

Medicaid 1115 Waivers

Considerations for HIV and Hepatitis Programs

Introduction

Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve demonstration projects that promote the objectives of the Medicaid program. To encourage innovative demonstration projects, section 1115 gives states additional flexibility to “waive” certain federal Medicaid requirements. An 1115 waiver or demonstration project typically lasts for five years, with the option to renew. Demonstration projects must also be “budget neutral” to the federal government, meaning that the federal Medicaid expenditures cannot be more than federal spending would have been without the project during the same period.

Waivers offer states an opportunity to respond to the needs of low-income individuals by improving and expanding the Medicaid program. States can use waivers to expand eligibility to populations not

otherwise eligible for Medicaid, to provide additional services not typically covered by Medicaid, or to test innovative approaches to delivering health care. However, many pending and recently approved waivers include provisions that would make it more difficult for consumers to enroll in Medicaid or access necessary benefits—for example, by placing limits on benefits or imposing burdensome eligibility requirements. This can jeopardize the health and well-being of people living with HIV, hepatitis (including hepatitis B and C), and other chronic conditions.

This issue brief explains how certain features of Medicaid waivers can harm people living with chronic conditions and describes steps that governmental public health HIV and hepatitis programs can take to protect Medicaid beneficiaries living with these conditions. For questions, please contact [Dori Molozanov](#).

ACTION STEPS

- ✓ Monitor state and federal public comment opportunities for Medicaid State Plan Amendments and 1115 waiver proposals.
- ✓ Work with Medicaid counterparts to ensure there are adequate protections for people living with HIV, hepatitis, and other chronic conditions, including exemptions from harmful waiver requirements for people living with HIV and hepatitis.
- ✓ Engage in outreach and education to support consumers as they navigate changes to their Medicaid coverage and come into compliance with new eligibility requirements.



Analysis of Specific Waivers and Impacts for PLWH/Hepatitis

Limits on Medicaid eligibility pose risks to both individual and public health. HIV and hepatitis are complex conditions that require reliable, consistent access to care. Even a temporary disruption in access to care for a person living with HIV or hepatitis can have adverse consequences. A person living with HIV can live a long, healthy life—but not if they lose access to antiretrovirals because they failed to submit their Medicaid redetermination on time. Furthermore, disruptions in access to medications can jeopardize viral suppression. Because people who are virally suppressed cannot transmit the virus to others, regular access to HIV treatment is also effective HIV prevention. Similarly, people living with hepatitis C (HCV) on curative direct-acting anti-virals must have uninterrupted access to their treatment regimen in order to eliminate the virus, and people living with hepatitis B must maintain access to treatment.

Individuals who lose access to Medicaid for failure to comply with new requirements may be able to regain coverage if they come into compliance. However, consumers who “churn” in and out of Medicaid are still at high risk of adverse health outcomes by losing even temporary access to life-saving medications. This type of churn puts a strain on safety net programs, like AIDS Drug Assistance Programs (ADAPs). Additionally, lock out periods, administrative hurdles to regaining coverage, and lack of knowledge about complicated new Medicaid rules increase the likelihood that consumers will remain uninsured and experience gaps in coverage for some time after they lose Medicaid eligibility.

Work Requirements

Federal requirements: Federal law does not authorize work requirements as a condition of eligibility in Medicaid. In January 2018, the Centers for Medicare & Medicaid Services [announced](#) that it would

allow states to use 1115 waivers to impose work requirements (defined broadly as engagement in a variety of work, education, community service, and other activities defined by the state) as a condition of eligibility.

In 2019, federal courts invalidated work requirements in three states (Arkansas, Kentucky, and New Hampshire) on the grounds that HHS violated federal law when it approved these waivers without considering whether work requirements furthered the objectives of the Medicaid program. In February 2021, CMS [withdrew](#) its previous guidance allowing work requirements and began reevaluating approved waivers.

As of December 2021, five states have withdrawn their proposed or approved work requirements, and CMS withdrew approvals in all but one remaining state. One state (Georgia) still has approval to implement work requirements, but has delayed implementation until at least the end of 2021. However, a number of states still have work requirement proposals pending with CMS.

What are states doing? Although approved Medicaid waivers authorizing work requirements vary somewhat in their details, the result is similar: clients who fail to meet work requirements will lose access to coverage for some amount of time. In most states with approved work requirements, enrollees who fail to comply will have their coverage terminated or “suspended,” and may be locked out for up to a year.

Pending: AR,¹ ID, KS,² MS, MT, OK, SD, TN

Approved but state has postponed implementation: GA³

Withdrawn by state: AL, KY, ME, NE, VA

Approval withdrawn by CMS: AZ, IN, MI, NH, OH, SC, UT, WI

¹ CMS withdrew its prior approval of Arkansas’ work requirements. Arkansas has proposed to reinstate work requirements as an “economic independence” incentive rather than as a condition of eligibility.

² Kansas has asked CMS to defer consideration of its work requirements proposal.

³ Georgia has delayed implementation of its waiver until at least the end of 2021.

Implications for people living with HIV and hepatitis:

Close to 80% of adult Medicaid beneficiaries are living in a working household, so many Medicaid enrollees living with HIV and hepatitis may already meet the work requirements just by living their daily lives. However, states with approved and pending work requirements are also considering administratively complex systems for tracking compliance that may cause some consumers to lose coverage for failing to meet burdensome documentation standards, even when they are meeting the work requirements.

Additionally, pending state applications do not necessarily limit work requirements to the Medicaid expansion population—for example, Georgia’s waiver subjects certain very low-income parents and caretakers to work requirements. Other states that have not adopted the ACA’s Medicaid expansion may seek to implement work requirements for other vulnerable populations. In states such as Georgia and Mississippi that have very low eligibility levels for adults, meeting work requirements could result in loss of coverage altogether—even low-wage, part-time work could make some people financially ineligible for Medicaid, and research shows that less than one-third of workers who earn at or below their state’s minimum wage have an offer of coverage through their employer.

Federal regulations require that certain “exempt” individuals with higher health needs, including people who are determined to be “medically frail,” have the option to enroll in the standard Medicaid benefits package. CMS policy specifically requires that all medically frail individuals are exempt from work requirements.

According to federal policy announced in January 2018, every state seeking to implement work requirements must provide for exemptions for individuals who are “medically frail.” The term “medically frail” broadly refers to individuals with serious and complex health conditions, among other things, but federal regulations give states flexibility to define “medically frail” and develop a process for identifying and exempting individuals that meet this criteria. Only Arizona, Indiana, Maine, Michigan, Nebraska, and Virginia specifically exempted or

proposed to exempt people living with HIV from work requirements (work requirement waivers in these states have since been withdrawn, either by the state or by CMS). Even in states that do not have such condition-specific exemptions, people living with HIV and hepatitis may qualify if their condition meets the state definition of medically frail or impacts activities of daily living, or if they meet the criteria for another exemption. States often provide for exemptions on the basis of age, disability, caregiving responsibilities, enrollment in school, or other circumstances (often referred to as “good cause” or “hardship” exemptions) that prevent individuals from meeting waiver requirements. To read more about exemptions for “medically frail” and other individuals with chronic illnesses, see NASTAD’s fact sheet: [Medicaid 1115 Waivers: Exemptions for People Living with HIV and Hepatitis](#).

Premiums

Federal requirements: States may not impose premiums on individuals with incomes below 150% of the federal poverty level (FPL). States may terminate coverage for failure to pay premiums after a 60-day grace period but may not impose “lock outs,” meaning that consumers who lose coverage must be permitted to reapply without a waiting period. Premiums and cost sharing are subject to an aggregate monthly or quarterly cap of five percent of household income.

What are states doing? A number of states have received approval to shift Medicaid costs to enrollees by charging monthly contributions for individuals with incomes below 150% FPL, with Wisconsin’s and Georgia’s waivers authorizing mandatory premiums for enrollees with income as low as 50% of the federal poverty line. States have chosen to implement premium contributions in different ways, including through health savings accounts and healthy behavior “rewards” systems that can be confusing to consumers. Some states do not disenroll consumers for failure to pay premiums, but may reduce optional benefits such as dental care or impose copays for medical services. Most approved and pending waivers allow disenrollment with a lock out period for failure to pay premiums.

Approved: AR, GA,⁴ IN, IA, MI, MT, WI

Pending: UT

Approved but state has postponed implementation: AZ⁵

Withdrawn by state: KY, NM, OK, VA

Rejected: OH

Implications for people living with HIV and hepatitis:

Premiums are a proven barrier to care for low-income individuals, and even nominal monthly contributions can decrease participation in health care programs. Disenrollment and lock out periods for failure to comply with premium requirements can lead to gaps in coverage and adverse health outcomes for consumers living with HIV and hepatitis. Michigan has exempted people living with HIV from premiums. Indiana will still charge premiums to people living with HIV, but will not impose a lockout period for non-payment. Other states provide for “medically frail” or other exemptions that could include people living with HIV and hepatitis.

Enrollment Limits and Lifetime Caps

Federal requirements: Federal law does not authorize lifetime caps or enrollment time limits in Medicaid.

What are states doing? A number of states have submitted waiver applications that would cap the number of months that certain individuals can receive Medicaid benefits over the course of their lifetime. CMS rejected Arizona’s proposal to impose a five-year lifetime coverage limit for individuals who fail to comply with work requirements. Kansas’ proposed 36-month lifetime cap, which did not exempt individuals who comply with proposed work requirements and would have authorized disenrollment of members who are actively employed, has also been rejected by CMS. Utah’s proposal to impose enrollment caps for its Medicaid expansion population was similarly rejected. However, South Carolina received approval to limit enrollment to 12 months for certain enrollees who are chronically homeless or in need of SUD treatment, with an exemption for enrollees who are actively engaged in SUD treatment.

Approved: SC

Rejected: AZ, KS, UT

Approval withdrawn by CMS: WI

Implications for people living with HIV and hepatitis:

Imposing enrollment time limits or lifetime caps on Medicaid eligibility is harmful for people living with chronic conditions that will worsen without access to coverage. Exceptions for those who are employed are not sufficient protections for people with chronic illness that are unable to work, and even individuals who can work risk losing coverage if they make a mistake adhering to complex and confusing monthly tracking requirements. In addition, taking away Medicaid eligibility for people living with HIV will put a significant strain on already scarce public health resources as ADAPs work to provide a safety net for these individuals.

Closed Formulary

Federal requirements: Medicaid must cover all FDA-approved drugs from manufacturers that offer Medicaid a discount, known as a rebate. States may implement formularies or preferred drug lists (PDLs), but must make drugs not on the PDL available pursuant to prior authorization from the prescriber.

What are states doing? Massachusetts’ proposal to implement a closed formulary with as little as a single drug per class was rejected by CMS, although CMS suggested that it would approve future proposals to substantially limit prescription drug coverage. Under the rejected proposal, the Medicaid program would have selected drugs that are cost-effective and “meet the clinical needs of a vast majority of members,” instead of covering all FDA-approved drugs from manufacturers that participate in the rebate program as required under federal law. The proposal would have expanded the state’s discretion to exclude drugs that may be more clinically effective if the state was unable to negotiate additional discounts with the manufacturer. Federal law already allows states flexibility to adopt some formulary management tools, but Massachusetts’ proposal would have gone further by excluding drugs based purely on a cost-cutting

4 Georgia has delayed implementation of its waiver until at least the end of 2021.

5 Arizona never implemented premiums and has requested CMS approval to remove premiums from its waiver.

6 Michigan has [postponed](#) implementation of premium requirements until October 1, 2020.

justification. Massachusetts also sought authority for its Medicaid program to cut costs by excluding drugs based on the state's own determination that these drugs lack clinical efficacy despite having been approved by the FDA. CMS indicated that it is open to approving future proposals for closed formularies, but only if states forego the mandatory rebates available through the federal Medicaid rebate program (the Massachusetts proposal would have retained the mandatory rebates and closed the formulary). However, in January 2021, CMS approved Tennessee's request to implement a closed formulary while still collecting rebates for covered drugs.

Approved: TN

Rejected: MA

Implications for people living with HIV and hepatitis:

Excluding drugs from the Medicaid formulary will limit access to medications that are critical for the health

and well-being of Medicaid enrollees. Individuals with chronic illnesses may find they do not have access to the most medically appropriate treatments for their conditions. Treatment of HIV and hepatitis is tailored to each patient based on their unique health needs. Patients may experience side effects, drug resistance, or harmful interactions with medications for comorbid health conditions, and must have the ability to switch to a different drug without interruption. Additionally, low-income individuals with chronic illnesses may not have access to new and innovative drug therapies. Although Tennessee is required to adopt an exceptions process to cover drugs not included in the formulary when medically necessary, this can cause delays for patients trying to get medications they need to manage chronic conditions. Disruptions in access to medication can jeopardize viral suppression, increase risk of transmission, and lead to other adverse health outcomes for people living with HIV and hepatitis.

Health Department Considerations

Monitor state and federal public comment opportunities for Medicaid State Plan Amendments and 1115 waiver proposals. Every waiver application must undergo state and federal comment periods before it can be approved. Health department staff can advocate for clients' interests by submitting comments on the state and federal level about the individual and public health implications of applying harmful provisions to people living with HIV and hepatitis, and by attending any public hearings or forums held by state agencies. Health departments may want to cite federal HIV treatment [guidelines](#) and HCV [guidelines](#) from The American Association for the Study of Liver Diseases (AASLD) and The Infectious Disease Society of America (IDSA). In addition, HHS, CMS, HRSA, and CDC have published comprehensive [joint guidance](#) describing best practices and opportunities for state Medicaid programs to support HIV care and prevention.

Work with Medicaid counterparts to ensure there are adequate protections for people living with HIV, hepatitis, and other chronic conditions, including exemptions from harmful waiver requirements. Ryan White program staff work directly with

people living with HIV, and are therefore uniquely positioned to advocate for exemptions from harmful waiver provisions that protect clients while still remaining sensitive to their unique needs and challenges. Additionally, Medicaid churning can impose a significant administrative burden on Ryan White programs; formal data-sharing agreements with Medicaid can facilitate identification of exempt individuals and, if needed, smooth client transition between programs.

Engage in outreach and education to support consumers as they navigate changes to their Medicaid coverage and come into compliance with new eligibility requirements. Clients will likely have a lot of questions about how Medicaid waivers will impact them. Health department staff, particularly ADAP case managers and benefits navigators, play a crucial role in helping clients understand these changes. Even in states where people living with HIV are explicitly exempt from certain waiver provisions, clients may still receive standardized notices that could lead to confusion absent guidance from health department staff.

This fact sheet was produced as part of a project supported by the [Elton John AIDS Foundation](#).

Resources

- NASTAD's [Medicaid Waiver Map](#) tracks pending and approved applications in every state.
- NASTAD's fact sheet, [Medicaid 1115 Waivers: Exemptions for People Living with HIV and Hepatitis](#), explains the process for identifying and exempting "medically frail" and other individuals with chronic illnesses from harmful waivers, and the importance of exemptions for people living with HIV and hepatitis.
- Other waiver tracking resources include those from [Families USA](#) and [The National Health Law Program](#).
- [Kaiser Family Foundation](#) collects and publishes state-specific information about Medicaid, including resources about [Medicaid waivers](#).
- Center on Budget and Policy Priorities conducts policy analysis related to health care and other safety net programs, including extensive assessment of [Medicaid](#) waivers.
- Georgetown University Health Policy Institute Center for Children and Families maintains a [list of public comments](#) from advocacy groups in response to proposed waivers.
- ["Impact of Medicaid 1115 Waivers on the Ryan White HIV/AIDS Program"](#) (HRSA, 2015) explains the role of Medicaid in ensuring access to care and efficient delivery of services for people living with HIV, and examines how states can use Medicaid waivers to enhance rather than hinder, access to care.
- ["Opportunities to Improve HIV Prevention and Care Delivery to Medicaid and CHIP Beneficiaries"](#) (joint HHS/CMCS/HRSA/CDC informational bulletin, 2016) highlights best practices and opportunities available to state Medicaid programs to drive improvements in access, quality, cost, and impact of HIV prevention and care services provided to Medicaid beneficiaries.