

Testimony in Support of HB 166 “Alzheimer's Disease and Dementia - Council and Coordination of Services (Dementia Services Act of 2022).”

Maryland House Health and Government Operations Committee
February 3, 2022

FAVORABLE

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

FROM: Halima Amjad, MD, MPH

My name is Halima Amjad, and I am a resident of Laurel in Howard County, Maryland. I am submitting this testimony in support of HB 166, the Dementia Services Act of 2022, which at its core creates a Director of Dementia Services Coordination at the Maryland Department of Health.

I am a physician member of the Virginia I. Jones Alzheimer’s Disease and Related Disorders Council. More importantly, I am the daughter of a father living with early onset dementia. My father was forced to stop working early while my mom was thrust into a full-time, unpaid job as his caregiver. As a family, we have navigated how to support my father and mother as he went from a dentist to a person needing help with simple activities, like getting dressed and eating. He slowly went from being the life of the party to being unable to speak or even laugh. Coordinating his care and what services and supports are affordable and available as he has declined is also a full time job.

I also have the privilege of caring for Marylanders with dementia and their families as a geriatrician and Assistant Professor of Medicine at Johns Hopkins. I work alongside dedicated colleagues at the Memory and Alzheimer’s Treatment Center. In this role, I watch as families struggle to understand the changes their loved one is experiencing and to patch together the support they need. Many families are not as fortunate as mine in having a family caregiver who is available full-time or in being able to afford the care that living well with dementia requires. We try our best to support our patients and families but run into challenges navigating a fragmented, expensive health care and support system. Families are often shocked that Medicare does not cover the supervision or assistance that people living with dementia need. At the same time, many families do not qualify for Medicaid. If they do qualify for Medicaid or other sources of support, accessing quality care remains difficult and often the services received still are not enough. I have listened as daughters and grandsons cry on the phone, struggling to ensure that dad gets cleaned up daily or to manage the severe anxiety and confusion their grandmother is expressing. Families are often left to figure out this devastating illness on their own. People living with dementia, their families, and clinicians in Maryland, your constituents, need your support.

Maryland is in a unique position to become an example of what coordinated, high quality dementia care and support should be. We have world-class universities and colleges at the forefront of medicine, nursing, public health, allied health professions, and social services. We have strong private and non-profit organizations active in advocating for and engaging with people and families living with dementia. We have counties implementing dementia-friendly communities. We have caregivers active on many fronts, serving on the Virginia I. Jones Alzheimer’s Disease and Related Disorders Council, running support groups, and even starting organizations such as YES! Young Onset Dementia Support and Education. Within the healthcare system, we have unique and innovative opportunities to advance dementia detection and support through the Maryland Total Cost of Care payment model. Within this model, the

Maryland Primary Care Program is actively providing advanced, holistic primary care for older Marylanders, including care management and behavioral health support.

With so many organizations, active programs, and opportunities, it is essential that we have a full-time Director of Dementia Services Coordination at the Maryland Department of Health. The Director will be instrumental in ensuring the work and efforts taking place across our State, including across State agencies, are coordinated and fully addressing the needs of struggling Maryland families. This individual will ensure we take advantage of the opportunities and innovation around us. As a Virginia I. Jones Alzheimer's Disease and Related Disorders Council member, I believe that establishing a Director of Dementia Services Coordination is the key to ensuring our updated Alzheimer's Disease and Related Dementias State Plan is translated to action and not just words on a page. This position is key to ensuring all Maryland families facing dementia, regardless of who they are and where they live, can readily access the care, education, and support they need.

The Dementia Services Act of 2022 would, at its core, establish and mandate funding for a full-time Director of Dementia Services Coordination at the Maryland Department of Health. The position will be responsible for the coordination of services affecting Marylanders with dementia and their caregivers and families, including: implementing the Maryland Alzheimer's state plan managing the Virginia I. Jones Alzheimer's Disease and Related Disorders Council; identifying and supporting the development of dementia-specific training; and applying for grants to expand and improve services for Marylanders with Alzheimer's and their caregivers.

There is precedent for this position; if enacted, Maryland's point person on dementia would join similar roles in 16 other states, including Virginia and the District of Columbia. This role would work, across government, to aid the 110,000 Marylanders with dementia and their loved ones. Our state spends over \$1.2 billion in Medicaid funding on this chronic disease; it is essential that we begin to build our infrastructure to help Marylanders in need.

The potential for this legislation is significant, in how it can help Marylanders. We can look just to the District of Columbia, where—not long into her role—the person in this role is doing significant work including: redrafting their State Plan, convening a multi-stakeholder committee to build awareness, launching a healthy brain website, and launching a public awareness campaign about their work. Maryland can do all of this too, if we devote the resources and build the infrastructure to address dementia.

I respectfully urge this committee to return a favorable report on HB 166.

Thank you,

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