



June 28, 2019

Utah Department of Health  
Medicaid and Health Financing  
PO Box 143106  
Salt Lake City, UT 84114-3106  
Attn: Jennifer Meyer-Smart

**Re: Utah 1115 Demonstration Waiver Application – Per Capita Cap**

Dear Ms. Meyer-Smart,

Thank you for the opportunity to comment on Utah’s 1115 Primary Care Network Demonstration Waiver Amendment: Per Capita Cap Application. The Cystic Fibrosis Foundation has serious concerns about how the proposed per capita funding limit may impact access to care for people with cystic fibrosis (CF) enrolled in Medicaid and, therefore, urge you not to submit 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. Medicaid is a crucial source of coverage for patients with serious and chronic health care needs, including those with CF—often serving as a payer of last resort, filling important gaps in coverage left by private health plans. Medicaid helps people living with CF to afford the increasingly costly co-pays and co-insurance rates for prescription medications and inpatient and outpatient care, ensuring access to life-saving services and helping them to maintain their health and well-being.

The purpose of the Medicaid program is to provide health care coverage for low-income or vulnerable individuals. In November 2018, Utah voters clearly decided to improve access to health care by expanding Medicaid coverage to individuals with incomes below 138 percent of the federal poverty level (\$28,577 for a family of three). This decision would have expanded coverage to 150,000 low-income individuals in the state. Instead – through both a waiver approved by the Centers for Medicare and Medicaid Services (CMS) on March 29, 2019 and the state’s current waiver application – Utah is moving forward with an alternative plan that will add new barriers to Utah’s 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 in this waiver:

Per Capita Cap Funding Mechanism

We are concerned that per capita caps create a framework to restrict Medicaid financing. While the state’s current proposal allows the program to revert back to the traditional financing system if costs

exceed the per capita cap, Utah may choose to constrain eligibility, reduce benefits, lower provider payments, or increase patient cost-sharing if costs continued to exceed the cap going forward. For patients with serious chronic conditions, like people living with CF, per capita caps could mean that Medicaid no longer provides access to their health care provider or covers the care and treatments they need. This is a particular concern for breakthrough therapies and technology, as such a rigid funding structure would restrict the state's ability to keep pace and provide access to new therapies. This could be devastating for people with serious diseases like CF, for whom groundbreaking treatments represent a new lease on life.

Per capita caps could also mean cuts to Medicaid when the need is greatest, because funding would no longer be responsive to demand. For instance, Medicaid has been a critical tool for states in responding to natural disasters. Under a per capita cap proposal, additional federal funds to help combat such emergencies would be limited. A rigid funding structure that provides little flexibility for states in the face of public health emergencies—whether due to natural disasters, shifting demographics, or changes in disease prevalence—is a stark contrast to partnership that exists today and would simply shift costs to the state or Utah taxpayers and families.

Implementing this type of funding mechanism, particularly on top of the Medicaid enrollment caps that were approved earlier this year, would almost certainly create barriers to care. Utah would be permitted to close enrollment for the adult expansion eligibility group “when projected costs exceed annual state appropriations.” Should the per capita cap trigger an enrollment limit, Utahns with CF who qualify for Medicaid could be denied access to the specialized care they require—and the implications could be devastating for those with complex health care needs like CF. People with CF 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. Therefore, we ask that you rethink this potentially harmful proposal.

#### 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. Since hospitalizations associated with pulmonary exacerbations last 18.3 days on average,<sup>1</sup> many people living with CF could be unable to report a change in circumstance within the proposed ten-day reporting period. A six-month lock-out for failure to report a required change within ten days is a dangerous penalty for a person relying on Medicaid for health coverage.

Furthermore, socioeconomic factors can 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

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<sup>1</sup> CF Patient Registry, 2017

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.

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

#### Presumptive Eligibility

Utah’s waiver would also 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. Presumptive eligibility allows hospitals to provide temporary Medicaid coverage to individuals likely to qualify for Medicaid. While retroactive eligibility is an important safeguard, we do not believe it is sufficient. Presumptive eligibility 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. The Cystic Fibrosis Foundation opposes eliminating presumptive eligibility for the adult expansion and targeted adult populations.

Given the above information, we urge you to reconsider your submission of this waiver application. The proposed policies could result in loss of health coverage for Utahns and does not align with Medicaid’s core program objective of furnishing coverage.

The Cystic Fibrosis Foundation appreciates your attention to these important issues. As the health care landscape continues to evolve, we look forward to working with the state of Utah to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,



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Cystic Fibrosis Foundation



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