



April 2, 2018

Administrative Secretary  
Alabama Medicaid Agency  
501 Dexter Avenue, P.O. Box 5624  
Montgomery, Alabama 36103-5624

*Transmitted via email to [PublicComment@medicaid.alabama.gov](mailto:PublicComment@medicaid.alabama.gov)*

**Re: Alabama Medicaid Workforce Initiative Section 1115 Demonstration Application (Public Comment)**

Dear Commissioner Azar:

On behalf of the 1-in-10 Alabama residents with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks the Alabama Medicaid Agency for the opportunity to provide comments on its 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. 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 the Agency's stated goal of enhancing the lives of Medicaid beneficiaries in Alabama. However, after reviewing the proposed alterations to Alabama's Medicaid program and consulting with our member organizations, we are concerned that the proposal to implement a work requirement will threaten access to care for many within Alabama's rare disease community.

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

We oppose the implementation of work requirements within Alabama's 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 Alabama 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.

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, "receiving 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 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.

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, “required to care for a disabled child or adult,” would be exempt.<sup>2</sup> The Demonstration does not say, however, how that would be adjudicated. It is not clear in this context how “disability” or “required” would be defined. 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 anyone who, “has a disability, is medically frail, or has a medical condition that would prevent them from complying with the work requirement, as validated by a medical professional.”<sup>3</sup> Yet, once again, the waiver does not articulate how such a determination would be made. It is not obvious from the Demonstration what it will involve to have something “validated by a medical professional.”<sup>4</sup>

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 Alabama’s rare disease patients and their families, the Agency would need to generate an absolutely airtight exemption process. Unfortunately, this proposal is anything but.

Further, this proposal would apply to those with incomes at or below 18 percent of the Federal Poverty Level (which is \$3,740 per year for a family of three or \$312 per month).<sup>5</sup> Medicaid exists to be a safety net for those who cannot access other forms of health care coverage. Substantially altering the program in ways that could eliminate benefits for people in need is not only diametrically opposed to the purpose of the program, but it will serve to worsen health care outcomes and increase costs for rare disease patients and their caregivers.

These concerns are not exhaustive, but they are representative of the ways in which the rare disease community might be harmed by this Demonstration. Continuity of care is absolutely critical for individuals with rare diseases. They cannot afford to lose access to care at the hands of bureaucratic malpractice.

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<sup>1</sup> Alabama Section 1115 Demonstration Application Pg. 6

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> Alabama Section 1115 Demonstration Application Pg. 5

Thank you once again for the opportunity to provide comments on the Agency's application for a Section 1115 Demonstration. NORD strongly urges you to reconsider the elements of the proposed Demonstration detailed in this submission. For further questions, please contact me at [tboyd@rarediseases.org](mailto:tboyd@rarediseases.org).

Sincerely,

A handwritten signature in black ink, appearing to read "T. Boyd". The signature is stylized with a large, sweeping initial "T" and a cursive "Boyd".

Tim Boyd  
Director of State Policy