



December 22, 2022

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

Re: Wisconsin 1115 Demonstration Waiver Extension

Dear Secretary Becerra:

Thank you for the opportunity to comment on Wisconsin's Section 1115 Demonstration Waiver Extension. On behalf of people with cystic fibrosis (CF), we strongly support the continuation of Medicaid coverage for childless adults with incomes up to 100% of the federal poverty level (FPL) and agree with Governor Evers that Wisconsin should fully expand the program to serve all adults up to 138% FPL. However, we write to express concerns with some of the provisions included in this waiver, specifically, disenrollment lockout periods, monthly premiums, and required copayments. We fear that these requirements could jeopardize patients' access to quality and affordable health care, especially at a time when many are already at risk of losing Medicaid coverage due to the impending end of the federal public health emergency (PHE). We urge CMS to reject these proposals.

About Cystic Fibrosis

Cystic fibrosis is a life-threatening genetic disease that affects close to 40,000 children and adults in the United States, including more than 700 people in Wisconsin. Over half of all children and a fourth of adults living with CF in the state rely on Medicaid for some or all of their health care coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage, and the associated symptoms of CF can lead to early death, usually by respiratory failure.

Disenrollment Lockout Periods

While we respect the need to enforce program rules and eligibility requirements, we urge CMS to consider how the policy to lock beneficiaries out of coverage as a consequence for not paying premiums or failing to complete health risk assessments (HRA) could be difficult for beneficiaries to adhere to and hard to enforce. For people with cystic fibrosis, consistent care and access to specialized therapies are a necessity, and any loss or gap in coverage—even for as little as one month—may put people with CF at risk of declining health by forcing them to forgo daily therapies.

This policy would increase the administrative burden on both patients and the state Medicaid program. Some may be unable to comply due to extenuating circumstances or may fail to understand the process for reporting changes that impact eligibility. Having patients locked out of coverage until they pay the accumulated amount of their missed premium(s), complete an HRA, or become eligible for Medicaid through a different eligibility pathway, further penalizes those who need care the most.

Socioeconomic factors can also influence an individual's ability to adhere to program rules and, therefore, this requirement may disproportionately affect certain populations. For instance, those experiencing employment and housing instability may not have consistent access to mail notifications and income. Low-income individuals may also work multiple jobs that could prevent them from complying with burdensome or complex administrative requirements like those outlined in the proposed waiver. This type of policy could create a cycle in which an individual fails to comply and is locked out of health coverage, leading to further declining health outcomes and additional barriers to care.

Premium Payments

We are concerned that the proposal to require individuals between 50% and 100% of the federal poverty level (FPL) to pay monthly premiums of eight dollars may impose unmanageable costs on financially vulnerable and medically complex adults. Our research shows that while 99% of people with CF have insurance, one-quarter of people delay or skip care due to cost concerns.¹ Such actions seriously jeopardize the health of people with CF and can lead to costly hospitalizations and fatal lung infections. Adding costs such as premiums can increase the risk of gaps in care, and we encourage you to reconsider cost-sharing provisions for this medically and financially vulnerable population.

Additionally, not only are nominal premiums often unaffordable for low-income individuals, but some populations may struggle administratively to pay bills. For instance, an analysis of Indiana's Medicaid program found that nearly 30 percent of enrollees never enrolled in coverage or were disenrolled from coverage because they failed to make premium payments during the study period. The analysis found 22 percent of individuals who never enrolled because they did not make the first month's payment cited affordability concerns, and another 22 percent said they were confused about the payment process.² Moreover, researchers found that many beneficiaries in Michigan used money orders to pay their premiums, as money orders are a common form of payment for individuals without a bank account or credit card, and beneficiary advocates and enrollment assisters noted that money order fees could sometimes equal or exceed the amount of premiums or copayments owed.³ For people with cystic fibrosis, losing coverage because they cannot make a premium payment could eliminate access to vital, life-saving care. On behalf of this medically and financially vulnerable population, we urge you to remove the monthly premium requirement and associated coverage lockout period.

Copayments

The CF Foundation also opposes Wisconsin's proposal to impose eight dollar copayments for non-emergent use of the emergency department. We know that cost-sharing can deter people from seeking needed care; one study of enrollees in Oregon's Medicaid program demonstrated that implementing a copay on emergency services decreased utilization of such services but did not result in cost savings because of subsequent use of more intensive and expensive services.⁴ Substantial cost-sharing for inpatient stays may incentivize people with CF to delay seeking care early, resulting in more intractable

¹ Cost, coverage, and the underuse of medications among people with CF (gwu.edu)
https://hsrsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

infections that are more expensive to treat. We urge the state to remove copays and support access to care for people living with chronic diseases like CF.

COVID-19 Public Health Emergency (PHE) Unwinding

The proposals were approved in 2018 but were not implemented due to the COVID-19 pandemic. Wisconsin states that they will suspend premiums, copayments, and lockout periods until after the calendar quarter in which the public health emergency ends. However, unwinding the PHE and conducting Medicaid eligibility redeterminations will already be a massive undertaking for states requiring new policies and procedures. We fear that implementing this waiver's concerning proposals close to the end of the PHE may further burden program staff and lead to unnecessary coverage losses.

Thank you for the opportunity to provide comments on the Wisconsin Section 1115 Demonstration Waiver Extension. The CF Foundation urges CMS to approve the continuation of Medicaid coverage for low-income childless adults but reject the state's requests to implement premiums, copayments, and lockout periods. We appreciate your attention to these important issues.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', is positioned above the typed name and title.

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy and Advocacy
Cystic Fibrosis Foundation