



February 22, 2018

The Honorable Seema Verma, Administrator  
Centers for Medicare & Medicaid Services  
200 Independence Avenue, SW  
Washington, DC 20201

**Re: Mississippi Section 1115 Revised Demonstration Waiver Application**

Dear Administrator Verma:

On behalf of the 30 million Americans with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) submits the following comments on the Mississippi Section 1115 Revised 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 Mississippi's stated goal of enhancing the lives of Medicaid beneficiaries in Mississippi. However, after reviewing the proposed alterations to its Medicaid program and consulting with our member organizations, we are concerned that the work requirement proposal will threaten access to care for many within Mississippi's rare disease community.

**Mississippi's Proposal to Implement Work Requirements:**

We oppose the implementation of work requirements within the Mississippi Medicaid program because we believe the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Mississippi 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 the caregivers will be unduly subjected to onerous and inappropriate work requirements.

For example, the determination of disability included within the demonstration is, in large part, tied to the Social Security Administration's standard of disability, with one exemption described as a beneficiary who, "receives Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI)."<sup>1</sup> Unfortunately, it is not uncommon in the rare disease community for individuals to have a great deal of trouble securing disability status from the Social Security Administration. With a

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<sup>1</sup> Mississippi 1115 Revised Demonstration Waiver Pg. 4

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.

Additional unwarranted applications of work requirements could arise from situations that are unaccounted for within this proposal. 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, “primary caregiver for a person who cannot care for himself or herself,” would be exempt.<sup>2</sup> The Demonstration does not say, however, how that would be adjudicated. It is not clear in this context what it means to not be able to care for oneself. 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 those who are, “physically or mentally unable to work.”<sup>3</sup> Yet, once again, the waiver does not articulate how such a determination would be made or, perhaps more importantly, who would be making it.

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 Mississippi’s rare disease patients and their families, the State would need to generate an absolutely airtight exemption process. Unfortunately, this proposal is anything but. Therefore, we urge the Centers for Medicare and Medicaid Services (CMS) to refrain from approving this provision.

Thank you for the opportunity to provide comments on Mississippi’s application for a Section 1115 waiver demonstration. Once again, NORD urges you to reject the provisions of the proposed Demonstration detailed in this submission. For further questions, please contact me at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org).

Sincerely,



Paul Melmeyer  
Director of Federal Policy

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<sup>2</sup> Mississippi 1115 Revised Demonstration Waiver Pg. 4

<sup>3</sup> Ibid.