qualify for the medically frail or special medical needs exclusion–making it utterly

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[16] See, e.g., *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents With HIV; Considerations for Antiretroviral Use in Special Populations; Substance Use Disorders and HIV*, HIV.gov, (Sept. 12, 2024), https://perma.cc/V83S-Y7LC.
[17] *Id.*
[18] *Drugs, Brains, and Behavior: The Science of Addiction Treatment and Recovery*, National Institute on Drug Abuse, (July 6, 2020), https://perma.cc/L99M-E7NE.
[19] *Id.*
[20] P.L. 119-21, § 71119(a)(5).

unclear what "reliable information" a state could use to determine whether someone has met this definition. Moreover, it will be difficult if not impossible for states to make these determinations based on existing data, since there is no diagnosis code for "too sick to work."

The IFR's limitation on the use of self-attestation to demonstrate medical frailty or special medical needs exacerbates this problem. Congress excluded these individuals from the work requirement because their medical needs make uninterrupted access to coverage especially important. Yet the IFR creates a separate verification process–for this exclusion only–that will make it very difficult to access the exclusion. Beginning in 2028, the rule arbitrarily limits the use of self-attestation under penalty of perjury to establish special medical needs to just once per eligibility period–even though more than two dozen states had planned to allow self-attestation and H.R. 1 contains no limitations on state use of self-attestation to establish excluded status.[21] Instead, the rule suggests that states may rely on provider documentation from "many types of practitioners," although states are again left to determine which types of providers will be able to do this. This system places additional, unnecessary administrative burdens on Medicaid enrollees with elevated medical needs and creates an avoidable risk that people who Congress intended to exclude from community engagement will nonetheless lose coverage because they cannot complete the verification process. It is also unfairly burdensome on providers, who will be asked to complete yet more paperwork for patients–and to apply a potentially ambiguous and highly subjective standard.

The process for establishing excluded status should protect people from the burdens associated with the work requirement, not create additional administrative burdens through a separate process that may be even more demanding and confusing. For people with HIV who are newly diagnosed and have not yet established care with a trusted provider these burdens may be especially difficult to overcome. Consistent with Congress' intent that Medicaid-eligible individuals with serious or complex conditions be spared burdensome administrative requirements that could disrupt access to necessary care, CMS should allow states to accept self-attestation to document medical frailty or special medical needs whenever verification of excluded status is required during the eligibility period.

b. The rule arbitrarily limits the lookback period for claims that support eligibility for the special medical needs exclusion (§§ 435.557(a)(vii), (viii); 435.557(f))

The IFR arbitrarily limits states to a 12-month lookback period for claims and encounter data used to determine whether someone is medically frail or has special medical needs. This limitation also has no basis in the statutory text and will likely result in people who should qualify for the exclusion having to navigate additional procedural hurdles and ultimately losing their coverage. This limitation harms people with well-documented, ongoing conditions such as HIV where relevant claims fall outside the 12-month window.

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[21] *Tracking Implementation of the 2025 Reconciliation Law: Medicaid Work Requirements*, KFF (June 29, 2026), https://perma.cc/Y8X2-WGFR (as of March 2026, 28 states indicated that they planned to allow self-attestation for medical frailty).

Given that HIV is an incurable condition, older claims remain reliable evidence of a person's HIV status; requiring duplicative proof of that diagnosis merely because the relevant claims are more than 12 months old creates an unnecessary administrative burden for Medicaid enrollees, providers, and Medicaid agency staff. Even if CMS is ultimately permitted to require evidence of functional limitations–a point HHCAWG disputes–that does not justify requiring states to disregard older claims that remain reliable evidence of a serious or complex condition.

A Medicaid enrollee living with HIV for more than a year may lack recent HIV-related claims because of disruptions in care or concerns about stigma and privacy that may cause them to delay or avoid care. Supporting these individuals to return to care is critical to ending the HIV epidemic. States should actively engage people with HIV who are out of care–not create additional administrative barriers to returning to care by making it harder for people without recent care engagement to keep their health coverage. CMS should allow states to consider all reliable claims and encounter data relevant to determining excluded status, regardless of when those records were created.

HHCAWG also notes that many people with HIV may not have claims or encounters (recent or old) that document their HIV status. For example, a person who was recently diagnosed may have little to no claim or encounter data documenting their HIV status, especially if they were diagnosed outside of a traditional care setting (such as a mobile testing van). Similarly, an individual who only recently gained Medicaid eligibility (because they were previously covered by an employer, moved from out of state, or recently became financially eligible) may have little or no relevant data available to the state. HHCAWG urges CMS to adopt a more comprehensive definition of reliable health data that states may consider to verify the medical frailty or special medical needs exclusion.

III. Outreach notices must be easily understood and meaningfully targeted to impacted populations (§ 435.561)

HHCAWG is already hearing from our community partners who work directly with Medicaid enrollees that there is significant confusion among enrollees about whether or not they will personally be subject to the new Medicaid work requirements. CMS should require states to provide notices in advance of January 1, 2027 to all enrollees that specify whether or not they are enrolled in a category of Medicaid that is subject to the new requirements. New applicants should be informed at the time of their enrollment whether they are in a category of Medicaid that is subject to the new requirement or not. Notices to people in a category of Medicaid that is subject to the new requirements should clearly indicate that there are exclusions and exemptions, what those exclusions and exemptions are, how enrollees can seek an exclusion or exemption, and where they can seek assistance to request an exclusion or exemption. Notices should be written in plain language with clear and concise information.

IV. States must be given more time to comply (§435.560)

States have been racing to meet the January 2027 deadline, spending tens of millions on eligibility systems built around the informal guidance they were receiving from CMS prior to the IFR. By reversing course at the last minute through an interim final rule that takes effect the

same day comments close, CMS is forcing states to undo significant and expensive preparatory work, rewrite notices, and retrain staff with little time for implementation and testing. Given the immense time crunch and the IFR's unworkability, it is extremely unlikely that states will be able to implement the IFR fully and accurately on the timetable required. The predictable consequences will be systems riddled with error. People living with HIV and other serious or complex conditions cannot afford to lose their coverage even temporarily due to administrative errors or unnecessarily complex red tape–as noted above, an HIV treatment lapse of even a few days or weeks may potentially lead to serious health consequences.[22] We urge CMS to approve all good faith effort exemption requests that are necessary for states to fully and accurately implement the new Medicaid work requirements, including implementing all exceptions and exclusions.

V. What we urge CMS to do

Coverage losses ripple outward: people who lose Medicaid for failing to meet these burdensome new eligibility processes are also treated as ineligible for Exchange premium tax credits, cutting off even that more-expensive fallback. People who lose Medicaid coverage because of work requirements will not stop needing care, and their existing conditions will worsen, creating unnecessary health risks and reducing quality of life while adding costs to the safety-net providers least able to absorb them.

We urge CMS to remove the requirement that a condition "significantly impair" the ability to comply with community engagement requirements, and to define "medically frail or otherwise has special medical needs" by the presence of a qualifying condition rather than a work-capacity test, consistent with the statute and Congressional intent. CMS should make clear that chronic conditions requiring continuous treatment, including HIV, qualify as a serious or complex condition. CMS should also preserve self-attestation where claims data cannot establish a condition, strengthen genuine *ex parte* verification to minimize paperwork burdens, and clarify notice requirements. Finally, CMS should delay implementation of these provisions and offer meaningful opportunities for broad input and transparency at the federal and state level.

Thank you for the opportunity to comment. Please contact Rachel Klein at The AIDS Institute (rklein@taimail.org), Leslie McGorman at AIDS United (lmcgorman@aidsunited.org), Dori Molozanov at NASTAD (dmolozanov@nastad.org), Terri Wilder at SAGE (twilder@sageusa.org), or Elizabeth Kaplan at the Center for Health Law and Policy Innovation (ekaplan@law.harvard.edu) with any questions.

[22] See *supra* note 2.

Respectfully submitted by:

Act Now: End AIDS (ANEA) Coalition
AIDS Alabama
AIDS Alliance for Women, Infants, Children Youth & Families
AIDS Foundation Chicago
AIDS United
Aliveness Project
Alliance Community Health Care, Inc.
American Academy of HIV Medicine
Amida Care
APLA Health
Association of Nurses in AIDS Care
Bienestar
Callen-Lorde Community Health Center
Center for Health Law and Policy Innovation
Community Access National Network
Community Research Initiative, Inc. (CRI)
Equality California
Five Horizons Health Services
Florida Keys HIV Community Planning Partnership (FKHCPP)
Georgia Equality
HealthHIV
HIV Dental Alliance
HIV Medicine Association
HIV+Hepatitis Policy Institute
iHealth
International Association of Providers of AIDS Care
Latino Commission on AIDS
Lifelong Health for All
NASTAD
National Alliance for HIV Education and Workforce Development
National Coalition for LGBTQ Health
National Coalition of STD Directors
National HIV/AIDS Housing Coalition
National Working Positive Coalition
Positive Women's Network-USA
Pride Action Tank
SAGE
San Francisco AIDS Foundation
Silver State Equality
Southern AIDS Coalition
The AIDS Institute
The Well Project
U=U plus
Vivent Health

Attachments

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.").

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.

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Medical Frailty and Medicaid Work Requirements: Challenges for People with HIV

Authors: Lindsey Dawson and Jennifer Tolbert

Published: Jul 1, 2026

On June 1, 2026, the Centers for Medicare and Medicaid Services (CMS) issued an interim final rule providing states with guidance for implementing Medicaid "community engagement" or Medicaid work requirements as part of the 2025 federal budget reconciliation law. The law requires states to condition Medicaid eligibility for enrollees with coverage through the Affordable Care Act (ACA) expansion or under certain waivers on meeting these requirements or qualifying for an exclusion, including one related to being "medically frail or otherwise" having "a special medical need." In defining medical frailty, the rule introduces a two-part test, requiring an enrollee to both have a qualifying condition *and* demonstrate that the condition impairs their ability to fulfill the community engagement requirement, differing from stakeholders' expectations. Early on, and as with Nebraska's early implementation, states believed they would be able to exclude people based on presence of a condition alone and several states planned to exclude all people with HIV.

On June 29, 2026, twenty-four (24) states and two (2) state governors sued CMS in Massachusetts District Court challenging aspects of the regulation, including its requirement that to qualify for the medical frailty exclusion an enrollee's condition must significantly impair their ability to comply with community engagement

requirements. Among other arguments, the plaintiff states claim this additional requirement is contrary to the reconciliation law (H.R.1) and that "H.R. 1's broad statutory exclusions exist for good reason. People with disabilities, patients in the middle of cancer treatment, or those struggling with another serious or complex health condition, shouldn't be at risk of losing the care that helps maintain their health." Whether the court grants their request to enjoin and vacate the challenged provisions, including the medical frailty two-part test, is yet to be seen.

In the meantime, because Medicaid is the primary source of insurance coverage for people with HIV, this new requirement and state implementation decisions, will have a significant impact on this population's access to Medicaid going forward and could affect the nation's efforts to address HIV.

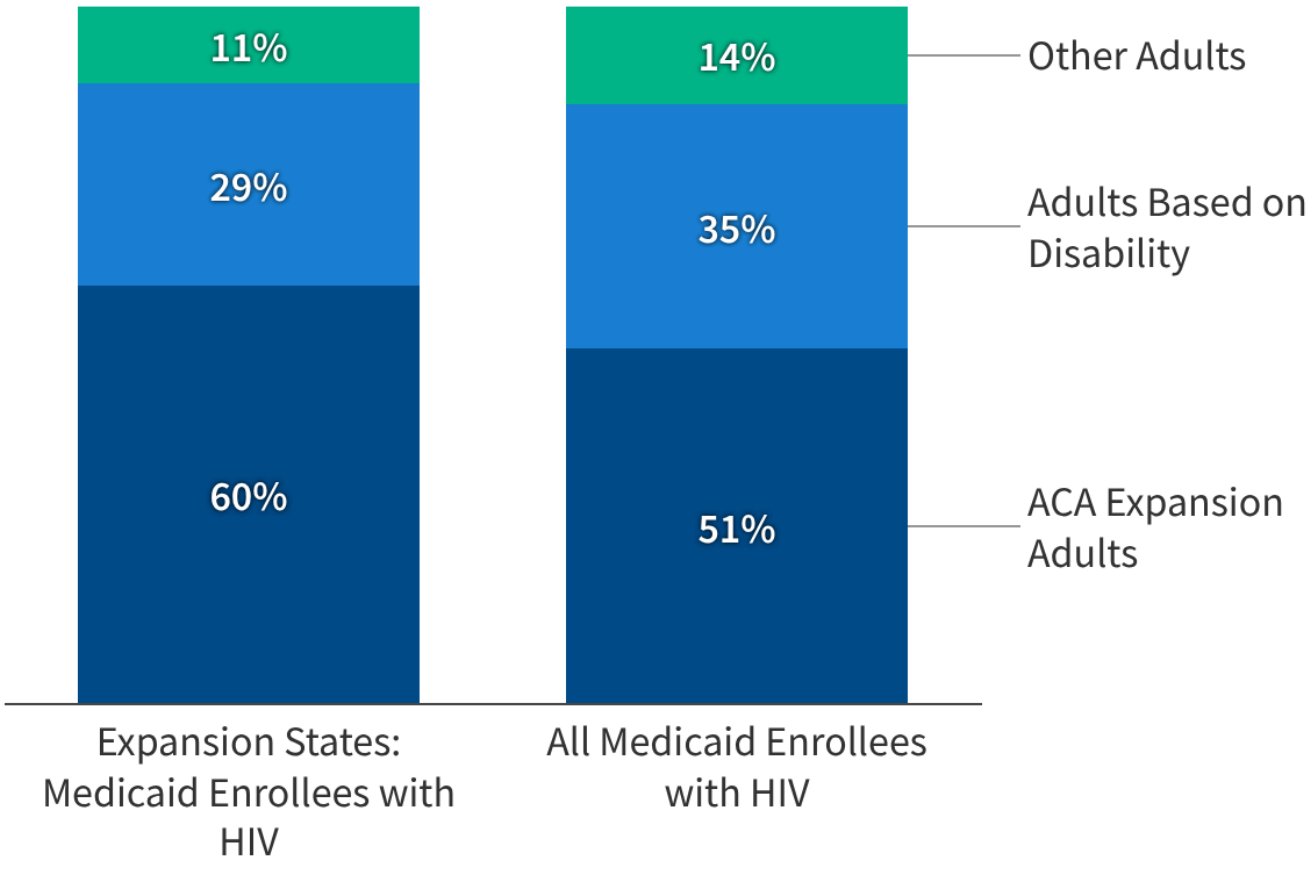
This analysis reviews the implications of the rule's definition of medical frailty for people with HIV. (For a broad overview of medical frailty, definition of terms, and the impact of the regulation beyond HIV, see this KFF analysis.)

Medicaid expansion is the most common pathway for Medicaid coverage for people with HIV, so many with HIV will be subject to new work / community engagement requirements. Medicaid is the largest source of insurance coverage for people with HIV and plays a larger role in covering adults with HIV than adults without HIV. Nationwide, nearly half (46%) of people with HIV had coverage through the Medicaid program in 2023. In states that have expanded their Medicaid programs, Medicaid expansion is the primary pathway to coverage for people with HIV. In 2023, 60% of adults under age 65 with HIV in expansion states had coverage through the expansion pathway and would be subject to work requirements (see Figure 1). Before states expanded Medicaid programs under the ACA, many people with HIV did not have access to affordable coverage until they had an advanced condition to qualify through a permanent disability pathway and many were uninsured, despite coverage and access to care having the potential to stave disability off in the first place.

Figure 1

In Medicaid Expansion States, Six in Ten (60%) Medicaid Enrollees with HIV Have Coverage Through the Expansion Pathway

Distribution of adult Medicaid enrollees with and without HIV, by eligibility group and state Medicaid expansion status, 2023



Note: This analysis reflects enrollees ages 19 to 64 with at least one month of Medicaid enrollment. In 2023, there were 332,000 enrollees with HIV and 57.5 million enrollees without HIV. As of December 2023, there were 41 expansion states, including DC. Enrollees with HIV were flagged if they had a relevant ICD 9 or ICD 10 code, any drug claims for a single tablet regiment (STR), or two or more other non-STR ARVs.

Source: KFF analysis of the T-MSIS Research Identifiable Files, 2023 (Preliminary)

KFF

The approach to determining medical frailty specified in the rule will make it more difficult for individuals with HIV to obtain a medical frailty exclusion from work requirements. The rule imposes a two-part test that defines as medically frail an

individual who is blind or disabled; has a substance use disorder; has a "disabling" mental disorder; has a physical, intellectual, or developmental disability that limits the ability to perform one or more activities of daily living (ADL); or has a "serious or complex" medical condition *and* whose condition impairs their ability to fulfill the community engagement requirements (including but not limited to work). While the rule includes HIV/AIDS as one of 19 example conditions that would be reasonable for states to consider as a serious or complex medical condition, it further specifies, using HIV as an example, that, "Individuals with HIV/AIDS are medically frail if they are determined to have a serious or complex medical condition that significantly impairs the individual's ability to comply with the community engagement requirement, which is less likely to be the case if the acuity of their condition is not severe." Access to antiretroviral medication, including through Medicaid, is necessary to manage HIV and prevent immune system dysfunction, illness, and ultimately death. To the extent people with HIV lose access to Medicaid due to work requirements, including failure to navigate reporting rules, they may develop more severe conditions.

People with HIV whose condition is well managed may qualify as medically frail if they have another medical condition that limits their ability to work. Nearly three-quarters (73%) of people with HIV enrolled in Medicaid have chronic conditions (other than HIV), compared with four in ten (42%) of those without HIV. Alternatively, people with HIV may qualify as medically frail under one of the other categories. Notably, people with HIV are more likely than other Medicaid enrollees to have an SUD or mental health condition. Nearly, one-quarter (23%) of people with HIV had an SUD diagnosis compared to 8% of Medicaid enrollees without HIV and over one-third (36%) of Medicaid enrollees with HIV had a mental health condition diagnosis, some of which may be considered "disabling," compared to 16% of Medicaid enrollees without HIV. People with HIV also experience high rates of disability--half (50%) of likely Medicaid expansion enrollees with HIV have a disability, including a functional disability (e.g. difficulty climbing stairs, dressing oneself, etc.) or an AIDS (stage III HIV) diagnosis.

The rule requires states to use claims and encounter data to identify individuals who may be medically frail, but does not provide guidance on how to assess whether a condition limits an individual's ability to meet the community engagement requirements. States will be required to maintain an auditable list of medically frail conditions (in the form of diagnosis codes) that could include HIV. States will have discretion over the creation of this list and may include only some codes for each condition. For example, Nebraska's list of ICD-10 codes released before the state implemented work requirements on May 1, 2026 only included one of several codes for HIV which would not capture all enrollees with HIV. The rule also makes clear that diagnoses alone cannot be used to determine medical frailty because of the need to assess whether the condition impairs the ability to work or engage in community service. This additional requirement will limit the ability to verify medical frailty on an automated, or ex parte, basis and will require states to use other verification methods.

The regulation offers examples of the types of providers that states could use to verify medical frailty including a range of clinicians. CMS's inclusion of "clinical social workers" on this list could be especially meaningful for people with HIV given that many get care through clinics with integrated social and support services whose staff help with insurance navigation. However, the administrative burden on treating providers is likely to be significant

For people with HIV, the reliance on data sharing, confirmation from treating providers, and health screeners and self-attestation to verify medical frailty exclusion status may raise unique privacy issues and barriers due to stigma:

- **Data sharing:** Some states are exploring using a data-sharing process between the state Medicaid and state public health/HIV office which could help them identify enrollees without HIV related claims histories, including those new to Medicaid. Some states already have a data sharing agreement in place. However, this public health data is highly sensitive, and some have raised concerns about data privacy and security related to HIV status.

Provider documentation. As noted, the rule permits states to accept documentation of qualifying conditions and medical frailty from providers. However, the requirement to assess and report the severity of patients' conditions and the impact on their ability to meet the work requirements may raise ethical concerns for these providers, particularly given the emphasis in HIV care on care engagement for both the patient's and public health.

Health screeners and self-attestation. The rule encourages states to use health screeners at application and renewal to identify individuals who may be medically frail, which could include people with HIV. Separately, though its use will be more limited starting in January 2028, most states will also likely allow self-attestation when existing data sources are insufficient to document a qualifying condition and the inability to work. However, the stigma associated with HIV may discourage individuals from disclosing their condition and how it impacts their life.

Coverage loss for people with HIV could negatively impact individual health, public health, and place an increased burden on already stretched HIV programs. Given the new requirements in the regulation, a blanket exclusion for people with HIV will not be possible which will mean a greater staff burden (at the state Medicaid agency and in clinics), higher costs, and potentially wide scale churn, disenrollment, or coverage rejections for those with HIV. While earlier KFF research found that one-third (33%) of likely expansion enrollees with HIV were working at least 20 hours per week and another 4% had dependents at home, the need to document work compliance or medical frailty status, could challenge coverage retention for people with HIV which could lead to disruptions in care and treatment and subsequently increased risk of morbidity, mortality, and HIV transmission. Such a scenario also runs counter to federal goals in the Administration's Ending the HIV Epidemic Initiative and the Ryan White Program Moving Forward (formerly Ryan White Program 2030) vision. Indeed, four in ten new HIV transmissions are associated with someone who is aware of their HIV status but not in care. Treatment interruptions can also lead to antiretroviral resistance, making future treatment and care more complex. Additionally, if people with HIV lose Medicaid coverage some may turn to the federal Ryan White Program. This comes at a time when state Ryan White Programs across

the country are facing budget crises due to a range of factors and coverage losses due to work requirements represent an additional challenge for programs to weather.

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