August 31, 2018

Becky Pasternik-Ikard
Medicaid Director
State of Oklahoma, Oklahoma Health Care Authority
4345 N. Lincoln Blvd.
Oklahoma City, OK 73105

Re: 2018 SoonerCare Choice and Insure Oklahoma 1115(a) Demonstration Waiver Public Notice and Amended Application

Dear Director Pasternik-Ikard:

The Epilepsy Foundation and Epilepsy Foundation of Oklahoma appreciate the opportunity to comment on the 2018 SoonerCare Choice and Insure Oklahoma 1115(a) Demonstration Waiver Public Notice and Amended Application.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures, including the more than 41,000 individuals in Oklahoma. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime, and more than one third of people living with epilepsy rely on Medicaid for their health coverage, including many children and those with the severest forms of epilepsy who cannot gain seizure control.

The Epilepsy Foundation and Epilepsy Foundation of Oklahoma believe healthcare should affordable, accessible and adequate. The purpose of the Medicaid program is to provide affordable healthcare coverage for low-income individuals and families. Unfortunately, Oklahoma’s application does not meet this objective and will instead create new administrative barriers that jeopardize access to healthcare for patients with epilepsy.

SoonerCare, Oklahoma’s Medicaid program, covers parents and caretakers and disabled individuals with incomes at or below 45 percent of the federal poverty level (approximately $779 per month for a family of 3). The proposed waiver amendment seeks to add new barriers to accessing coverage. Individuals between the ages of 19 and 50 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.

Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. According to the state’s own report on the second month of implementation, 5,426 individuals did not meet the reporting requirement for two consecutive months and are at risk of losing coverage on September 1, at which point they would be locked out of coverage until January 2019.1 An
additional 6,531 individuals did meet the reporting requirement for one month and also remain at risk for losing their coverage. Similarly, 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.

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, including epilepsy. If the state finds that individuals have failed to comply with the new requirements for three months, they will be locked out of coverage until the individual is able to meet the requirement. 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 Epilepsy Foundation and Epilepsy Foundation of Oklahoma are 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 meeting these requirements. While we are pleased that patients will have the option to demonstrate that they qualify for an exemption through self-attestation, the reporting process still creates opportunities for administrative error that could jeopardize coverage. No exemption criteria can circumvent this problem and the serious risk to the coverage and health of the people we represent.

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. A recent study, published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan’s Medicaid enrollees.

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.

**Lack of Key Information**

The Epilepsy Foundation and Epilepsy Foundation of Oklahoma are troubled, as the waiver application lacks key information. There is little detail on how the new requirements will be implemented and enforced, but more troubling, the application claims the proposal will have no impact on enrollment as part of the budget neutrality assumption. The proposal does not predict the impact of the waiver on enrollment (with or without waiver baseline) or cost savings over 5 years. The federal rules at 431.408 pertaining to state public comment process require at (a)(1)(i)(C) that a state include an estimate of the expected increase or decrease in annual enrollment and expenditures if applicable. The intent of this section of the regulations is to allow the public to comment on a Section 1115 proposal with adequate information to assess its impact. In order to meet these transparency requirements, Oklahoma must include these projections and their impact on budget neutrality. If Oklahoma intends to move ahead with this proposal, the state should at a minimum provide the required information to the public and reopen the comment period for an additional 30 days.

The Epilepsy Foundation and Epilepsy Foundation of Oklahoma believe everyone should have access to quality and affordable healthcare coverage. Oklahoma’s 2018 SoonerCare Choice and Insure Oklahoma
1115(a) Demonstration Waiver Public Notice and Amended Application does not advance that goal. Thank you for the opportunity to provide comments.

Sincerely,

Jenniafer Walters
Executive Director
Epilepsy Foundation of Oklahoma

Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation

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3 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.
