December 13, 2019

Seema Verma, Administrator

Centers for Medicare and Medicaid Services

U.S. Department of Health and Human Services

200 Independence Avenue, S.W.

Washington, D.C. 20201

Dear Administrator Verma:

On behalf of The Arc Tennessee board, staff, and members, thank you for the opportunity to provide public comment on Amendment 42, TennCare’s proposal that would convert a portion of the TennCare program to a block grant. The Arc Tennessee is a statewide advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families. We have an affiliated network of fifteen local chapters throughout the state as well as an affiliation with our national office, The Arc of the United States. The Arc Tennessee opposes the conversion of the federal Medicaid program to a block grant, and we oppose the conversion of any portion of Tennessee’s TennCare program to a block grant.

While TennCare is to be commended for their efforts to address the concerns of the numerous advocacy organizations that submitted public comment at the state level, the reality is that the proposal remains too vague to warrant our support. Historically, block grants fail to expand or improve services for vulnerable populations and in fact often result in reductions in services, provider rates, and enrollment. Our organization and its members have several general concerns about Amendment 42:

* The proposal relies upon a theoretical “savings” that cannot be proven.
* The proposal assumes that both TennCare and the federal government have the data systems and processes in place to implement the funding mechanisms proposed in an efficient, accurate, and timely manner. TennCare has a poor track record related to data and payment systems. There were significant challenges with 1915c service payments when they were transitioned from the Department of Intellectual and Developmental Disabilities (DIDD) to TennCare, and providers had difficulty getting reimbursed. TennCare did not have the necessary systems in place for online applications when the ACA became law and people had to use the marketplace instead. More recently, thousands of Tennessee children were reportedly disenrolled from TennCare even though they were still eligible – presumably due to errors in redetermination paperwork getting where it needed to be. This history suggests that there will be challenges implementing Amendment 42 that would negatively impact its members and providers of services
* The proposal requests exemptions from any new federal mandates over the life of the demonstration project that could have a material impact on the state’s Medicaid expenditures, which could negatively impact Tennessee’s most vulnerable populations
* The proposal requests even greater flexibility from the federal government than already exists under its current demonstration project to minimize “unnecessary or excessive interference or mandates,” yet mentions nothing of how it would simplify processes for those receiving TennCare benefits.
* The proposal requests relief from federal requirements related to the oversight of Managed Care Organizations (MCOs). The fact that Tennessee has operated under a managed care system for decades should not be the basis for eliminating that oversight. TennCare has a long history of lawsuits related to its provision (or lack thereof) of services. Administrations change. People change. Oversight exists to provide consistency across changes in administration and leadership.

In addition to our general concerns, The Arc Tennessee and its members have many specific concerns about how Amendment 42 will impact Tennesseans with I/DD and their families.

There are approximately 7,000 people with I/DD on the "referral list" for the Employment and Community First (ECF) CHOICES program. ECF CHOICES provides home and community-based (HCBS) long term services and supports (LTSS). Though the revised version of Amendment 42 suggests that the “savings” from the block grant will be used to eliminate the waiting list for this program, we are not convinced. People on the waiting list could be enrolled into ECF CHOICES but not receive the services they need because funding is limited or because MCOs are attempting to contain their costs. And with little MCO oversight, individuals and families would have little recourse to address the issue. People on the waiting list could also be enrolled into ECF CHOICES but not receive services because there are no providers available. We already see challenges with providers because the low reimbursement rates for many services make it difficult to hire and retain qualified workers. Elimination of the waiting list is only relevant if people are getting what they need when they need it.

The Arc Tennessee and its members are concerned that an exemption from federal mandates could negatively impact people with I/DD. Specifically, should the CMS ever make HCBS LTSS mandatory and change the current institutional bias in the Medicaid system, people with I/DD would lose out on an important federal change that could positively impact their lives.

Amendment 42 requests permission to shift to a commercial-style closed prescription drug formulary instead of having to cover all prescription medications included in the federal Medicaid drug rebate program. While we fully understand that prescription drugs are one of the largest cost drivers in the TennCare system, this move to a commercial-style closed prescription drug formulary means TennCare could significantly limit the prescriptions covered, in particular specialty medications that could benefit a discrete population of people. People with I/DD, especially those dually diagnosed with a co-occurring mental illness, often do not respond to the medications in the same way as someone without I/DD. For individuals with particularly challenging behavioral health needs, it is critical that they have access to the most effective medications available to help manage their conditions. A closed prescription drug formulary that requires “at least one drug per diagnosis” will negatively impact the health and safety of this population since it means they only have to offer one. Though Amendment 42 references the availability of an exceptions process to cover drugs NOT included in their formulary in certain circumstances, the reality is that the exceptions process may take too long or be too onerous for doctors and/or patients to attempt.

Amendment 42 requests TennCare be exempt from the federal Medicaid comparability mandate that requires covered benefits extend to all covered populations. Though we understand and respect TennCare’s assertion that not every population covered under TennCare has the same needs, people with I/DD have historically been a low priority with respect to covered services or expansion of HCBS LTSS. We are concerned that being exempt from the federal Medicaid comparability mandate will lead to people with I/DD struggling to access to the types of services they need even more than they struggle to now, which will adversely impact their health and safety.

Amendment 42 requests that TennCare be exempt from reapplying to CMS or being re-evaluated by the federal government. No program should be exempt from some level of oversight by its funder. No state agency would presume its vendors/contractors be exempt from their oversight. Removal of any level of federal oversight for the TennCare program is particularly troubling for people with I/DD and their families. Federal oversight has traditionally been critical to protecting people with I/DD because states have not done the right thing for this population. It took the federal Justice Department’s lawsuits against the state’s Arlington and Cloverbottom Developmental Centers, and ongoing federal oversight, for Tennessee to begin offering community-based services for people with I/DD. The Americans with Disabilities Act (ADA) was and is necessary because states didn’t voluntarily make buildings accessible. The Individuals with Disabilities Education Act (IDEA) was and is necessary because states did not see the need to provide a free and appropriate public education to children with I/DD.

Furthermore, The Arc Tennessee board and staff frequently hear from families of children and adults with I/DD who experience difficulties getting needed services now even though they receive TennCare and ECF CHOICES benefits. Amendment 42 requests to do away with federal safeguards governing the MCOs, which includes ensuring that they have adequate provider networks, pay providers promptly, and use actuarially sound rates. If the provider network is a challenge now, what will the future hold when the block grant funding isn’t sufficient to meet the needs of this population and the provider pool shrinks even more?

Amendment 42 requests TennCare be allowed to make changes to the benefits it provides, TennCare enrollment processes, and service delivery systems without federal government approval or oversight. Again, federal oversight has traditionally been critical to protecting people with I/DD.  Without federal oversight, TennCare has the ability to limit TennCare eligibility for people with I/DD who are a traditionally more expensive population to support. This population is an easy target if funding becomes tight and enrollment could effectively be reduced simply by making redetermination and enrollment processes more challenging to complete than they already are. Often times people just give up. Further, while the new Katie Beckett program will not be included in the block grant for the first three years of operation, ongoing funding (whether or not enrollment is at full capacity) will be through the block grant after that three-year period. We are deeply concerned that eligibility for the Katie Beckett program will be restricted in the name of cost containment, and that children with complex disabilities and medical needs will be adversely impacted as a result.

While TennCare has in many ways been innovative in many ways of its healthcare delivery, it has also faced many challenges over the years and continues to face challenges. It is extremely difficult for The Arc Tennessee and its members to hear Tennessee brag about how much money the state has saved with TennCare over the years, yet for nearly 20 years there has been 6,000-7,000 people with I/DD waiting for needed services. Tennessee has not had a true Katie Beckett program for children with the most complex disabilities and medical needs until legislation passed in 2019. Tennessee has frequently been more concerned about cost savings and efficiency rather than addressing the real needs of its most vulnerable populations. It is only because of the work of disability advocacy organizations in this state that some of the most critical needs have begun to be addressed.

The Arc Tennessee and its members are being asked to blindly trust the state of Tennessee and TennCare to create a system of healthcare delivery for Tennessee’s most vulnerable populations that fundamentally changes the relationship between the state and federal government. The proposal eliminates virtually any federal oversight of the program and significantly minimizes the opportunity for public input. As we have demonstrated in this letter, history prevents us from giving them that trust. We oppose Amendment 42 and any attempt to convert TennCare funding to a block grant.

Thank you again for the opportunity to submit public comment on Amendment 42. Should you have any questions, you may reach me at [cguiden@thearctn.org](mailto:cguiden@thearctn.org).

Sincerely,



Carrie Hobbs Guiden

Executive Director

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Doria Panvini

Public Policy Committee Chair