Secretary Alex M. Azar, II
United States Department of Health and Human Services
Washington, DC
via electronic submission – December 13, 2019

RE: TennCare Waiver Amendment 42

Dear Secretary Azar,

The Tennessee Disability Coalition offers these comments on Amendment 42, which proposes dramatic changes to convert federal Medicaid funding to a block grant. Our comments are based on the recommendations and input we received from many of our over 40 member organizations and the experiences of nearly 2 million individuals with disabilities and their families in Tennessee.

Risk to Most Vulnerable Populations

TennCare, like other state Medicaid programs, helps insure some of our most vulnerable populations including children, seniors, people with low incomes, and people with disabilities. According to the Kaiser Family Foundation (2019), seniors and people with disabilities make up a national average of 1 in 4 Medicaid beneficiaries while accounting for almost two-thirds of total Medicaid spending. In fact, the highest-cost five percent of these enrollees account for over half of Medicaid's national spending. (Kaiser Family Foundation, 2019). Private insurance is often insufficient or unattainable for people with high-cost, low incidence diagnoses, and typically costs about 25% more per enrollee than Medicaid because of lower Medicaid payment rates for providers.

The Amendment 42 block grant proposal plans to alter the funding mechanism for the "core medical services to TennCare's core population." This core population is made up of children, seniors, people with low incomes and people with disabilities. The Amendment does not substantively articulate the ways this systemic funding shift can produce a reduction in costs, equal or better patient outcomes and shared cost-savings with the federal government.

TennCare provides the fundamental care that allows people with disabilities to live and contribute to our communities and society. These services are too critical to our well-being for the changes proposed to proceed with as much uncertainty as is written into Amendment 42. TennCare represents a vital safety net for our state that must be protected.

In the Amendment, the State writes that "Any savings achieved under the block grant will be reinvested in the health of TennCare members, not just their healthcare" (page iv). The lack of specificity in the request does not provide surety that the State would not utilize the monies taken from the TennCare Program to fund other parts of the State budget. This creates a real threat to people with disabilities who rely on TennCare.

We are appreciative that the State made clear that the proposal does not seek authority to reduce the amount, scope or duration of benefits without CMS approval (page 23). Nor do they propose, as a part of this Amendment, changes in eligibility requirements. However, advocates and people with disabilities long remember the history of the State's previous cuts to the TennCare Program and are deeply

apprehensive about the potential for recurrence of program cuts. Even with the partnership of the federal government, TennCare has a history of benefit reductions that have caused problems for those with disabilities and chronic health care needs. Program cuts that have moved people off the program have been even more devastating In 2005-6 coverage for approximately 200,000 residents was eliminated. More recently, in 2019 at least 128,000 children -- 1 in every 8 -- were removed from TennCare or CoverKids, two Tennessee government health insurance programs for low-income families. Futhermore, we are gravely concerned that although the State says that "costs associated with any new population the state opts to cover in the future….will be excluded from the block grant calculation," the second part of that sentence – "for a period of years until the state has enough experience paying for services for this population to update the block grant formula in a financially sound manner" (page iv) signals potential future program cuts.

Prescription Drug Access

The block grant proposal requests that the TennCare Bureau have flexibility under the demonstration to adopt a commercial-style closed formulary where as few as one drug would be available per therapeutic class. Although commercial payers have the choice to elect whether or not certain drugs are covered based on affordability and clinical efficacy, TennCare has traditionally been required to cover any drug whose manufacturer participates in the federal Medicaid drug rebate program.

Use of a commercial style formulary is antithetical to a safety net program such as Medicaid. Limiting access to needed medications would be detrimental to people with disabilities and other covered TennCare populations with chronic health needs. Prescription drugs in the same class can still have different indications, mechanisms of actions, and side effects depending on the individual, their diagnosis, or comorbidities. For example, we recently heard from a family in which the mother and all three of her children have hemophilia type A. Though this disease runs in the family, the way it manifests is as unique as a fingerprint. The mother and her children each take a separate specialty medication based on their associated symptoms and level of efficacy.

Any changes in the formulary will result in benefit reductions for some TennCare members. Medicine has advanced to the point that the effectiveness of specific drugs rely on an individual's genes, resulting in doctors being able to more accurately predict which treatment and prevention strategies will work for their patients. The proposed formulary could limit prescription drug coverage to one drug per therapeutic class. This means that some TennCare some patients who would be impacted by this benefit reduction would only be able to access drugs that are compatible for them if they pay hefty out-of-pocket costs.

A closed formulary's restriction on drug benefits would also limit providers' abilities to choose the best medical treatment for their patients who have complex conditions, co-morbidities, or low incidence conditions. If an individual is forced to switch to a drug covered under the new restrictions and reacts poorly, there is no detail as to how the TennCare will proceed to improve and maintain the health of the individual. The state's proposed, but vaguely crafted, exceptions process is insufficient and detrimental to the health of people with disabilities. Experience has taught us that an individually applied exceptions process is often hard to access, difficult to use, and takes too much time.

Managed Care Organizations (MCOs) Oversight, Provider Networks, and Parity

One of the most troubling features of the proposal is TennCare officials' request to, "Operate a managed care program that does not comply with the requirements of [federal rules regulating Medicaid contractors]." Those rules are especially important in Tennessee, because the entire TennCare Program is contracted out to private managed care organizations (MCOs) to operate. Each year the state pays them nearly $10 billion in advance to manage the care of TennCare's 1.4 million patients. There are powerful incentives that, if unchecked, lead to denials of care and the diversion of treatment funds into corporate profits. The federal regulations were developed to protect against such abuses.

These federal regulations are critical to ensure that the state is able to operate with the Program's stated core values of providing high quality care that promotes improved health outcomes. Many states, including Tennessee, have been accused of mishaps and scandals that prompted passage of the very federal rules that Tennessee now wants waived. Twenty years ago, two large MCOs that contracted with TennCare were mismanaged and became insolvent. Because they did not pay providers, tens of thousands of their desperate patients were unable to find any doctors willing to treat them. The federal courts became involved, the plans went into receivership, taxpayers were stuck with the bill, and ultimately these actions threatened the stability of the entire TennCare Program. A third MCO was working with an already indicted state legislator to try to get a TennCare contract, a plan that was disrupted by the legislator's indictment. Our constituents are anxious that if the state were released from the requirement of these rules, it would reopen the door to program abuses and financial scandals that led their adoption.

The rules that TennCare seeks to waive require contractors to have enough doctors in their networks to meet patients' needs. The rules also prohibit conflicts of interest, require financial soundness, and mandate prompt payment of providers.

All patients must obtain their care from networks of doctors, hospitals and other providers that contract with MCOs. Insufficient networks in long-term care supports and services could worsen under the proposed changes. Our constituents have had negative experiences with network adequacy in both acute and long-term care. By eliminating federal managed care rules, the waiver would let the state pay MCOs rates that are too low to cover the cost of patients' care and/or allow MCOs to operate "hollow" provider networks that lack enough doctors, hospitals and other providers, and the full array of specialty care to meet patients' needs. The effect would be to leave patients unable to get vitally necessary care.

Additionally, of great concern is the attempt to eliminate "mental health parity" rules. Parity rules require that services for treating mental illness and addictions must be equivalent to those services that treat physical illnesses. The proposed waiver would eliminate that protection, so Tennesseans with postpartum depression, eating disorders, PTSD, addictions, bipolar, suicidal thoughts, or other mental illnesses, would not get the help they need. Permission to treat people inequitably is inappropriate. Suicide is the ninth leading cause of death in Tennessee, and it's the leading cause of death among Tennesseans ages 10-17 years of age. We need these rules to ensure parity.

With $10 billion in public funds at stake, protections and safeguards should be strengthened, not eliminated. Without the federal safeguards, Tennessee companies and legislators could be tempted to repeat mistakes made in the past. Sacrificing the health needs for vulnerable Tennesseans for flexibility could lead Tennessee to repeat past errors.

Lack of Details and Permission to be Excused from Oversight

Medicaid is an essential safety net that represents a shared commitment of the state and the federal government to the health and vitality of all Americans. This 60-year partnership is based on a foundation of joint funding and shared oversight. These checks and balances were created to ensure the Medicaid program provides fair and equal care. Amendment 42, as written, proposes explicit permissions to be excused from federal oversight. The proposal offers a lack of details as to how it will protect the individuals it serves now and in the future or how it plans to save money in the process. On pg. 19, the proposal asserts, "In the cases of mature demonstrations like TennCare (which have been re-approved multiple times and which have demonstrated positive results), CMS should re-evaluate its current policy to allow for a more permanent approval status." In this, Tennessee is asking to never have to reapply or have TennCare re-evaluated by the federal government. This would remove essential oversight of the program. Federal oversight has traditionally been critical to protecting people with disabilities.

Under this proposal, the state could, "Modify enrollment processes, service delivery system, and comparable program elements" without justifying the changes and getting federal approval. The state would be free to make it even more difficult than it already is to apply or maintain coverage, or to get medical services. TennCare has already demonstrated that it can save money just by erecting paperwork barriers, and this will give the state a free hand to double down on red tape. We are deeply concerned that the "comparable program elements" might be manipulated to make health care harder to get.

"Given the proposed changes to the state's federal funding, it is expected that Tennessee will be exempt from any new federal mandates over the life of the demonstration that could have a material impact on the state's Medicaid expenditures (pg. 11)." This means, for example, if the federal government mandated that states cover a particular medication or provide a new type of service, Tennessee would be exempt from that rule and not have to do so. For example, recent medical advances have developed a cure for hepatitis C; a debilitating and potentially lethal disease of the liver. The drugs to cure hepatitis C are expensive and range from $80-$150,000 per treatment regimen. However, less-expensive and less-effective drugs spread over the course of an entire lifetime could easily dwarf the cost to cure the disease outright. Citizens and state and federal governments are better protected when there is shared responsibility for oversight.

Future Outlook

For 60 years Tennesseans, like all Americans, have had the certainty of a comprehensive Medicaid program should they need it. Should Tennesseans face disability, a catastrophic illness or dramatic economic downturn we need the certainty of a pathway to basic care through Medicaid. Converting Medicaid funding into a block grant introduces significant uncertainty into what should be a cornerstone of our democracy. For our most vulnerable, including children and adults with disabilities and growing baby boomer population whose services will be impacted by the block grant, the lack of essential details about this proposed change is unacceptable. There is no room in this block grant proposal to serve individuals already on "referral lists" who are waiting for services and folks who will need these services soon. Proposed changes are coupled with significantly reduced oversight of a complex and important program. This would leave the people served unprotected.

Public feedback is important to ensuring the quality and success of any public program. Were the provisions of Amendment 42 to go into effect and new policy changes made without notice or public input, there is increased risk of leaving people behind and the program failing to meet the needs of those it was designed to serve. The proposed Amendment asks to start Tennessee down a "pathway to

permanency” for the waiver. With so much uncertainty about the ability of this proposal to maintain quality healthcare for Tennesseans and to improve rather than hurt our healthcare system, there must be opportunity for revision.

On behalf of the Tennessee Disability Coalition,

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