



T E N N E S S E E D I S A B I L I T Y C O A L I T I O N

October 14, 2015

Ms. Victoria Wachino, Director *via email: Victoria.Wachino1@cms.hhs.gov*
Center for Medicaid and CHIP Services
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Baltimore, MD

Re: Amendment 27: Employment and Community First Choices
TennCare II Demonstration (No. 11-w-00151/4)

Dear Ms. Wachino:

We are writing to express our serious concerns regarding the State of Tennessee's proposed Amendment 27 to its Section 1115 waiver, which governs the operation of the TennCare program. Amendment 27, which is currently pending before your agency, would establish eligibility requirements and other terms and conditions for the provision of waiver services to individuals with intellectual and/or developmental disabilities (I/DD). As a coalition of agencies with extensive experience serving and advocating for these individuals, we respectfully request that CMS disallow a key provision of Amendment 27 that will result in the inappropriate denial of services to many of Tennessee's most vulnerable residents.

As explained below, this will be the unintended result of the amendment's requirement that I/DD consumers meet acuity criteria that apply to TennCare's CHOICES program. CHOICES provides nursing facility and home and community-based services to a primarily geriatric population. Nursing facility acuity criteria are entirely inappropriate for persons with I/DD and will result in a refusal of the highest level of services for many persons who have a severe intellectual or developmental disability. For example, a person with a severe level of intellectual disability who is non-verbal, cannot understand simple verbal instructions and is not able to make decisions to prevent a risk of harm would not qualify for the highest level of services if they are able to eat food that is prepared and placed before them and take medicine if it is placed in their hand.

Background: Tennessee's restructuring of I/DD services

Earlier this year CMS approved Tennessee's restructuring of its existing Medicaid 1915(c) home and community based services waivers for individuals with intellectual disabilities. The waiver revisions imposed *individual* cost caps of:

- \$36,000 for persons receiving services through a self-determination waiver (Control # TN.0427); and
- the cost (currently \$153,440) of an ICF/MR (now designated as ICF/IID) placement for persons in the Statewide Waiver (Control # TN.0128).

The revisions imposed a more flexible *aggregate* cost cap only for persons in the Comprehensive Aggregate Capped (CAC) Waiver (Control # TN.0357). The CAC waiver group is closed to new consumers: it included existing enrollees with the most severe limitations, including persons being transitioned from large state institutions that have been or are being closed.

Eligibility for all of these programs is based on the criteria for placement in an ICF-IID facility. These criteria require a need for a program of specialized services for mental retardation and a significant impairment in adaptive functioning in either communication, comprehension, behavior or activities of daily living. (Please see Attachment 1: Tennessee Regulation 1200-13-01-.15(4)(b)(3).) These recently approved eligibility criteria for services under the revised 1915(c) waiver are worth noting, because pending Amendment 27 to the 1115 waiver will establish a substantially different set of eligibility criteria for consumers who have the greatest need for services in the future.

Amendment 27 to the main TennCare 1115 waiver will determine the level of services available and the eligibility criteria for all new recipients of I/DD services:

- The Essential Family Supports (EFS) benefit group provides services up to \$15,000 per year for children under 21 who are living at home with family. (Please see Attachment 2: Amendment 27 at Table 2, p. 7.)
- The Essential Supports for Employment and Independent Living (ESEIL) benefit group provides services up to \$36,000 per year for adults 21 and older. *Id.*
- Finally, the Comprehensive Supports for Employment and Community Living (CSECL) provides services up to \$60,000 per year, with an exception up to the cost of an ICF-IID for adults with the greatest needs.

While persons receiving benefits in the two lower cost benefit programs (EFS and ESEIL) will not have to prove that they meet the eligibility criteria to qualify for nursing home placement, persons who need extensive services in the family home or who need a community residential placement will have to do so. That is because Amendment 27 provides that individuals must meet “NF LOC” criteria in order to qualify for CSECL services. It is that requirement that raises grave concerns and prompts us to submit these comments.

The inappropriateness of applying nursing home criteria to I/DD consumers

Table 2 at page 7 of Amendment 27 states that persons with I/DD must meet “NF LOC” in order to qualify for the “Comprehensive Supports for Employment and Community Living. “NF LOC” is not defined in Amendment 27. However, we have confirmed with Tennessee Medicaid officials that this is a reference to the Level of Care criteria necessary to establish the need for care in a nursing facility. (Please see Attachment 3: Tennessee Rules and Regulations (“Regulation”) 1200-13-01-.10(6).) Eligibility is established by having a total score of “at least nine (9) on the TennCare NF LOC Acuity Scale.” Regulation 1200-13-01-.10(4)(b)(2)(i)(I).

The Acuity Scale awards points if physical assistance is needed with respect to transfer, mobility, eating, toileting and medication administration. Regulation 1200-13-.01(4)(b)(2)(iii). Points are also available for skilled nursing needs which require greater frequency than daily home health visits. *Id.* The

only cognitive limitations which can earn points are expressive and receptive communication (maximum of 1 point if cannot speak or understand spoken instructions), orientation (maximum of 4 points if disoriented as to person or place or situation) and behavior (maximum of four points if require persistent staff or caregiver intervention and behavior is not due to a mental health condition). Regulation 1200-13-01-.10(4)(b)(2)(iii). So even if an I/DD consumer has no ability to speak or understand instructions and is not oriented to person, place or situation, she scores only 5 points, and fails to meet the NF LOC threshold of 9 points, even if she requires constant supervision and assistance to perform essential activities of daily living. For example, she receives no points for functional limitations on her ability to eat, even if she is cannot remember how or when to eat, as long as she is physically able to ingest food if someone places it in front of her. (Regulation 1200-13-01-.10(4)(b)(2)(iii)(III)) Similarly, she receives no points for functional impairment of her ability to take medication, is she is incapable of knowing what medications to take, or when, so long as she can ingest the medication if it is handed to her. (Regulation 1200-13-01-.10(4)(b)(2)(iii)(VII)).

As another example of their limitations, the NF LOC used by the CHOICES program give insufficient consideration to functional impairments that a person with I/DD may have related to behavior. Under the NF LOC scoring system, even a person whose behaviors require constant supervision (3 points), who is totally disoriented (4 points), and who is incapable of oral communication (1 point) scores a total of only 8 points. Because the NF LOC requirements demand a score of 9 points, that individual cannot meet the criteria that Amendment 27 would impose. (Regulation 1200-13-01-.10(6)(c)(3), at p. 115.)

The failure of these CHOICES criteria to take adequate account of cognitive impairments has caused serious problems for some older adults who need nursing facility care or equivalent HCBS. (Please see Attachment 4: N. Bernstein, “Pitfalls Seen in a Turn to Privately Run Long-Term Care”, New York Times, March 6, 2014, <http://www.nytimes.com/2014/03/07/nyregion/pitfalls-seen-in-tennessees-turn-to-privately-run-long-term-care.html?hp>) The application of those criteria to a population comprised entirely of individuals with cognitive limitations is ill-conceived and wholly inappropriate.

The number of people who will be adversely affected by Amendment 27’s proposed criteria is substantial. Under the revised 1915(c) waiver, there are currently thousands of Tennesseans with intellectual disabilities who are receiving waiver services in excess of \$30,000 per year, based on a determination by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) that they need services at that level. Services provided above the \$30,000 level include home services for persons living with family, as well as community residential programs including companion care and supported living. The consumers in this group have needs that correspond to the CSECL group established by Amendment 27 and therefore provide an indication of the large number of people who will be affected by the proposed criteria.

In Amendment 27, the state attempts to justify use of the CHOICES criteria with the explanation that the ICF/IID criteria used in the existing 1915(c) waivers apply to services that, under the 1915(c) waivers, are limited to persons with intellectual disabilities. The state asserts that the ICF/IID criteria are therefore inadequate to assess the needs of individuals with developmental disabilities, who will also qualify for services under the 1115 waiver. (Please see Amendment 27 at 5.) However, Tennessee certainly could have simply expanded the ICF/IID level of care definition to include persons with developmental disabilities as the State of North Carolina has done. (Please see Attachment 5: North Carolina Innovations 1915(c) waiver at p. 17, Appendix B Par. D.) Instead, Tennessee has made the

unfortunate decision to apply a standard that was not designed to apply to persons with I/DD, is far more restrictive than the ICF/IID standard, and which will deny needed services for Tennesseans with very severe I/DD impairments.

When the TennCare Bureau and the Tennessee Department of Intellectual and Developmental Disabilities held community meetings in 2014, we were told that modifications were in process in the nursing facility level of care criteria “to ensure that cognitive and behavior needs are appropriately considered.” (Please see Attachment 6: *Renewal and Redesign of Tennessee’s Long Term Services and Supports Delivery System for Individuals with Intellectual and Developmental Disabilities Community Meetings about the Concept Paper for Stakeholder Review and Input* at Slide 21.) That did not happen.

We have made our concerns about the use of the NF LOC known to the TennCare Bureau and will have continued dialogue with them about these issues. However, because of the potential impact on individuals in our state, and as we continue to try to address these issues, we respectfully request that CMS disallow so much of Amendment 27 as would impose nursing facility level of care criteria as eligibility requirements to receive I/DD services under the TennCare 1115 waiver. Alternatively, if CMS is uncertain whether to approve Amendment 27, we would like to request that CMS ask the following questions of the TennCare Bureau concerning the Amendment:

1. Were any written resources or experts in the field of intellectual and developmental disabilities relied upon in making the decision to apply the NF LOC criteria? If so, please identify them and if experts were consulted, what you were told by them.
2. Were the Commissioner and the Medical Director of the Tennessee Department of Intellectual and Developmental Disabilities consulted with respect to the use the NF LOC criteria? If yes, please inform us what their comments were. If no, please provide their comments.
3. What, if any modifications have been made in the NF LOC criteria to account for the cognitive and behavior needs of the I/DD population?

We would welcome an opportunity to meet with your staff to discuss these concerns. Thank you for considering our comments on behalf of those Tennesseans with intellectual and developmental disabilities whom we are privileged to serve. Thank you for all that you and your staff do to serve our country.

Sincerely yours,

Carol Westlake, Executive Director

cc: Ms. Alissa Deboy, Director *via email:* alissa.deboy1@cms.hhs.gov
Ms. Melissa Harris *via email:* Melissa.Harris@cms.hhs.gov
Disabled and Elderly Health Program Group
Mr. Patrick Edwards, Project Officer *via email:* Patrick.Edwards@cms.hhs.gov
Division of State Demonstration & Waivers