



Jami Snyder  
Director  
State of Arizona, Arizona Health Care Cost Containment System  
801 East Jefferson, MD 4100  
Phoenix, AZ 85034

Dear Ms. Snyder:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the draft proposal for the five-year renewal of Arizona's Demonstration project under Section 1115 of the Social Security Act. NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease. We believe that all patients should have access to quality, accessible, and affordable health coverage that is best suited to their medical needs.

Medicaid is a lifeline to many rare disease patients, providing critical health care coverage for low-income individuals and families. NORD does support the state's decision to discontinue enforceable premiums for Medicaid enrollees in the proposed waiver application. This is a positive change that furthers the core objective of the Medicaid program, which is to provide health care coverage to low income Americans. However, many sections of this draft 1115 waiver do not promote patient care, and indeed may cause harm to the patients that we represent. We urge the state to revise this proposal to eliminate the proposed work requirements and to reinstate retroactive eligibility before the waiver is submitted to the Centers for Medicare and Medicaid Services (CMS).

#### Waiving Retroactive Eligibility

Retroactive eligibility prevents gaps in coverage by covering individuals for up to 90 days prior to the month of application, assuming the individual was eligible for Medicaid coverage during that timeframe. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. This is especially common in the rare disease community, as many rare disease patients face long diagnostic journeys and are not diagnosed until later in life. Therefore, retroactive eligibility allows patients who have been diagnosed with a serious illness, such as a rare disease, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Furthermore, Medicaid paperwork can be burdensome and often 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. When Ohio was considering a similar provision in 2016, one estimate predicted that hospitals could accrue as much as \$2.5 billion more in uncompensated care as a result of the waiver. An increase in the volume of uncompensated care would add to the financial challenges hospitals are facing as a result of the ongoing COVID-19 pandemic.

NORD would oppose this proposal under any circumstances, but it is especially dangerous to continue this policy during a widespread public health emergency. If someone without health care coverage is exposed to COVID-19, they are less likely to seek testing or treatment due to fears about the cost of care. This puts all Arizonans, but especially rare disease patients who may have compromised immune systems, at greater risk.

### Work Requirements

As part of this waiver proposal, individuals between the ages of 19 and 49 are required to prove that they work at least 80 hours per month or meet exemptions. This proposal would again increase the administrative burden on Medicaid beneficiaries, and will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not.

Failing to navigate these burdensome administrative requirements could have serious consequences for people living with a rare disease. If the state finds that an individual has failed to comply with the new requirements, they will lose coverage for the next two months. People living with rare diseases often depend on regular visits with providers and specialists or must take daily medications to manage their conditions. A sudden interruption in care can be devastating for these patients.

Furthermore, NORD is concerned that the current exemption criteria may not capture all individuals with rare health conditions that prevent them from working. Regardless, even exempt enrollees may have to report their exemption, creating opportunities for administrative error that could jeopardize their coverage. For example, when Arkansas implemented a similar policy requiring Medicaid enrollees to report their hours worked, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for an exemption.<sup>1</sup> No exemption criteria can circumvent this problem and the serious risk to the health of the people we represent.

---

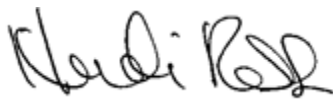
<sup>1</sup> Jessica Greene, "Medicaid Recipients' Early Experience With the Arkansas Medicaid Work Requirement," Health Affairs, Sept. 5, 2018. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20180904.979085/full/>.

## Conclusion

Affordable health care coverage is critical to ensuring that rare diseases patients, and others with serious and chronic conditions, can access needed health care services. Unfortunately, this 1115 waiver extension would continue policies that place unacceptable administrative and financial barriers on health coverage by withholding retroactive eligibility and imposing ineffective work requirements, the results of which can lead to significant financial and health challenges for beneficiaries. Therefore, NORD urges its revision to exclude these harmful policies prior to the submission of this waiver extension to CMS for approval.

Thank you again for the opportunity to submit comments. For questions regarding NORD or the above comments please contact Corinne Alberts at [calberts@raredisease.org](mailto:calberts@raredisease.org).

Sincerely,



Heidi Ross, MPH  
Director of Policy  
National Organization for Rare Disorders



Melinda Burnworth  
Volunteer State Ambassador  
Arizona Rare Action Network

