



June 30, 2020

Mary C. Mayhew
Secretary
Agency for Health Care Administration
Bureau of Medicaid Policy
2727 Mahan Drive, MS #8
Tallahassee, Florida 32308

Re: Florida's 1115 Managed Medical Assistance Waiver Extension Request

Dear Secretary Mayhew:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the two-year extension of Florida's 1115 Managed Medical Assistance (MMA) waiver. 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. Unfortunately, this 1115 waiver extension would continue a policy that places unacceptable administrative and financial barriers on health coverage by withholding retroactive eligibility for many beneficiaries.

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 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. 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 insurance 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 Floridians, but especially rare disease patients who may have compromised immune systems, at greater risk. This proposal will also compound the economic strain felt by many families during this crisis.

Affordable health insurance is critical to ensuring that rare diseases patients, and others with serious and chronic conditions, are able to access needed health care services. This MMA waiver does not further the core objective of the Medicaid program, will not promote patient care, and indeed may cause harm to the patients that we represent. We urge the state to withdraw this waiver application and instead reinstate retroactive eligibility immediately.

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.

Sincerely,

Heidi Ross, MPH
Director of Policy

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Florida Rare Action Network
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