Maryland
DEPARTMENT OF AGING

Wes Moore | Governor Aruna Miller | Lt. Governor Carmel Roques | Secretary

The Honorable Wes Moore
Governor
100 State Circle
Annapolis, Maryland 21401

The Honorable Bill Ferguson
President
Senate of Maryland
State House, H-107
Annapolis, Maryland 21401

The Honorable Adrienne A. Jones
Speaker
Maryland House of Delegates
State House, H-101
Annapolis, Maryland 21401

The Honorable Pamela Beidle
Chair, Finance Committee
Senate of Maryland
3 East Miller Senate Office Building
11 Bladen Street
Annapolis, Maryland 21401

The Honorable Joseline A. Pena-Melnyk
Chair, Health and Government Operations Committee
Maryland House of Delegates
241 Taylor House Office Building
6 Bladen Street
Annapolis, Maryland 21401

Re: Human Services Article § 10-1301 and State Government Article § 2-1257 First Annual Report on Long-Term Care and Dementia Navigation Program.

Dear Governor Moore, President Ferguson, and Speaker Jones:

Pursuant to Human Services Article § 10-1301 and State Government Article § 2-1257 we submit the first required annual report on the Department of Aging's new Long-Term Care and Dementia Care Navigation Program. This report covers the first quarter of the new Long-Term Care and Dementia Navigation Program.

Please contact MDOA Legislative Director Andrea Nunez at andreah.nunez@maryland.gov or 410-414-8183 with any questions.

Sincerely,

Carmel Roques
Secretary

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The Department of Aging (Department) receives mandated funding for the new Long-Term Care and Dementia Care Navigation Program (Program) pursuant to its founding legislation, SB228/HB614 of 2023. This legislation included a mandated annual appropriation of $2.4 million beginning July 1, 2024. Thus, this first report only covers the first quarter of funded Program work by the Department. We note that the Program was included in the state's operating budget reductions proposed by the Governor and approved by the Board of Public Works in July 2024, reducing the Program's FY2025 budget by 50%, from $2.4 million to $1.2 million.

Pursuant to Human Services Article §10-1301 this annual report in the future should address the number of direct contacts each long-term care and dementia navigation program has with State residents, the results of those contacts including referrals, cognitive screenings conducted, number of outreach events conducted, and the number of state residents contracted through those events. The Department will also publish this report and future annual reports on our website. By fall 2025, the Department anticipates it will have collected its first full year of data in the categories mandated in Human Services Article §10-1301, which the Department will be able to reflect in its second annual report due October 1, 2025. The Department submits the information below regarding its work under this legislation's mandates to date:

Program Overview:

The Maryland legislation tasks the Department with developing and overseeing an effective dementia navigation strategy to address the needs of individuals with Alzheimer's Disease and Related Dementias (ADRD) and their caregivers in Maryland's rapidly growing older adult population. To accomplish this objective, the legislation instructed the Program plan be embedded within the Department to provide guidance and direction to Maryland's Area Agency on Aging (AAA) network. The mandates of the statute will be embedded across long-term services and support programs, initially focusing on the Maryland Access Point (MAP) aging and disability resource center and caregiver support services. Before mandated state Program funding began, the Department became a subgrantee of the Maryland Department of Health (MDH) on an ADRD Plan Implementation Grant from Chronic Disease and Prevention Control. These funds supported delivery of multiple evidence-based dementia caregiver and provider training programs, created and archived evidence-based dementia content for future dementia certification efforts, and funded Community Based Organizations (CBO's) to provide innovative, hyper-local dementia programming within communities. In preparation for the development and implementation of the Program plan, the Department hired a Cognitive and Behavioral Health Specialist in 2023 to collaborate with AAAs to co-develop the Program plan. Plan co-development is being realized through a workgroup composed of AAA members who meet bi-weekly and incrementally review and recommend the direction of plan development. The Department's Cognitive and Behavioral Health Specialist's responsibilities also include ensuring the Program plan design aligns with the Virginia I. Jones Alzheimer's Disease and Related Dementias Council (Council) and the Maryland State Plan on Aging (State Plan on Aging).

Dementia care navigation is generally recognized as a system that provides tailored, strengths-based support to persons living with dementia and their care partners across the illness continuum and settings to mitigate the impact of dementia through collaborative problem solving and coaching. It is intended to ensure that all persons with dementia and their caregivers receive equitable, quality dementia care navigation services. The Department has been and will continue to use a health equity lens when co-designing and determining components of dementia care navigation. The Department will emphasize that the delivery of dementia navigation services be able to be delivered by non-clinical professionals. The Department will focus on opportunities to convene with practices and health care networks to participate in dementia navigation.

The Vision of Maryland's Dementia Navigation Program is one that will –

- Be person- and family-centered to ensure collaboration and enhance engagement.
- Be culturally responsive and address disparities in access to health care and support services.
- Include well-defined roles and responsibilities for all members of the dementia care navigation team.
- Address barriers relating to medical, legal, financial, emotional, and other domains facing the person living with dementia and their care partners.
- Provide coaching, education, and coordination in a manner that is empowering, solution-focused, and strengths-based.
- Focus on the family unit as defined by the person living with dementia.
- Ensure processes and protocols are evidence-based.

The Program' goals, which reflect the legislative mandates and overarching goals of the Department, the Virginia I. Jones Alzheimer's Disease and Related Dementias Council, and the State Plan on Aging, are to:

1. Provide training to the dementia care network on long-term care and dementia care navigation best practices.
2. Provide cognitive screening opportunities for individuals concerned with memory and thinking.
3. Collect dementia navigation interaction data to ensure statewide program integrity.
4. Provide programs to engage individuals experiencing symptoms of dementia that interfere with Activities of Daily Living (ADLs).
5. Provide support for caregivers of individuals experiencing symptoms of dementia that interfere with ADLs.
6. Provide consulting and technical assistance to AAA staff.
7. Facilitate establishing relationships between AAAs and Health Care Providers.

<u>AAAs and Program Service Areas</u>

AAAs in Maryland work collaboratively with the Department to provide services to older adults at the local level. AAAs may be a unit of local government or a private, nonprofit corporation. Utilizing a mix of federal, state, and local funds, AAA-coordinated services include congregate

and home-delivered meals, transportation assistance, in-home care, caregiver support, activities at senior centers, health and wellness programs, legal assistance, and more, all with the goal of maintaining independence and a high quality of life for older adults.

Program Structure and Organization

The Program relies on the guidance of the Virginia I. Jones Alzheimer's Disease and Related Dementias Council and direction provided by the State Plan on Aging. The Department's Cognitive and Behavioral Health Specialist sits on the council and regularly reports on the Department's ADRD efforts and Program progress. The Department has purposefully initiated the development of the Program plan as a co-design process that involves close collaboration with Maryland's AAAs and their MAP teams to design and implement the Program plan. In preparation for the 2025 fiscal year, the Department convened an ad hoc committee of dementia clinical practitioners, researchers, and community provider experts to offer insight into best practices in a dementia navigation program in Maryland and to identify available data sources for outcome and dashboard reporting. The Department also convened a AAA Dementia Work Plan Workgroup consisting of a representative sample of Maryland's 19 AAAs. Considerations made in creating this representative workgroup included a AAA's size, regional demographics, physical location, and organizational structure. The workgroup provides feedback and direction on Program development and acts as a pilot group to test programmatic developments prior to distributing changes throughout the larger AAA network. The group meets bi-weekly, and AAA members report the workgroup's progress to the entire AAA network during their larger meetings of the Maryland Association of Area Agencies of Aging. The following AAAs and organizations participate in the workgroup:

- Alzheimer's Association (Maryland)
- Baltimore City
- Baltimore County
- Carol County
- Cecil County
- Frederick County
- Garrett County
- Living Well Center of Excellence/MAC- Upper Shore Aging
- Prince George's County
- St. Mary's County

The Department notes the following significant work to date under the Program's five goals:

Goal 1: Provide Training to the Dementia Care Network on Long-Term Care and Dementia Care Navigation Best Practices

Central to the development of the Program is providing each AAAs/MAP staff the training and supports necessary to be able to capably provide dementia navigation, which requires training and educational opportunities on a variety of topics related to ADRD, including, but not limited to the ability to recognize signs and symptoms of cognitive decline, effective communication with persons experiencing cognitive decline and their caregivers, delivery of cognitive screening

and referral to a medical professional; family caregiving and respite opportunities; complex conversations about safety and independence; and information on health care and finances. These training and educational opportunities are underway and will continue significantly throughout the coming years.

Goal 2: Provide Cognitive Screening Opportunities for Individuals Concerned with Memory and Thinking

A crucial component of the Program is ensuring cognitive health screening through an effective and validated tool. The Ascertain Dementia 8 (AD:8) dementia screening tool was developed by Washington University in St. Louis in 2005 and was specifically selected because it is a validated tool that is appropriate to be self-administered by non-clinical professionals. The tool is brief (taking less than 3 minutes to complete), is easy to administer and is sensitive to early cognitive changes associated with many common dementing illnesses, including Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. The AD:8 was designed to help individuals who are concerned about their thinking or memory by distinguishing between age-associated memory loss and mild cognitive impairment.

The AD:8 was embedded as an online tool for MAP program staff at the AAAs in 2021 and has been adapted for effective data collection on whether and how MAP staff are utilizing it for screening activities. The updated version of the AD:8 Dementia Screening Tool was added to the Department's central MAP webpage, improving the utility of the tool for the Department, AAA staff, and the general public. Marylanders can access and complete the AD:8 dementia screening at their convenience online, and can be self-administered, completed by a caregiver, or from assistance from MAP staff. In addition, when used as an informant-based questionnaire, it is less prone to bias from cultural norms and education level than direct assessments.[1] To date, the Department has scheduled multiple AD:8 training sessions for MAP staff, with the goal of all AAA/MAP staff working with persons living with dementia and their caregivers to be trained by January 2025.

Goal 3: Collect Dementia Navigation Interaction Data to Ensure Statewide Program Integrity

As discussed in the Program Overview section, the Department is developing the capacity within the AAAs to provide legislatively mandated Program data while attempting to reduce administrative burden on AAAs by identifying existing data sources to provide the information requested. This includes investigating, and where possible, extracting dementia navigation data from current AAA reporting platforms such as the federally required Older Americans Act Performance System, National Family Caregiver Survey, and MAP quarterly reporting, and adjusting requests for additional needed Program information.

[1] Hendry K, Green C, McShane R, Noel-Storr AH, Stott DJ, Anwer S, Sutton AJ, Burton JK, Quinn TJ. AD-8 for detection of dementia across a variety of healthcare settings. Cochrane Database Syst Rev. 2019 Mar 4;3(3):CD011121. doi: 10.1002/14651858.CD011121.pub2. PMID: 30828783; PMCID: PMC6398085.

The Department has adapted the AD:8 to auto-generate screening results and recommended best practices based on an individual's responses. Also provided upon completion of the dementia screening are links to information on finding a doctor, what to bring to an appointment, and what to expect at an appointment. Data collected from the AD:8 includes the county where an individual lives, the number of results that indicate the potential for impairment in thinking and memory, the number of results that do not indicate potential impairment in thinking or memory, who completed the screening (individual, caregiver, MAP staff, practitioner), and the number of individuals recommended for follow-up professional assessment.

Goal 4: Provide Programs to Engage Individuals Experiencing Symptoms of Dementia that Interfere with ADLs

The Department's guidance to AAAs as the Program begins has been to enhance or adapt existing programming, such as MAP, National Family Caregiver Support Program, health promotion, state-funded Long-Term Services and Supports, and programs that fulfill the intent of the Program's founding legislation to provide new or existing services for persons with symptoms of dementia that interfere with ADLs and their caregivers, including:

- Participating in outreach activities
    - AAAs must conduct or participate in at least one (1) outreach event to contact persons living with dementia and their caregivers quarterly.
- Providing programs that engage individuals in regular exercise, and social activities
    - AAAs must directly or in partnership with community partners deliver one (1) regular (at least monthly) opportunity promoting dementia related strength-based exercises or one (1) regular (at least monthly) social activity to promote activities of daily living.

As previously stated, the Department anticipates it will provide the outcomes of these activities in the next annual report.

Goal 5: Support Caregivers of Individuals Experiencing Symptoms of Dementia that Interfere with ADLs

While the AD:8 is sensitive in detecting early cognitive/somatic changes associated with many common dementing illnesses, it is insufficient at determining the social determinants of health or non-physical factors that lead individuals and caregivers to increased stress and poorer health outcomes. Social determinants of health may include factors such as safe housing, adequate transportation, poor job or educational opportunities, little or no access to nutritious foods, severe economic stressors, and persistent exposure to racism and violence. To help identify these critical needs, the Program intends to adapt the Johns Hopkins Memory Care Family Checklist to better understand the stressors caregivers may be experiencing. Based on the Mind at Home program, the checklist assesses multiple domains of concern and unmet needs for dementia caregivers. Some of these domains include home and personal safety, general medical care concerns, meaningful daily activities, legal issues/advanced care planning, and needed caregiver

education. The Program plan intends to provide the same automation to the Johns Hopkins Memory Care Family Checklist as it did with the AD:8 screening tool, namely, providing a summary of results, recommended best practices, and follow-up resources. The Department plans to work with its partners, including those who developed the checklist, to adapt it to meet the needs of MAP and the Program. Part of the checklist development process will include linking domains identified as problematic to available community resources within the 211 Maryland MAP resource database. Identifying these resources will improve the ability of AAAs to provide additional information on community services, caregiver resources, and health care options.

Goal 6: Provide Consulting and Technical Assistance to AAA Staff

The Department's Cognitive and Behavioral Health Specialist has actively engaged with AAA leadership and staff and will continue to provide heavy technical and consulting support as part of co-developing the Program plan. This support includes ongoing staff education on the components of the Program plan as it is developed, training on all implemented screenings, checklists and reporting tools, such as the dementia screening tool and the Johns Hopkins Memory Care Checklist, and others.

Goal 7: Facilitate Establishing Relationships Between AAAs and Health Care Providers

The Department plans to host Dementia Navigation Health Forums to open dialogue and awareness between dementia providers and available community resources. These opportunities look to create or enhance relationships between care providers and local community-based resources. The goal of the Program is that in addition to supplying a dementia screening tool and caregiver checklist, these health forums will engage health care providers willing to accept AAA client referrals while becoming more aware of community resources available among the AAA network. Efforts to broaden relationships between AAAs and Health Care Providers will expand the dementia resource network and improve the dementia care experience in Maryland.

Finally, for more information about MAP services, including appropriate AAA contact information, visit the Maryland Department of Aging Caregiver and Dementia Support page.