



January 22, 2019

Joshua D. Baker  
Director  
South Carolina Department of Health and Human Services  
P.O. Box 8206  
Columbia, SC 29202

**Re: South Carolina 1115 Demonstration Waiver Application – South Carolina Medicaid Community Engagement**

Dear Mr. Baker:

The Cystic Fibrosis Foundation appreciates the opportunity to submit comments on the South Carolina 1115 Demonstration Waiver Application – South Carolina Medicaid Community Engagement.

Cystic Fibrosis (CF) is a life-threatening genetic disease that affects more than 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. 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 Cystic Fibrosis Foundation is committed to ensuring that Medicaid provides adequate, affordable and accessible healthcare coverage. Several 1115 waiver proposals submitted to and approved by the Centers for Medicare and Medicaid Services (CMS) in recent months have jeopardized patients' access to quality and affordable healthcare coverage.<sup>i</sup> The purpose of the Medicaid program is to provide affordable healthcare coverage for low-income individuals and families. Unfortunately, South Carolina's application does not meet this objective and will instead create new administrative barriers that jeopardize access to healthcare for patients with serious and chronic diseases. The Cystic Fibrosis Foundation urges the South Carolina Department of Health and Human Services (SCDHHS) to withdraw their Section 1115 Demonstration Waiver.

The proposed South Carolina 1115 Demonstration Waiver seeks to add new barriers to accessing coverage. Individuals between the age 19 and 64 would be required to either demonstrate that they work at least 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on all patients. Individuals will need to attest that they meet certain exemptions or have worked the required number of hours on a monthly basis. The proposal does not specify how often individuals would need to validate their community engagement activities in order to remain in compliance.

Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. During the first six months of implementation, the state has terminated coverage for over 18,000 individuals and locked them out of coverage until January 2019.<sup>ii</sup> In another case, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.<sup>iii</sup> Battling administrative red tape in order to

keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases like CF. If the state finds that individuals have failed to comply with the new requirements for just one month, they will lose their coverage. People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

The Cystic Fibrosis Foundation is also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from working. Additionally, South Carolina's "case specific basis" exemption as "determined by SCDHHS" is vague and does not provide sufficient detail on how this exclusion would be implemented. Individuals with chronic disease, women, African Americans and those living in rural communities will be disproportionately impacted by the community engagement requirement. The outlined exemptions are not sufficient to protect patients. In Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption.<sup>iv</sup>

Regardless of system integration, administering these requirements will be expensive for South Carolina. States such as Michigan, Pennsylvania, Kentucky and Tennessee have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.<sup>v</sup> These costs would divert resources from Medicaid's core goal – providing health coverage to those without access to care.

Ultimately, the requirements outlined in this waiver do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.<sup>vi</sup> A study published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan's Medicaid enrollees.<sup>vii</sup> The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work. In another report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).<sup>viii</sup> The report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Terminating individuals' Medicaid coverage for non-compliance with these requirements will hurt rather than help people search for and obtain employment. For these reasons, the Cystic Fibrosis Foundations opposes the proposed South Carolina Medicaid Community Engagement demonstration program.

The Cystic Fibrosis Foundation believes everyone should have access to quality and affordable healthcare coverage. The South Carolina 1115 Demonstration Waiver Application does not meet that standard. Thank you for the opportunity to provide comments.

Sincerely,

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

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

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- <sup>i</sup> American Lung Association, A Coordinated Attack: Reducing Access to Care in State Medicaid Programs, July 2018. Accessed at <http://www.lung.org/assets/documents/become-an-advocate/a-coordinated-attack.pdf>.
- <sup>ii</sup> 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. Accessed at: <https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/>; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: [http://d31hzhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519\\_AWReport.pdf](http://d31hzhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf)
- <sup>iii</sup> Tricia Brooks, "Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP," Georgetown University Health Policy Institute Center for Children and Families, January 2009.
- <sup>iv</sup> Jessica Greene, "Medicaid Recipients' Early Experience With the Arkansas Medicaid Work Requirement," Health Affairs, Sept. 5, 2018. Accessed at: <https://www.healthaffairs.org/doi/10.1377/hblog20180904.979085/full/>.
- <sup>v</sup> Michigan House Fiscal Agency, Legislative Analysis of Healthy Michigan Plan Work Requirements and Premium Payment Requirements, June 6, 2018, <http://www.legislature.mi.gov/documents/2017-2018/billanalysis/House/pdf/2017-HLA-0897-5CEEF80A.pdf>; House Committee on Appropriations, Fiscal Note for HB 2138, April 16, 2018, <http://www.legis.state.pa.us/WU01/LI/BI/FN/2017/0/HB2138P3328.pdf>; Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018, <https://www.rollcall.com/news/politics/medicaid-kentucky>.
- <sup>vi</sup> Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017, <http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>.
- <sup>vii</sup> Renuka Tipirneni, Susan D. Goold, John Z. Ayanian. Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan. *JAMA Intern Med*. Published online December 11, 2017. doi:10.1001/jamainternmed.2017.7055
- <sup>viii</sup> Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Accessed at: <http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Final-Report.pdf>