Dear Ms. Melby,

Thank you for the opportunity to comment on New Hampshire’s 1115 Demonstration Waiver Amendment. On behalf of people with cystic fibrosis (CF), we write to express our concern with the state’s proposals to add work and community engagement requirements as a condition of Medicaid eligibility and eliminate retroactive coverage. We urge you to consider the Cystic Fibrosis Foundation as a resource as the state plans for and implements these policies. Work and community engagement requirements create an additional barrier to accessing the high-quality care that people with chronic conditions like CF need. As such, we ask the state to specifically and automatically exempt people with cystic fibrosis from these requirements. Retroactive coverage in Medicaid helps ensure continuous access to high-quality, specialized CF care which is essential to the health and well-being of people with cystic fibrosis and we therefore ask the state to reject the proposal to eliminate this policy.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 209 people in New Hampshire and 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 approximately 24 adults living with cystic fibrosis in New Hampshire. Medicaid plays an important role in helping this patient population access the high-quality care and treatment necessary to maintain or improve health. Continuous access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis.

Within the state’s 1115(a) Demonstration Waiver Amendment, we are concerned with the following provisions:

**Work and Community Engagement Requirements**

Making work a condition of Medicaid eligibility threatens access to care for people with CF, as their ability to work vary greatly 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 as well, 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. Sustained
employment may not be possible due to the time required to undergo necessary treatment, which includes an intense and time-consuming daily regimen.

While we appreciate the state’s decision to exempt from work requirements a person who is “medically frail” or temporarily unable to participate due to illness or incapacity—which reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment—we urge the state to work with us to specifically exempt people with CF. We also ask the state to use its own data to identify people with CF for exemptions in order to minimize the risk of inappropriate disenrollment and administrative burden on recipients.

As experts in cystic fibrosis care and research, the CF Foundation is a partner to states during the rulemaking and implementation process. Our goal is to ensure people with CF are exempt from work requirements and help states minimize unintended errors. In particular, we can provide clinical expertise on service utilization, co-morbidities, and other factors that may help the state identify people with CF through claims data.

**Waiving Retroactive Coverage Requirement**

We oppose the proposal to waiver retroactive coverage. Retroactive coverage allows individuals with chronic conditions, like cystic fibrosis, to receive care and treatment immediately, rather than waiting for their official Medicaid eligibility determination and without incurring medical debt. A medical complication could be serious enough to make someone with CF eligible for Medicaid by health status or preclude them from working, jeopardizing their employer-sponsored insurance coverage. We therefore ask the state to continue to provide three months of retroactive coverage for individuals, especially those with serious medical conditions like cystic fibrosis.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. As the health care landscape continues to evolve, we look forward to working with the state of New Hampshire to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis.

Sincerely,

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