August 3, 2018

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

Dear Secretary Azar,

Thank you for the opportunity to comment on Utah’s 1115 Primary Care Network Demonstration Amendment: Adult Expansion Medicaid. We support the state’s decision to expand Medicaid coverage for childless adults and ask you to approve the expansion proposed in the submitted waiver. However, we have serious concerns about the proposal to add community engagement requirements as a condition of eligibility and we ask that you direct the state to specifically and automatically exempt people with cystic fibrosis from these requirements.

**Medicaid Expansion**

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 30,000 people 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.

Research shows Medicaid expansion increases coverage rates and improves access to care.\(^1\) While we would have preferred the state of Utah expand Medicaid eligibility to the full extent allowed under law, in light of the state’s request, we urge you to approve Utah’s proposal to expand Medicaid to 95 percent of the federal poverty level. 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. Approval of Medicaid expansion will increase access to affordable, high-quality health care and ensure a safety net for those who might otherwise be left without access to coverage.

**Community Engagement and Work Requirements**

We are concerned with the proposal to add community engagement requirements as a condition of Medicaid eligibility and we ask you to direct the state to exempt people with cystic fibrosis. Community engagement requirements introduce additional barriers to access, which may cause interruptions and delays in treatment and care. Many people with CF work full or part-time; however, their ability to work can vary over time with changes in health status. Declines in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce for significant periods of time. Patients bear a significant treatment burden on a daily basis, amounting to

---

hours of chest physiotherapy, delivery of nebulized treatments, administration of intravenous antibiotics, and/or other activities required to maintain or improve their health. Maintaining sustained employment may not be possible due to the time required to undergo necessary treatment, which includes an intense and time-consuming daily regimen.

We appreciate the state’s decision to exempt from community engagement requirements those determined to be physically or mentally unable to work, which reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment. While an individual with CF may fall into this exemption category, we are unsatisfied with the specificity of this language and potential bureaucratic hurdles involved in obtaining an exemption for someone with CF. As such, we urge you to direct the state to specify an automatic lifetime exemption for people with CF. We ask that the state use its own data to identify people with CF for exemption to minimize the risk of inappropriate disenrollment and administrative burden on recipients.

The Cystic Fibrosis Foundation appreciates your attention to this important issue. As the health care landscape continues to evolve, we look forward to working with the state of Utah to ensure access to high-quality, specialized CF care and 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