The Association for Frontotemporal Degeneration
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2700 Horizon Drive, Suite 120
King of Prussia, PA 19406
267.514.7221
info@theaftd.org
www.theaftd.org

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August 15, 2023

Alison Barkoff
Acting Assistant Secretary for Aging and ACL Administrator
Administration for Community Living
Department of Health and Human Services
Attention: ACL-AA17-P
330 C Street, SW

Submitted electronically via http://www.regulations.gov.

RE: RIN 0985-AA17 Older Americans Act: Grants to State and Community Programs on Aging; Grants to Indian Tribes for Support and Nutrition Services; Grants for Older Hawaiian Natives; and Allotments for Vulnerable Elder Rights Protection Activities

Dear Acting Secretary Barkoff:

On behalf of The Association for Frontotemporal Degeneration (AFTD), the only non-profit organization solely dedicated to improving the quality of life of people affected by frontotemporal degeneration (FTD) and driving research to a cure for all FTD disorders, we are writing in response to the notice of proposed rulemaking (NPRM) to modernize the implementation regulations of the Older Americans Act (OAA or the Act).

Frontotemporal Degeneration is the most common form of dementia in people under 60, with connections to both Alzheimer's disease (AD) and amyotrophic lateral sclerosis (ALS - also known as Lou Gehrig's disease). It covers a group of disorders caused by the loss of neurons in the frontal and/or temporal lobes of the brain including primary progressive aphasia, corticobasal syndrome, progressive supranuclear palsy as well as behavioral variant frontotemporal dementia. The symptoms of FTD vary according to where the loss of neurons is most concentrated and includes the loss of

language and communication, impaired movement and muscle control as well as changes in behavioral and personality. The age of disease onset ranges from 21 to 80, but most FTD cases occur between ages 45 and 64. People under 60 with FTD have a high level of need for OAA services but cannot access them due to their age.

The Association for Frontotemporal Degeneration (AFTD) has identified the following key priorities and offers corresponding comments for consideration as ACL finalizes the NPRM and issues subsequent sub-regulatory guidance:

- Clarify the definition of "Family Caregiver" so that people under 60, with FTD or any other young onset dementia, are clearly and unequivocally eligible for the family caregiver support services made available through Title III of The Act. (§ 1321.3, 1322.3)
- Specify that the States may define the term "Greatest Social Need" to include people under 60 with FTD and other forms of early-onset dementia. (§ 1321.3)
- Identify people under 60 with FTD or another type of young onset dementia as a distinct service population and a special target for any assessments and evaluations of unmet need conducted by an Area Agency on Aging. (§ 1321.65 (3))

Family Caregiver Support Program – Definition of Family Caregiver (§ 1321.3, 1322.3)
Dementia is generally considered to be a condition that affects seniors. In most cases, this is appropriate, and it follows that resources and services for dementia care are delivered through healthcare systems and networks that serve people over 60. But FTD is different. The clinical presentations of FTD are heterogeneous and typically do not include memory problems characteristic of Alzheimer's disease. The age of onset is also variable but averages about a decade earlier than in Alzheimer's. Because of the earlier age of onset in FTD, a significant portion of the population with FTD are excluded from dementia care and services provided by the aging services network.

One exception to the over 60 eligibility criteria is the Act's definition of family caregiver as including "adults who are caring for an individual of any age with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction" (Sect. 1321.3). Frontotemporal degeneration is generally included in federal legislation through the term "related disorder" but never explicitly. **AFTD's asks that the definition of family caregiver be clarified so that people under 60 with FTD or any other young onset dementia are clearly and unequivocally eligible for the family caregiver support services made available through Title III of The Act.** For example**,** using the phrase "Alzheimer's disease or a related disorder with neurological and organic brain dysfunction, *such as frontotemporal degeneration (FTD) or any other neurodegenerative disease*" would be clearer and more inclusive than the language currently used.

Greatest Social Need (§ 1321.3)

Clarifying the phrase "related disorders" to explicitly include FTD, as described above, would make family members and others providing care for someone under 60 with FTD eligible, but the person living with the disease themselves would still not be able to access the many resources and services The Act makes available under Title III and IV. AFTD requests that it be made clear that **the States may define the term "Greatest Social Need" to include people under 60 with FTD and other forms of early-onset dementia.** FTD is clearly a noneconomic factor that causes physical and mental disability. People under 60 with FTD also frequently experience isolation, particularly social isolation. The fact that these people are not eligible for most dementia care and services because of their age despite having a neurodegenerative disease invariably leads to greater social isolation. When combined with the loss of employment and disruption of family and other social relationships it is easy to see how this isolation becomes a substantial social need, unique to people under 60 with young onset dementia like FTD.

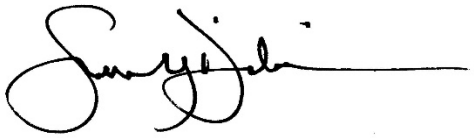
Data collection and reporting (§ 1321.65 (3))

We currently do not know how many people with FTD utilize OAA services. In addition to clarifying the term "Greatest Social Need" to include people under 60 with FTD and other types of young onset dementia, AFTD requests that it **be made clear that this group is also a target for any assessment and evaluation of unmet need conducted by an Area Agency on Aging, and that this group be explicitly included as a service population in any policy and procedure established by a State Agency as described in the proposed section 1321.9(c)(1).**

Conclusion

The Older American Act of 1965 provides essential resources and services for individuals with dementia and their families and caregivers. The Association for Frontotemporal Degeneration respectfully requests that the above changes be implemented so that The Act can benefit all people for whom it is intended.

Respectfully Submitted,
Susan L-J Dickinson, MS, CGC



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2700 Horizon Drive, Suite 120
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