

# Protecting Individuals with HIV/AIDS from Losing Medicaid Coverage:

## Recommendations on Implementing the H.R. 1 Work Reporting Requirements

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# INTRODUCTION

H.R. 1 (Public Law 119-21) reduced federal funding for Medicaid by nearly \$1 trillion—the largest cut in the history of the program. Among other harmful provisions, the law creates new work reporting requirements for the Medicaid expansion population. To satisfy these requirements, individuals must demonstrate “community engagement”—through work, community service, education, and/or training activities—for at least 80 hours a month. This provision could result in as many as [5.3 million people](#) losing Medicaid coverage. These coverage losses loom large for individuals living with HIV/AIDS. Medicaid is the nation’s largest source of health insurance for this population, covering [40% of nonelderly adults](#) with HIV, and accounts for 45% of federal HIV spending.

[42% of Medicaid enrollees](#) living with HIV receive coverage through Medicaid expansion and will be subject to these new requirements, either by reporting participation in “community engagement” activities or qualifying for an “exemption” from the reporting requirement. Experience with Medicaid work requirements at the state level has shown that these policies result in individuals frequently losing coverage due to bureaucratic red tape, rather than ineligibility. If procedural hurdles lead to even temporary disruptions in coverage for those with HIV, the consequences could be devastating; just a 30-day interruption in treatment [can greatly increase](#) the risk that subsequent medication therapy will be less effective for viral suppression.

People living with HIV can and do work and participate in other “community engagement” activities, though many also face [systemic barriers](#) to gainful employment. While the Americans with Disabilities Act (ADA) prohibits discrimination based on HIV status or AIDS, individuals living with these conditions still encounter [stigma and discrimination](#) in the workplace. Employment gaps—often due to health-related interruptions or workplace discrimination—when combined with HIV stigma in the community and other systemic barriers, continue to create obstacles for people with HIV/AIDS in securing and maintaining employment.

In H.R. 1, Congress has established a number of exemptions to the 80-hour work reporting requirement, which could mitigate the harm of onerous reporting burdens and discriminatory employment practices for people living with HIV/AIDS. As states begin to implement these new policies, they should aim to (1) maximize the exemptions to ensure people with HIV/AIDS are protected; (2) minimize the burdens required to demonstrate eligibility; and (3) more broadly,

advance additional policies that improve access to quality care and coverage for individuals living with HIV.<sup>1</sup>

1. Maximize the exemptions;
2. Minimize the burdens; and
3. Advance policies that help more people access coverage and care.

## Maximize Exemptions

One of the mandatory exemptions to the work requirements applies to “medically frail” individuals.<sup>2</sup> The statute specifies that individuals with certain health needs—those who are blind or disabled (using the Supplemental Security Income (SSI) definition); as well as those with a substance use disorder; a “disabling mental disorder;” a physical, intellectual, or developmental disability; or a “serious or complex medical condition”—fall under this exemption. Existing statutory definitions and regulations demonstrate that Congress and the U.S. Department of Health & Human Services (HHS)—including the Centers for Medicare & Medicaid Services (CMS)—consider HIV and AIDS to be serious or complex medical conditions, and thus individuals living with these conditions must be exempt from the new Medicaid work reporting requirements.

**The federal government and states should explicitly include HIV and AIDS in the definition of a “serious or complex medical condition”** for the purposes of the “medically frail” exemption. H.R. 1 does not define “serious or complex medical condition,” but the same term is used in the No Surprises Act as passed in the Consolidated Appropriations Act of 2021. That statute defines a “serious and complex condition,” in part, as a chronic illness or condition that “(i) is life-threatening, degenerative, potentially disabling, or congenital; and (ii) requires specialized medical care over a prolonged period of time.”<sup>3</sup> HIV/AIDS fits squarely within this definition. First, HIV is clearly a “life-threatening” condition; without treatment, it typically progresses to AIDS, at which point an individual has a life expectancy of only [three years](#). HIV is also “potentially disabling.” HHS regulations define a disability as a “physical or mental impairment

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<sup>1</sup> See Deborah Steinberg, Protecting People with Substance Use Disorders and Formerly Incarcerated Individuals from Losing Medicaid Coverage: Recommendations on Implementing the H.R. 1 Work Reporting Requirements,” Legal Action Center (Sept. 3, 2025), <https://www.lac.org/assets/files/Protecting-People-with-SUDs-and-Formerly-Incarcerated-Individuals-from-Losing-Medicaid-Coverage.pdf>.

<sup>2</sup> An Act, Pub. L. No. 119-21, § 71119(a), 139 Stat. 72, 312 (2025) (to be codified at 42 U.S.C. 1396a(xx)(9)(A)(ii)(V)). There are a number of other exemptions that may apply to this population or others.

<sup>3</sup> 45 U.S.C. § 2799A-3(b)(2).

that substantially limits one or more of the major life activities.”<sup>4</sup> The regulations explicitly list HIV, whether symptomatic or asymptomatic, as an example of such an impairment.<sup>5</sup> Notably, these regulations mimic those implementing the Americans with Disabilities Act (ADA), which similarly include HIV, whether symptomatic or asymptomatic, within the definition of “physical or mental impairment.”<sup>6</sup> As to the second element of the statutory definition, HIV “requires specialized medical care over a prolonged period of time,” since those with the virus must generally take antiretroviral therapy (ART) for the rest of their lives.

CMS has also issued regulations that support the explicit inclusion of HIV/AIDS as a “serious or complex medical condition.” This same phrase is used in the CMS regulations defining “medically frail” individuals for purposes of exemptions to alternative benefit plans (ABPs). Upon requests for clarification, CMS confirmed in the final regulations, “We agree with the commenters that illnesses such as HIV/AIDS...are all serious chronic medical conditions.”<sup>7</sup> As a more recent example, CMS added a new universal billing code that provides additional reimbursement for care delivered to a patient with a “single, serious condition or a complex condition.” In the final regulations for this add-on code, CMS explicitly stated, “HIV is a single, serious condition, and/or a complex condition” for which this code would apply,<sup>8</sup> which CMS also reaffirmed in subsequently [released guidance](#).

Finally, the statutory language for the other sub-categories under the “medically frail” exemption makes it clear that having a serious or complex medical condition does not need to interfere with the individual’s ability to work or do other activities in order to be exempt from the H.R. 1 work reporting requirements. For example, there is a separate exemption for individuals who are blind or disabled as defined by the Supplemental Security Income (SSI) statute,<sup>9</sup> such that individuals’ whose conditions prevent them from working are already exempt. To that end though, individuals living with HIV, AIDS, or any other health conditions who meet the SSI definition of being unable to perform substantial gainful work would also be exempt.<sup>10</sup> Similarly, individuals “with a physical ... disability that significantly impairs their ability to perform 1 or more activities of daily living” are also separately exempt as medically frail.<sup>11</sup> Thus, having a serious or complex medical condition also does not need to impair an individual’s ability to perform activities of daily living for the individual to be exempt, or this too

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<sup>4</sup> 45 C.F.R. § 84.4(a)(1)(i).

<sup>5</sup> § 84.4(b)(2).

<sup>6</sup> 28 C.F.R. § 35.108(b)(2).

<sup>7</sup> 78 Fed. Reg. 42160, 42233 (July 15, 2013).

<sup>8</sup> 88 Fed. Reg. 78818, 78974 (Nov. 16, 2023).

<sup>9</sup> Pub. L. No. 119-21, § 71119(a) (to be codified at 42 U.S.C. 1396a(xx)(9)(a)(ii)(V)(aa)).

<sup>10</sup> 20 C.F.R. pt. 404, app. 1.

<sup>11</sup> Pub. L. No. 119-21, § 71119(a) (to be codified at 42 U.S.C. 1396a(xx)(9)(a)(ii)(V)(dd)).

would be redundant. As before though, individuals living with HIV, AIDS, or any other health conditions who have trouble performing an activity of daily living would also be exempt.

Accordingly, people living with HIV and AIDS unambiguously fit into the “medically frail” exemption, regardless of whether they are unable to work or perform other activities, and thus it is imperative that HHS and states ensure they are exempt from the H.R. 1 work reporting requirements to maintain their access to the care and coverage they need.

Finally, recognizing the ongoing stigma and discrimination against individuals living with HIV and AIDS, individuals may not wish to disclose their HIV status on their application or redetermination to the state. However, many of these individuals may be exempt under other co-morbid health conditions that count as “medically frail” or other exemptions. Since Congress’s clear intent was to protect individuals with serious or chronic health conditions such as HIV or AIDS from losing their Medicaid, it is important that HHS and states also maximize the exemptions for commonly co-morbid conditions to ensure that this population remains covered.

## Minimize Reporting Burdens

In H.R. 1, there is no requirement for individuals to demonstrate or states to verify the exemptions to the work reporting requirements. Instead, the statute includes explicit permission for states to elect not to do so. The statutory language only requires that “applicable individuals” regularly verify their compliance, whereas individuals who meet the exemptions are deemed compliant, and the state may elect not to verify the information resulting in such deeming.<sup>12</sup> Federal policymakers must maintain this flexibility, consistent with the statute, and **state policymakers should adopt the approach of not requiring individuals to verify their exemption(s).**

If states choose to verify exemptions, they should impose the least possible burden on enrollees, as required by the statute. H.R. 1 requires states to “establish processes and use reliable information available to the State...without requiring, where possible, the applicable individual to submit additional information.”<sup>13</sup> This means that, to the extent possible, states must utilize data matching to determine whether an individual qualifies for an exemption. Because every step, party, and piece of paper added to the application or eligibility determination process is another point where someone could—and often does—drop off and lose access to the care to which they are entitled, policymakers should utilize a framework in which they prioritize the least burdensome options for determining eligibility and compliance

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<sup>12</sup> *Id.* (to be codified at 42 U.S.C. 1396a(xx)(3)(a)).

<sup>13</sup> *Id.* (to be codified at 42 U.S.C. 1396a(xx)(5)).

—and for verifying exemptions for states that choose to do so. To be consistent with the statutory intent, states should require only the minimum additional actions, documentation, and number of involved parties deemed necessary, as outlined in the below recommended framework.<sup>14</sup> Data matching, the first option, represents the least burdensome tactic; each subsequent tactic should only be implemented when completely necessary—such as, if the preceding tactic is precluded or unavailable to the individual:



Recognizing that HIV must be classified as a “serious or complex medical condition,” any data indicating a positive HIV test or an HIV diagnosis would suffice to identify an individual who meets this exemption, as well as to verify the exemption if the state requires it. Most importantly though, **states should partner with community-based organizations and people with lived experience to identify sources of data matching that adequately preserve privacy.** One example provided in H.R. 1 is the use of Medicaid payments or encounter data.<sup>15</sup> That is, claims for antiretroviral medications or any other prescriptions and claims or encounter data related to HIV or AIDS or in which HIV or AIDS is listed as a primary or secondary diagnosis should be sufficient to identify an individual for purposes of this exemption. Additionally, all states have implemented [HIV name reporting](#), which requires the names of individuals who test positive to be reported to the state. States could potentially use this data to match individuals

<sup>14</sup> For a more detailed overview of this framework, see Deborah Steinberg, Protecting People with Substance Use Disorders and Formerly Incarcerated Individuals from Losing Medicaid Coverage: Recommendations on Implementing the H.R. 1 Work Reporting Requirements,” *supra* note 1, at 3-8. The appendix to the report also includes a sample self-affidavit and a sample third-party verification letter as detailed in this section.

<sup>15</sup> Pub. L. No. 119-21, § 71119(a) (to be codified at 42 U.S.C. 1396a(xx)(5)).

who qualify for this exemption, if permitted under state law.<sup>16</sup> Given the sensitive nature of this information, it is imperative for states to ensure that this data is merely *matched*, rather than shared. All data matching efforts must prioritize confidentiality and abide by the privacy protections set forth in HIPAA and state-specific laws that govern the confidentiality of HIV-related information.

If data matching proves inconclusive, or if states determine that privacy considerations must limit the types of data sources used, **policymakers must allow individuals to self-attest—within the application itself—that they meet an exemption**, without providing additional documentation and without disclosing diagnostic information.<sup>17</sup> In other words, individuals should only be required to indicate that they fall under the “medically frail” category without specifying the condition that qualifies them, especially recognizing that subsequent Medicaid claims would substantiate this attestation. Nonetheless, the application should still explicitly identify “HIV or AIDS” in a list of serious or complex medical conditions so individuals with these conditions know to select “medically frail.” Having the attestation streamlined in this way will also be particularly helpful for minimizing stigma and reducing burden and confusion in this population, who frequently have other co-occurring chronic health conditions caused or exacerbated by HIV or AIDS.

If the federal government or state standards require additional information for identifying someone with an exemption or verifying this status, then **they should develop, make publicly available, and accept as sufficient proof an affidavit in which an enrollee can attest to their exemption status**. They should still limit the amount of personal health information—including diagnosis—that needs to be disclosed to minimize privacy concerns, stigma, and burdens on both the individual and the state. No further documentation or information should be required, as doing so would impose a substantial, additional burden on both the state and the individual that goes beyond what is necessary under the law and would lead to greater privacy risks.

Nonetheless, if the federal government or states require some form of third-party verification, then the application should **integrate an electronic verification form (also made available on the state’s Medicaid website)** that can be shared directly with and signed and submitted by a

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<sup>16</sup> For example, [Indiana’s State Plan Amendment](#) describes: “Members with disability determination from the Social Security Administration or who have been confirmed as having HIV/AIDS by the Indiana State Department of Health will be confirmed medically frail on initial determination of eligibility.”

<sup>17</sup> [Indiana’s State Plan Amendment](#) also allows individuals to self-identify or self-attest to their medically frail status, at which point the managed care entity either confirms this status via claims data or [manually applies the guidelines](#) – i.e., automatically classifying an individual with HIV as medically frail – for a new member or a newly diagnosed member where claims are not yet available. [Michigan](#) also allows individuals to self-identify or self-attest to their medically frail status through the application for Medicaid, as well as through a separate form.

third party who can confirm the exemption status. Regardless of whether states can integrate electronic forms, they should also ensure that a **standardized third-party letter—submittable by any means available, including via fax, mail, as well as any formats that are deemed appropriate for outreach<sup>18</sup>—is deemed sufficient proof**, with the minimum amount of personal health information necessary. Furthermore, states should place the fewest possible limitations on who can complete and submit these verifications. At a minimum, this must include health care providers, laboratories or other sites for HIV testing, patient navigators, and any community-based organizations that provide services and supports for people living with HIV or AIDS.

Finally, **since HIV is a lifelong condition, Medicaid enrollees undergoing the redetermination process should not need to submit any additional documentation** to demonstrate that they still meet this exemption and should automatically retain their exempt status.

## Advance Policies that Increase Coverage and Access to Care

In addition to maximizing exemptions to protect vulnerable populations and simplifying the process for identifying exemption status, states can adopt other policies to mitigate coverage losses for those entitled to benefits. For one, states should **proactively screen Medicaid expansion enrollees for exemptions to the work reporting requirements, other Medicaid eligibility pathways, and other coverage and benefits (such as disability benefits)**. One effective way to do this would be to **expand coverage for services provided by community health workers (CHWs)**. These workers play a vital role in connecting individuals with healthcare services and with the support necessary for treatment adherence. CHWs can build on the trust they have developed within their communities to educate people about these new policies and to help individuals obtain any documentation that might be required to verify exemptions, while also ensuring they have access to the most comprehensive coverage, services, and supports they need.

Policymakers should also **invest in employment and training programs** targeted toward the unique health- and stigma-related challenges faced by those living with HIV. For example, states can partner with organizations that combine job placement assistance with services that support the health needs of those living with HIV once employed, including access to reasonable accommodations or other legal protections. Should individuals be denied exemptions to the work reporting requirements, these programs could help them satisfy the community engagement activity hours. Moreover, research shows that employment status is

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<sup>18</sup> Pub. L. No. 119-21, § 71119(a) (to be codified at 42 U.S.C. 1396a(xx)(8)(B)).

[positively correlated](#) with HIV testing, access to and retention in care, and treatment adherence. Nonetheless, participating in work or other such activities should not dictate whether someone living with HIV or AIDS has access to affordable, life-saving health care, especially when stigma and discrimination can often interfere with access to these community engagement opportunities in the first place.

States must also look beyond the harms of work requirements to take actions that **increase access to prevention and care** and improve health outcomes generally. Since early detection and treatment is critical for those living with HIV, state Medicaid programs [should adopt policies](#) that incorporate testing into routine care delivery, reimburse additional provider types (such as pharmacists and CHWs) for screening services, and remove cost-sharing barriers. By expanding access to testing, states will ensure that individuals get timely treatment, while also reducing future HIV transmissions; this will improve public health and decrease the burden on healthcare systems from higher infection rates. Effective treatment for HIV requires long-term care, so states must ensure sustainable and adequate funding for providers and services. To address inevitable budget constraints, states can [experiment with new ways](#) to manage costs, such as seeking supplemental rebates from drug manufacturers to reduce the price of medications. States can also decrease spending by increasing the efficiency of service delivery with care models that integrate primary care and HIV, substance use, and mental health treatment services.

## CONCLUSION

In this moment, state action is more important than ever. The threat to coverage and care for individuals living with HIV likely does not end with H.R. 1, as even further cuts to federal HIV spending [now loom](#). Moreover, these new work requirements and other cuts to the Medicaid program will deprive many individuals of the care and services that would help prevent HIV transmission in the first place. States must act now to protect their populations from the devastating effects of these federal policies.

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