CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

December 6, 2019

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

Re: Utah 1115 Primary Care Network Demonstration Waiver Amendment - Fallback Plan

Dear Secretary Azar:

Thank you for the opportunity to comment on Utah's 1115 Primary Care Network Demonstration Waiver Amendment: Fallback Plan. While the Cystic Fibrosis Foundation strongly supports Medicaid expansion, we have serious concerns about a number of provisions proposed in this waiver, including the addition of premiums, eligibility restrictions, and intentional program violation lock-outs. We also continue to express our concerns about previously approved work requirements and enrollment limits. Therefore, we urge you not to approve this application.

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults in the United States. 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. For those with CF, health care coverage is a necessity and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease.

The CF Foundation urges CMS to reject Utah's waiver due to the concerns outlined below.

<u>Medicaid Expansion</u>
In November 2018, Utah voters approved a measure to improve access to health care by expanding Medicaid coverage to a projected 150,000 low-income Utahns. We strongly support the state's decision to follow this directive and implement full Medicaid expansion.

Medicaid is a crucial source of coverage for patients with serious and chronic health care needs—often serving as a payer of last resort, filling important gaps in coverage left by private health plans. For people with CF, Medicaid helps them afford medications and inpatient and outpatient care, ensuring access to life-saving services and allowing people with CF to maintain their health and well-being. Medicaid expansion will increase access to affordable, high-quality health care and provide a safety net for Utahns who might otherwise be left without access to coverage.

While we are encouraged by the decision to expand Medicaid coverage to individuals with incomes below 138 percent of the federal poverty level (FPL), we are nonetheless concerned that Utah is moving forward with this Fallback Plan—through both a waiver approved by the Centers for Medicare and Medicaid Services (CMS) on March 29, 2019 and the state's current waiver amendment application—that will add new barriers to Utah's

CYSTIC FIBROSIS FOUNDATION
NATIONAL OFFICE
4550 MONTGOMERY
AVENUE SUITE 1100N
BETHESDA, MD 20814
TEL: 800.FIGHT.CF
FAX: 301.951.6378
WEB: WWW.CFF.ORG

Medicaid program and result in fewer individuals with comprehensive, affordable health insurance coverage than the plan approved by voters. Specifically, we are concerned with the following proposals listed below.

Premiums and Co-Payments

We are concerned that adding premium contribution and co-payments requirements for beneficiaries with incomes above 100 percent FPL may impose unmanageable health care costs on financially vulnerable and medically complex adults. Imposing such requirements could lead to increased barriers to care, greater unmet health needs, and increased financial burdens. We therefore ask that you deny the request to implement this policy.

Research shows that adding premiums and cost-sharing requirements can result in decreased enrollment and reduced utilization of necessary health care services.[1] For example, a 2017 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.[2] Additionally, when Oregon implemented premiums and cost-sharing in its Medicaid program, almost half of enrollees lost coverage.[3] A study of Wisconsin's Medicaid program also found that premiums made enrollees 12 percentage points less likely to remain enrolled for a full year.[4]

Furthermore, adding to the significant cost burden already experienced by people with CF could cause them delay care or skip treatments. A recent 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. The consequences of skipping or delaying care for someone with CF are serious and can result in costly hospitalizations and fatal lung infections.

For these reasons, we oppose this provision and urge you to reject this proposal.

Retroactive, Prospective, and Presumptive Eligibility

Utah's waiver amendment seeks permission to make future changes to eligibility, including through the elimination of retroactive eligibility and implementation of prospective eligibility for beneficiaries above 100 percent FPL. The state is also requesting permission to prevent hospitals from making presumptive eligibility determinations for individuals in the adult expansion population and continue to prevent hospitals from making these determinations for the targeted adult population. To ensure people with CF do not face gaps in coverage and costly medical bills, we urge to you reject these proposals that would allow the state to limit Medicaid eligibility.

Retroactive eligibility serves as an important safeguard for low-income Medicaid beneficiaries and providers by ensuring continuous coverage for people with CF who experience changes in insurance status and become Medicaid eligible. There are many reasons why Utahns, including people with CF, may not be able to submit a

[1] Artiga, S., Ubri, P., & Zur, J. (2017). The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings. *Kaiser Family Foundation*. Retrieved from https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

[2] The Lewin Group, Healthy Indiana Plan 2.0: POWER Account Contribution Assessment, Prepared for Indiana Family and Social Services Administration (FSSA), (Washington, DC: Lewin Group, March 2017). 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

[3] Neal T Wallace, et. al., "How Effective are Copayments in Reducing Expenditures for Low-Income Adult Medicaid Beneficiaries? Experience from the Oregon Health Plan," *Health Services Research* 43, 3 (April 2008):515-530.

[4] Laura Dague, "The Effect of Medicaid Premiums on Enrollment: A Regression Discontinuity Approach," *Journal of Health Economics* 37 (May 2014): 1-12.

timely Medicaid application when they become eligible. Someone with CF may be consumed by a complicated medical situation—such as an extended hospitalization—that may make it difficult to complete Medicaid paperwork. People may also not realize their coverage has lapsed until they seek care. Eliminating retroactive eligibility could create gaps in coverage for people with cystic fibrosis so we urge Utah to maintain retroactive eligibility. We have similar concerns regarding the proposal to implement prospective eligibility for beneficiaries above 100 percent FPL, as it would delay coverage until the first of the month after application. Therefore, we recommend CMS reject the state's proposal for prospective eligibility to prevent any gap in coverage for people with CF.

Furthermore, we have concerns regarding the request to eliminate hospital determination of presumptive eligibility. Presumptive eligibility allows hospitals to provide temporary Medicaid coverage to individuals likely to qualify for Medicaid and is an important entry point for individuals who qualify for Medicaid but are not yet enrolled, helping them gain prompt access to care and protecting patients from large medical bills. We ask CMS to reject this request as well.

Lock-Out due to Intentional Program Violation

While we respect the need to enforce program rules and eligibility requirements, we urge you to consider how the policy regarding Intentional Program Violations (IPV) 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 itself 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. For instance, more than 40 percent of people with CF experience at least one pulmonary exacerbation per year.[5] Since hospitalizations associated with pulmonary exacerbations last 18.3 days on average, [6] people living with CF could be unable to report a change in circumstance within the proposed ten-day reporting period. Moreover, a six-month lock-out for failure to report a required change within ten days is a dangerous penalty for a person with CF relying on Medicaid for health 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. 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 then locked-out of health coverage, leading to further declining health outcomes and additional barriers to care.

Finally, "intent" can be subjective and difficult to prove. We urge you to direct the state to revisit this list and consider fair, reasonable, and realistic guidelines for ensuring the integrity of Utah Medicaid.

Previously Approved Provisions

Utah's application also requests to extend certain policies already approved by CMS in the state's existing waiver. As we've previously noted, the CF Foundation continues to have serious concerns about the impact of these policies on Medicaid beneficiaries with CF.

Work Requirements

Continuous access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis. Making work a condition of Medicaid eligibility threatens access to care for people with CF, as their ability to work can vary with changes in health status. Additionally, based on the experience in other states,

[5] CF Patient Registry, 2017

[6] Ibid

the Cystic Fibrosis Foundation has serious concerns about the administrative challenges someone with CF could face in navigating these requirements and the exemption process—potentially resulting in coverage losses for people with CF who rely on Medicaid.

While many people with CF are able to work full or part-time, others are unable to maintain employment due to their health status. For instance, variations in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce temporarily or for long periods of time. Denying coverage because an individual is unable to satisfy work requirements is excessively punitive for people with a life-threatening condition like cystic fibrosis.

Moreover, a study in *The New England Journal of Medicine* found that implementation of Arkansas's work requirement was associated with a significant loss of Medicaid coverage but no corresponding increase in employment, indicating that individuals did not find other jobs that may have increased their incomes and provided other healthcare coverage.[7] Arkansas, one of only two states with experience implementing a work requirement, disenrolled more than 18,000 people from their Medicaid program within just 6 months for failing to report their number of hours worked.[8] Over the first five months of the program, an average of 12.6 percent of those disenrolled from Medicaid lost coverage as a result of an increase in income, while almost a quarter of closures over the same period of time were due to failing to meet the requirement.[9]

Although we recognize that Utah's proposed work requirement is structured differently than Arkansas's, the threat of coverage losses remains—and we expect individuals will not lose coverage because they find jobs, but because they are unable to navigate the system to report their work. Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with cystic fibrosis. People with CF, who rely on regular visits with an accredited CF care team and must take daily medications to manage their condition, cannot afford a sudden gap in their care.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. The Cystic Fibrosis opposes this proposed requirement.

Enrollment Limits

Because limiting enrollment "would be tantamount to 'partial expansion,'" we understand that CMS has noted their intent to deny Utah's request to cap enrollment for the adult expansion population when receiving an enhanced matching rate.[10] However, the Cystic Fibrosis Foundation would still like to note our strong opposition to enrollment limits in the Medicaid program.

Implementing enrollment limits in Medicaid would almost certainly create barriers to care. Under Utah's proposal, the state would be permitted to close enrollment for the adult expansion eligibility group "when

---

[7] Benjamin Sommers, et al. Medicaid Work Requirements—Results from the First Year in Arkansas. *New England Journal of Medicine*. 2019. Retrieved from https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B

[8] 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. Retrieved from https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/

[9] Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Retrieved from http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

[10] Centers for Medicare & Medicaid Services. Utah Per Capita Cap Notification Letter, August 16, 2019. Retrieved from https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ut/per-capita-cap/ut-per-capita-cap-correspondence-ltr-20190816.pdf

projected costs exceed annual state appropriations." Should the state enact an enrollment limit, Utahns with CF who qualify for Medicaid could be denied access to the specialized care they require, including visits with CF care teams and lifesaving therapies needed for treatment of the disease. The effects of reduce access care would be devastating for people with CF, who do not have the luxury to wait weeks or months to receive treatment. Any delay in could lead to reduced pulmonary function and extended hospital stays. This denial of coverage is not consistent with the statutory objectives and purpose of the Medicaid program.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. We believe that the proposed policies could result in loss of health coverage for Utahns and do not align with Medicaid's core program objective of furnishing coverage. As the health care landscape continues to evolve, we look forward to working with CMS and the state of Utah to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

Mary B. Dwight
Senior VP of Policy & Advocacy
Cystic Fibrosis Foundation

Lisa Feng, DrPH
Senior Director of Policy & Advocacy
Cystic Fibrosis Foundation

Fadi Asfour, MD
Director, Pediatric Cystic Fibrosis Care Center
Primary Children's Hospital
Salt Lake City, UT

Theodore G. Liou, MD
Director, Cystic Fibrosis Care Center
University of Utah Hospital
Salt Lake City, UT