



August 17, 2018

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

**Re: Kentucky HEALTH - Application and CMS STCs**

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) appreciates the opportunity to submit comments on the Kentucky HEATLH Section 1115(a) Demonstration Waiver and the Centers for Medicare and Medicaid Services (CMS) Special Terms and Conditions (STC).

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 Kentucky's stated goal of enhancing the lives of Medicaid beneficiaries in Kentucky. However, after reviewing the proposed alterations to its Medicaid program and consulting with our member organizations, we are concerned that a couple of the provisions within the demonstration will threaten access to care for many within Kentucky's rare disease community.

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

We oppose the implementation of work requirements within the Kentucky HEALTH 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, we believe the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Kentucky 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, 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

“[p]rimary caregiver[] of a dependent, including either a dependent minor child or an adult who is disabled,” would be exempt.<sup>1</sup> The demonstration 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.

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 not.

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 Kentucky’s rare disease patients and their families, we urge the Centers for Medicare and Medicaid Services (CMS) to refrain from re-approving this provision.

### **Kentucky’s Proposal to Implement Premiums:**

We have strong reservations regarding Kentucky’s proposal to implement monthly premiums for Medicaid beneficiaries as we believe complying with monthly premium payments, no matter how low, will create administrative and logistical hurdles. Premiums will be no less than \$1 and can be up to 4 percent of household income.

According to the demonstration, inability to pay premiums within 60 days of receiving an invoice will result in the beneficiary in question being disenrolled from Kentucky HEALTH and “prohibited from re-enrollment in the demonstration for up to six months.”<sup>2</sup> As previously stated, it is crucial that rare disease patients have uninterrupted access to healthcare. Medicaid exists to be a safety net for those who cannot access other forms of health care coverage. Completely removing access to care for an inability to continually pay a monthly premium is in direct opposition to the intent of the program and will greatly afflict the rare disease community. We urge CMS to deny this provision.

Once again, we thank you for the opportunity to provide comments on the Kentucky HEALTH demonstration and urge you to not re-approve it. For further questions regarding NORD or the above comments, please contact me at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org).

Sincerely,



Paul Melmeyer  
Director of Federal Policy

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<sup>1</sup> Centers for Medicare and Medicaid Services. KY HEALTH Section 1115 Demonstration. January 12, 2018. Pg. 32. Accessed at: <https://kentuckyhealth.ky.gov/SiteCollectionDocuments/Kentucky%20HEALTH%20Demonstration%20Approval.pdf>

<sup>2</sup> Ibid. Pg. 29.