



February 7, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Georgia Section 1115 Waiver

Dear Secretary Azar,

The Cystic Fibrosis Foundation appreciates the opportunity to submit comments on Georgia's 1115 Demonstration Waiver Application for its Georgia Pathways to Coverage initiative.

Cystic fibrosis (CF) is a rare, life-threatening genetic disease that affects approximately 830 people in Georgia and roughly one quarter of adults with CF rely on Medicaid for some or all of their health coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection can be irreversible and have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications.

People with cystic fibrosis need quality, affordable health coverage and Medicaid plays an important role in covering this population, filling gaps left by other insurers and helping people with CF afford vital medications and care. Fully expanding Medicaid would increase access to affordable, high-quality health care and ensure a safety net for those who might otherwise be left without access to coverage.

The Georgia Pathways plan is not a solution to improving access to quality and affordable healthcare for low-income Georgians. The state estimates that approximately 50,000 individuals would gain coverage under the plan, whereas over 500,000 Georgians could access coverage if the state fully expanded its Medicaid program. The Cystic Fibrosis Foundation has concerns about the state's proposal to limit Medicaid expansion to working adults below 100 percent of the federal poverty level (FPL); exclude exemptions for those with serious medical conditions; impose premium and cost-sharing requirements on some beneficiaries; and not provide wraparound coverage to Medicaid eligible individuals who enroll in employer coverage. We oppose the Georgia Pathways program and offer the following comments on the draft waiver application.

Eligibility

The Cystic Fibrosis Foundation opposes Georgia's unprecedented proposal to only expand coverage to low-income adults who are able to comply with a work requirement prior to enrolling. Under the Georgia Pathways plan, only individuals with incomes below 100 percent of the federal poverty level (\$1,778 per month for a family of three) who can prove that they work at least 80 hours per month would be eligible for Medicaid. This would make Georgia the first state to require enrollees to comply with the work reporting requirement prior to enrolling in the Medicaid program, which could prevent otherwise eligible individuals from gaining coverage. Moreover, changing the eligibility for Medicaid is the sole purview of Congress and cannot be waived.

We are also concerned that onerous, ongoing work requirements could cause Georgians to lose Medicaid coverage. For the first six months, members will have to report their hours and work activities monthly. This will put a significant administrative burden on enrollees, which will likely decrease the number of individuals with Medicaid coverage. For example, Arkansas also implemented a work reporting requirement where Medicaid enrollees had to report their hours worked or their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals.ⁱ Failing to navigate these burdensome administrative requirements could have serious—even life or death—consequences for people with cystic fibrosis. If the state finds that individuals have failed to comply for one month, their coverage will be suspended, and if the state finds that individuals have failed to comply for three months, they will be disenrolled. Georgia has not provided an estimate of the coverage losses associated with this proposal in its waiver application.

Finally, under the Georgia Pathways plan, if individuals do not report a change in their employment status, they will be responsible for any capitation and cost-sharing expenses. This exposes already low-income individuals to enormous financial risk and jeopardizes their access to care. People with CF already face significant costs for their care; 45 percent of people with CF spend \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and noncovered services.

If Georgia truly cares about incentivizing and promoting employment, full Medicaid expansion would be the best way to achieve this goal. In a report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).ⁱⁱ That report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Preventing individuals from enrolling in Medicaid coverage until they comply with these requirements will therefore hurt rather than help people search for and obtain employment.

Financial Barriers

For the few individuals who are able to meet this limited eligibility criteria, the proposal still creates numerous financial barriers that will jeopardize their coverage. Individuals with incomes above 50 percent of the federal poverty level will have to pay monthly premiums and will lose coverage if they fail to pay premiums for three months. This policy would likely increase the number of enrollees who lose Medicaid coverage, as nominal premiums are often unaffordable for low-income beneficiaries and the process of making a premium payment can create barriers to care for a population that may not have bank accounts or

credit cards. For example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of \$20 per month, almost half of enrollees lost coverage.ⁱⁱⁱ An analysis of Indiana's Medicaid program also 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 22 percent said they were confused about the payment process.^{iv}

Research has also shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary healthcare services.^v Georgia's proposal includes a number of copayments for individuals with incomes above 50 percent of the federal poverty level that could be a significant financial burden for patients. People with CF bear a significant cost burden and out-of-pocket costs can present a barrier to care. Specifically, a survey conducted by George Washington University of 2,500 people living with CF found that while 98 percent of people with CF have some type of health insurance coverage, 58 percent postpone necessary medical care or forgo prescribed treatments due to cost concerns. Such actions seriously jeopardize the health of people with CF and can lead to costly hospitalizations and fatal lung infections.

Reduced Benefits

The Cystic Fibrosis Foundation opposes the requirement to enroll in employer-sponsored insurance (ESI) without wraparound services and full financial protection for patients. Individuals would be required to enroll in ESI if it is available and determined to be cost-effective for the state. However, the state would not provide any wraparound services for individuals regardless of the benefit package in their ESI. As a complex, multi-system condition, CF requires targeted, specialized treatments and medications, all of which require access to comprehensive care. Low-income individuals who would be otherwise eligible for Medicaid should not be required to enroll in coverage that potentially has with fewer benefits.

The Cystic Fibrosis Foundation opposes this waiver proposal. Instead, we urge Georgia to focus on solutions that promote adequate, affordable and accessible coverage, including a full expansion of the state's Medicaid program.

Sincerely,

Mary B. Dwight

Senior Vice President of Policy & Advocacy
Cystic Fibrosis Foundation

Lisa Feng, DrPH

Senior Director of Policy & Advocacy
Cystic Fibrosis Foundation

Caralee Forseen, MD

Director, Adult Cystic Fibrosis Care Center
Augusta University

Kathleen McKie, MD

Director, Pediatric Cystic Fibrosis Care Center
Augusta University

Rachel Linnemann, MD

Director, Cystic Fibrosis Care Center
Children's Healthcare of Atlanta and
Emory University Cystic Fibrosis Care Center

ⁱ Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, “A Look at November State Data for Medicaid Work Requirements in Arkansas,” Kaiser Family Foundation, December 18, 2018. Available at:

<https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/>; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018.

Available at: http://d31hzhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

ⁱⁱ Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Accessed at: <http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Final-Report.pdf>.

ⁱⁱⁱ Id.

^{iv} Lewin Group. Healthy Indiana Plan 2.0: POWER Account Contribution Assessment. March 31, 2017. Retrieved from <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acct-cont-assesmnt-03312017.pdf>

^v Samantha Artiga, Petry Ubri, and Julia Zur, “The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings,” Kaiser Family Foundation, June 2017. Available at: <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.