LEGISLATIVE PROPOSAL FOR INCREASING AVAILABILITY OF ID/DEMENTIA DIAGNOSTIC AND POST-DIAGNOSTIC SUPPORTS

Intent

It is proposed to amend relevant sections of the Older Americans Act (PL 114-144) to include a provision for the state aging agency to enter into a cooperative agreement with and to liaise and coordinate with the state agency overseeing programs and services for persons with intellectual and developmental disabilities to identify and make available information about dementia diagnostic resources for adults with disability (including intellectual disability). The intent is to expand awareness about dementia diagnostic clinics specializing in assessing and diagnosing adults with intellectual disability and the stimulate an increase in the number of such specialty diagnostic resources.

Although generic dementia assessment and diagnostic resources exist across the United States, rarely do they have the understanding and expertise to assess adults with intellectual disability showing signs for cognitive decline. This provision for identification and inclusion would fill a void in awareness within the state about available specialty diagnostic resources for this segment of America’s older population.

- Depending upon the state, such specialty diagnostic resources can be found as a part of a university-based center in aging or university center for excellence in disability [UCED]; potentially a leadership education in neurodevelopmental and related disabilities program [LEND]; other dementia assessment and diagnostic programs at a hospital or clinic; or other community-based entities cited in the Older Americans Act. They could also be an entity associated with one of the Alzheimer’s Disease and Related Dementias Public Health Centers of Excellence, where one their functions is ‘supporting early detection and diagnosis of Alzheimer’s disease and related dementias’ (as noted in PL 115-406, the BOLD Infrastructure for Alzheimer’s Act).

- Such specialty diagnostic resources, to be acknowledged and noted within a state’s information and referral resource guide, would attest that they do provide assessment and diagnostic services for people with intellectual and developmental disabilities, advise and assist family and other caregivers, and liaise and coordinate with other community-based entities, including area agencies on aging, aging and disability resource centers, and local aging, health, and intellectual disability services providers, to obtain referrals and provide post-diagnostic supports.
• Such specialty diagnostic resources would also agree to serve, within available resources, as regional or national specialty technical resources for local practitioners and other clinicians lacking locally-based information and clinical resources capable of assessing and diagnosing aging-related cognitive impairments and dementia in persons with intellectual disability.

• Identification and inclusion in the state’s aging services resource guides would be accomplished through cooperative agreements between the state aging agency and the state authority for intellectual and developmental disabilities. Further, the rationale for such identification and listing would be noted in the State plan [defined in section 504: Administration of the OAA] and would be shared for input from the State’s Council on Developmental Disabilities, established under section 125 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402). This would help promote the availability of such diagnostic resources through education and sharing of information regarding the need for such resources.

Basis for inclusion of these provisions in the Older Americans Act (OAA)

Given that adults with intellectual disability are one of the ‘specific populations’ noted by the federal Advisory Council on Alzheimer's Research, Care, and Services in the National Plan to Address Alzheimer’s Disease, and the National Institutes for Health have noted that many adults with intellectual disability, especially those with Down syndrome, are at significant risk of dementia (mainly resulting from Alzheimer’s disease) and many experience early onset dementia, and that numerous national intellectual disability, and Down syndrome organizations have noted that many such adults affected by dementia may be subject to neglect or abuse or are at risk of institutional placement, and would benefit from early screening and assessment and access to knowledgeable diagnostic services, and knowing that many such resources are difficult to access and almost negligible in most non-urbanized areas and that few clinicians currently are specialists in the differential diagnosis of dementia among adults with intellectual disability, it is proposed to amend sections of the Older Americans Act to increase availability of specialty diagnostic resources for this particularly at-risk population and increase the provision of post-diagnostic supports.

The National Task Group on Intellectual Disabilities and Dementia Practices, in its seminal report, My Thinker’s Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports noted that “given the expected upward trend in prevalence as a result of population aging, it is likely that three times the number of adults, some 27,000 nationally, would be affected [by dementia] at this time. Also, doubling that number to potentially accommodate those persons not known to providers, on the margins of the intellectual disabilities definition, or adults with mild cognitive impairment (MCI) would provide a prevalence estimate of some 54,000 adults with an intellectual disability with mild cognitive impairment or dementia by the end of this decade.” It is has been noted that most adults with intellectual disability are projected to receive a diagnosis of Alzheimer’s disease and other cause of dementia at about the same rate as the general population. However, adults with Down syndrome, which make up over a tenth of the adult intellectual disability population, are at very high risk and more than two-thirds of aging adults with Down are expected to exhibit the signs and symptoms of Alzheimer’s disease. Thus, having
access to early detection and diagnostic services can aid in providing early intervention and services that can mitigate debilitation, ease progression, and help families and providers prepare and plan for eventualities and prevent or defer institutional placement.

Even though adults with an intellectual disability – particularly those with Down syndrome – begin to exhibit symptoms of early or younger onset dementia at age less than 60 (usually in their early 50s for Down syndrome), provisions of this legislative proposal would be applicable as (a) some Older Americans Act programs already recognize serving persons with disability at age younger than 60 [e.g., NFCSP funding may be used to serve caregivers age 55+ of adult children with disabilities], (b) provisions exist within the Older Americans Act for a focus on ‘disease prevention and health promotion services’ related to Alzheimer’s disease within the state’s older population and do not proscribe services to adults affected by early- or younger-onset dementia, and (c) the diagnostic resources will not be funded under the Older Americans Act and thus age-related constraints would not apply.

In the current iteration of the Older Americans Act, the following sections contain supportive 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.”

• Section 102 (28) defines the term “information and assistance service” as assessing problems and capabilities of individuals and linking individuals to opportunities and services that are available; ensuring that individuals receive the services the need; and serving particularly older individuals with the greatest social need, greatest economic need, and older individuals at risk of institutional placement.

### Concept Specifics

Given existing aspects of the statute, it is proposed to incorporate into the Older Americans Act a provision to identify and promote use of specialty diagnostic resources for adults with disability (including intellectual disability), specifically designed to be resources for the screening, assessment, and diagnosis of Alzheimer’s disease and related disorders with neurological and organic brain dysfunction.

Specifically, it is proposed that such specialty diagnostic resources, to be included in state aging agency guides to diagnostic services:

• Would 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 of neglect, and who are high risk of dementia or who are suspected of experiencing cognitive decline or other neurodegenerative mental or physical conditions associated with aging.

• Would 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.

• Would agree to serve families and adults with intellectual disability resident outside of their immediate area.

• Would be capable of primary screening, assessment, and diagnosis of cognitive impairment such as those resulting from 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.

• Would 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.
• Would provide **consultation on assessment, diagnosis, and post-diagnostic supports to primary care physicians, general practitioners, and other health providers** not located geographically proximate to the center, via Internet and other distance communication methodologies, such as telemedicine.
• Would liaise with and **link to Aging and Disability Resource Centers** within the state.

**To support this provision, specifically, the State agency:**

• Would be tasked to arrive at a cooperative agreement between itself and other state agencies involved in dementia services coordination or provision, such as the agency responsible for services to people with intellectual and developmental disabilities.
• Would be tasked to identify the scope of need for dementia diagnostic resources within the State as part of its State plan requirements.
• Would be tasked to incorporate recognized specialty diagnostic resources within its services’ guides after consulting with the state intellectual and developmental disabilities authority, 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.

**Proposed Legislative Language**

1. **New Section 102 (14)** “(K) diagnostic supports for assessing and diagnosing Alzheimer’s disease and related disorders with neurological and organic brain dysfunction in older individuals with severe disability and organic brain dysfunction;”

   *Retitle* “(K) gerontological counseling; and” as “(L) gerontological counseling; and”

   *Retitle* “(L) counseling regarding social services and follow-up health services based on any of the services described in subparagraphs (A) through (K).” as “(M) counseling regarding social services and follow-up health services based on any of the services described in subparagraphs (A) through (K).”

2. **New Section 102 (55)** The term “specialty diagnostic resources” means a program with clinical specialists experienced in screening, assessing, and diagnosing older adults with intellectual disability who may be at risk of dementia or who are suspected of experiencing cognitive decline or other neurodegenerative mental or physical conditions associated with aging.

3. **New Section 202 (b) (8) (G)** to provide technical assistance for information and referral on the identification and listing of specialty diagnostic resources for individuals with intellectual disability at risk of Alzheimer’s disease or other dementias to aid families and providers with supporting such individuals in the community.

4. **New Section 305 (a) (3) (C) (iv)** aid the State agency with identifying specialty diagnostic resources for individuals with intellectual disability to permit early detection and diagnosis of Alzheimer’s disease and other dementias;
5. **Addition to Section 307 (a) (16) (vi) (Added wording):** (vi) older individuals with Alzheimer’s disease and related disorders with neurological and organic brain dysfunction (and caretakers of such individuals), as well as individuals with disability (including intellectual disability) at risk of Alzheimer’s disease and other dementias; and

6. **Existing Section 307 (a) (17):** The plan shall provide, with respect to the needs of older individuals with severe disabilities, assurances that the State will coordinate planning, identification, and assessment of needs, and services 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.

**New Section 307 (a) (17) (A):** The plan shall provide for identifying specialty diagnostic resources for adults with disability (including intellectual disability) that would determine the presence of aging-related cognitive impairment and Alzheimer’s disease and related disorders with neurological and organic brain dysfunction among older individuals with severe disability, including adults with intellectual disability.

The Secretary, in legislative language to be determined would also be tasked to (a) provide guidance for the identification of services within the states that provide specialty diagnostic resources for older adults (or adults with younger onset) with severe disabilities at particular risk of, or suspect to have, Alzheimer’s disease or a dementia originating from other causes, and (b) provide guidance for the establishment of cooperative agreements between the State agency and other agencies concerned with people with severe disabilities (including intellectual disabilities) that would address common programs and provide State guidance to Aging and Disability Resource Centers concerning aiding individuals affected by dementia.

**Assessment of Cost Impact**

An estimate of the cost of the implementation of the legislation upon the state aging agencies is that it will be minimal as the setting up of the standards or guidance for such identification of specialty diagnostic resources would be delegated to the Secretary. Any costs incurred at the state level would be associated with staff time in liaising with other state agencies with an interest in such specialty diagnostic resources for adults with disability (including intellectual disability), and time allocated to negotiating the designations with such specialty diagnostic resources requesting or being nominated for such inclusion in services and resources guides. No funds under this provision would be allocated to support or otherwise fund such specialty diagnostic resources or their regulation. Any obligatory certification or regulatory reviews would be handled by state agencies already charged with overseeing such generic or specialized dementia diagnostic resources in the normal course of their state’s legislatively mandated activities.

It is estimated that in densely populated states, there may be from one to a dozen such specialty diagnostic resources which may seek or be nominated for such designations, and in less densely
populated states, there may none to a limited number. These numbers would be expected to increase over time, but the impact of state agency workload would be minimal once it becomes routinized.

Ancillary costs may be associated with augmentation of state aging agency websites and published materials where listings of general diagnostic resources may be provided, and their updating periodically when new specialty diagnostic resources are identified as well as in staff time in liaising with representational associations with interest in such specialty diagnostic resources.

Assessment of Benefit

It is expected that the legislation would increase the public awareness of the availability of specialized diagnostic resources for people with intellectual disability, increase their utilization rate, and increase the rate of early detection of dementia among people with intellectual disability, reduce costs due to earlier interventions and treatments provided and mitigation of care problems associated with undiagnosed dementia, reduce the rate of premature or unnecessary institutionalization, and provide supports to caregivers earlier with a focus to enhance care practices and mitigate stress among caregivers.

Background

Although some communities have diagnostic resources focusing on adults with cognitive impairment within the general population, there is a dearth of reliable and knowledgeable resources that can aid with screening for, and diagnosing, cognitive impairment and dementia among adults with intellectual disability at risk of Alzheimer’s disease and causes of other dementias. Also, although there exist some specialty clinics serving children and young adults with Down syndrome, appropriate diagnostic resources for aging adults with intellectual disability (including Down) are scarce. These deficiencies in availability, known for years by families and organizations serving aging people with intellectual disability, are generally linked to lack of interest in lower incident conditions linked to risk of dementia, the inadequacies in training and education of healthcare personnel assessing adults showing signs of decline, and insufficient investment in resource centers specializing in neurocognitive decline and neurodegenerative conditions evident in aging adults with intellectual disability.

The elevated risk for Alzheimer’s disease among some adults with intellectual disability, particularly those with Down syndrome, has been known for some time, and has received notice in the US National Plan to Address Alzheimer’s Disease. The National Institute for Health has invested substantial resources and funding for research into the biological and neurological basis for this risk. The most recent effort is the underwriting of a multi-site investigation into biomarkers which may lead to a process for readily identifying earlier those adults with Down syndrome who may be a risk for dementia as they age. Further, NICHD’s investment in organizing and managing the Down Syndrome
Consortium and DS-Connect® network shows the interest in bringing together various stakeholders to speak to this issue.

Yet, little other investment has occurred to aid those adults with intellectual disability and their families already aging and possibly affected by early-onset or age-related onset of dementia. Families and provider organizations are often at loss as where they may obtain a competent assessment of cognitive decline and an evidence-based diagnosis of the underlying cause of dementia. Screening those at risk often is a hit or miss event, often linked to an active program by a provider, but in most cases, linked to a family caregiver’s special request. According to the National Down Syndrome Society and the Global Down Syndrome Foundation, across the United States only a few pockets of excellence exist where specialty health professionals have set up clinics with the capacity and competence to assess adults with intellectual disability and determine whether Alzheimer’s disease or other causes of neurodegeneration may be present. However, such specialty clinics, or individual practitioners often have limited resources to extend consultation to families or providers outside of their immediate geographic area or remain formally unrecognized within State efforts to manage Alzheimer’s disease services.

Generic dementia diagnostic services across the United States usually lack personnel who understand the distinction between natural performance related to level of intellectual disability and cognitive impairment related to a neurodegenerative disease or condition. The same often applies to individual practitioners, who often reflexively diagnose dementia in adults with Down syndrome, even if the decline expressed might be due to benign age-related changes, depression, nutritional imbalances, or endocrine factors – due to the popular association of Down syndrome and Alzheimer’s disease. Such mis-diagnoses can prevent or delay treatment for conditions that can be helped with medication or other therapeutic interventions.

As noted in the National Task Force on Intellectual Disabilities and Dementia Practices’ document, “My Thinker’s Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports”:

“Formal diagnostics are the domain of specialists generally found in more urbanized settings. The proximity of a regional diagnostic center can provide valuable support with early diagnosis and ongoing evaluations. Access to such specialized services outside major centers is, however, a barrier. There is a potential role for technology to be used to better support individuals, agencies, and professionals living in smaller cities, towns, and rural areas. Diagnostic resources also need to be reliable and accurate, as some instances of symptom presentation and change may be attributable to other causes, and not to dementia. Often adults with an intellectual disability, particularly those with multiple complications or severe intellectual impairment, may be misdiagnosed and the course of treatment consequently misdirected. Loss of function, personality and emotional changes, and loss of activity may be the result of other diseases or physical or sensory problems (such as nutritional deficiencies, thyroid abnormalities, or hearing impairments). Having well-trained and reliable diagnostic resources available to aid in assessing adults with an intellectual disability is crucial to accurate diagnosing and appropriate remedial treatment.”

Another factor is the lack of agreement on the structure and provision of screening, assessment, diagnostic, and post-diagnostic supports. Clinics and practitioners vary as to the clientele they see, the instruments they use prior to and at the patient visits, and the procedures they undertake in the diagnostic process. Consensus or practice guidelines on systematic approaches to screening,
assessment, and diagnostics are necessary to help standardize procedures, terminology, follow-up processes, and practices helpful to families and other caregivers. Such standardization would provide guidance for the formation of new clinics, exchanges of information, telemedicine and virtual home visit programs, and publications.

Beyond the inadequacies of the screening and diagnostic process, deficiencies also exist in the follow-up after diagnosis. In most localities, such post-diagnostic supports are often lacking or unlinked to the diagnostic process. Families are often left to ferret out assistance on their own and to cobble together a package of supports (depending on their capability and geography). This may include getting more information about the effects and course of the type of dementia present – such as what may be the trajectory of decline both mentally and physically, what are the timelines, what behaviors may become more evident, and what to expect of losses from current abilities. Also, these include what supports might be drawn up from existing resources, such as home modifications, respite, health checks, information on care management, hospice, and other care issues. Agency personnel, providing direct support, are often without information or resources to provide dementia-capable services. Provider agencies, wrestling with an aging clientele, are often without access to consultative resources to help them plan for their aging clientele, help with screening for cognitive decline, re-assess the utility of their residential supports, training of staff on aging and dementia, and develop targeted family support units that can help that clientele residing at home.

Remediation

Thus, what is the solution? There is a need for

1. more education and training of health care professionals who may be asked to ascertain the underlying cause of a cognitive impairment in an adult with an intellectual disability;

2. more upgrading of skills, via continuing education, of specialty dementia diagnosticians in making differential diagnoses of MCI or dementia among adults with intellectual disability;

3. provision of resources to states, university aging or disability clinical centers, medical centers, and specialty clinics to upgrade existing and developing new diagnostic programs that would expand their services to adults with intellectual disability, or establish specialized life-long disability geriatric assessment centers;

4. channeling resources to existing intellectual disability specialty diagnostic resources or new centers to expand their consultative reach, via new technologies [e.g., telemedicine, virtual home visits, etc.] – to provide real time assessment consultation to other clinics or practitioners when assessing patients presenting with suspected cognitive impairment or dementia (including adults who are identified as part of the cognitive impairment assessment provision of the Annual Wellness Visit under the Affordable Care Act).

5. supporting local systems for on-going post-diagnostic supports, that would include a reliable and stable point of contact, information on financial and social supports, counseling and help with decision-making related to future care, support (peer-to-peer or other) groups, consultation on home modification or home proofing, linkages to generic Alzheimer’s and other dementia organizations’ local resources, and aid with end-of-life care decision making.
(6) organizing a national effort to **identify and promote clinical practices** related to screening, assessment, and diagnostic services, as well as post-diagnostic supports and the issuance of a set of practice guidelines that can aid in the organization of programs, certification of services, and evaluation of efficacy and utility of existing efforts.

**The First Step**

Although having in place all these components of a system would be ideal to aid adults with intellectual disability at risk of dementia, and their family and other caregivers, the process to establishing such a system of resources must begin with the ‘first step.’ Thus, it is proposed that several minor adjustments to the Older Americans Act, calling for the State aging agency to note the presence of specialty clinics for diagnosing dementia in this group, would lead to greater awareness and attention to this need and begin the contribution and involvement of other state resources and the non-for-profit sector’s engagement in constructing this system.

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