



August 27, 2021

To Whom it May Concern:

The Alzheimer's Association is grateful for the opportunity to provide comments on the draft State Plan Goals of Maryland's Virginia I. Jones Alzheimer's Disease and Related Disorders Council (VJADRDC Council). Thank you to the Council for this substantive vision to improve the lives of Marylanders with Alzheimer's disease and related dementia, along with their caregivers.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. In Maryland, our organization serves the 110,000 individuals with Alzheimer's and dementia, along with families and loved ones. In addition, we provide support available to the 238,000 Maryland caregivers. This is done through the work of two chapters; the National-Capital Area Chapter (serving Calvert, Charles, Montgomery, Prince George's, and St. Mary's County) and the Greater Maryland Chapter (serving all other counties).

OVERVIEW

Maryland [Chapter 410 of 2019](#) re-organized and re-authorized the VJADRDC Council through September 30, 2024. This law, along with appointing a new multi-stakeholder group of Council members, mandated that the new State Plan address three specific areas:

- examine the needs of individuals with Alzheimer's disease and related disorders and their caregivers;
- identify methods through which the State of Maryland can effectively and efficiently assist in meeting those needs; and
- develop and promote strategies to encourage brain health and reduce cognitive decline;

The Association's comments on the draft Plan Goals—and the recommendations within them—are submitted through the lens of these three areas. Concrete recommended actions, with mentions of the state of Maryland agencies which can “effectively and efficiently assist” in meeting those actions, are essential for each step of the State Plan development.

Lastly, the Plan Goals would benefit from more specific mentions of COVID-19. The pandemic has had an extraordinary impact on Marylanders with Alzheimer's, on issues ranging from social isolation to long-term care and so much more. Yet the pandemic is referenced sparingly throughout these goals.

GOAL 1: EXPAND EFFORTS TO SUPPORT PUBLIC AWARENESS, PREVENTION, AND EARLY DETECTION OF ADRD

Strategy 1A is extraordinarily important; public awareness is essential because of the lack of knowledge about dementia, and the stigma associated with this disease, which hinders the lives of Marylanders with this disease in countless ways. The Council has rightly inserted Action 1A1, to get a dementia-specific staff person funded within the Maryland Department of Health (MDH). Action 1A4, around a public awareness campaign, is also essential; state agencies can better coordinate their actions on Alzheimer's disease and related dementia.

Throughout Goal 1, these Actions [1A2, 1A3, 1B2-1B4, 1C2] would benefit from naming the specific state agencies (and communication channels) that can effectively and efficiently assist in leading these actions. Those mentions can be more consistently coupled with requests for funding, emphasizing the resources necessary for implementation of the Council's vision.

Goal 1 - Draft Plan Actions/Recommended Revisions:

- In Action 1A4—akin to the earlier recommendation which calls for a Director level position specifically in MDH—specify which state agency or private partner should be responsible for leading this multi-pronged campaign.

This action can also be revised to specify the importance of targeting the campaign to effectively reach rural populations (who may not have equal access to care and information) and minority populations (who are disproportionately impacted by Alzheimer's and related dementia).

This recommendation might also call on the Governor and legislative leaders to appropriate funding for this campaign.

- For example, in Minnesota, [HF 33 of the 1st Special Session \(Chapter 7 of 2021\)](#), the Department of Human Services budget, appropriated \$1.5 million across the biennium for grants to increase public awareness and education around Alzheimer's, with an emphasis around cognitive testing, early detection and diagnosis, and caregiving.
- And in Wisconsin, [A.B. 632 \(Act 186 of 2017\)](#) appropriates \$500,000 for grants to increase awareness of Alzheimer's and other dementias in rural and underserved urban areas.
- Strategy 1A can address the Behavioral Risk Factor Surveillance System (BRFSS), which does not need to be limited to Goal 5.
 - The Council can stress the importance of public awareness around the BRFSS. There is an enormous amount of work done to conduct this survey; MDH can coordinate with its communications team and commit to doing a regular webinar or fact sheet, which it can publicize internally and through its partners in government and the private/non-profit sector.
- In Action 1B2, please specify who the "Dear Colleague" letter should be coming from. Is this something that should emanate from the Maryland Medical Society? The Maryland Department of Health? Similarly, in Actions 1B3 and 1B4, is the Maryland Primary Care Program responsible? Or another entity?

Additionally, for Strategy 1B more broadly, this recommendation may call on the Governor and legislative leaders to appropriate funding for this work.

- For example, in Washington State, [HB 1109 \(Chapter 415 of 2019\)](#) appropriates \$1 million to support physician education, reducing public stigma around dementia, and educating legal professionals supporting people with dementia.
- In Action 1C2, the Council can specify and provide examples of who manages the school health programs.

Additionally, for Action 1C3, we ask the Council to mention the importance of Maryland securing funding through the federal Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act. Over half of the states in our country, but not Maryland, have received significant CDC funding through this initiative.

GOAL 2: ENHANCE QUALITY, ACCESS, AND COORDINATION OF ADRD CARE

A range of health care professionals, adult protective services staff, first responders, direct care workers and social workers play an important role in dementia care. These providers include primary care physicians, geriatric physicians, neurologists, and direct care professionals. However, the United States is experiencing a well-documented health care workforce shortage that could jeopardize care for individuals living with Alzheimer's and other dementias.

This goal's actions address a range of important issues. Financial incentives (2A1) and standardized dementia training (2A3) are foundations for improving ADRD care. Strategy 2A, however, is missing specifics; for example, Maryland would benefit from training adult protective services (APS) and law enforcement staff on Alzheimer's and dementia.

Lastly, as noted, we hope that the Council will be more specific about which state of Maryland agency can effectively and efficiently assist in meeting the 23 different actions outlined [there are none mentioned]. The effectiveness of these actions is muted, if there are no references to the entity who could accomplish them.

Goal 2 - Draft Plan Actions/Recommended Revisions:

- Action 2A3 can be made more specific.
 - We encourage the Council to replace “healthcare professionals” with a reference to the need for training among all direct service, administrative, supervisory, and other staff who are involved in the delivery of care to those with Alzheimer's and other dementias in licensed long-term care facilities, the home, and adult day settings.
 - This action can also address the need for dementia training among APS workers and law enforcement personnel
 - These front-line workers must be able to recognize cognitive impairment, effective intervention in cases involving the abuse and exploitation of individuals who are cognitively impaired, and be able to secure the safety of exploited individuals with dementia
- Strategy 2B can more fully address the expansion of access to Maryland's home and community-based options waiver (HCBOW). Maryland, which maintains a 7,500-person cap on waiver, has well over 15,000 individuals waiting for services; the longest such waiting list in the country. Legislation, including [Senate bill 700 of 2019](#), have sought to address this issue and expand access.

Additionally, there is an opportunity to speak to Medicaid in Action 2B around expanding access (and not solely in Action 2D). Specifically, we encourage the VJADR Council to consider a recommendation which reviews Medicaid financial and functional eligibility requirements for home and community-based services at a level that ensures the ability of individuals with Alzheimer's and other dementias to live in the most appropriate setting.

Lastly, we urge revisions to Strategy 2B to address COVID-19 and long-term care quality. The Association has issued a set of [policy recommendations](#) in this area; it is unfortunate that—despite the disproportionate impact of the pandemic on nursing homes and assisted living facilities (roughly 40 percent of Maryland's reported COVID-19 fatalities have come in these settings)—there is no mention of improving their care, as a result of the pandemic.

- Strategy 2C's actions can be condensed and revised.
 - Specifically, Actions 2C2 and 2C5 appear similar; what is the difference between a stakeholder group and an advocacy group?
 - Additionally, we encourage consideration of a new action to stress protecting persons with dementia who display common behavioral symptoms from improper displacement in residential settings.

While Maryland maintains a patient's bill of rights to prevent improper "patient dumping"; this issue remains, and amidst COVID-19, MDH's [Directives and Orders for Nursing Homes](#) specifically noted "If the residents must temporarily go to other facilities, every effort must be made by the receiving and original nursing homes to transfer the residents back to their original nursing homes as soon as possible."

- Throughout the 23 goal actions, whenever possible, insert a specific government entity or private/nonprofit organization who could be responsible for implementation. This series of suggested actions, without clarity about who would actually implement them, mutes the effectiveness of this goal.

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS

This section on caregiving is an important component to the State Plan Goals. In Maryland, according to the state's 2019 BRFSS data, more than 1 in 5 unpaid caregivers are providing care to a loved one with Alzheimer's or another dementia. More than half of dementia caregivers have been providing care for at least two years. More than 1 in 3 dementia caregivers provide 20 or more hours of care per week.

Goal 3 - Draft Plan Actions/Recommended Revisions:

- Actions 3A1 and 3A2 rightly note the importance of understanding caregiver needs. Yet these actions would benefit from a responsible entity, and also could note the importance of funding. Additionally, this is an area that the State Commission on Caregiving could get engaged on.
- Action 3B4 rightly notes the importance of integrating family caregivers in all aspects of care planning. Yet this action lacks an explanation of how this could be accomplished. While this detail may be outlined in the final State Plan, the Plan Goals would benefit from an additional explanatory sentence.
- Strategy 3C outlines 12 substantive actions to promote and expand family caregiver supports. Yet we urge a mention of funding or the creation of a new state role to accomplish these actions. For example:
 - In 2020, New York dedicated over \$20 million to provide direct services to support people with dementia and dementia family caregivers.
 - In 2021, North Dakota enacted [HB 1012](#), which appropriates \$1.3 million to the state's Dementia Care Services Program;
 - And in Wisconsin, [AB 68 \(Act 58 of 2021\)](#) appropriates over \$7.5 million for the biennium to directly support people with dementia and their

caregivers, including \$7.12 million for the Dementia Care Specialists program (a \$3 million increase), and \$5.6 million for the Alzheimer's Family and Caregiver Support Program (a \$500,000 increase).

- Strategy 3E calls for “addressing the COVID-19 pandemic and similar events.” This is an important component of addressing caregiving in Maryland, yet goal 3 is unfortunately the lone area where the pandemic is mentioned.
 - The Council can more fully consider the pandemic through the entirety of these plan goals.

GOAL 4: ADVANCE ADRD RESEARCH AND ENCOURAGE EVIDENCE BASED PRACTICES

The escalating Alzheimer's epidemic has profound implications for government budgets: one in every 5 dollars of Medicare spending is spent on people with Alzheimer's and other dementias. In Maryland, according to Association data, the state spends over \$1.2 billion in Medicaid costs for ADRD treatment; that figure is expected to rise by 24.7 percent in the next four years.

Like other aspects of this plan, specifics are needed, even at this goal stage. We applaud Action 4B1 for identifying key stakeholders; Strategy 4B overall is incredibly important, yet as discussions are convened, additional and ongoing resources are essential for implementation.

Goal 4 - Draft Plan Actions/Recommended Revisions:

- Overall, this goal's actions would benefit from a specific mention of the role for State universities, hospitals and research centers. These partners are often making new discoveries enhancing our understanding of Alzheimer's and related dementia, and could be more specifically noted throughout this goal.
 - For example, Arizona enacted legislation ([HB 2747 \(Chapter 263 of 2019\)](#)), which includes a \$2 million appropriation for Alzheimer's research to be distributed to universities, research centers, and hospitals.
- Strategy 4B, as noted, is essential. One action to consider including in this plan action is a recommendation for] legislation which authorizes a voluntary income tax checkoff to fund Alzheimer's research.
 - Illinois [SB 262 \(Public Act 101-0007 of 2019\)](#) appropriates \$250,000 for Alzheimer's research from the state's voluntary tax check off.
 - California [A.B.2400 \(Chapter 299\)](#) renews the state's voluntary Alzheimer's research tax check off through 2025. In 2018, \$3.1 million in funds received from the tax check off was allocated for dementia research.

GOAL 5: ENHANCE DATA CAPABILITIES RELATED TO DEMENTIA IMPACT AND EFFECTS OF INTERVENTIONS

Through public health campaigns and data collection—including broader use of the Behavioral Risk Factor Surveillance System (BRFSS)--state governments can further address Alzheimer's in their states. Data is an essential foundation to educate health care providers and the public about the importance of early detection and diagnosis, and improve access to and awareness of resources such as the Medicare Annual Wellness visit.

The Council has outlined an appropriate and necessary list of recommended actions. In particular, we welcome Action 5A5 for a state-funded position to lead dementia-related data analysis, further dementia training efforts and seek relevant grant opportunities.

Goal 5 - Draft Plan Actions/Recommended Revisions:

- Goal 5 overall would benefit from a more specific mention of funding.
 - For example, Texas enacted [HB 1 of 2019](#), which appropriates \$1 million over FY 2020 and FY 2021 to implement a statewide public awareness campaign to educate Texans on identifying the signs of Alzheimer's and encouraging early detection and diagnosis and to improve dementia-related data collection.
- Action 5A1 appropriately addresses the BRFSS. Yet, as noted in the conversation around public awareness, there is a prime opportunity to do more with the BRFSS. While MDH, once every few years, has posted a fact sheet or done a webinar; the BRFSS can be better utilized—in coordination with private and non-profit partners—to communicate the information gathered.

CONCLUSION

The Alzheimer's Association is here to support, partner, and work collaboratively with the Maryland Department of Health, the VJADR Council and our other state partners.

Thank you for the opportunity to provide comments on this component of the VJADR Council's work. Our organization looks forward to our continued partnership and participation with and serving on the Council. If you have any questions, please do not hesitate to contact me at ercolchamiro@alz.org.

Sincerely,



Eric Colchamiro
Alzheimer's Association Director of Government Affairs
Maryland and the District of Columbia