



October 18, 2019

Gabe Roberts  
Director of TennCare  
Deputy Commissioner, State of Tennessee  
Department of Finance and Administration  
310 Great Circle Road  
Nashville, TN 37243  
*Transmitted via email to [public.notice.tennCare@tn.gov](mailto:public.notice.tennCare@tn.gov)*

**Re: TennCare II Demonstration Amendment 42 (Project No. 11-W-00151/4)**

Dear Director Roberts:

On behalf of the 1-in-10 individuals in Tennessee with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for the opportunity to submit comments on the TennCare II Demonstration Amendment 42 (Project No. 11-W-00151/4).

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.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families. NORD is committed to ensuring that TennCare provides quality and affordable healthcare coverage. Unfortunately, this waiver proposal to convert the funding structure of the TennCare program to a block grant will jeopardize beneficiaries' access to care. NORD opposes Tennessee's proposal and offers the following comments.

***Block Grant Structure***

NORD opposes Tennessee's proposal to change the financing structure for its Medicaid program to a block grant. NORD fears that the state will cut coverage for certain treatments completely or impose additional barriers to important services, making it more difficult for patients to access the care that they need. Additionally, Tennessee may choose to cut payments to providers to help keep spending under the new block grant. As the gap between the block grant and actual costs of care increases over time, the pressure on Tennessee to limit enrollment, reduce benefits or increase cost-sharing for patients will only increase. These cuts are unacceptable.

This structure will not protect either the state or beneficiaries from financial risk. The per capita adjustments to the block grant will not be sufficient if an unexpected event, such as a public health crisis, increases per person healthcare costs. For example, there are many ground-breaking treatments in development for patients with serious and chronic illnesses. If an expensive but highly effective

treatment became available, Tennessee's spending could rise, putting the state's budget at risk and creating an incentive for the state to impose additional barriers for that treatment. Tennessee's proposal would include vulnerable eligibility groups such as children and people with disabilities in the block grant. We have serious concerns about how this will impact their care.

Additionally, under this proposal, current and future administrations would not need to get approval to make changes to benefits and services, putting these patients' care at grave risk. Changing TennCare to a block grant through the 1115 waiver process is illegal. The Secretary of Health and Human Services is not permitted to waive Sections 1903 and 1905, where the financing structure of the Medicaid program is located, through these types of waivers, as multiple experts have noted.<sup>i,ii</sup> Such a change would require congressional authority, yet Congress has repeatedly declined to pass legislation on this issue, most recently during the debate over repealing and replacing the Affordable Care Act in 2017.

### ***Prescription Drug Access***

NORD opposes the proposal to create a closed formulary with as few as one drug per class and exclude prescription drugs approved through the Food and Drug Administration's (FDA) accelerated approval process. Limiting access to medications will be detrimental.

Prescription drugs have different indications, different mechanisms of action, and different side effects, depending on the person's diagnosis and comorbidities. Restricting TennCare's drug benefits to a closed formulary would limit the ability of providers to make the best medical decisions for the care of their patients, effectively taking the clinical care decisions away from the doctor and patient and giving them to the state.

Allowing TennCare to exclude prescription drugs approved through FDA's accelerated processes will harm patients by restricting access to novel and lifesaving therapies.

The waiver proposal does not include an appeals process for patients to access prescription drugs that are no longer covered. TennCare patients include very low-income pregnant women, the elderly, children and the blind and disabled. These individuals rely on Medicaid to provide treatment and may need access to a medication no longer covered under the new restrictions. Without an appeals process to access denied medications, these patients could experience worse health outcomes and even death.

### ***State Flexibilities***

NORD opposes a number of proposals in the waiver application considered under the broad moniker of "state flexibilities."

Tennessee is asking to be exempt from federal standards and requirements for its managed care program, including the Managed Care Rule. This important safeguard ensures Medicaid Managed Care Organizations (MCOs) have to meet certain requirements related to patient care. For example, the managed care rule sets standards related to adequate networks, so patients can actually see the appropriate providers and receive the care they need. The managed care rule requires MCOs to comply with standards of time and distance to measure this network adequacy, helping patients access both primary care providers and specialists they need.

Tennessee is asking to change the “amount, duration, and scope” of benefits, which could allow the state to put caps on services or only cover critical services for certain individuals. The Medicaid population, by definition is a vulnerable population, allowing Tennessee to change the “amount, duration, and scope” of benefits could impact negatively impact patient care and outcomes.

Finally, the state would no longer need to get approval to make changes to benefits and services in the future and would like to make this demonstration permanent, removing important opportunities for the public to provide feedback on the how the program is working for key stakeholders before any policies are implemented or continued. It is especially important that beneficiaries impacted by the demonstration waiver have the ability to provide feedback to the state and CMS. TennCare is a joint venture between Tennessee and CMS. Both entities, as well as the people it serves, should have a voice in how the program is administered.

### ***Fiscal Sustainability***

If Tennessee is truly concerned about the fiscal sustainability of its Medicaid program, the state could submit a state plan amendment to fully expand Medicaid to 138 percent of the federal poverty level and receive a 90 percent match from the federal government for all expenses for the adult expansion population. This policy would both benefit the state financially and extend access to care to more low-income individuals in need of coverage, a core objective of the Medicaid program.

Tennessee has also failed to provide a complete budget neutrality estimate with details of the projected changes in spending with the waiver and any impact on coverage. The federal rules at 431.408 pertaining to state public comment process require at (a)(1)(i)(C) that a state include an estimate of the expected increase or decrease in annual enrollment and expenditures if applicable. The intent of this section of the regulations is to allow the public to comment on a Section 1115 proposal with adequate information to assess its impact. Given that this waiver represents a fundamental change to Tennessee’s demonstration, the state should include these projections and their impact on budget neutrality provisions.

The core objective of the Medicaid program is to furnish healthcare to low-income and needy populations. This waiver does not further that goal and NORD opposes the proposal.

Thank you for the opportunity to comment on this legislation. For further questions, please do not hesitate to contact me at [ddelcarlo@rarediseases.org](mailto:ddelcarlo@rarediseases.org).

Sincerely,

/s/

Danielle Del Carlo  
Director of State Policy

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<sup>i</sup> Joan Alker. Pending CMS Guidance on Medicaid Block Grants: Executive Overreach Strikes Again. Georgetown University Center for Children and Families. June 27, 2019. Available at: <https://ccf.georgetown.edu/2019/06/27/pending-cms-guidance-on-medicaid-block-grants-executive-overreach-strikes-again/>.

<sup>ii</sup> <https://theincidentaleconomist.com/wordpress/tennessee-wants-to-block-grant-medicaid-is-that-legal/>