



August 31, 2018

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

Transmitted via email to OHCCommunityEngagement@okhca.org

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

Dear Director Pasternik-Ikard:

On behalf of the 30 million Americans with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the 2018 SoonerCare Choice and Insure Oklahoma 1115 Demonstration Waiver Public Notice and Amended 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. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD recognizes Oklahoma's stated goal of "improving health outcomes for Oklahomans through the demonstration."¹ However, after reviewing the proposed alterations to its Medicaid program and consulting with our member organizations, we are concerned that the proposed work/community engagement requirement to the SoonerCare program will threaten access to care for many within Oklahoma's rare disease community.

Oklahoma's Proposal to Implement Work Requirements:

We oppose the implementation of work requirements within the SoonerCare program as it is counter to the fundamental goals of the Medicaid program and does not help low-income individuals improve their circumstances without needlessly compromising their access to care.

Further, if implemented, we believe the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Oklahoma rare disease patients and their families. While the list of exemptions appears comprehensive, we can still easily envision many scenarios in

¹ SoonerCare 1115(a) Research and Demonstration Waiver Amendment Request Pg. 4

which individuals with rare diseases or their caregivers will be unduly subjected to onerous and inappropriate work requirements.

For example, it remains unclear from the given information within the demonstration what would happen to caregivers of those with a rare disease. The demonstration notes that a beneficiary who is a “parent or caretaker responsible for the care of an incapacitated person” would be exempt.² The demonstration does not say, however, how that would be adjudicated. It is not clear in this context what it means to be incapacitated. Consequently, it is not difficult to imagine a scenario in which this exemptions process would leave out a deserving caregiver.

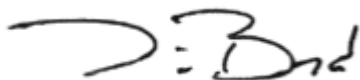
Similarly, the demonstration proposes to exempt individuals who, “are medically certified as physically or mentally unfit for employment” or have “a disability” as defined by federal statute.³ Yet, once again, the waiver does not articulate how such a determination would be made and who would be making it. It is not obvious from the demonstration what having something “medically certified” will involve.⁴ With a scarcity of physicians familiar with rare diseases and the prevalence of undiagnosed conditions, it is often difficult, even impossible, for rare disease patients to adequately convey the extent of their symptoms in a timely manner.

Finally, a 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 eighty hours per month. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or working.

These are just a handful of ways in which rare disease patients and their loved ones could slip through the cracks and lose access to their health care. In order to avoid the kind of delay or termination of care that could gravely impact the lives of Oklahoma’s rare disease patients and their families, we urge the Authority to reconsider this provision.

Thank you once again for the opportunity to provide comments on the Authority’s application for a 1115 demonstration. For further questions, please contact me at tboyd@rarediseases.org.

Sincerely,

A handwritten signature in black ink, appearing to read 'T. Boyd', written in a cursive style.

Tim Boyd
Director of State Policy

² SoonerCare 1115(a) Research and Demonstration Waiver Amendment Request Pg. 8

³ Ibid.

⁴ Ibid.