



October 26, 2022

Elizabeth Hertel  
Director  
Department of Health and Human Services  
333 S. Grand Avenue  
Lansing, MI 48913

Re: Healthy Michigan Plan Section 1115 Demonstration Waiver Extension

Dear Director Hertel,

Thank you for the opportunity to comment on Michigan's Section 1115 Demonstration Waiver Extension. On behalf of people with cystic fibrosis (CF), we strongly support the continuation of Medicaid expansion in Michigan but express concerns with some of the provisions included in the waiver. Specifically, we are concerned about the disenrollment lockout periods, increased monthly premiums, and required copayments. We fear that these requirements jeopardize patients' access to quality and affordable health care and therefore urge the state to remove these harmful provisions.

#### **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 nearly 1,200 people in Michigan. 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 you to consider how the policy to disenroll beneficiaries and lock them out of coverage for not paying premiums or for not completing health risk assessments (HRA) after 48 cumulative months of Medicaid coverage could be difficult for beneficiaries to adhere to and hard to enforce.

This policy would increase the administrative burden on both patients and the state Medicaid program and, as the state acknowledges, result in coverage losses. 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.

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. New enrollees, regardless if they qualify as medically

frail, will need to apply for an exemption but may not understand the process or requirements, putting their health at risk should they end up locked out of coverage.

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 100%-133% of the federal poverty level (FPL) to pay monthly premiums of 5% of an individual's income 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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup>

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**

Furthermore, Michigan's demonstration includes several copays imposed on almost all expansion adults with incomes above 100 percent with less than 48 months of cumulative enrollment in Medicaid. Individuals would not be subject to copayments within their first six months of enrollment; after that,

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<sup>1</sup> Cost, coverage, and the underuse of medications among people with CF (gwu.edu) [https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs\\_policy\\_briefs](https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs)

<sup>2</sup> Lewin Group. Healthy Indiana Plan 2.0: POWER Account Contribution Assessment. March 31, 2017.

<sup>3</sup> Kaiser Family Foundation. An Early Look at Medicaid Expansion Waivers and Implementation in Michigan and Indiana. (Online). January 2017. Available: <http://kff.org/medicaid/issue-brief/an-early-look-at-medicaid-expansion-waiver-implementation-in-michigan-and-indiana/>

individuals would have to pay copayments for certain services, including physician office visits, prescription drugs, emergency room visits, and inpatient hospital stays (ranging from \$1 to \$100 depending on the type of service and income level).

While all copayments can be concerning for low-income populations, the copayments of \$100 per inpatient stay for those at or above 100% FPL is particularly concerning. People with CF may face frequent hospitalizations, and \$100 is a significant amount of money for those living at or slightly above the poverty line. 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.<sup>4</sup> Substantial cost-sharing for inpatient stays may incentivize people with CF to delay seeking care early, resulting in more intractable 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.

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Thank you for the opportunity to provide comments on the Healthy Michigan Plan Section 1115 Demonstration Waiver Extension. As the healthcare landscape continues to evolve, we look forward to working with the state of Michigan to improve the lives of all people with cystic fibrosis. We stand ready to serve as a resource as you consider additional waiver changes. Please contact Sage Rosenthal, State Policy Specialist, at [srosenthal@cff.org](mailto:srosenthal@cff.org) if you would like to discuss these issues further.

Sincerely,



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

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<sup>4</sup> Wallace NT, McConnell KJ, et al. How Effective Are Copayments in Reducing Expenditures for Low-Income Adult Medicaid Beneficiaries? Experience from the Oregon Health Plan. *Health Serv Res.* 2008 April; 43(2): 515–530.