



January 22, 2019

Joshua D. Baker  
Director  
South Carolina Department of Health and Human Services (SCDHHS)  
ATTN: Community Engagement Waiver  
Post Office Box 8206  
Columbia, SC 29202-8206

*Transmitted via email to [CEWaiver@scdhhs.gov](mailto:CEWaiver@scdhhs.gov)*

**Re: Community Engagement Section 1115 Demonstration Waiver Application**

Dear Director Baker:

On behalf of the 30 million Americans with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks SCDHHS for the opportunity to submit comments on its Community Engagement Section 1115 Demonstration Waiver 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 appreciates SCDHHS's stated goal of "improving the health and well-being of South Carolina's Medicaid population."<sup>1</sup> However, after reviewing the proposal, we are concerned that the Community Engagement Demonstration Waiver will threaten access to care for many within South Carolina's rare disease community.

We oppose the implementation of work requirements within South Carolina's Medicaid program for several reasons, the most basic of which being that work requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care.

Further, this would increase the administrative burden on all Medicaid patients. Individuals will need to either attest to the number of hours they have worked or that they meet certain

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<sup>1</sup> Community Engagement Section 1115 Demonstration Waiver Application Pg. 1

exemptions. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt. Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. In the final months of 2018, the state terminated coverage for over 18,000 beneficiaries.<sup>2</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. SCDHHS seems to recognize this concern, yet it provides very little detail within its proposal on how the state will seek to verify compliance.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with rare diseases. If the state finds that individuals have failed to comply with the new requirements, their coverage will be suspended until they can demonstrate their compliance.<sup>3</sup> 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.

We are also concerned that the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of South Carolina rare disease patients and their families. While the list of exemptions appears comprehensive, we can still easily envision many scenarios in which individuals with rare diseases or their caregivers will be unduly subjected to onerous and inappropriate work requirements. 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 convey the extent of their symptoms on a standard form.

For example, it remains unclear from the given information within the proposal what would happen to caregivers of those with a rare disease. SCDHHS notes that a beneficiary who is “the primary caregiver... of someone who is disabled” would be exempt.<sup>4</sup> SCDHHS does not say, however, how that would be adjudicated. It is not clear in this context what it means to be disabled. Consequently, it is not difficult to imagine a scenario in which this exemptions process would leave out a deserving caregiver.

Similarly, SCDHHS proposes to exempt “disabled individuals, including individuals who have a medical condition that would prevent them from participation in this project.”<sup>5</sup> Yet, once again, SCDHHS does not articulate how such a determination would be made. It is not obvious from the proposal what it will involve for a condition to be validated as preventing participation.<sup>6</sup>

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<sup>2</sup> Rudowitz, Robin, MaryBeth Musumeci, and Cornelia Hall. "Year End Review: December State Data for Medicaid Work Requirements in Arkansas." The Henry J. Kaiser Family Foundation. January 17, 2019. Accessed January 18, 2019. <https://www.kff.org/medicaid/issue-brief/state-data-for-medicaid-work-requirements-in-arkansas/>.

<sup>3</sup> Community Engagement Section 1115 Demonstration Waiver Application Pg. 4

<sup>4</sup> Community Engagement Section 1115 Demonstration Waiver Application Pg. 2

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

Finally, SCDHHS's "case specific basis" exemption is not sufficient to protect rare disease patients. In Arkansas, many individuals were unaware of the new requirements and, therefore, unaware that they needed to apply for such an exemption.<sup>7</sup> In August 2018, the state granted just 45 good cause exemptions while terminating coverage for 4,353 individuals at the end of the month.<sup>8</sup> No exemption criteria can circumvent this problem and the serious risk posed to the health of the rare disease community.

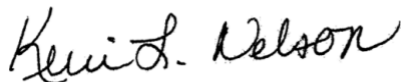
These are just a handful of ways in which rare disease patients and their loved ones could slip through the cracks and lose access to their healthcare. In order to avoid the kind of delay or termination of care that could gravely impact the lives of South Carolina's rare disease patients and their families,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

NORD strongly believes healthcare should be affordable, accessible, and adequate. The Community Engagement Section 1115 Demonstration Waiver does not meet that standard, and we urge SCDHHS to withdraw this proposal. Thank you again for the opportunity to provide comments.

Sincerely,



Tim Boyd  
Director of State Policy  
[tboyd@rarediseases.org](mailto:tboyd@rarediseases.org)



Kerri Nelson  
South Carolina Rare Action Network Volunteer State Ambassador  
[kerri.nelson@rareaction.org](mailto:kerri.nelson@rareaction.org)  
[www.RareSC.org](http://www.RareSC.org)

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<sup>7</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>8</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: [https://humanservices.arkansas.gov/images/uploads/newsroom/091218\\_AWReport\\_Final.pdf](https://humanservices.arkansas.gov/images/uploads/newsroom/091218_AWReport_Final.pdf).