



April 14, 2020

Melody Anthony
Medicaid Director
Oklahoma Health Care Authority
Federal Authorities Unit
4345 N. Lincoln Blvd.
Oklahoma City, Oklahoma 73105

Re: SoonerCare 2.0 Section 1115 Demonstration Application

Dear Director Anthony:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the SoonerCare 2.0 Section 1115 Demonstration Application.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families, and NORD is committed to ensuring that SoonerCare provides quality and affordable healthcare coverage. We strongly support the State Plan Amendment (SPA) submitted on March 6, 2020 that will expand Medicaid coverage in Oklahoma to individuals making less than 138 percent of the federal poverty level (\$2,498 for a family of three) beginning July 1, 2020. We urge the state to implement this expansion as quickly as possible as this will help provide health care coverage to an economically and often medically vulnerable population.

Unfortunately, the SoonerCare 2.0 proposal would greatly reduce the benefits of Oklahoma’s Medicaid expansion and jeopardize beneficiaries’ access to care. This proposal would shift the program to a capped funding structure, reduce patients’ access to critical benefits and services, and add new administrative and financial barriers to the program that would undoubtedly lead to coverage losses – the state itself estimates 7,600 fewer individuals would be enrolled due to the premium and work requirements in the first year of the demonstration alone. These coverage losses are unacceptable to NORD. NORD would oppose this proposal under any circumstances, but it is especially dangerous to move forward with this proposal during a public health emergency such as the current COVID-19 pandemic. NORD urges the state to immediately withdraw this proposal.



Block Grant Structure

While the state uses an application template for its proposal which is to be used by states “applying to use either an aggregate or a per capita cap financing model for certain populations” the proposal includes no details about the cap, how it would work or how much capped funding the state would receive. NORD is extremely concerned with the lack of detail in Oklahoma’s proposal. Such a drastic change in Oklahoma’s Medicaid program will undoubtedly have a dramatic impact on patients, but without additional details, it is difficult for NORD to fully comment on all of the possible impacts of a block grant or per capita cap on the patients we represent.

NORD opposes the use of block grants and per capita caps in the Medicaid program. Neither financing structure will protect either the state or patients from enormous financial risk. As the gap between the capped allotment and actual costs of patient care increases over time, states will likely limit enrollment, reduce benefits, lower provider payments or increase cost-sharing, all of which would cause significant harm to the patients we represent.

Many situations could lead Oklahoma to exceed a funding cap. A public health emergency like COVID-19 will greatly increase healthcare costs above negotiated caps and an economic recession would similarly increase enrollment in and costs associated with SoonerCare. Allowing states to renegotiate their caps due to special circumstances like a public health emergency will not protect states and patients from the financial risks of block grants; there is no guarantee that CMS would authorize additional funding via a potentially lengthy re-negotiation process and, in the interim, Oklahoma would face strong incentives to make cuts to the Medicaid program that would harm patients. Moreover, the federal government will likely be focused on responding to the emergency at hand – putting the renegotiation of complex budget neutrality agreements on the back burner. Again, while it would be dangerous for Oklahoma to pursue a capped funding structure at any time, it is especially dangerous to do so now.

At the time of this letter, there have been more than 580,000 coronavirus cases diagnosed in the United States, including approximately 2,069 cases in Oklahoma. Furthermore, an estimated 16.8 million Americans have filed for unemployment benefits, including more than 71,500 Oklahomans who filed initial unemployment claims in the first three weeks of March, which will surely result in a significant loss of income and employer-sponsored health care coverage. Establishing a capped funding structure will create unnecessary and detrimental barriers to care for Oklahoma’s citizens and hinder the ability of Oklahoma’s Medicaid program to properly respond in times of crisis.

Barriers to Coverage

Retroactive Coverage

Oklahoma has requested the authority to waive retroactive eligibility, a policy that prevents gaps in coverage by covering individuals for up to 90 days prior to the month of application, assuming the individual is eligible for Medicaid coverage during that timeframe. It is common that



individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. This is especially common in the rare disease community, as many rare disease patients face long diagnostic journeys and are not diagnosed until later in life. Therefore, retroactive eligibility allows patients who have been diagnosed with a serious illness, such as a rare disease, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Medicaid paperwork can be burdensome and often times confusing. A Medicaid enrollee may not have understood or received a notice of Medicaid renewal and only discovered the coverage lapse when picking up a prescription or going to see their doctor. Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy. When Ohio was considering a similar provision in 2016, one estimate predicted that hospitals could accrue as much as \$2.5 billion more in uncompensated care as a result of the waiver.ⁱ Additional uncompensated care would be especially problematic at the current time because it would add to the financial challenges hospitals are facing as a result of COVID-19. NORD opposes a waiver of retroactive coverage.

Premiums and Cost-Sharing

Under Oklahoma's application, individuals with incomes above 42 percent of the federal poverty level would have to pay premiums ranging from \$5 to \$15 per month. Individuals could not enroll in coverage until they pay their first premium and could lose their coverage if they are unable to pay future premiums. This policy would likely both increase the number of enrollees who lose Medicaid coverage and also discourage eligible people from enrolling in the program. For example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of \$20 per month, almost half of enrollees lost coverage.ⁱⁱ NORD believes that these premiums will create significant financial barriers for patients that jeopardize their access to needed care and therefore opposes this policy.

Oklahoma's application also includes copays for its Medicaid program, including an \$8 copay for non-emergent use of the emergency department (ED). Many rare disease patients have complex conditions that can turn quickly into situations that require emergency interventions that could be deemed non-emergent. For example, patients with Ehlers Danlos Syndrome (EDS) often experience excruciating pain that is unable to be controlled by regular measures and requires emergency room intervention. Chest pain is another symptom of EDS, which often necessitates emergency intervention to ensure more serious cardiac complications are not occurring. Implementing co-pays and leaving unclear the definition of "non-emergent" could deter people from seeking necessary care during an emergency. Furthermore, evidence suggests this type of cost sharing may not result in the intended cost savings.ⁱⁱⁱ For example, a study of enrollees in Oregon's Medicaid program demonstrated that implementation of a copay on emergency services resulted in decreased utilization of such services but did not result in cost savings because of subsequent use of more intensive and expensive services.^{iv} NORD opposes this punitive proposal for a \$8 copayment for non-emergent use of the ED.



Finally, Oklahoma requests the authority to increase premiums and cost-sharing up to five percent of household income. This would put an enormous financial burden on patients that would again jeopardize their coverage. Additionally, any future increases in cost-sharing should go through a full public comment process and review by CMS, which are important opportunities for the public to provide feedback on how the program is working for key stakeholders before any policies are implemented or continued. It is especially important that beneficiaries impacted by the demonstration waiver have the ability to provide feedback to the state and CMS. NORD urges Oklahoma to withdraw this request.

Work Requirements

Under the application, individuals between the ages of 19 and 60 be required to prove that they work up to 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on individuals in the Medicaid program. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, when Arkansas implemented a similar policy, the state terminated coverage for over 18,000 individuals,^v and in New Hampshire, nearly 17,000 individuals would have lost coverage if the state had not suspended implementation of its requirement.^{vi} The U.S. Court of Appeals for the District of Columbia recently reaffirmed that the purpose of the Medicaid program is to provide healthcare coverage and that Arkansas' restrictive waiver, including the work requirement policy, did not meet that objective.^{vii}

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases. If the state finds that individuals have failed to comply with the new requirements after one month, they will be disenrolled from coverage. For rare disease patients who require daily, weekly or monthly medications and/or health care provider engagement, this sudden disenrollment in Medicaid coverage could result in their being unable to meet with their provider or get prescriptions filled, leading to hospitalization or death.

NORD 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. While some rare disease patients are able to maintain regular employment, the ability of other rare disease patients to work continuously fluctuates as a result of their disorder which could jeopardize their Medicaid coverage under this proposal. Regardless, even exempt enrollees may have to report their exemption, creating opportunities for administrative error that could jeopardize their coverage. In Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption.^{viii} No exemption criteria can circumvent this problem and the serious risk to the health of the people we represent.

Administering these requirements will also be expensive for the state of Oklahoma. States such as Kentucky, Tennessee and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.^{ix} This would



divert federal resources from Medicaid's core goal – providing health coverage to those without access to care – and compromise the fiscal health of Oklahoma's Medicaid program.

The evidence is clear that most people on Medicaid who can work already do so, and those who are unable to work often have physical or mental health conditions that interfere with their ability to work.^{x,xi} Evaluations of Arkansas's waiver demonstrate that it did not lead to increased employment among the Medicaid population.^{xii} In contrast, continuous Medicaid coverage can actually help people find and sustain employment. For example, a report examining Medicaid expansion in Ohio found that the majority of enrollees reported that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).^{xiii} Terminating individuals' Medicaid coverage for non-compliance with work requirements will hurt rather than help people search for and obtain employment.

Benefit Package

Oklahoma's application also jeopardizes access to vital services for low-income patients served by the Medicaid program, particularly those with serious and chronic diseases.

Oklahoma's application proposes to waive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) for individuals aged 19 and 20. EPSDT provides access to critical services and treatments for kids and young adults living in poverty. Continuity of coverage and care is particularly critical for rare disease patients as they transition to higher education or jobs.. Disruption in medical treatment could have negative consequences for their long-term health and economic security. NORD opposes this provision.

Oklahoma has also requested to eliminate Non-Emergency Medical Transportation (NEMT) benefits. Due to the often significant economic and health care costs associated with having a rare disease, many patients may not own a car and may lack access to reliable public transportation, especially in rural areas like Oklahoma. Rare disease patients may also have to travel a significant distance to see a health care provider with expertise in their condition. Maintaining NEMT is one less thing for patients to have to worry about and enables them to attend medical appointments they need to maintain their health or may have to wait months to get given high demand. One study found patients with asthma, hypertension or heart disease who needed multiple visits to a medical professional more likely to keep their appointments if they had NEMT.^{xiv} NORD opposes this policy.

Finally, the proposal also states that Oklahoma will "continue to investigate the potential benefits of a limited prescription drug formulary and request the flexibility to make changes to our prescription drug benefit, following appropriate advance notice procedures." NORD believes that any changes to the prescription drug benefit that limit access to medications will be detrimental to the rare disease community. Without proper drug coverage, a patient who may have been asymptomatic on current medication regimen, may relapse and begin to be symptomatic. For example, patients diagnosed with Neurotrophic Keratitis, a rare disorder that affects the retina,



depend on prescription medications to prevent the further degeneration of the cornea that could lead to blindness. If a Neurotrophic Keratitis patient's prescription coverage were to change and the medication was no longer covered, the patient could go blind, requiring additional assistance to survive. Prescription drugs have different indications, different mechanisms of action, and different side effects, depending on the person's diagnosis and comorbidities. Restricting prescription drug benefits would limit the ability of providers to make the best medical decisions for the care of their patients.

Public Comment Process

A robust public comment process is an essential component on any Section 1115 demonstration proposal. Unfortunately, Oklahoma's public comment process has been rushed and it has been difficult for individuals to participate. This has made meaningful comment impossible for many critical stakeholders.

The core objective of the Medicaid program is to furnish healthcare to low-income populations. This demonstration application does not further that goal and NORD opposes the proposal. We instead urge Oklahoma to move forward with implementing its SPA for Medicaid expansion as soon as possible without imposing any additional barriers to coverage. Thank you for the opportunity to submit comments.

Sincerely,

A handwritten signature in black ink that reads "Heidi Ross".

Heidi Ross, MPH
Director of State Policy

A handwritten signature in black ink that reads "Tamra Misak".

Tamra Misak
Oklahoma Rare Action Network
Volunteer State Ambassador

ⁱ Virgil Dickson, "Ohio Medicaid waiver could cost hospitals \$2.5 billion", Modern Healthcare, April 22, 2016. (<http://www.modernhealthcare.com/article/20160422/NEWS/160429965>)

ⁱⁱ Artiga, Samantha, Petry Ubri and Julia Zur. The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings. Kaiser Family Foundation. June 1, 2017. Accessed at: <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.

ⁱⁱⁱ See for example: Chernew M, Gibson TB, Yu-Isenberg K, Sokol MC, Rosen AB, Fendrick AM. Effects of increased patient cost sharing on socioeconomic disparities in health care. *J Gen Intern Med.* 2008. Aug; 23(8):1131-6. Ku, L and Wachino, V. "The Effect of Increased Cost-Sharing in Medicaid: A Summary of Research Findings." Center on Budget and Policy Priorities (July 2005), available at <http://www.cbpp.org/5-31-05health2.htm>.

^{iv} Wallace NT, McConnell KJ, et al. How Effective Are Copayments in Reducing Expenditures for Low-Income Adult Medicaid Beneficiaries? Experience from the Oregon Health Plan. *Health Serv Res.* 2008 April; 43(2): 515–530.

^v Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at February 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://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fdb6c891d9bacb6/011519_AWReport.pdf.

^{vi} New Hampshire Department Health and Human Services, DHHS Community Engagement Report, June 2019. Available at: <https://www.dhhs.nh.gov/medicaid/granite/documents/ga-ce-report-062019.pdf>.

^{vii} US Court of Appeals for the District of Columbia Circuit, Gresham v. Azar, Feb. 14, 2020. Available at: <https://healthlaw.org/wp-content/uploads/2020/02/Gresham-v.-Azar-DC-Circuit-Ruling-Feb-14.pdf>.

^{viii} Jessica Greene, "Medicaid Recipients' Early Experience With the Arkansas Medicaid Work Requirement," *Health Affairs*, Sept. 5, 2018. Available at: <https://www.healthaffairs.org/do/10.1377/hblog20180904.979085/full/>.

^{ix} Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018. Available at <https://www.rollcall.com/news/politics/medicaid-kentucky>.

^x Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017. Available at: <http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>.

^{xi} 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.

^{xii} Benjamin D. Sommers, MD, et al. "Medicaid Work Requirements—Results from the First Year in Arkansas," *New England Journal of Medicine*. Published online June 18, 2019, https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B.

^{xiii} 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>.

^{xiv} Michael Adelberg and Marsha Simon, "Non-Emergency Medical Transportation: Will Reshaping Medicaid Sacrifice An Important Benefit?" *Health Affairs*, September 20, 2017. Accessed at:

<https://www.healthaffairs.org/do/10.1377/hblog20170920.062063/full/>