



October 20, 2018

Jennifer Lee, M.D.  
Director  
Virginia Department of Medical Assistance Services  
600 East Broad Street  
Richmond, VA 23219

*Transmitted via email to [1115Implementation@dmass.virginia.gov](mailto:1115Implementation@dmass.virginia.gov)*

**Re: Virginia Department of Medical Assistance Services 1115 Demonstration Extension Application**

Dear Director Lee:

On behalf of the 30 million Americans with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks the Department of Medical Assistance Services for the opportunity to submit comments on the Virginia “Creating Opportunities for Medicaid Participants to Achieve Self Sufficiency” (COMPASS) Waiver.

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 Virginia’s stated goal of “empower[ing] individuals to improve their health and well-being...while simultaneously ensuring the [Medicaid] program’s long-term sustainability.”<sup>1</sup> However, after reviewing the extension application and consulting with our member organizations, we are concerned that the COMPASS Waiver will threaten access to care for many within Virginia’s rare disease community.

**Virginia’s Proposal to Implement Work Requirements:**

We oppose the implementation of work requirements within Virginia’s Medicaid 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.

---

<sup>1</sup> Virginia Department of Medical Assistant Services 1115 Demonstration Extension Application Pg. 3

Further, this would increase the administrative burden on all Medicaid patients. Individuals will need to either attest that they meet certain exemptions or the number of hours they have worked. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. As of October 1, four months into implementation, the state has terminated coverage for 8,462 individuals and locked them out of coverage until January 2019.<sup>2</sup> An additional 12,589 individuals had one or two months of noncompliance and are at risk for losing coverage in the coming months.<sup>3</sup> Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with rare diseases. If the state finds that individuals have failed to comply with the new requirements for three months within a 12-month period, they will be locked out of coverage until they demonstrate their compliance.<sup>4</sup> People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers, or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

We are also concerned that the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Virginia 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 application notes that a beneficiary who is a “[p]rimary caregiver for a dependent child under age 19 [or a] [p]rimary caregiver for an adult dependent with a disability or a non-dependent relative” would be exempt.<sup>5</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.

Additionally, Virginia's “good cause” exemption that includes circumstances like hospitalizations or serious illnesses is still not sufficient to protect patients. In Arkansas, many individuals were unaware of the new requirements and, therefore, unaware that they needed to apply for such an exemption,<sup>6</sup> and in August the state granted just 45 good cause exemptions while terminating coverage for 4,353

---

<sup>2</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August and September 2018. Accessed at: <https://humanservices.arkansas.gov/newsroom/toolkits>.

<sup>3</sup> Ibid.

<sup>4</sup> Virginia Department of Medical Assistant Services 1115 Demonstration Extension Application Pg. 9

<sup>5</sup> Virginia Department of Medical Assistant Services 1115 Demonstration Extension Application Pg. 8

<sup>6</sup> Jessica Greene, “Medicaid Recipients’ Early Experience With the Arkansas Medicaid Work Requirement,” Health Affairs, Sept. 5, 2018. Accessed at: <https://www.healthaffairs.org/doi/10.1377/hblog20180904.979085/full/>.

individuals at the end of that month.<sup>7</sup> No exemption criteria can circumvent this problem and the serious risk to the health of the rare disease community.

### **Virginia's Proposal to Implement Premiums:**

We have reservations regarding Virginia's proposal to implement monthly premiums for some Medicaid expansion enrollees as we believe it will result in an insurmountable hurdle to care for some rare disease patients.

Premiums will range from \$5 - \$10 per month. If an enrollee fails to pay a month's premium, following a three-month grace period, coverage will be suspended until the enrollee is able to pay the premium. Additionally, enrollees above 100 percent of the federal poverty level will be required to contribute, through the monthly premiums, either \$50 or \$100 depending on income level and participate in a healthy behavior activity to access a premium account to pay for non-covered medical or health-related services.<sup>8</sup> This program is unnecessarily confusing and will not promote coverage.

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 \$5- \$10 a month is in direct opposition to the intent of the program and will greatly afflict the rare disease community.

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 Virginia's rare disease patients and their families, we urge the Department to reconsider this provision.

Thank you once again for the opportunity to provide comments on Virginia's COMPASS Waiver. NORD strongly urges you to reconsider the elements of the proposed Waiver 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'.

Tim Boyd  
Director of State Policy

---

<sup>7</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: <https://humanservices.arkansas.gov/newsroom/toolkits>.

<sup>8</sup> Virginia Department of Medical Assistant Services 1115 Demonstration Extension Application Pg. 11, 12