



June 27, 2020

The Honorable Alex Azar, Secretary  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Ave., S.W.  
Washington, D.C. 20201

Dear Secretary Azar:

Epilepsy Foundation and Epilepsy Foundation Oklahoma appreciate the opportunity to submit comments on the SoonerCare 2.0 Medicaid Section 1115 Demonstration Waiver. The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 3.4 million Americans living with epilepsy and seizures. Our local chapter, Epilepsy Foundation Oklahoma, provides services and advocates for the approximately 41,100 Oklahomans living with epilepsy and seizures. Together, we foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. While we support Oklahoma's proposal to expand coverage to low-income adults, including thousands of people with disabilities and chronic conditions, CMS should not approve the SoonerCare 2.0 Demonstration.

The Secretary may only approve a Section 1115 project that is experimental and likely to promote the objectives of the Medicaid Act.<sup>1</sup> The purpose of Medicaid is to enable states to furnish medical assistance to individuals who are unable to meet the costs of necessary medical care and to furnish rehabilitation and other services to attain or retain capability for independence or self-care.<sup>2</sup> Oklahoma's proposed project includes work requirements, premiums, a per capita cap, and other harmful provisions that would reduce coverage and access to care, particularly for people with disabilities. As such, it is inconsistent with the provisions of § 1115 and the Medicaid Act. Instead of creating barriers to care, Oklahoma should invest in program features known to improve coverage and care for people with disabilities.

In addition to requesting many project features that have proven to reduce access to coverage and care, Oklahoma also seeks to be the first state to implement a block grant or per capita cap per CMS' recent [guidance](#). CMS' guidance and Oklahoma's proposal represent a drastic departure from traditional Medicaid financing. Since the portion of the statute setting forth Medicaid's financing is not within the provisions the Secretary may waive, the request for a per capita cap is not permitted by Section 1115. Further, the lack of detail on the per capita cap

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<sup>1</sup> 42 U.S.C. § 1315(a) (also note that under the statute, the Secretary may only waive compliance a) with requirements in 42 U.S.C. § 1396a; and b) to the extent and for the period necessary to carry out the experiment.

<sup>2</sup> 42 U.S.C. § 1396-1.



and on other aspects of the proposal makes it impossible to provide meaningful comments, and CMS should not have approved the State's application as complete.

We also are concerned that many of Oklahoma's proposals and enrollment projections were based on an expectation that Oklahoma would have implemented a Medicaid expansion in July 2020 pursuant to a State Plan Amendment (SPA). When the Governor withdrew the SPA, CMS should have withdrawn its certification of the proposal as complete and returned the application to the State to develop new enrollment and other projections.

### **Medicaid Expansion Covers Millions of People with Disabilities & Their Caregivers**

Medicaid expansion fills critical coverage gaps for people with chronic conditions and disabilities, like epilepsy and seizures, and their caregivers. Depending on how you define it, roughly 20 to 30 percent of newly eligible Medicaid expansion enrollees live with a disability.<sup>3</sup> This could include:

- a person with epilepsy whose job earnings exceed the low threshold for her state's disability category (\$1,063/month in Oklahoma) but who does not or has not yet qualified for Medicare;
- someone who suffered a brain injury in a car crash but is still in the lengthy process of obtaining a formal disability determination from the Social Security Administration (SSA); or
- a person with a bipolar disorder who may not meet the strict requirements for Social Security Disability Insurance but needs medications or other treatment to function effectively and hold down a job.

These are just some examples of the many people with disabilities who, without access to Medicaid through the adult expansion group, would likely have no access to affordable coverage at all.

Expansion also fills coverage gaps for caregivers of people with disabilities, both paid and unpaid. Currently, Oklahoma's Medicaid coverage for parents and caregivers is only available for households earning less than \$668 per month (\$8,016/yr.) for a family of three.<sup>4</sup> Medicaid expansion would raise that level to just under \$30,000 annually. In Oklahoma, direct care workers -- including personal care aides, home health workers, and nursing home assistants -- earned an average of \$10.66 per hour in 2018, which translates to just \$21,320 per year at full

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<sup>3</sup> Ohio Medicaid Assessment Survey, *The Changing Landscape of Healthcare Coverage Across Ohio: What Does It Mean for Our Health?*, 17 (Aug. 19, 2015), [http://grc.osu.edu/sites/default/files/inline-files/OMASSLIDEDECK\\_FINAL%281%29\\_0.pdf](http://grc.osu.edu/sites/default/files/inline-files/OMASSLIDEDECK_FINAL%281%29_0.pdf); Asst. Sec. of Planning & Eval., U.S. Dept. Health & Human Servs., *Benefits of Medicaid Expansion for Behavioral Health*, 4 (Mar. 28, 2016).

<sup>4</sup> Okl. Health Care Authority, *Soonercare 2.0 Healthy Adult Opportunity (HAO) Section 1115 Demonstration Application*, 34 (May 6, 2020), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ok-soonercare-2-pa.pdf> [hereinafter "OK Soonercare 2.0 Proposal"].



time.<sup>5</sup> Over two-thirds (68%) work part-time or part-year.<sup>6</sup> Nationally, about one in three home-care workers (34%) have earnings that would qualify them for the adult Medicaid expansion, and in non-expansion states, one in four of them remain uninsured.<sup>7</sup> Medicaid expansion thus fills important insurance gaps and provides the security of health care coverage for parents and direct care workers who provide life-sustaining supports to people with disabilities.

Unfortunately, Oklahoma's waiver proposal includes multiple eligibility restrictions like premiums, work requirements, and the elimination of retroactive coverage that would cause tens of thousands, including people with disabilities and their caregivers, to lose coverage. Proposed waivers of mandatory services, increased cost sharing, and a per capita cap would restrict access to critical health care services for thousands of others.

### **Work Requirements**

Oklahoma's proposed project would require enrollees to complete at least 80 hours of work or work-related activities per month to maintain Medicaid coverage. Enrollees who do not complete and report their work hours monthly would lose their coverage. Oklahoma's proposed work requirement would unquestionably lead to reduced Medicaid enrollment, without providing any benefits. In addition, individuals who fail to complete work requirements cannot re-enroll in the Medicaid program unless they complete the work requirements or meet one of the stated exemptions, meaning many people will not be able to re-enroll. This policy will hurt thousands of people with disabilities, despite the State's claim that they will be exempt.

People with disabilities experience discrimination at various stages of employment, including at hiring, resulting in low employment rates and wage levels. For example, employees with disabilities that would not affect their job performance are 26 percent less likely to be considered for employment.<sup>8</sup> In addition, compared to people without a disability, people with a disability are nearly twice as likely to be employed part time because they cannot find a job with more hours or their hours have been cut back. Individuals with disabilities also experience difficulties obtaining necessary work supports or reasonable accommodations from their employer. All told,

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<sup>5</sup> PHI National, *Workforce Data Center: State Data*, (Last visited June 9, 2020), <https://phinational.org/policy-research/workforce-data-center/>.

<sup>6</sup> PHI National, *U.S. Home Care Workers: Key Facts*, 5 (2019), <https://phinational.org/resource/u-s-home-care-workers-key-facts/>.

<sup>7</sup> PHI National, *U.S. Home Care Workers: Key Facts*, 5 (2019), <https://phinational.org/resource/u-s-home-care-workers-key-facts/>; PHI, *The Impact of the ACA on Health Coverage for Direct Care Workers* 5 (2017), <https://phinational.org/resource/the-impact-of-the-affordable-care-act-on-health-coverage-for-direct-care-workers/>.

<sup>8</sup> Mason Ameri et al., *The Disability Employment Puzzle: A Field Experiment on Employer Hiring Behavior* (2015) [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2663198](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2663198).



people with disabilities actually saw their labor force participation drop from 1980 to 2015 and remain more than twice as likely to not have employment.<sup>9</sup>

Oklahoma itself predicts that the combination of work requirements and premiums will trigger a five percent reduction in overall enrollment.<sup>10</sup> However, when Arkansas implemented a similar work requirement on a younger Medicaid cohort in June 2018, roughly 23% of Medicaid enrollees subject to the requirement—over 18,000 people—lost their coverage by the end of the year.<sup>11</sup> Fewer than one in four Arkansans terminated for failure to meet the work requirements had reenrolled five months after their lockout period ended.<sup>12</sup> And unlike Oklahoma’s proposal, Arkansas did not require compliance with the work requirements prior to reenrollment. Similarly, in New Hampshire, nearly two-thirds of enrollees who needed to report work activities in June 2019, or 17,000 people, had not reported sufficient hours and were at risk for coverage loss before the State suspended the work requirements.<sup>13</sup>

Experience with other programs shows that work requirements disproportionately impact people with disabilities, even when the policies include exemptions.<sup>14</sup> Numerous studies of state Temporary Assistance for Needy Families (TANF) programs found that participants with physical or mental health conditions are more frequently sanctioned for not completing the work requirement or related work activities.<sup>15</sup> Similarly, researchers raised

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<sup>9</sup> Grace Donnelly, *See How Your State Ranks in Employment among Works with Disabilities*, FORTUNE (Feb. 28, 2017), <http://fortune.com/2017/02/28/disability-employment-rank/> (citing the Annual Disability Statistics Compendium).

<sup>10</sup> OK Soonercare 2.0 Proposal, at 22.

<sup>11</sup> Jennifer Wagner, Ctr. on Budget and Pol’y Priorities, *Medicaid Coverage Losses Mounting in Arkansas from Work Requirement* (Jan. 17, 2019), <https://www.cbpp.org/blog/medicaid-coverage-losses-mounting-in-arkansas-from-work-requirement>.

<sup>12</sup> Harris Meyer, *More Arkansans Uninsured, Unemployed Post-Medicaid Work Requirement*, Modern Healthcare (June 19, 2019), <https://www.modernhealthcare.com/medicaid/more-arkansans-uninsured-unemployed-post-medicaid-work-requirement>.

<sup>13</sup> Letter from Jeffrey A. Meyers, Comm’r N.H. Dep’t of Health & Human Servs. to Gov. Christopher T. Sununu et al. (July 8, 2019), <https://www.dhhs.nh.gov/medicaid/granite/documents/ga-ce-findings.pdf>.

<sup>14</sup> See, e.g., Andrew J. Cherlin et al., *Operating within the Rules: Welfare Recipients’ Experiences with Sanctions and Case Closings*, 76 SOC. SERV. REV. 387, 398 (2002) (finding that individuals in “poor” or “fair” health were more likely to lose TANF benefits than those in “good,” “very good,” or “excellent health”); Vicki Lens, *Welfare and Work Sanctions: Examining Discretion on the Front Lines*, 82 SOC. SERV. REV. 199 (2008) [hereinafter Lens, *Welfare and Work Sanctions*].

<sup>15</sup> See, e.g., Yeheskel Hasenfeld et al., Univ. of Pennsylvania School of Social Pol. and Practice, *The Logic of Sanctioning Welfare Recipients: An Empirical Assessment* (2004), [http://repository.upenn.edu/cgi/viewcontent.cgi?article=1028&context=spp\\_papers](http://repository.upenn.edu/cgi/viewcontent.cgi?article=1028&context=spp_papers); Lens, *Welfare and Work Sanctions*; MaryBeth Musumeci & Julia Zur, Kaiser Family Found., *Medicaid Enrollees and Work Requirements: Lessons From the TANF Experience* (Aug. 18, 2017), <https://www.kff.org/medicaid/issue-brief/medicaid-enrollees-and-work-requirements-lessons-from-the-tanf-experience/>; Mathematica Pol. Research, *Assisting TANF Recipients Living with Disabilities to Obtain and Maintain Employment: Conducting In-Depth Assessments* (2008) [https://www.acf.hhs.gov/sites/default/files/opre/conducting\\_in\\_depth.pdf](https://www.acf.hhs.gov/sites/default/files/opre/conducting_in_depth.pdf); Pamela Loprest, Urban Inst., *Disconnected*



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concerns that states might incorrectly determine that many of the nearly 20 percent of all SNAP participants who have a disability, but do not receive disability benefits, are subject to the work requirement.<sup>16</sup> In one study, a third of SNAP participants referred to an employment and training program to keep their benefits reported a physical or mental limitation, and 25 percent of those individuals indicated that the condition limited their daily activities. In addition, almost 20 percent of the individuals had filed for SSI or SSDI within the previous two years.<sup>17</sup>

Oklahoma's inclusion of exemptions for enrollees who are "medically certified as physically or mentally unfit for employment" or have a disability as defined under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, or Section 1557 of the Affordable Care Act will not resolve these concerns.<sup>18</sup> Many people who could qualify for an exemption will lose coverage because they are not aware of the work requirements, do not understand that they qualify for an exemption, or do not know how to seek one. The State's proposal provides few details on how an individual will receive notice or find out they qualify for a disability exemption, what verification will be required, or how long the exemption will last. In fact, the proposal's only reference to duration is where the State lists the ADA disability exemption in its description of "good cause" exemptions. These appear to apply for just a single month.<sup>19</sup> News accounts from Arkansas described individuals with chronic conditions who lost their coverage due to confusion about the work requirements.<sup>20</sup> A recent Kaiser Family Foundation study similarly found that despite the purported exemptions and safeguards, significant numbers of individuals with a disability still lost coverage. The study found that safeguards were complex and difficult to navigate and so exempted very few enrollees.<sup>21</sup> Mass coverage losses occurred despite Arkansas "using existing data sources when possible" to confirm disability status.<sup>22</sup> Oklahoma's proposal provides no reason to expect a different result.

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*Welfare Leavers Face Serious Risks* (2002), <http://www.urban.org/sites/default/files/publication/59036/310839-Disconnected-Welfare-Leavers-Face-Serious-Risks.PDF>.

<sup>16</sup> See Michael Morris et al., Burton Blatt Inst. at Syracuse Univ., *Impact of the Work Requirement in Supplemental Nutrition Assistance (SNAP) on Low-Income Working-Age People with Disabilities* 4, 14 (2014), <https://researchondisability.org/docs/publications/snap-paper-8-23-2014-with-appendix.pdf?sfvrsn=2>.

<sup>17</sup> Ohio Association of Foodbanks, *Comprehensive Report: Able-Bodied Adults without Dependents* (2015), <https://cfpa.net/CalFresh/ExternalPublications/OAFB-WEP-ABAWD-report-2015.pdf>.

<sup>18</sup> OK Soonercare 2.0 Proposal, at 14.

<sup>19</sup> OK Soonercare 2.0 Proposal, at 14.

<sup>20</sup> PBS News Hour, "With New Work Requirement, Thousands Lose Medicaid Coverage in Arkansas" (November 19, 2018), <https://www.pbs.org/newshour/show/with-new-work-requirement-thousands-lose-medicaid-coverage-in-arkansas>; Benjamin Hardy, *Locked out of Medicaid: Arkansas's Work Requirement Strips Insurance from Thousands of Working People*, ARKANSAS TIMES, <https://www.arktimes.com/arkansas/when-arkansas-works-doesnt/Content?oid=25890378>.

<sup>21</sup> MaryBeth Musumeci, Kaiser Family Found., *Disability and Technical Issues Were Key Barriers to Meeting Arkansas' Medicaid Work and Reporting Requirements in 2018* (Jun. 11, 2019), <https://www.kff.org/medicaid/issue-brief/disability-and-technical-issues-were-key-barriers-to-meeting-arkansas-medicaid-work-and-reporting-requirements-in-2018/>.

<sup>22</sup> Sommers et al., *Medicaid Work Requirements – Results from First Year in Arkansas*, at 8.



Oklahoma's proposal also creates administrative reporting barriers that will cause many people with a disability—including those who are working—to lose coverage. For example, the State fails to describe in any detail how it will make reporting mechanisms, including requests for exemptions, accessible for people with disabilities who require accommodations.<sup>23</sup> The fact that substantial portions of the State's proposal document are not screen-readable does not inspire confidence.<sup>24</sup>

## Premiums

Oklahoma proposes Medicaid expansion premiums. Individuals with household income that falls between the parent/caretaker income standard and 100% FPL would pay \$5.00 per month (\$7.50 for families). Those with income from 100-133% FPL would pay \$10.00 (\$15.00 for families). Importantly, no one can access benefits until they pay their first premium. Individuals who successfully enroll in coverage but fail to pay subsequent premiums will lose their Medicaid coverage after a ninety-day grace period. The State also requests flexibility to impose premiums up to 5% of household income – up to \$120/month for a family of three at 133% FPL – without requesting an additional amendment to its project.<sup>25</sup>

The premiums thus create a major enrollment barrier for individuals who cannot or do not know how to pay the initial premium. Others will lose coverage due to nonpayment after they enroll. Decades of research has repeatedly confirmed the obvious – premiums deter and reduce enrollment among low-income individuals.<sup>26</sup> As noted above, Oklahoma itself predicts that premiums and work requirements will depress enrollment by at least five percent. Recent evidence from states that have enacted similar premium structures indicates the coverage losses would be much higher. For example, when Indiana implemented required premium payments for individuals and households above 100% FPL, 23% of otherwise eligible individuals who were required to pay an initial premium to begin coverage did not pay it, and as a result, did not enroll in coverage. Another 7% of those who successfully enrolled and had to pay premiums to stay eligible later lost coverage for failing to pay subsequent premiums.<sup>27</sup> Oklahoma's proposal is even harsher than Indiana's in that it plans to require premiums for individuals falling below 100% FPL. Studies have shown that the impacts of premiums and cost-sharing in

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<sup>23</sup> OK Soonercare 2.0 Proposal, at 11.

<sup>24</sup> The proposal attachments describing the Alternative Benefit Plan and parts of the summary of comments received are not accessible.

<sup>25</sup> OK Soonercare 2.0 Proposal, at 34.

<sup>26</sup> Samantha Artiga, Petry Ubri, and Julia Zur, Kaiser Family Found., *The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings* (2017), <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.

<sup>27</sup> The Lewin Group, *HIP 2.0: POWER Account Contribution Assessment*, ii (2017), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acct-cont-assesmnt-03312017.pdf>.



Medicaid becomes more pronounced as income decreases, meaning coverage losses will likely be more severe.<sup>28</sup> In short, imposing premiums serves no experimental purpose. We know that premiums simply reduce enrollment, which is not consistent with the objectives of the Medicaid Act.

The State offers limited exemptions from premiums, including individuals diagnosed with HIV/AIDS, a substance use disorder (SUD), or serious mental illness (SMI). These are narrower than the exemptions for Medically Frail individuals in Indiana and Michigan, which will lead to greater loss of coverage due to premiums for people with disabilities. Nor does the State provide any information on how new applicants will know about these limited exemptions, how they will be screened and verified, or how applicants and enrollees will be identified as eligible for an exemption. Because premiums must be paid prior to enrollment, this omission could result in people with these conditions who should be exempt never accessing coverage because they are forced, inappropriately, to pay premiums just to enroll.

### **Retroactive Coverage**

Oklahoma proposes eliminating retroactive coverage for enrollees in the Medicaid expansion population. Waiving retroactive coverage poses substantial harm for both enrollees and health care providers. People with disabilities and chronic conditions may be more likely have an emergency hospitalization or require other services before they learn they are eligible for, and have had a chance to enroll in, Medicaid expansion. This is exactly why Congress added retroactive eligibility to the Medicaid statute. Eliminating that coverage exposes many people to the financial burden of those initial treatment costs.

By definition, this proposal reduces access to coverage, leaving some enrollees facing substantial medical debt that they cannot afford to pay. Retroactive coverage also helps ensure the financial stability of health care providers and reduces uncompensated hospital care. Evidence from states that have eliminated retroactive coverage reinforces that these waivers cause widespread coverage loss and create significant problems for health care providers.<sup>29</sup>

### **Hospital Presumptive Eligibility**

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<sup>28</sup> Samantha Artiga, Petry Ubri, and Julia Zur, Kaiser Family Found., *The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings* (2017), <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>; Leighton Ku & Teresa A. Coughlin, *Sliding-Scale Premium Health Insurance Programs: Four States' Experiences*, 36 *Inquiry* 471 (1999).

<sup>29</sup> MaryBeth Musumeci & Robin Rudowitz, Kaiser Family Found., *Medicaid Retroactive Coverage Waivers: Implications for Beneficiaries, Providers, and States* 4 (2017), <https://www.kff.org/medicaid/issue-brief/medicaid-retroactive-coverage-waivers-implications-for-beneficiaries-providers-and-states/>.



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Oklahoma proposes to eliminate hospitals' option to make presumptive eligibility (PE) determinations for the expansion population. PE covers individuals immediately upon completing a short application/screening and continues while the state makes a final eligibility determination. It helps ensure financial stability for low-income individuals and protects providers from uncompensated care costs. Eliminating PE is particularly egregious when combined with the State's request to eliminate retroactive coverage. While Oklahoma asserts that the State will continue to use its Notification of Date of Service (NODOS) process to determine eligibility, that process includes restrictions and deadlines far less protective than hospital presumptive eligibility.

### **Non-Emergency Medical Transportation**

Oklahoma proposes to exclude coverage of non-emergency medical transportation (NEMT) for the Medicaid expansion population. NEMT is essential for many individuals enrolled in the Medicaid program, and of particular importance to individuals living with uncontrolled seizures. Transportation barriers pose a significant problem for many low-income individuals and families, particularly people with disabilities. Research shows that NEMT significantly improves access to health care and is cost-effective for states.<sup>30</sup> Transportation barriers are often associated with reduced medication adherence,<sup>31</sup> and studies demonstrate that enrollees with chronic conditions are more likely to participate in care-management visits when they have access to reliable transportation.<sup>32</sup> In addition, by reducing costly hospitalizations and emergency department visits due to delayed or foregone care, NEMT can actually save states money.<sup>33</sup>

Data from states that have eliminated NEMT for the Medicaid expansion population has shown that individuals have missed medically necessary appointments or reported unmet health needs due to transportation barriers.<sup>34</sup>

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<sup>30</sup> Hughes-Cromwick et al.; J. Joseph Cronin, Jr., et al., Florida State Univ., *Florida Transportation Disadvantaged Programs Return on Investment Study* (2008), [https://ctd.fdot.gov/docs/AboutUsDocs/roi\\_final\\_report\\_0308.pdf](https://ctd.fdot.gov/docs/AboutUsDocs/roi_final_report_0308.pdf).

<sup>31</sup> Timothy E. Welty et al., *Effect of Limited Transportation on Medication Adherence in Patients with Epilepsy*, 50 J. AM. PHARM. ASSOC. 698 (2010), <https://pubmed.ncbi.nlm.nih.gov/21071313/>.

<sup>32</sup> Jinkyung Kim et al., *Transportation Brokerage Services and Medicaid Beneficiaries' Access to Care*, 44 HEALTH SERVS. RES. 145 (2009), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2669622/>; P. Hughes-Cromwick et al., *Transportation Research Board, Cost Benefit Analysis of Providing Non-Emergency Medical Transportation* (Oct. 2005), [https://altarum.org/sites/default/files/uploaded-publication-files/05\\_project\\_report\\_hsd\\_cost\\_benefit\\_analysis.pdf](https://altarum.org/sites/default/files/uploaded-publication-files/05_project_report_hsd_cost_benefit_analysis.pdf).

<sup>33</sup> Hughes-Cromwick et al.; J. Joseph Cronin, Jr., et al., Florida State Univ., *Florida Transportation Disadvantaged Programs Return on Investment Study* (2008), [https://ctd.fdot.gov/docs/AboutUsDocs/roi\\_final\\_report\\_0308.pdf](https://ctd.fdot.gov/docs/AboutUsDocs/roi_final_report_0308.pdf); The Stephen Group, *Recommendations to the Ark. Health Reform Task Force* (2015), <https://www.stephengroupinc.com/images/engagements/Final-Report-Volume-II.pdf>.

<sup>34</sup> See, e.g., Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan*, 26 (Mar. 2016), [https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1131&context=ppc\\_health](https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1131&context=ppc_health); The Lewin Group, *Indiana HIP 2.0: Evaluation of Non-Emergency Medical Transportation (NEMT) Waiver* (Nov. 2016), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-nemt-final-evl-rpt-11022016.pdf>.



Notably, people in relatively poorer health (58% higher odds), with multiple physical ailments (63%), or who have any functional deficit (245%) were all much more likely to report unmet transportation needs.<sup>35</sup> Women, people of color, and younger enrollees were also significantly more likely to face these barriers. Eliminating NEMT in Oklahoma will lead to unmet care needs and will exacerbate health disparities in the State.<sup>36</sup>

Under Oklahoma law, individuals who are not seizure free for a period of six months or more are prohibited from holding a valid drivers' license. Medically fragile individuals must have a reliable mode of transportation so that they can obtain the care necessary to try to control their seizures. Without NEMT, some beneficiaries may face substantial barriers to their medical care, and caregivers may experience further strain of resources. We oppose any proposal that would limit an individual's ability to seek necessary and critical medical care.

### **Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)**

Oklahoma proposes to eliminate EPSDT services for nineteen- and twenty-year-olds in the expansion population. Congress included EPSDT in the Medicaid program to provide comprehensive coverage of screening, diagnosis and treatment services for individuals under the age of 21. Nineteen- and twenty-year-olds can face serious health conditions that can be detected and treated through EPSDT. For young adults with disabilities, EPSDT ensures they get prompt access to the comprehensive range of services and supports necessary to correct and ameliorate their condition(s). EPSDT provides an opportunity to identify significant health conditions, allows for early intervention, and can dramatically improve health outcomes. Eliminating EPSDT will lead to unmet care needs, leaving young adults without necessary screening and treatment services that could help prevent more serious and costly conditions as they age.

### **Long-Term Supports and Services (LTSS)**

For individuals with disabilities and chronic-health conditions, long-term care services are absolutely critical to health and well-being. Medicaid expansion has allowed millions of Americans with chronic health conditions and disabilities, who do not qualify for Medicaid through a disability pathway, to gain coverage and access to state plan LTSS. While the Alternative Benefit Package that applies to most expansion enrollees can differ from state plan services, the Medicaid Act requires that Medicaid expansion enrollees who are Medically Frail have the option to select state plan coverage. In Oklahoma, that encompasses an array of important LTSS, including state plan personal care services.

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<sup>35</sup> Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan, 26 (Mar. 2016), [https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1131&context=ppc\\_health](https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1131&context=ppc_health).

<sup>36</sup> While Oklahoma suggests that it might cover NEMT "in limited cases," the application does not provide enough detail to determine the extent to which (if at all) this potential exception could mitigate the harm. See Application at 24.



Most states avoid having to identify Medically Frail expansion enrollees by fully aligning the expansion benefit package with state plan benefits. But Oklahoma proposes to not provide LTSS through SoonerCare 2.0, meaning it would have to develop a process to identify expansion enrollees who are Medically Frail. The project proposal fails to clarify key details about this process, including how the state will identify applicants and enrollees who are Medically Frail; how people with disabilities will be notified about the Medically Frail pathway and the state plan alternative; how they will be screened and verified; and whether such a screening will exempt them from certain conditions of eligibility. Without these details, we cannot provide meaningful comment on the extent of a barrier that this additional hurdle will create for expansion enrollees who need state plan LTSS.

If, alternatively, the state intends simply to exclude access to state plan LTSS for all expansion enrollees, including the Medically Frail, that would require a waiver that amounts to no more than a simple benefit cut for expansion enrollees with disabilities and chronic conditions who need state plan LTSS. Such a benefit cut would be inconsistent with the purpose of the Medicaid Act and would not be approvable.

### **Prescription Drug Coverage**

Oklahoma's proposal requests the flexibility to impose a limited Medicaid formulary on its Medicaid expansion population with only "advance notice procedures." There is not enough information in the application to allow us to comment in any meaningful way on this vague proposal, as there is no substance here to describe an experiment.

In general, allowing Oklahoma to adopt a commercial-style closed formulary would likely have limited effect on drug pricing, but might have serious consequences for beneficiary health. In many cases, people cannot tolerate or do not benefit from one drug in a therapeutic class, and therefore need an alternative. Under a limited formulary, that alternative might be restricted, while other enrollees might have to switch prescriptions if their current medication is excluded. In one study of people with epilepsy, people who had their medication switched had a 16.7% rate of seizure reoccurrence over 6 months, compared to 2.8% among those who were not switched.<sup>37</sup> The imposition of a closed formulary would have serious health consequences for people with disabilities and chronic conditions in the expansion.

Treatment for epilepsy and seizures is not one-size-fits all and treatment is dependent on a variety of circumstances such as age, sex, seizure type, and daily routine. It is critical that individuals living with epilepsy and seizure and their treating providers have access to the full litany of treatment options. To change, limit, or deny access to treatment options – particularly treatment options that have worked to control a beneficiary's seizures – can be dangerous and even life-threatening.

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<sup>37</sup> J.M. Finamore et al., *Seizure Outcome After Switching Antiepileptic Drugs: A Matched, Prospective Study*, 57 *EPILEPSIA* 1294 (2016).



Finally, section 1115 permits the Secretary to waive only requirements in § 1396a of the Social Security Act. The statutory authority for Medicaid formulary protections lies outside § 1396a. The Secretary lacks the authority to approve the State's request for "flexibility" to impose unilaterally an undefined closed formulary at some future date.

### **Per Capita Caps**

It is impossible for us to offer meaningful comments on the State's request to use per capita caps for the expansion population because the proposal provides almost no information about the funding transformation the State seeks. The proposal does not explain how the transformation will affect stakeholders from enrollees to health care providers.

Regardless of the specific details, Oklahoma's request for a per capita cap is illegal. The Social Security Act constrains what provisions of the Medicaid Act the Secretary may waive.<sup>38</sup> It only permits waivers of the requirements included in 42 U.S.C. § 1396a. Medicaid's funding mechanism is not included in this section. Thus the very structure of the Social Security Act makes it very clear that Congress did not grant CMS the authority to authorize PCC/block grant funding.

As we understand per capita caps in general, the State would receive a fixed amount of money based on the number of enrollees. The State would be liable for any costs that exceed its allotted cap. For example, a national disaster could easily cause the State to exceed its capitated funding. Capitated funding could also limit access to new, innovative, and intensive medical treatments. The current COVID-19 pandemic and predicted economic downturn should serve as warning signals to Oklahoma about the potentially devastating consequences of a per capita cap.

In addition, over time, the costs of the Medicaid program will likely grow faster than the proposed inflation rate (Consumer Price Index-Medical).<sup>39</sup> This would increase pressure for the State to cut benefits or enrollment to save money. Oklahoma has previously looked to cut HCBS programs in response to budget pressures, and nothing in this proposal would prevent the State from seeking to cut services or eligibility outside of the expansion if it

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<sup>38</sup> 42 U.S.C. § 1315 (Section 1115 of the Medicaid Act).

<sup>39</sup> Rachel Garfield et al., Kaiser Family Foundation, Data Note: What if Per Enrollee Medicaid Spending Growth Had Been Limited to CPI-M from 2001-2011? (March 23, 2017), <https://www.kff.org/medicaid/issue-brief/data-note-what-if-per-enrollee-medicaid-spending-growth-had-been-limited-to-cpi-m-from-2001-2011/>. CMS proposed in its guidance on HAO 1115 projects that the CPI-M would be the growth factor for previously non-expansion states.



exceeds the expansion cap.<sup>40</sup> By their very nature, per capita caps are designed to control spending and likely to reduce access to care over time. Like the other provisions discussed in these comments, they do not serve a demonstration purpose and run counter to the purpose of the Medicaid Act.

## Conclusion

We thank HHS for the opportunity to submit comments on the SoonerCare 2.0 Medicaid Section 1115 Demonstration Waiver. As we have noted throughout these comments, we are concerned that the proposed project contains provisions that would cut health benefits and lead to significant coverage losses for enrollees in the expansion population, including thousands of people with disabilities and chronic conditions and their caregivers. Given this, we ask that HHS not approve the current application.

Our comments include citations to supporting research and documents for the benefit of HHS in reviewing our comments. We direct HHS to each of the items cited and made available to the agency through active hyperlinks, and we request that these, along with the full text of our comments, be considered part of the formal administrative record on this proposed rule.

Thank you for your time and attention. If you have any questions, please feel free to contact Abbey Roudebush, Senior Manager, Government Relations & Advocacy at [aroudebush@efa.org](mailto:aroudebush@efa.org) with questions.

Sincerely,

Gregg Fort  
Acting State Director  
Epilepsy Foundation Oklahoma

Laura Thrall  
President & CEO  
Epilepsy Foundation

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<sup>40</sup> Eriech Tapia, *Oklahoma's Home Health Care Program in Jeopardy*, Tulsa World (June 19, 2017), [https://www.tulsaworld.com/news/local/government-and-politics/oklahomas-home-health-care-program-in-jeopardy/article\\_32583e59-a87a-52b2-9120-bc815bb58556.html](https://www.tulsaworld.com/news/local/government-and-politics/oklahomas-home-health-care-program-in-jeopardy/article_32583e59-a87a-52b2-9120-bc815bb58556.html).