

May 5, 2026

Dear Director Whitehorn,

On behalf of AIDS Foundation Chicago (AFC) and the undersigned below organizations, we write urging you to exempt people living with HIV from the new Medicaid work reporting requirements under the statutory exemption for people with a serious or complex medical condition. We also ask that you share these recommendations with federal officials as they finalize guidance for implementation.

In July 2025, Congress passed the budget reconciliation act of 2025 (P.L. 119-21) establishing federal community engagement (work) requirements for Medicaid expansion/ACA Adult enrollees ages 19-64. There are approximately 9,500 people living with HIV in Illinois who are Medicaid expansion/ACA Adults. The statute requires Illinois to verify work, education, training, or volunteer participation for Medicaid expansion/ACA Adult enrollees and defines required exemptions and optional short-term hardship exceptions. One important mandatory exemption is for people with special medical needs, including those with a serious or complex chronic medical condition.

HIV is both a serious and complex chronic medical condition.

HIV is both a serious and a complex medical condition under H.R. 1¹ because HIV requires consistent, continuous, lifelong treatment to prevent advancement to AIDS. HIV is serious because it requires regular treatment – doctor visits, labs, consistent medication, wraparound support services - and if left untreated, has serious consequences to a person’s health, including worsening the person’s condition if there are treatment lapses. HIV is complex because it requires specialty care, care coordination and especially for long-term survivors, means an increased likelihood to develop other chronic health conditions—often at an earlier age—than the general population. While effective treatment has greatly increased life expectancy, chronic inflammation and immune system activation, even when suppressed, contribute to higher risks of cardiovascular disease, cancer, diabetes, and kidney disease for people living with HIV.

Ensuring access to effective HIV care, treatment, and supports through the Medicaid program is vital 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 virally suppressed, people living with HIV can live healthy lives—including engaging in work, education, or other pursuits—and there

¹ OBBA’s health and functional status exemptions require states to exempt from work requirements a person with “a serious or complex medical condition”. See § 71119 (a)(xx)(9)(A)(ii)(V)(ee) (emphasis added) HIV meets both categories.

is no risk of sexual transmission. These outcomes require continuous access to HIV medications and related care, which in turn require uninterrupted insurance coverage.

As HIV advocates and providers, we are concerned that subjecting people living with HIV to work reporting requirements will create administrative barriers leading to improper terminations that will disrupt access to crucial healthcare, even for people who are working. For people living with HIV, loss of Medicaid due to these types of arbitrary 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, costly hospitalizations or even premature death. Additionally, more than half of people living with HIV are age 50 and older, a group that is particularly likely to have difficulty complying with work requirements.

People with an HIV diagnosis should be exempt from the work reporting requirement.

P.L. 119-21 requires states to exempt a person “who is medically frail *or otherwise has special medical needs*” —including people with “serious or complex medical conditions”—from work reporting requirements. See § 71119 (a)(xx)(9)(A)(ii)(V) (emphasis added). As the state moves forward to implement the work reporting requirement in Illinois, we urge you to clearly define the exemption due to serious or complex chronic illness but also to ensure that the “special medical needs” portion of the statute is effectuated. Further, because HIV is a serious or complex condition requiring continuous access to treatment, we urge you to include HIV diagnosis in that definition. Illinois must not limit the special medical needs exemption to people who meet the Social Security definition of disability or similarly strict standards and must ensure its eligibility criteria are inclusive of all people described in the statute as exempt.

Do not unlawfully narrow the definition of “special medical needs” by requiring inability to work.

The state should determine eligibility for a work reporting requirement exemption based on whether an individual has a serious or complex chronic illness, not whether an individual is able to work. Unlike work requirements in other programs, P.L. 119-21 clearly intended to preserve Medicaid eligibility for people with ongoing medical management needs, whether or not they are “able” to work. The law requires states to exempt people with a serious or complex condition regardless of whether that individual is also disabled by that condition.

The exemption for people with special medical needs should not require proof of unemployment or inability to work, and evidence of recent or current employment should not be considered in determining exemption eligibility. Indeed, many people living with HIV are employed—ensuring they have the exemption in place will help protect them from coverage loss should their employment status change, which is particularly common for people with serious health conditions. Medicaid is a work support for people with serious conditions like

HIV—continuous access to effective HIV treatment is necessary to help them stay healthy and able to participate in community activities such as work or school.

Utilize screening questions and ex parte verification to minimize administrative burden and procedural churn.

We support the state using claims data, with proper privacy protections in place, to exempt people living with HIV automatically from the work requirements (i.e., *ex parte*). However, it is also important to identify people outside of this data, which requires direct outreach to individuals who have not yet demonstrated an exemption. To reduce administrative barriers for both Medicaid enrollees and the state, screening questions based on an applicant’s declaration should be accepted as verification for special medical needs exemptions, as the statute permits. We also urge the state to reduce administrative burden by automatically renewing exemptions for conditions like HIV that are unlikely to change over time.

Ensure privacy and respect in screening questions and ex parte verification.

Unlike many other health conditions, people living with HIV face ongoing stigma and discrimination. Therefore, it is essential that the application and verification processes for Medicaid maintain individual privacy and agency regarding HIV status. For example, information regarding a Medicaid member’s eligibility for health-based exemptions should only be accessible to agencies that need this information for related health services (such as HFS and IDPH) and should not be provided to anyone for other purposes, such as law enforcement, without the express permission of the individual. Any written notifications that include exemption information should refer to “special medical needs” rather than the specific condition.

Provide clear information and options for assistance.

Given the extensive and confusing nature of these work reporting requirements, it is essential for the state to provide clear and accessible information to applicants and enrollees. This includes plain-language, accessible notices in multiple formats and languages explaining the reporting requirements, exemptions, and information about requesting accommodations. It is especially important that the state test applications and any technology and includes older adults among the testers. It is important to know how people understand terms like “serious,” or “complex,” and how people self-identify. And as described above, it is also important that screening questions not connect one’s health condition to their capacity to work. Notices, websites, and informational bulletins should include clear definitions of exemptions, including those for special medical needs, how that information will be protected, and how applicants and enrollees can get assistance if they think they fall into one of the exemption categories.

Conclusion

We appreciate your careful consideration of these recommendations and urge Illinois to adopt these policies and practices to protect access to care while implementing work reporting requirements. Establishing clear exemption rules and processes consistent with Congress's intent to exempt people with a special medical need or a serious or complex health condition, prioritizing screening tools and ex parte renewals, and providing robust privacy protections will reduce wrongful terminations and other harmful consequences for people living with HIV.

For more information or should you have any questions, please contact Nadeen Israel, nisrael@aidschicago.org, (847) 620-9758 and Timothy S. Jackson, tjackson@aidschicago.org (256) 200-8878.

Sincerely,

AIDS Foundation Chicago (AFC)
Legal Council for Health Justice
Vivent Health +TPAN
Access Living
Agape Missions, NFP
AgeOptions
Asian Human Services DBA Trellus
Association for Individual Development (AID)
Chicago Black Gay Men's Caucus
Chicago Coalition to End Homelessness
Chicago House and Social Service Agency
Chicago Women Take Action (CWTA)
Chicago Women's AIDS Project
Children's Place Association
Christian Community Health Center
Citizen Action Illinois
Cook County Department of Public Health
Cook County Health
Erie Family Health Centers
EverThrive Illinois
Golden Rainbows of Illinois South
Greater Chicago Food Depository
Haymarket Center
Health & Medicine Policy Research Group
Housing Opportunities for Women, Inc. (HOW)
Howard Brown Health

Illinois Harm Reduction & Recovery Coalition
Illinois Public Health Association
Lake County Health Department & Community Health Center
Legal Aid Chicago
Michael Reese Care Program
Michael Reese Research and Education Foundation
Mother and Child Alliance
Nefuse Case Management
Open Door Health Center of Illinois
Planned Parenthood Great Rivers Action
Planned Parenthood Illinois Action
Prairie Pride Coalition
Projects Advancing Sexual Diversity
Public Health Institute of Metropolitan Chicago
Puerto Rican Culture Center
Sinai Chicago
The Porchlight Collective SAP
The Project of the Quad Cities
TuxVerMex Care Solutions LLC
West Side Heroin/Opioid Task Force
Workers Center for Racial Justice