



August 10, 2017

The Honorable Thomas Price
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Price:

Re: Amendment to the Special Terms and Conditions for the Arkansas Works Section 1115 Medicaid demonstration

Thank you for the opportunity to comment on the amendment to the Special Terms and Conditions for the Arkansas Works Section 1115 Medicaid Demonstration. We applaud the state for its success in increasing access to health care coverage and improving health for low-income beneficiaries through the Arkansas Works program.^{1,2} However, we are concerned that several proposals included in the amendment would erode this progress and create barriers to access for people with cystic fibrosis. In particular, the Cystic Fibrosis Foundation recommends that the state pay special attention to the needs of individuals with rare genetic diseases who require multidisciplinary specialty care in any reform effort.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 285 people in Arkansas 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. Given the role that Medicaid plays in helping this patient population access the high-quality care and treatment they need to maintain or improve their health, we urge the state to ensure the needs of CF patients are met as the state makes changes to its Medicaid program. Within the state's 1115 demonstration amendment request, we are concerned particularly with the following provisions:

Work requirements and lock-out for non-compliance

We appreciate the state's decision to exempt from employment requirements those who are "medically unfit" which reflects the important reality that health status can significantly affect an individual's ability to search for and sustain employment. We are concerned that this definition does not specify what will qualify an individual for exemption, and that people with cystic fibrosis may lose coverage because they are unable to satisfy the requirement due to health status. Some people with cystic fibrosis may not qualify for disability but their ability to work may vary over their lifetimes. While many are able to work full or part-time, others are not able to maintain employment due to their health status or the amount of time they need to spend on their treatments. 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 longer periods of time. Furthermore, many patients bear a significant treatment burden, 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, which can interfere with their ability to work. For these reasons, many people with CF experience periods when they are unable to work or attend school, despite being ineligible for disability benefits.

Furthermore, disenrolling individuals and locking them out of coverage because they were unable to satisfy work requirements is excessively punitive for people with a life-threatening condition like cystic fibrosis. For people with CF, continuous 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.

We urge CMS to reject the proposal to impose work requirements tied to lock-out periods, as all people with CF need consistent access to coverage.

Should CMS allow the state to impose the work requirement, Arkansas should develop a list of conditions – including cystic fibrosis – that qualifies an individual for exemption. Furthermore, the state should articulate a clear process for applying for an exemption based on “medically unfit” status, as well as a timeline for determination. Clear rules around the application process, eligibility requirements, and timeframes will help ensure that eligible individuals are able to get an exemption and obtain coverage in a timely manner.

Lowering income eligibility for expansion adults to 100% of FPL

We are concerned with the proposal to decrease the Medicaid income eligibility threshold from 138 percent to 100 percent of the federal poverty level. For Arkansans with cystic fibrosis, this is a step in the wrong direction. Medicaid is a vital safety net for more than 65 percent of CF patients in Arkansas, many of whom are adults. While historically a children’s disease, breakthrough treatments have added years to the lives of people with cystic fibrosis and today the median predicted survival age is close to 40. This is a dramatic improvement from the 1950s, when a child with CF rarely lived long enough to attend elementary school. For this reason, it is vitally important that adults with CF retain access to this critical source of coverage. We request that CMS reject this proposal, so that this vital safety net is preserved and the state can continue to reap the benefits of Arkansas Works.

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 Arkansas 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,

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References:

¹ Hayes, Susan L. et al., “A Long Way in a Short Time: States’ Progress on Health Care Coverage and Access, 2013–2015,” The Commonwealth Fund

² Sommers, Benjamin D. et al. “Three-Year Impacts Of The Affordable Care Act: Improved Medical Care And Health Among Low-Income Adults,” Health Affairs, May 17, 2017