Testimony in Support of HB 731: "Department of Aging – Dementia Care Coordinator and Dementia Care Navigation Programs."

Maryland House Health and Government Operations Committee February 17, 2022

FAVORABLE with Amendments

TO: Chair Pendergrass, Vice Chair Pena-Melnyk, and members of the Health and Government Operations Committee

FROM: Kate Gordon, MSW

I am delighted to testify in support of House Bill 731, **Dementia Care Coordinator and Dementia Care Navigation Programs**. The bill establishes and funds a position of Dementia Care Coordinator in the Maryland Department of Aging (DOA) to oversee dementia care navigation programs and requiring each area agency on aging to employ a dementia care navigator.

I am a health policy analyst, specializing in dementia policy. For the past 12 years, I have provided dementia policy consultation services to the federal Administration for Community Living/Administration on Aging through a contract with Research Triangle International, where I have provided technical assistance to the Dementia Care Specialist (DCS) program in the State of Wisconsin, upon which this legislation is modeled. In this capacity, I have also provided technical assistance to MAC, Inc., the Area Agency on Aging in Salisbury, MD as they have implemented their federally-funded Alzheimer's cooperative agreement with ACL/AoA. I have advised ADRD planning efforts in various capacities locally, nationally, and internationally through my work with a Maryland-based consultation business. I teach dementia policy at UMBC and consult health researchers who are developing evidence-based dementia interventions for persons with dementia and their caregivers, such as the MEMORI Corps program at Johns Hopkins. Of most relevance, I am currently a caregiver for my 95-year-old grandmother with advanced dementia, providing care in my multi-generational home in Silver Spring, MD.

The **Dementia Care Coordinator and Dementia Care Navigation Programs** will replicate a successful state model with over a decade of program evaluation evidence and statewide reach through a network of area agencies on aging. The Wisconsin State Legislature recently funded the model for state-wide implementation, including Tribal Entities. The planning for coordinated, state-wide programs and local support for ADRD and brain health comes at an auspicious time, as national initiatives and funding opportunities for ADRD state and local capacity building is available now at unprecedented levels.

In this context, I offer the following amendments for your consideration:

1. Page 2, Line 10 (Subtitle 13 10-1301 (A)(1): Replace the word **DISSEMINATE** with the term "COORDINATE IMPLEMENTATION"

Dissemination is often equated with sharing best practices via email or webinar with no follow-up on implementation. Changing this terminology is consistent with the WI model, where state agency staff act in a coordinating role to: design, implement, update and track consistent, statewide initial training and continuing education of all DCSs; develop and maintain a community of work in which all DCSs participate at least monthly in a state agency-hosted calls; coordinate data collection of programs, outcomes and persons served, including de-identified information on dementia screening and diagnostic referrals; and maintain quality assurance, including fidelity to evidence-based interventions for persons with dementia and their caregivers.

- 2. Page 3, Line 4-6 (Subtitle 13 10-1302 (B)(1): Add **Brain Health and Dementia Risk Reduction programs** for caregivers and persons at high risk of dementia to read:
 - (1) PROVIDING COGNITIVE SCREENING, PROGRAMS THAT ADDRESS BRAIN HEALTH AND DEMENTIA RISK REDUCTION FOR PERSONS AT HIGH RISK OF DEMENTIA AND CAREGIVERS, AND PROGRAMS THAT ENGAGE INDIVIDUALS WITH DEMENTIA IN REGULAR EXERCISE AND SOCIAL ACTIVITIES;

This is consistent with the activities being implemented by DCSs in Wisconsin. It reflects the priorities in the new MD State Alzheimer Plan and the newly added sixth priority of the US National Plan to address ADRD. It is also consistent with recommendations and related funding from the CDC, who views the course of dementias as a continuum across the life course that begins with healthy cognitive functioning. The CDC recently published data that subjective cognitive decline (SCD), the self-reported experience of worsening or more frequent confusion or memory loss over the past year, could affect caregivers' risk for adverse health outcomes and affect the quality of care they provide. CDC's analysis noted that, among adults aged ≥45 years, SCD was reported by 12.6% of caregivers. The CDC recommends activities to address brain health with the aging population and understanding the cognitive health and needs of caregivers to better support them and their care recipients. In addition, ACL supports addressing educating older adults and adults with disabilities about brain health.

- 3. Page 3, Line 4-6 (Subtitle 13 10-1302 (B)(2): Add evidence-based or evidence-informed interventions programs for caregivers and persons with dementia to read:
 - (2) PROVIDING SUPPORT FOR **PERSONS WITH DEMENTIA AND** CAREGIVERS OF INDIVIDUALS WITH DEMENTIA, INCLUDING PROVIDING **ACCESS TO EVIDENCE-BASED OR EVIDENCE-INFORMED**INTERVENTIONS, ASSISTANCE WITH CARE PLANNING AND REFERRAL TO SUPPORT GROUPS:

Persons in the early stage of dementia, or who have mild cognitive impairment, can participate in their own care planning. Wisconsin's DCS program provides support to persons with dementia and their caregivers at all stages of dementia and does not require the presence of a caregiver to provide care planning services. Adding their voice to the services defined here is consistent with personcentered service provision. In addition, adding specific language around the use of evidence-based and evidence-informed interventions is consistent with the MD State Aging Plan, MD Area Aging Plan requirements and priorities of the CDC, ACL and the Older Americans Act and the US National Plan. WI's AAA-based grant program requires the implementation of at least two evidence-based or evidence-informed programs from a state-approved list of interventions.

I respectfully urge the committee to favorably consider this bill with amendments as a commitment to the long term cognitive and behavioral health and wellbeing of Maryland's citizens, including families like my own. It is a wise investment in Maryland's brain health and dementia infrastructure to ensure that appropriate care, services, and resources are available to all Marylanders in their local communities.

Thank you, Kate Gordon, MSW Silver Spring, MD