



**Alzheimer's Disease and Related Disorders Commission
Legislative Committee**

Tuesday, May 14, 2024 at 1:00 pm

Electronic Meeting

Join via: <https://dsa-virginia.zoomgov.com/j/1600280520>

Or call +1 669 254 5252 Meeting ID: 160 028 0520

Meeting Minutes

Members Present:

Bea González, *Chair*
Karen Darner
Karen Garner
Josh Myers
Margie Shaver

Members Absent:

Rick Jackson
Lana Sargent, *Ex officio*

Guests:

None

Staff:

George Worthington, DARS

Meeting Summary:

| Agenda Items: | Speaker: |
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| Welcome Bea González called the meeting to order at 1:05pm. Ms. González noted that members will discuss potential legislative recommendations for the 2025 session. Members and staff introduced themselves. | Bea González |
| Adoption of Agenda <i>Action: Adopt Agenda</i> Josh Myers made a motion to adopt the agenda as presented. Margie Shaver seconded the motion, and it was unanimously approved. | Bea González |
| Adoption of Prior Meeting Minutes (April 18, 2023) Members reviewed the minutes from the previous meeting. No changes were noted and Ms. González adopted the minutes as presented. | Bea González |
| Public Comment No public comment was received. | Bea González |
| Discussion of Legislative Platform Items George Worthington provided an overview of the outcomes of the previous year's recommendations. | Bea González |

Legislative Committee Recommendations for 2024 Session

1. Expand Dementia Care Management to Underserved Areas of Virginia

2024 outcome: no action

Virginia's Dementia State Plan provides a blueprint for a fully dementia capable state. A key component of that is the availability of quality, person-centered care management services to families living with dementia (Goal 4). In 2019, the General Assembly approved funding to provide 100 families a year with dementia care management at the University of Virginia's Memory Disorders Clinic. Due to the pandemic and other factors, funding is currently set to support 88 families per year with dementia care management at the University of Virginia with participation by the Alzheimer's Disease and Related Disorders Association. Using an evidence-based program, dementia care management is expected to help reduce hospitalizations and emergency room visits, and reduce depression and anxiety while improving quality of life. Informal caregivers receiving care management are better able to cope with challenging dementia-related behaviors, so potentially reducing the risk of involuntary psychiatric admissions and helping reduce the burden on private and public psychiatric hospitals. Care coordination can increase the length of time that people living with dementia are able to remain safely in their homes, and delay the need for facility-based long-term care.

Coordinated care programs using trained Dementia Care Managers (DCMs) are needed for successful community-based dementia care. Streamlining dementia care using DCMs would realize significant cost savings, decrease health care utilization, and improve health outcomes. Most areas of the state have little or no access to existing dementia care coordination programs at UVA and Riverside's Center for Excellence in Aging and Lifelong Health. The Commission recommends using \$1,000,000 in state funds to deliver a large-scale pilot of dementia care management in six additional areas of the state (suggested areas include Eastern Shore, Southwest Virginia, Shenandoah Valley, Fredericksburg region, Tidewater and Southside. In addition to providing care coordination for a total of at least 300 families, the dementia care managers would serve as subject matter experts to provide information and referral services, dementia-capability training to Area Agency on Aging (AAA) and partner agency staff, and offer community cognitive screening.

This is a legislative request with budgetary implications. This proposal aligns with recommendations under Goal 4B of the Dementia State Plan.

2. Dementia Services Budget Increase

2024 outcome: no action

A key recommendation to come out of the Aging Services workgroup that convened in 2022 and 2023 was the need for more resources (staff and funding) to serve the growing numbers of people living with dementia in the Commonwealth. Since 2013, when funding to establish the Dementia Services Coordinator role was initiated, the number of people living with Alzheimer's disease (60-80% of all dementias) in Virginia has risen by 25% from an estimated 120,000 people to more than 150,000 people and is expected to rise further to 190,000 in 2025. Data from the Virginia Department of Health indicates that roughly 300,000 Virginians over the age of 45 are experiencing some level of cognitive decline that is worsening. Despite the sharp increase in people living with dementia, the funding for dementia services has remained unchanged at \$100,000 per annum since 2013.

The Dementia Services Coordinator (DSC) role has been successful in advancing supports and services for Virginians using federal and other grant funds. The DSC has helped bring more than \$2m in federal funding to Virginia to support new initiatives, some of which are sustained with state and local funding. Sustaining these programs is difficult without additional state funding. A case in point is the evidence-based Dealing with Dementia program, which the DSC helped establish in most areas of the state using a \$25,000 Geriatric Training and Education grant from the Virginia Center on Aging. Despite strong support from local agencies, providers and program participants, the program has proven difficult to sustain due to competing demands for local agencies' limited funds. Providing dementia services with additional funding would allow the DSC to support and sustain evidence-based educational and other programs for people living with dementia and their caregivers, potentially delaying the need for a long-term care placement. The ADRDC recommends that \$100,000 be appropriated for the support of new and existing dementia programs, and to support dementia-related resource development and dissemination.

This is a budgetary request. This proposal aligns with recommendations under Goal 1B of the Dementia State Plan.

3. Support Dementia Capable Training for First Responders

2024 outcome: HB 933 (LeVere Bolling) enacted. Amends § 9.1-102, adds § 9.1-203.2 and § 32.1-111.5:2. Requires ADRD training for dispatchers, firefighters and emergency medical services personnel.

Bill: <https://lis.virginia.gov/cgi-bin/legp604.exe?241+sum+HB933>

The Commission supports efforts underway in communities in several areas across the Commonwealth to train first responders, including dispatchers, fire, police, emergency medical personnel and others in dementia capability. The Commission also recognizes and applauds the inclusion of other dementias (non-Alzheimer's disease dementia) into the required DCJS curriculum for police recruits in 2023. More needs to be

done to ensure that these professions are dementia capable, having the knowledge and ability to effectively communicate and interact with people living with dementia, and knowing local resources that can be referral points. Often current training efforts are in the context of Dementia Friendly Community initiatives, and they utilize programs such as Dementia Friendly @ Work, Dementia Friends, Approaching Alzheimer's: First Responder Training, and other sector-specific training modules. Sector-specific training can be supplemented with programs like Dementia Friends to provide these vital workers with the tools they need to confidently interact with this particularly vulnerable segment of the population.

The Commission recommends including basic dementia capability as an element of initial training programs for these professions. The Commission also recommends expanding the availability of these trainings to all areas of the Commonwealth, and supports their inclusion as programs that satisfy the respective continuing education requirements of these professions, where applicable.

This is a legislative recommendation that has no budgetary implications. This proposal aligns with recommendations under Goal 3B of the Dementia State Plan.

Changes to Code resulting from HB 933

10. Establish compulsory minimum training standards for all **dispatchers** employed by or in any local or state government agency, whose duties include the dispatching of law-enforcement personnel. Such training standards shall apply only to dispatchers hired on or after July 1, 1988. *Such training shall include training in the identification of, communication with, and facilitation of the safe return of individuals diagnosed with Alzheimer's disease and dementia, which shall include (i) techniques for respectful and effective communication with individuals with Alzheimer's disease and dementia and their caregivers; (ii) techniques for addressing the behavioral symptoms of Alzheimer's disease and dementia, including alternatives to physical restraint; (iii) protocols for identifying and reporting incidents of abuse, neglect, and exploitation of individuals with Alzheimer's disease and dementia to adult protective services; (iv) protocols for contacting caregivers when an individual with Alzheimer's disease or dementia is found wandering or during an emergency or crisis situation; (v) a reference list of local resources available for individuals with Alzheimer's disease and dementia; and (vi) a reference list of 2 of 6 local and national organizations that assist law-enforcement personnel with locating missing and wandering individuals with Alzheimer's disease and dementia and returning them to their caregivers;*

§ 9.1-203.2. **Firefighter** Alzheimer's disease and dementia training. A. Each fire department as defined in § 27-6.01 shall develop curricula for Alzheimer's disease and dementia training for its personnel, which shall include training regarding the following: the identification of, communication with, and facilitation of the safe return of individuals

diagnosed with Alzheimer's disease and dementia, which shall include (i) techniques for respectful and effective communication with individuals with Alzheimer's disease and dementia and their caregivers; (ii) techniques for addressing the behavioral symptoms of Alzheimer's disease and dementia, including alternatives to physical restraint; (iii) protocols for identifying and reporting incidents of abuse, neglect, and exploitation of individuals with Alzheimer's disease and dementia to adult protective services; (iv) protocols for contacting caregivers when an individual with Alzheimer's disease or dementia is found wandering or during an emergency or crisis situation; (v) a reference list of local resources available for individuals with Alzheimer's disease and dementia; and (vi) a reference list of local and national organizations that assist law-enforcement personnel with locating missing and wandering individuals with Alzheimer's disease and dementia and returning them to their caregivers.

B. Any fire department may develop the mental health awareness training curricula in conjunction with other fire departments or firefighter stakeholder groups or may use any training program, developed by any entity that satisfies the criteria set forth in subsection A.

C. Firefighters who receive mental health awareness training in accordance with this section shall receive appropriate continuing education credits from the Department of Fire Programs and the Virginia Fire Services Board.

§ 32.1-111.5:2. Emergency medical services personnel Alzheimer's disease and dementia training. *A. Each emergency medical services agency shall develop curricula for Alzheimer's disease and dementia training for its personnel, which shall include training regarding the following: the identification of, communication with, and facilitation of the safe return of individuals diagnosed with Alzheimer's disease and dementia, which shall include (i) techniques for respectful and effective communication with individuals with Alzheimer's disease and dementia and their caregivers; (ii) techniques for addressing the behavioral symptoms of Alzheimer's disease and dementia, including alternatives to physical restraint; (iii) protocols for identifying and reporting incidents of abuse, neglect, and exploitation of individuals with Alzheimer's disease and dementia to adult protective services; (iv) protocols for contacting caregivers when an individual with Alzheimer's disease or dementia is found wandering or during an emergency or crisis situation; (v) a reference list of local resources available for individuals with Alzheimer's disease and dementia; and (vi) a reference list of local and national organizations that assist law-enforcement personnel with locating missing and wandering individuals with Alzheimer's disease and dementia and returning them to their caregivers.*

B. Any emergency medical services agency may develop the Alzheimer's disease and dementia training curricula in conjunction with other emergency medical services agencies or emergency medical services

personnel stakeholder groups or may use any training program, developed by any entity that satisfies the criteria set forth in subsection A.

C. Emergency medical services personnel who receive Alzheimer's disease and dementia training in accordance with this section shall receive appropriate continuing education credits from the Office of Emergency Medical Services.

4. A Dementia Capable No Wrong Door

2024 Action: Budget item 319 #1c to provide \$100,000 in each year to DARS for the NWD Dementia Capability project (LeVere Bolling)—sent to Governor

No Wrong Door (NWD) is a person-centered system and statewide network of partners supporting older adults, caregivers, individuals with disabilities, veterans and their families. It uses secure technology to link providers together, collaboratively supporting individuals and families seeking long-term services and supports. This system connects individuals and families living with dementia to services and supports across the Commonwealth, as well as the network of Area Agencies on Aging, local Departments of Social Services and many other partner organizations. The Commission supports a fully dementia capable No Wrong Door system that would improve the identification of people living with dementia, particularly those living alone, to better connect them with supports and services that can help them remain as independent as possible for as long as possible.

An additional outcome would be enhanced data collection that would allow for better identification of areas of need, and that would expand this source of information about the number of people living with dementia in Virginia.

In 2019, the Dementia Services Coordinator convened a working group of Area Agency on Aging staff working in NWD to develop a cognitive screening question and follow-up protocol. This protocol will serve as the basis for the NWD Dementia Capability project.

The Commission recommends \$100,000 be appropriated to support the NWD Dementia Capability project. This would be accomplished through the addition of a cognitive screening question and relevant reports in the technology that underpins the system, the creation and delivery of a training module for NWD staff and users, and financial support for data collection and training time.

This is a budget request. This proposal aligns with recommendations under Goals 2A and 4B of the Dementia State Plan.

Budget language:

H. Out of this appropriation, \$100,000 the first year and \$100,000 the second year from the general fund shall be provided for the No Wrong Door (NWD) Dementia Capability Project to improve the identification of people living with dementia, particularly those living alone, to better

connect them with supports and services that can help them remain as independent as possible for as long as possible. The Project shall add a cognitive screening question and relevant reports in the technology that underpins the system, the creation and delivery of a training module for NWD staff and users, and financial support for data collection and training.

Other Dementia related legislation or budget items 2024:

1. HB 1455 Virginia Memory Project Codification (Carr) enacted

Bill: <https://lis.virginia.gov/cgi-bin/legp604.exe?ses=241&typ=bil&val=hb1455>

Dementia State Plan Objective 2.2 Support the Virginia Memory Project (VMP) as it builds the Pathway to Care ADRD Registry

Strategy: Advocate for legislation to codify Virginia's ADRD registry.

Code of Virginia § 23.1-2311.1 added:

§ 23.1-2311.1. Virginia Center on Aging; Virginia Memory Project.

A. There is established within the Virginia Center on Aging the Virginia Memory Project.

B. The purpose of the Virginia Memory Project shall be to collect and analyze data on Alzheimer's disease, related dementias, and other neurodegenerative disorders in the Commonwealth, provide responsive assistance to individuals with Alzheimer's disease, related dementias, and other neurodegenerative disorders by connecting them with relevant service providers, and assist in the development of public policy and planning relative to Alzheimer's disease, related dementias, and other neurodegenerative disorders. The Virginia Memory Project shall provide and maintain a central database of individuals with Alzheimer's disease, related dementias, or other neurodegenerative disorders.

C. The executive director of the Virginia Center on Aging shall also direct the Virginia Memory Project. The executive director shall establish provisions for: 1. The collection and evaluation of data regarding the prevalence of Alzheimer's disease and related disorders in the Commonwealth, including who shall report the data to the central database; 2. The determination of what information shall be maintained in the central database and the length of time such data shall be available; 3. The process for sharing data for policy planning purposes; 4. The process for disclosing nonidentifying data to support research on Alzheimer's disease and related disorders; 5. The methodology by which families and physicians of persons who are reported to the central database shall be contacted to gather additional data; and 6. The provision of information to families and physicians about public and private resources.

D. The collected data in the Virginia Memory Project shall be confidential, and all persons to whom the data in the Virginia Memory Project is released shall maintain patient confidentiality. No publication of information shall be made that identifies any patient by name.

That the provisions of this act shall become effective on January 1, 2025.

2. SB 176 Substitute: Acts on JLARC Report on State Psychiatric Hospitals Recommendations 1-4 (Favola) enacted

JLARC report: <https://jlarc.virginia.gov/landing-2023-virginias-state-psychiatric-hospitals.asp>

Bill: <https://lis.virginia.gov/cgi-bin/legp604.exe?ses=241&typ=bil&val=sb176>

SB 176 Civil commitments and temporary detention orders; definition of mental illness; neurocognitive disorders and neurodevelopmental disabilities; Secretary of Health and Human Resources to evaluate placements for certain individuals; report. Specifies that for the purpose of civil commitments and temporary detention orders, behaviors and symptoms that manifest from a neurocognitive disorder or neurodevelopmental disability are excluded from the definition of mental illness and are, therefore, not a basis for placing an individual under a temporary detention order or committing an individual involuntarily to an inpatient psychiatric hospital. The bill provides that if a state facility has reason to believe that an individual's behaviors or symptoms are solely a manifestation of a neurocognitive disorder or neurodevelopmental disability, the state facility may require that a licensed psychiatrist or other licensed mental health professional reevaluate the individual's eligibility for a temporary detention order before the individual is admitted and shall promptly authorize the release of an individual held under a temporary detention order if the licensed psychiatrist or other licensed mental health professional determines the individual's behaviors or symptoms are solely a manifestation of a neurocognitive disorder or neurodevelopmental disability. **The foregoing provisions of the bill do not become effective unless reenacted by the 2025 Session of the General Assembly. The bill also directs the Secretary of Health and Human Resources to convene a work group to evaluate, identify, and develop placements for individuals with neurocognitive disorders and neurodevelopmental disabilities, as well as any statutory or funding changes needed to prevent inappropriate placements for such individuals, and to report his findings and recommendations by November 1, 2024.** As introduced, this bill is a recommendation of the Joint Legislative Audit and Review Commission and the Behavioral Health Commission. This bill is identical to [HB 888](#).

3. Budget Item 315 #3h to provide \$700,000 each year to support the VMP registry. (Carr) –defeated in committee

This amendment adds \$700,000 each year from the general fund for the fiscal impact of legislation establishing the Alzheimer's Disease and Related Disorders Registry

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| <p><u>4. Budget Item 315 #1c to provide \$200,000 each year for dementia care coordination at Riverside Martha W Goodson Center (Hayes) –sent to Governor</u></p> <p>J. Out of this appropriation, \$200,000 the first year and \$200,000 the second year from the general shall be provided for an interdisciplinary plan of care and dementia case management for 100 individuals diagnosed with dementia. This service shall be provided through a partnership between the Martha W. Goodson Center of Riverside Health Services and the Peninsula Agency on Aging. The Department for Aging and Rehabilitative Services shall report the status and provide an update on the results of the dementia case management program to the Chairs of the House Appropriations and Senate Finance and Appropriations Committees by November 1 of each year.</p> <p>Mr. Worthington noted that the budget had been passed the previous day, and that the funding for No Wrong Door and the Riverside Dementia care management program had been included in the final budget.</p> | |
| <p>Recommendations to the Commission <i>Action Item:</i> Approve recommendations to the Commission</p> <p>Members discussed the first two items that had no action in 2024 and decided to update them and include them again in the 2025 recommendations.</p> <p>Additionally, members discussed the upcoming changes to the Emergency Custody Order and Temporary Detention Order system, and felt that including a recommendation around expanding the RAFT program that serves Northern Virginia to other areas of the state would not pre-empt work on that new system that includes a workgroup to take place in 2024 that will examine and recommend an alternative to the state psychiatric system for people living with dementia with severe behavioral challenges.</p> <p>Members also discussed a possible recommendation around increasing respite opportunities for caregivers. Mr Worthington will develop language around both of these proposals and share with the members for approval ahead of the Commission meeting on July 11. The full recommendations will be presented to the Commission for approval as the Commission’s policy recommendations for the 2025 session.</p> <p>A vote was deferred pending the development of the proposals, but members agreed in principle to supporting these four initiatives.</p> | <p>Bea González</p> |

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| <p>Ms. González proposed developing an advocacy plan for Commission members. This would include developing a questionnaire for members of the legislature to be sent by the Commission chair and collated by Ms. González. This would potentially include the following questions that Ms. González described during the meeting :</p> <ol style="list-style-type: none"> 1. Do you have a family member or friend diagnosed with Alzheimer's or dementia? 2. Does your family member or friend need a caregiver or specialized services? 3. If a constituent calls your office looking for information or services for Alzheimer's or dementia, do you know who to call? 4. Do you know if your region has a full-time care coordinator for these type of services? 5. Do you know the wait times to be evaluated by a neurologist or a specialized caregiver in your area? (give three choices – a. 6 months b. 7-9 months or c. 9-12 months) <p>Members also discussed developing a one-pager with information about the Dementia State Plan, Dementia Capable Virginia, key Virginia data on dementia and other vital information for members of the legislature and their staffs to use in their interactions with constituents. The goal would be to send the questionnaire out in July and August, to share a one-pager in September and to support advocacy efforts by Commission members in their constituent capacity in the autumn. Ms. González noted that she would be unable to attend the meeting in June, but a member of the Committee will put forward these recommendations for approval and the advocacy plan and approval in principle by the Commission.</p> | |
| <p>Meeting adjournment Ms. González thanked members for their time and adjourned the meeting at 2:30pm.</p> | <p>Bea González</p> |