



November 25, 2019

Matthew Van Patton  
Director, Division of Medicaid & Long-Term Care  
State of Nebraska, Department of Health and Human Services  
301 Centennial Mall South, 3rd Floor PO Box 95026  
Lincoln, NE 68509-5026

**Re: NORD Comments on Nebraska's 1115 Medicaid Waiver Application**

Dear Mr. Van Patton:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Nebraska's Medicaid Section 1115 Heritage Health Adult Expansion Demonstration.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD believes everyone, including Medicaid enrollees, should have access to quality and affordable health coverage. Medicaid expansion, as the voters approved in November, will expand coverage to 90,000 low-income Nebraskans. This will provide individuals with prevention, early detection and diagnostic services as well as disease management and treatment for their conditions. Medicaid expansion is critical for patients with rare diseases.

Unfortunately, this waiver proposal will delay the implementation of Medicaid expansion until October of 2020, almost two years after the voters approved the measure. This is unacceptable and will delay access to quality and affordable for 90,000 Nebraskans. NORD urges Nebraska to implement Medicaid expansion as soon as possible, without the proposed delay, to follow the will of the voters.

Tiered Benefit Structure

NORD supports Nebraska's Medicaid expansion, but is worried that some provisions of the waiver proposal will limit the potential benefit of the program.

The Heritage Health Adult Expansion Demonstration waiver creates a two-tiered benefit structure. Initially, all expansion enrollees will have the "Basic" plan but can qualify for the "Prime" plan if they complete a set of wellness, personal responsibility and work reporting requirements. The Prime plan includes all of the benefits of the Basic plan plus vision, dental and over-the-counter drugs.



The requirements to receive the Prime benefit package are very onerous. Patients have to “actively participate” in care and case management, which includes completing a health risk screening, completing a “social determinants of health” assessment, routinely refilling prescriptions and having recommended labs performed. Additionally, beneficiaries will be required to have an annual visit with their primary care provider. Beneficiaries would also have to comply with a personal responsibility requirement, which includes not missing more than three appointments within six months, maintaining commercial coverage if available, and notifying the state within 10 days of any changes that may affect a beneficiary’s eligibility for Medicaid or benefit tier. This level of complexity could harm rare disease patients who rely on Medicaid for lifesaving care.

Additionally, starting in Year Two of the demonstration, the expansion population between the ages of 21 and 59 would be required to prove that they work at least 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on individuals in the Medicaid program. Increasing administrative requirements will likely decrease the number of individuals with Medicaid Prime coverage, regardless of whether they are exempt or not. For example, Arkansas implemented a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals and locked them out of coverage until January 2019.<sup>i</sup> In other states with similar policies, enrollees have found the reporting requirements confusing and added stress and anxiety to enrollees’ lives.<sup>ii</sup>

The state estimates that 40 percent of enrollees will not be able to comply with all the requirements and will receive the Basic benefit rather than Prime benefit. Each of these requirements adds additional red tape for Medicaid enrollees. Many of the requirements require significant access to transportation that can be a barrier for the low-income population. NORD encourages Nebraska to provide the Prime benefit to all Medicaid enrollees in the expansion population. This will eliminate confusion and additional paperwork for patients with rare diseases.

### Removing Retroactive Coverage

As part of the 1115 waiver, Nebraska is asking to waive retroactive eligibility and start coverage on the first day of the month of the application. Retroactive eligibility in Medicaid prevents gaps in coverage, by covering individuals for up to 90 days prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Retroactive eligibility allows patients who have been diagnosed with a serious illness, including rare diseases, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Medicaid paperwork can be burdensome and often times confusing. A Medicaid enrollee may not have understood or received a notice of Medicaid renewal and only discovered the coverage lapse when picking up a prescription or going to see their doctor. Without retroactive eligibility,



Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy. For example, when Ohio was considering a similar provision in 2016, a consulting firm advised the state that hospitals could accrue as much as \$2.5 billion more in uncompensated care as a result of the waiver.<sup>iii</sup> Nebraska estimates that over 29,000 adults will lose retroactive coverage as a result of the waiver. NORD urges Nebraska to remove this provision from the waiver application.

#### Lack of Evaluation Plan

The proposed 1115 waiver currently lacks an evaluation plan. While the state claims it will create a robust evaluation plan, there is nothing that is currently set up to evaluate the waiver. NORD encourages Nebraska to write and solicit feedback on an evaluation plan so the public can accurately comment on the proposal.

NORD urges Nebraska to expand Medicaid without delay to fulfill the will of the voters. However, this waiver should be modified to provide optimal care to all Medicaid enrollees by eliminating the tiered benefit approach and keeping retroactive coverage. Thank you for the opportunity to submit comments.

Sincerely,

/s/

Rachel Sher,  
Vice President of Policy and Regulatory Affairs

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<sup>i</sup> Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at November State Data for Medicaid Work Requirements in Arkansas," Kaiser Family Foundation, December 18, 2018. Available at: <https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/>; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: [http://d31hzhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519\\_AWReport.pdf](http://d31hzhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf)

<sup>ii</sup> Musumeci, MaryBeth, Robin Rudowitz, Barbara Lyons. Medicaid Work Requirements in Arkansas: Experience and Perspectives of Enrollees. Kaiser Family Foundation. Dec 18, 2018. Available at: <https://www.kff.org/medicaid/issue-brief/medicaid-work-requirements-in-arkansas-experience-and-perspectives-of-enrollees/>

<sup>iii</sup> Virgil Dickson, "Ohio Medicaid waiver could cost hospitals \$2.5 billion", Modern Healthcare, April 22, 2016. (<http://www.modernhealthcare.com/article/20160422/NEWS/160429965>)