

### Alzheimer's Disease and Related Disorders Commission Annual Report

### Report to

Governor of Virginia and the Virginia General Assembly

Richmond, Virginia

**October 1, 2023** 

## THE 2023 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION

### **RECOMMENDATIONS AND ACTIVITIES**

**Authority:** Pursuant to the Code of Virginia § 51.5-154, the Virginia Alzheimer's Disease and Related Disorders Commission (Commission) must submit to the Governor, General Assembly, and Department for Aging and Rehabilitative Services (DARS) a report regarding the recommendations and activities of the Commission each year. The Commission, chaired by Laura Bowser, develops and oversees the implementation of the Commonwealth's Plan for meeting the needs of individuals with Alzheimer's disease and related disorders and their caregivers.

## Commission Recommendations for the 2024 General Assembly

Expand Dementia Care Management to Underserved Areas of Virginia

Dementia Services Budget Increase

Support Dementia Capable Training for First Responders

A Dementia Capable No Wrong Door

Details of the recommendations are found starting on page 5 of this report.

### 2022-2023 HIGHLIGHTS



2023 VIRGINIA DEMENTIA CAPABLE SUMMIT: The inaugural Virginia Dementia Capable Summit was supported through a mixture of grant funding and sponsorships and brought together 150 stakeholders from across the state to provide input into the next iteration of the Dementia State Plan. See page 3 for more information.

#### **DEMENTIA CAPABLE VIRGINIA**

**INITIATIVE:** The first full year of the Dementia Capable Virginia web presence and broader initiative that includes resources and information for families and professionals supporting people living with Alzheimer's disease or another form of dementia was a huge success. See page 8 for updates on the initiative.

#### **DEMENTIA STATE PLAN 2024:**

The Dementia State Plan workgroup had a busy year working on the four-yearly update of the Plan as well as holding the Dementia Summit in May. The Dementia State Plan is expected to see a major expansion reflecting feedback from stakeholders at the Summit that overwhelmingly supported adding a new goal to the Plan to address brain health and dementia risk reduction. The next iteration of the Plan is due to be published in October 2023 to cover the four-year period starting in 2024. See page 2 for more information.

### **VIRGINIA'S DEMENTIA STATE PLAN 2024**

In December 2011, the Commission released the first Dementia State Plan. This was updated in 2015, 2019 and again in 2023. The Commission will now work on implementing the <u>Dementia State Plan 2024: Building a Dementia-Capable Virginia</u> that will be published on October 1, 2023. The Plan will maintain a focus on coordinated care through a network of memory assessment clinics and connections to public health initiatives, but this year will add, in line with the National Alzheimer's Plan, a new sixth goal related to brain health and dementia risk reduction. Elevating brain health and risk reduction in this way recognizes both the dramatic increase in knowledge in recent years that supports dementia prevention efforts, and the ongoing BOLD grant-funded activity by the Virginia Department of Health, DARS and other partners.

The Plan guides legislators, other public officials, health and human services professionals, advocates, and other interested people on best practices and specific strategies for dementia-focused data collection, care, training, and research and prevention.

The goals of Virginia's Dementia State Plan 2024 will be:

- 1. Coordinate quality dementia services to ensure dementia capability;
- 2. Use dementia-related data to support policy development and service provision, and to improve public health outcomes;
- 3. Increase awareness and promote dementia-specific training;
- 4. Provide access to quality coordinated care for individuals living with dementia in the most integrated setting;
- 5. Expand resources for dementia-specific translational research and evidence-based practices; and
- 6. Enhance brain health and address modifiable risk factors for dementia.

Virginia's Dementia State Plan 2024, working in tandem with the National Alzheimer's Plan, provides the best opportunity for responding to dementia and providing support to the estimated 190,000 Virginians expected to be living with Alzheimer's disease by 2025, a projected 27% increase from 2020. This rapid growth highlights the importance of the Plan and the Commission's ongoing efforts.

#### **Developing the Dementia State Plan 2024**

The Commission reconstituted the Dementia State Plan Workgroup in Spring 2022 to begin work on the fourth iteration of Virginia's Dementia State Plan. The Plan is expected to include 100 strategies grouped under six goals to provide a blueprint for a fully dementia-capable state. The revised Plan is to be published on October 1, 2023.

### COMMISSION MEMBERSHIP 2023

Laura Bowser, Chair Lana Sargent, PhD, Vice-Chair

Travonia Brown-Hughes, PhD Hon. Vanessa R. Crawford L. Karen Darner Karen H. Garner G. Richard Jackson, MPA Kim Kutner, MPH Destiny LeVere Bolling Carol Manning, PhD Margie Shaver Pamela B. Teaster, PhD Ishan C. Williams, PhD

Since the publication of the previous Plan, there was a sharp increase in scientific knowledge and understanding of the importance of brain health, and of the possibility of reducing the incidence of dementia through addressing modifiable risk factors. According to the <u>Lancet Commission</u>, addressing I2 potentially modifiable risks of dementia across the board could reduce the number of dementia cases by up to 40%. These modifiable risk factors include several that are already being addressed by public health efforts in Virginia, including diabetes, hypertension, smoking and physical inactivity.

### Virginia Dementia Capable Summit: May 10, 2023

Stakeholders have had multiple ways of providing input into the next Dementia State Plan, such as a public comment period when the draft Plan was published in August 2023. Different to previous years, when the Commission had held public listening sessions in five locations across the Commonwealth, this year saw the first Virginia Dementia Capable Summit, held at the Richmond Downtown Marriott in conjunction with the Governor's Conference on Aging on May 10, 2023.

The one-day event was attended by 150 stakeholders, thought leaders, service providers and local Delegate Rodney Willett. Attendees were welcomed by Commission Chair Laura Bowser and heard opening remarks from DARS Commissioner Kathryn A. Hayfield. Bonnie Wattles, Executive Director of Hilarity for Charity, a national non-profit that is the largest provider of in-home care grants for families living with dementia, spoke about



(From left) DARS
Commissioner Kathy Hayfield,
Hilarity for Charity Executive
Director and Keynote speaker
Bonnie Wattles, DARS
Dementia Services
Coordinator George
Worthington, and ADRD
Commission Chair Laura
Bowser at the 2023 Virginia
Dementia Capable Summit

the importance of including youth in efforts to address dementia in her keynote address: "The Brain Health Revolution: A Youth-Focused Approach." Dr. Paul Aravich of Eastern Virginia Medical School delivered a fascinating talk on Brain Health and Dementia Risk Reduction, in which he memorably characterized the risk factors as the 'Visigoths laying siege to your brain.' Finally, to close out the morning, Commission members Margie Shaver, Laura Bowser, Kim Kutner, Ishan Williams and Lana Sargent, and the

### **Definitions**

**Dementia Capable:** being skilled in identifying people with possible dementia and working effectively with them and their care partners or caregivers through the stages of their disease.

**Dementia Friendly:** being accessible to people living with dementia and their care partners, and enabling their continued engagement with their community.

(Alzheimer's Association, 2016)

Dementia Services Coordinator, George Worthington, delivered a goal-by-goal look at activities and accomplishments under the Dementia State Plan.

These talks laid the groundwork for attendees to provide input into the Dementia State Plan through breakout sessions tied to the five existing and one potential Plan goals. Reflecting the high level of engagement among the participants, the number one piece of feedback received was that the breakout sessions were not long enough. The day closed with brief reports out from the various sessions and a rousing call to action delivered by Commission member Karen Garner.

All materials from the Summit, and recordings of all plenary sessions, are available on the DARS website https://vda.virginia.gov/dementiasummit.htm

### **Dementia Friendly Virginia**

DARS collaborates with LeadingAge Virginia as state co-leads for dementia friendly efforts through the Dementia Friendly Virginia initiative. Dementia friendliness is a key component of a robust dementia capable structure, as it includes efforts to help people living with dementia and their caregivers thrive in their communities, which can support their needs thanks to efforts to improve dementia capability.





Communities across the state continue to join others across the United Scates in lostering demenda friendliness by affiliating with Dementia Friendly America. Expansion since the pandemic has slowed, with only one new community joining the national network in the reporting period, Dementia Friendly Dumfries, to bring the total affiliated communities in Virginia to ten. Some local efforts have also expanded their reach, such as Dementia Friendly Central Virginia which now includes Dementia Friendly Culpeper in addition to efforts underway in Charlottesville and Albemarle County. Several local communities are providing regular virtual programs to help to raise awareness and reduce stigma that are accessible across the state.

Dementia Friendly America provides tool kits, webinars, and other resources, but each community decides what it needs to do to better support people with dementia and their caregivers. Businesses and government agencies also can learn how to make their offices and stores safer and more inviting for people with dementia at <a href="https://www.dfamerica.org">www.dfamerica.org</a>. The Commission expects to continue supporting Dementia Friendly Communities through the new Dementia State Plan 2024 in recognition of this initiative's role in dementia capability.

Dementia Friendly Communities and the allied Dementia Friends initiative help raise awareness of dementia and reduce stigma, helping to improve the quality of life for individuals living with dementia, their families and care partners. Since launching <u>Dementia Friends Virginia</u> in 2018, more than 650 Dementia Friends Champions have delivered 60-minute information sessions attended by more than 7,500 Virginians.

### **COMMISSION RECOMMENDATIONS FOR 2024 GENERAL ASSEMBLY**

Acting in its advisory capacity and to further the Dementia State Plan goals, the Commission recommends the following actions to effectively and efficiently serve individuals with Alzheimer's disease and related dementias (ADRD) and their caregivers:

### Expand Dementia Care Management to Underserved Areas of Virginia

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.

### Dementia Services Budget Increase

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.

### **Support Dementia Capable Training for First Responders**

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 potential budgetary implications. This proposal aligns with recommendations under Goal 3B of the Dementia State Plan.

### A Dementia Capable No Wrong Door

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 though 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.

### **Dementia Capable Virginia Initiative**



**Dementia Capable Virginia** brings together resources available for the public and for providers under one unified and recognizable brand: <a href="https://vda.virginia.gov/DementiaCapableVA.htm">https://vda.virginia.gov/DementiaCapableVA.htm</a>. The page is broken into three sections: Resources for Individuals and Families, Resources for Providers (including healthcare and community services providers) and Resources for Researchers.

In the year since first going live in April 2022, the DCV web page received 3,952 visitors, a significant percentage of the 9,322 visitors to the main Dementia Services page (https://vda.virginia.gov/dementia.htm). The Virginia Dementia Road Map was the most downloaded file from the Division for Aging Services site, with a total of 1,772 downloads through April 2023. The DSC and the Commission continue to seek ways of making this popular publication more available through the provision of a printed version. The Virginia Department of Health printed copies of the Road Map and made copies available through Area Agencies on Aging, Local Departments of Health, and others with support from the BOLD Act grant highlighted on page 9. The most recent addition to the Dementia Capable Virginia is a set of four cobranded guides to advance planning developed by the National Alzheimer's Disease Resource Center supported by the Administration for Community Living. Highlighting the desire for dementia-related resources, 8 of the top 10 most downloaded publications from the Division for Aging were from the Dementia Capable Virginia or the Dementia Services webpages.

New additions to the Resources for Individuals and Families section of the Dementia Capable Virginia webpage

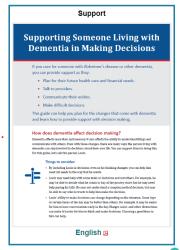
#### Advance Planning for People Living with Dementia

Advance planning empowers people to make their own decisions about important topics like finances, health care, and living arrangements before the need arises. These guides should help people living with dementia and their family members or other care partners know what to plan for and how to get started. The guides cover 4 topics: 1) health care planning; 2) financial planning; 3) care planning; and 4) supporting someone living with dementia in making decisions.









### **COMMISSION ACTIVITIES**

George Worthington is Virginia's Dementia Services Coordinator (DSC). The DSC is a critical recommendation of the Commission's first Dementia State Plan to work towards creating a dementia-capable service delivery system in the Commonwealth. Persons may contact the DSC and review a copy of the current Dementia State Plan 2020-2024 at <a href="https://dx.virginia.gov/dementia.htm">vda.virginia.gov/dementia.htm</a>.

Commission Workgroups: The Commission accomplishes much of its work through its various workgroups. Currently, there are four workgroups in addition to the Legislative Committee that develops the Commission's annual legislative recommendations. Three of the workgroups are tied to the five goals of the Dementia State Plan: Coordinated Care (Goals I and 4), Data and Research (Goals 2 and 5), and Training (Goal 3). The Dementia State Plan workgroup has focused on updating the Plan every four years, and additionally managed the 2023 Virginia Dementia Capable Summit through its Summit Subcommittee. A new workgroup is expected to be set up to work on the proposed new goal addressing brain health and dementia risk reduction. The workgroups could not effectively do their work without the participation of members from outside of the Commission who volunteer their time and expertise to support Commission activities.

Workforce Training and Education: The DSC continues to identify training opportunities to support a dementia-capable workforce in Virginia, and to deliver trainings to direct service workers, such as long-term care facility staff and workers supporting people living with intellectual and developmental disabilities at risk of dementia. The DSC also provides community education opportunities. In SFY 2023, the DSC delivered training and education sessions attended by a total of 825 individuals.

Additionally, the DSC works with the Virginia State Police Academy to provide dementia awareness training for each cohort of cadets and has collected training materials to share with first responders across the Commonwealth.



# Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act

In 2020, the Virginia Department of Health (VDH) was awarded a BOLD Public Health Programs Enhanced grant for a three-year period, in partnership with DARS and the Alzheimer's Association. The main purpose of this grant funding is to "create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving." (CDC, 2021). Virginia was able to secure an enhanced grant thanks to the existing dementia infrastructure of the Commission, the DSC, and the Dementia State Plan.

This grant project has supported Commission efforts such as the Dementia Capable Virginia initiative and materials developed or adapted through that initiative such as the Virginia Dementia Road Map, the Primary Care Dementia Toolkit, and others. In 2022, the grant supported the inclusion of the optional Cognitive Decline and Caregiving modules in the annual BRFSS survey conducted by VDH. The Commission and DSC have contributed to grant deliverables through providing dementia capable and dementia friendly training and education, through educating the public about the Commission and Dementia State Plan, and by providing input and assistance on projects like the redevelopment of the Brain Health Virginia website.

Caregiver Education and Support: In 2021, DARS received new federal grant funding of \$1,349,480 in federal funding to support the Virginia Lifespan Respite Voucher Program over five years. This program provides respite opportunities for family caregivers who are caring for someone with a chronic condition, such as Alzheimer's disease or a related dementia. Further information about this program is available on www.vda.virginia.gov/vlrv.htm.

DARS is looking to reboot the evidence-based Dealing With Dementia program in SFY2024. The Covid-19 pandemic prevented this program from being fully rolled as expected in 2020. Although a few of the agencies that were involved in the original rollout continue to offer the workshops, DARS is looking to embed this program in all of Virginia's 25 Area Agencies on Aging by the end of SFY2024. In the meantime, DARS has continued to support the existing workshops through the provision of grant-purchased Dealing With Dementia Guides that are an integral part of the Workshop.

### CURRENT FOCUS: Development and Implementation of the Dementia State Plan 2024

The Commission continues to partner with public and private partners throughout Virginia and at the national level to implement the Dementia State Plan. Ahead of and during the 2024 General Assembly session, the Commission will promote its recommendations for expanded support for people with dementia and their caregivers and facilitating dementia education and access to services. The Commission will be devoting significant time and effort to developing a workplan including measurable outcomes that will be attached to the fourth iteration of Virginia's Dementia State Plan, and then working to achieve those through its workgroups and other community partnerships. Additional information about the Commission and its activities may be found at: <a href="https://www.vda.virginia.gov/boardsandcouncils.html">www.vda.virginia.gov/boardsandcouncils.html</a>.