I and Dr. Seth Keller are the co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) (www.aadmd.org/ntg). The NTG is an affiliate of the American Academy of Developmental Medicine and Dentistry.

Today, we would like to comment on the deficiency in reliable and available specialized dementia diagnostic and post-diagnostic services for adults with intellectual disability (including those with Down syndrome) and speak to a proposal to remediate this deficiency.

Given that adults with intellectual disability are one of the ‘specific populations’ recognized by the Advisory Council on Alzheimer’s Research, Care, and Services in the National Plan to Address Alzheimer’s Disease, and that the National Institutes for Health has noted that many

(a) adults with Down syndrome, an intellectual disability, are at significant risk of dementia (mainly resulting from Alzheimer’s disease),

(a) some experience symptoms of cognitive impairment earlier in life,

(b) may be subject to neglect or abuse or are at risk of institutional placement,

(c) would benefit from early screening and assessment and access to knowledgeable diagnostic services,

(d) often live with older caregivers who, or are served by provider agencies that, have difficulty finding knowledgeable clinicians who can provide accurate assessments or diagnoses, as well as post-diagnostic supports, and

(e) knowing that many such resources are difficult to access and scarce in most non-urbanized areas and that few clinicians currently are specialists in the differential diagnosis of dementia among adults with intellectual disability,

we propose that there is a need to increase the availability of intellectual disability focused dementia assessment and diagnostic resources and post-diagnostic supports across the United States. Currently, there is a serious lack of such specialized diagnostic services across the states and there is no national register of such specialists. A remedy would be to raise the
awareness of the availability of such services and increase the interest of existing (or emerging) dementia diagnostic services to also be recognized as an intellectual disability specialty provider.

We note that the report on intellectual disability and dementia that emanated from the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers stated that early diagnosis is essential to ensure timely interventions, such as proffering medications for symptom management, establishing advance care plans, and applying psychosocial interventions for adults with intellectual disabilities. Further, the report noted the need for increased diagnostic competency among diagnosticians, more public awareness in general, and accessible information designed to raise the “index of suspicion” for caregivers of adults with intellectual disability. The report recommended with respect to screening and diagnostics, that there be increased screening for dementia, raised public and professional awareness; and more readily available diagnostic services.

To this end, the NTG and other aging and disability organizations have proposed a legislative remedy that would increase such awareness, focus attention on available and newly recognized diagnostic services, and enhance post-diagnostic supports. Consequently, we recommend that the Older Americans Act, which is up for reauthorization this year, be amended to include provisions that would increase availability of specialized diagnostic resources and increase the provision of post-diagnostic supports for this specific population.

In the current iteration of the Older Americans Act, there are several sections that contain foundational language:

- **Section 102 (14)** of the OAA states that the term “disease prevention and health promotion services” means— (J) information concerning diagnosis, prevention, treatment, and rehabilitation concerning age-related diseases and chronic disabling conditions, including osteoporosis, cardiovascular diseases, diabetes, and Alzheimer’s disease and related disorders with neurological and organic brain dysfunction”; and Section (14) (L) “counseling regarding social services and followup health services based on any of the services described in subparagraphs (A) through (K).”

- **Section 201(e)(3)(f)(2)** of the OAA states that “It shall be the duty of the Assistant Secretary, acting through the individual designated under paragraph (1), to develop objectives, priorities, and a long-term plan for supporting State and local efforts involving education about and prevention, detection, and treatment of mental disorders, including age-related dementia, depression, and Alzheimer’s disease and related neurological disorders with neurological and organic brain dysfunction.”

- **Section 307 (a) (16) (A)** of the OAA states that the State agency would require outreach efforts that will identify individuals eligible for assistance under this Act, with special emphasis on “(i) older individuals residing in rural areas; (ii) older individuals with greatest economic need (with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas); (iii) older individuals with greatest social need (with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas); (iv) older individuals with severe disabilities; (v) older individuals with limited English-speaking ability; and (vi) older
individuals with Alzheimer’s disease and related disorders with neurological and organic brain dysfunction (and the caretakers of such individuals);

- **Section 307 (a) (17)** of the OAA states that “The [State] plan shall provide, with respect to the needs of older individuals with severe disabilities, assurances that the State will coordinate planning, identification, assessment of needs, and service for older individuals with disabilities with particular attention to individuals with severe disabilities with the State agencies with primary responsibility for individuals with disabilities, including severe disabilities, to enhance services and develop collaborative programs, where appropriate, to meet the needs of older individuals with disabilities.”

Given these requirements under the statute, it is proposed to incorporate into the Older Americans Act a provision to identify and promote use of state **designated intellectual disability geriatric assessment centers**, specifically designated as resources for the screening, assessment, and diagnosis of Alzheimer’s disease and related disorders with neurological and organic brain dysfunction.

Specifically, the legislation would enable such centers to:

- Have at minimum one or more clinical specialists experienced in screening, assessing, and diagnosing older adults with intellectual disability, including adults with Down syndrome, developmental disabilities, and other neurodevelopmental conditions who may be at risk of institutional placement, precocious aging, abuse or neglect, and who are at high risk of dementia or who are suspected of experiencing cognitive decline or other neurodegenerative mental or physical condition associated with aging.
- Offer their assessment and diagnostic services to adults with intellectual disability and with those with severe disability, suspected of or affected by cognitive impairment such as Alzheimer’s disease and related disorders with neurological and organic brain dysfunction, and their primary caregivers.
- Be capable of primary screening, assessment, and diagnosis of cognitive impairment, such as Alzheimer’s disease and related disorders with neurological and organic brain dysfunction, following referral from primary care or general practitioners, social care agencies, family members, community-based entities, and via self-referral.
- Liaise with and provide consultation to social care and other community-based agencies, and referral sources, on post-diagnostic supports and enable or provide follow-along post-assessment or post-diagnostic clinical assessments.
- Provide consultation on assessment, diagnosis, and post-diagnostic supports to primary care physicians, general practitioners, and other health providers (including neurologists, geriatricians, and psychiatrists) not located geographically proximate to the center, via Internet and other distance communication methodologies, such as telemedicine.
- Liaise and link to the Aging and Disability Resource Centers within the state.

To support this provision, specifically, the State [aging] agency:

- Would be tasked to identify the scope of need for such a center or centers within the State as part of its State plan requirements.
- Would be tasked to make such designations in consultation with the state developmental disabilities authority, the state’s developmental disabilities planning council, the state’s
Aging and Disability Resource Centers, and the state entity responsible for administering or organizing the state’s plan to address Alzheimer’s disease and other dementias.

A proposal for legislative language has been prepared that addresses this issue and is being circulated among organizations and associations involved in disability and aging advocacy which have an interest in dementia and are contributing specificity to changes in the next iteration of the Older Americans Act.

We ask for your support, to the extent possible, for this legislative proposal and for due consideration in otherwise addressing this need in the 2019 update of the National Plan.

Thank you.

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