

DEMENTIA STATE PLAN

Building a dementia-capable Virginia

Virginia Alzheimer's Disease and
Related Disorders Commission

AlzPossible.org

2020-2024

TABLE OF CONTENTS

Letter from the Chair to the Governor and General Assembly	3
Vision	4
The Changing Landscape of Dementia	5
The Issue: Alzheimer’s Disease/Dementia	6
How Dementia Affects Virginia	8
Accomplishments 2015-2019	12
Overview of Goals	14
Goal 1 Coordinate quality dementia services in the Commonwealth to ensure dementia capability	15
Goal 2 Use dementia-related data to improve public health outcomes	17
Goal 3 Increase awareness and create dementia-specific training	18
Goal 4 Provide access to quality coordinated care for individuals living with dementia in the most integrated setting	21
Goal 5 Expand resources for dementia-specific translational research and evidence-based practices	23
Dementia State Plan Development Process	25
Contributions and Acknowledgments	26
Glossary	27
References	30



COMMONWEALTH OF VIRGINIA
Alzheimer's Disease and Related Disorders Commission

October 1, 2019

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The Honorable Ralph Northam and Members of the Virginia General Assembly:

The Alzheimer's Disease and Related Disorders Commission is pleased to present the *Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia*.

The Commission has revised and updated the Dementia State Plan in collaboration with researchers and stakeholders, and through a series of public listening sessions held across the Commonwealth attended by individuals living with dementia, their families and caregivers, and service providers. Over 100 Virginians attended the public listening sessions held in partnership with the four chapters of the Alzheimer's Association serving Virginia and with Mountain Empire Older Citizens in Big Stone Gap. The Commission also accepted comments from the public by telephone, mail and e-mail from March 19, 2019 through June 30, 2019.

An estimated 150,000 Virginians are now living with Alzheimer's disease or another form of dementia, and this number is forecast to rise to 190,000 by 2025. It is essential both to plan now for the increased demand for supports and services, and to embrace a public health approach to dementia in order to mitigate its future impact. The five goals of the Dementia State Plan offer a comprehensive vision of a dementia-capable Virginia:

1. Coordinate quality dementia services to ensure dementia-capability
2. Use dementia-related data to improve public health outcomes
3. Increase awareness and create dementia-specific training
4. Provide access to quality coordinated care in the most integrated setting
5. Expand resources for translational research and evidence-based practices.

To continue building a dementia-capable Virginia, the Commission has developed recommendations and strategies that will be overseen by focused workgroups based within the Commission to facilitate the realization of the five goals. The Commission will evaluate and track progress on the recommendations and looks forward to reporting accomplishments under the Plan in the future. Although achieving the vision contained in the Plan will likely require additional resources, progress toward the goals can also be made through innovation and collaboration with stakeholders across the Commonwealth. We welcome your thoughts and ideas. To share them with the Commission, please contact any of the Commission members or staff at the Virginia Department for Aging and Rehabilitative Services.

Sincerely,

A handwritten signature in black ink that reads 'Lory L. Phillippo'.

Lory L. Phillippo, MPH, OTR/L, Chair
Alzheimer's Disease and Related Disorders Commission

alzpossible.org

www.vda.virginia.gov/boardsandcommittees.htm

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VISION

The Alzheimer's Disease and Related Disorders Commission, and its partners, envision a dementia-capable Virginia that provides ethical, person-centered, evidence-based and high quality care across the continuum of the disease through a coordinated system that meets the needs of individuals of any age living with dementia and their caregivers.

CHANGING LANDSCAPE OF DEMENTIA

In 2011, the Alzheimer's Disease and Related Disorders Commission (the Commission) published the first Dementia State Plan as a blueprint for achieving dementia capability in the Commonwealth, and updated that Plan in 2015. The concept of **dementia capability** means 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 (Alzheimer's Association, 2016). Guided by the Plan, the Commission has achieved much over the past eight years to improve Virginia's dementia capability.

Virginia now supports a Dementia Services Coordinator (DSC), a recommendation from the first Dementia State Plan. Since 2013, the DSC has supported the Commission in its efforts, increased grant funding to support new programs helping individuals living with dementia and care partners, and spearheaded training and workforce education efforts on dementia knowledge and related issues. Innovative programs to support individuals and family caregivers have been devised and piloted in Virginia using a mix of federal, state, local and private funding. Workforce training efforts have helped to increase the awareness and understanding of dementia-related issues that may arise for first responders, healthcare workers and the financial and legal professions. Data sources useful for informing policy at a state and local level have been identified, and information collected. Support for vital research into treatments and cures, as well as to support individuals and care partners in their daily lives, has increased through sources like the Alzheimer's and Related Diseases Research Award Fund (ARDRAF).

These successes have gone a distance towards making Virginia a dementia-capable state, and

efforts will continue in that direction as identified in the Dementia State Plan 2020-2024. But dementia capability is only part of the overall picture of supporting individuals living with dementia.

In this new Plan, the more recent concept of **dementia friendly** is incorporated as a critical element of dementia capability. A dementia-friendly community is one that is both accessible to people living with dementia and their care partners and enables their continued engagement with the community (Alzheimer's Association, 2016). Using the two concepts together ensures that the lived experience of people living with dementia, their caregivers, and families, is supported and enhanced.

The Commission has also adopted more dementia-friendly terms throughout the Plan. Examples of this are replacing 'person with dementia' with '**person living with dementia**', recognizing that people do live with dementia and that the individual is more than the disease. Similarly, '**care partner**' is being used interchangeably throughout the Plan together with the term '**caregiver**' in recognition that the language used for people supporting individuals living with dementia is shifting.

The 2020-2024 Plan contains new recommendations to support dementia-friendly initiatives by working with the public health system and others to promote greater awareness and understanding of dementia, and to reduce the stigma surrounding dementia. The Commission expects that success in these areas will help individuals, families and communities affected by Alzheimer's disease and other forms of dementia enjoy an improved quality of life.

THE ISSUE: ALZHEIMER'S DISEASE/DEMENTIA

Dementia is an umbrella term referring to a collection of symptoms affecting cognition and memory caused by a number of different diseases that damage brain cells and affect daily functioning. The symptoms experienced by people living with dementia vary widely by individual and specific disease, but typically include significant impairment of at least two of the following areas: memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception (Alzheimer's Association, 2019d).

Alzheimer's disease. Although there are some indications that the risk of developing dementia at any given age is declining, possibly due to increased educational levels and improved cardiovascular health (Langa et al., 2017), the absolute number of people living with Alzheimer's disease continues to rise as the large cohort of baby boomers ages and people live longer.

Other non-modifiable risk factors include family history, APOE-e4 gene and mild cognitive impairment (MCI). Potentially modifiable risk

DEMENTIA DOES NOT JUST AFFECT OLDER AMERICANS

<65

200,000 people under age 65 live with dementia in the US

80% of family care partners are under age 65

Alzheimer's disease is the most common form of dementia, causing 60-80% of dementia cases (Alzheimer's Association, 2019a). Other common diseases that cause dementia include vascular dementia, frontotemporal lobar degeneration, dementia with Lewy bodies, and Parkinson's disease dementia. Mixed dementia refers to a combination of diseases, often Alzheimer's disease and vascular dementia. It appears to be more common in those over 75 and may affect a majority of those living with dementia. Throughout this document, dementia includes Alzheimer's disease and related disorders that cause dementia.

Risk Factors

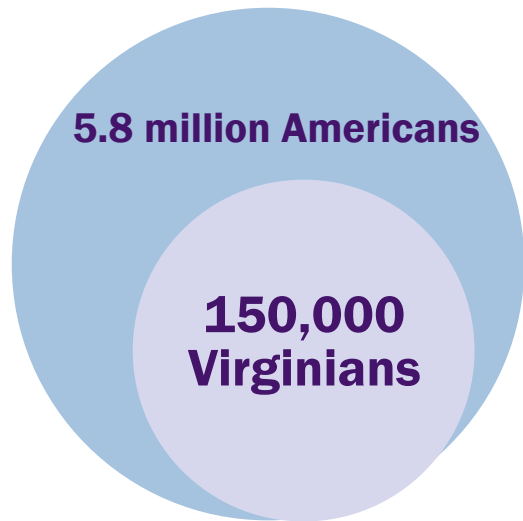
Risk factors may be modifiable or non-modifiable. Age is the most important risk factor for

factors that can be addressed in public-health campaigns include cardiovascular risk factors, poor social and cognitive engagement, low educational attainment, and traumatic brain injury (Alzheimer's Association, 2019a).

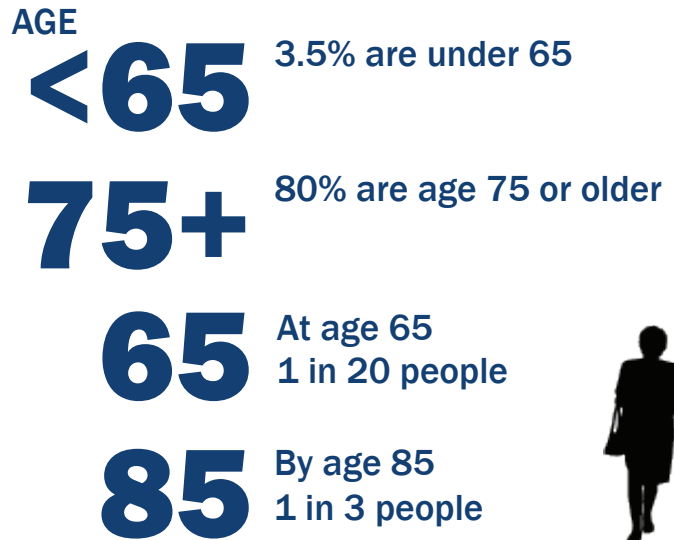
A report by The Lancet (Livingston et al., 2017) indicates that the number of new cases of dementia could be reduced by up to 35% through modifying risk factors throughout the lifespan. These include improvements to education in early life, addressing hearing loss, obesity and hypertension in mid-life, and by reducing smoking, depression, inactivity and social isolation, and managing diabetes, in later life. A recent study provided strong support for intensive management of hypertension to reduce the risk of developing mild cognitive impairment or probable dementia later in life (Williamson, 2019).

THE ISSUE: ALZHEIMER'S DISEASE/DEMENTIA

People Living with Alzheimer's Disease



Source: Alzheimer's Association (2019a)



Treatments

Currently there are no treatments available to slow or stop the progression of Alzheimer's disease or related disorders. The US Food and Drug Administration (FDA) has approved six drugs to treat Alzheimer's disease, but their effectiveness is time-limited and varies between individuals. Providers, individuals and care partners or caregivers are encouraged to discuss potential medications with medical and pharmacy staff to ensure they are appropriate for the stage and type of dementia. A thorough and clear diagnosis is vital as some of these medications may have negative side effects if used inappropriately.

Non-pharmacological treatments, those that do not involve drugs, may have some efficacy in symptom

management or improving quality of life, but do not slow or stop the damage caused by Alzheimer's disease. Exercise and cognitive stimulation may be beneficial, although the research is incomplete. Active management of dementia has been shown by a number of studies to improve quality of life for people living with dementia and their care partners. Active management includes appropriate use of available treatments, effective management of other health conditions, care coordination, participation in meaningful activities, opportunities to connect with others living with dementia, becoming educated about the disease and planning for the future (Alzheimer's Association, 2019a).

HOW DEMENTIA AFFECTS VIRGINIA

Estimated Number of People Aged 65 and Older with Alzheimer’s Disease by Age, Virginia

YEAR	65-74	75-84	85+	TOTAL	% increase from 2015
2015	21,000	58,000	53,000	130,000	
2019	24,000	64,000	57,000	150,000	15%
2025	29,000	89,000	68,000	190,000	46%

There are an estimated 150,000 adults age 65 or older currently living with Alzheimer’s disease in Virginia. This number is expected to rise to 190,000 by 2025 (Alzheimer’s Association, 2019a). According to the Centers for Medicare and Medicaid Services (CMS), 92,277 fee-for-service or traditional Medicare beneficiaries in Virginia had received a clinical diagnosis of Alzheimer’s disease or a related dementia in 2015 (US CMS Chronic Conditions, 2015).

The estimated number of people living with Alzheimer’s disease is much higher for several reasons. The increasing numbers of people enrolling in Medicare Advantage plans are not counted in traditional Medicare data. Of equal concern, less than 50% of people living with Alzheimer’s disease or a related disease has received a clinical diagnosis (National Institute on Aging, 2017b), and not all of those who have received a clinical diagnosis are enrolled in Medicare. By definition, these numbers exclude individuals with younger-onset Alzheimer’s disease.

For more information on this data, including the prevalence rates of Alzheimer’s disease for Medicare beneficiaries at the county level, please visit AlzPossible.org/data-and-data-sets.

Subjective Cognitive Decline

In 2015, Virginia included the optional Cognitive Decline module in the annual Behavioral Risk Factor Surveillance System (BRFSS), providing a snapshot of the breadth of cognitive issues reported by residents. The results, added to those from 2012 and 2013 when this module was also included, offer state health and human resource agencies a deeper perspective of cognitive impairment issues and how they may interfere with an individual’s functioning.

The most recent data revealed that 8.9% of the 3.4 million Virginians age 45 or older reported **subjective cognitive decline**, memory problems that have been getting worse over the past year. Of these, 29.6% reported needing help with household chores and 35.6% reported giving up day-to-day activities as a result of their cognitive difficulties.

People Living with Subjective Cognitive Decline

45+ 300,000 Virginians over age 45

48% had not talked to a doctor about memory concerns

Source: Alzheimer’s Association (2019a); Alzheimer’s Association (2018)

HOW DEMENTIA AFFECTS VIRGINIA

For two out of every five of these people, cognitive decline interfered with social activities, work or volunteering. More worrying, many of those reporting subjective cognitive decline already have or will eventually develop mild cognitive impairment or dementia, yet nearly half had not spoken with a healthcare provider about it (Alzheimer’s Association, 2018).

Caring for People Living with Dementia



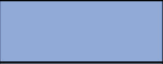

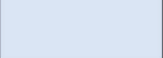
Although a wide variety of care options exist, the vast majority of care for people living with dementia is provided by family or other informal care partners in the home. Supporting these care partners is a vital component of dementia-capability. In 2017, an estimated 465,000 Virginians provided 529 million hours of unpaid care worth \$6.7 billion for people living with Alzheimer’s

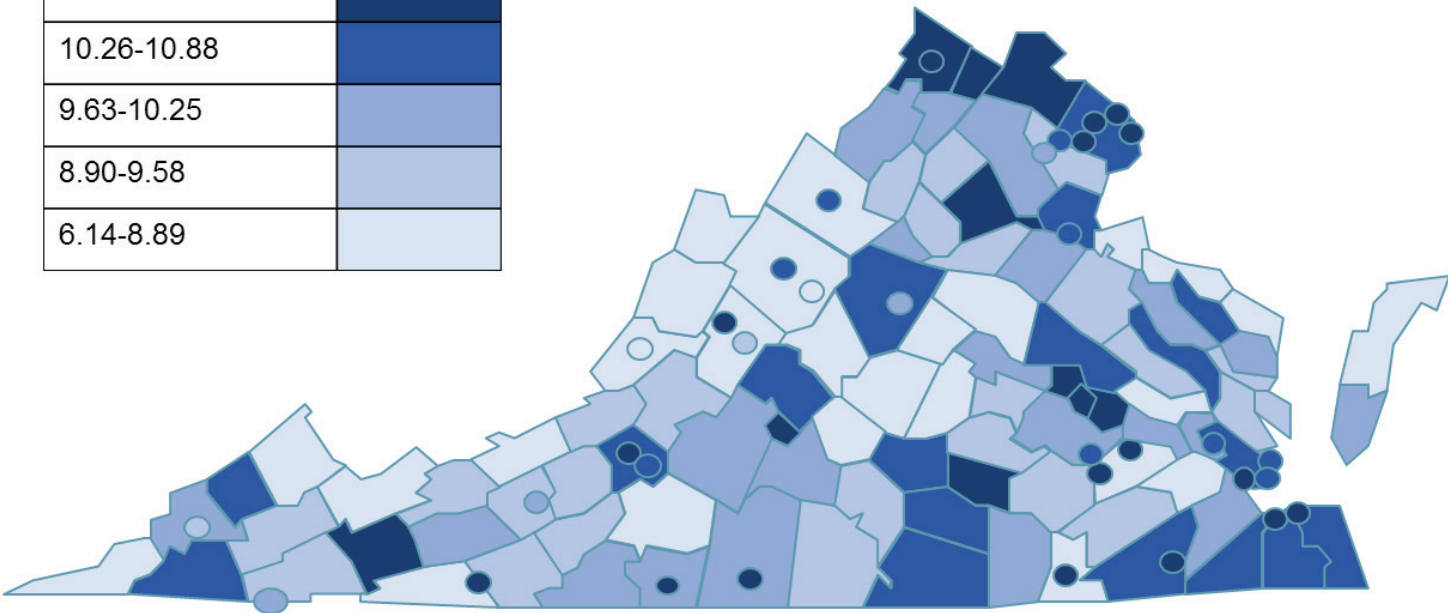
disease (Alzheimer’s Association, 2019a).

The optional Caregiving module of the 2015 BRFSS revealed that one in five adult Virginians provided regular care or assistance to a friend or family member with a health problem or disability. Of these, 8% provided care to someone living with dementia (Centers for Disease Control and Prevention, 2018).

Providing care for a person living with dementia can be both intensive and of long duration: 53% of individuals living with dementia received assistance from informal care partners with activities of daily living (bathing, dressing, toileting and similar tasks) and 57% of family care partners had provided care for four or more years (Kaspar et al., 2015). Two-thirds of care partners are women, one-third are age 65 or older, and one quarter are also

Percentage of Fee-for-Service (Traditional) Medicare beneficiaries diagnosed with Alzheimer’s disease and dementia (ADD) in 2015

% with ADD diagnosis	
10.96-13.70	
10.26-10.88	
9.63-10.25	
8.90-9.58	
6.14-8.89	



Source: Centers for Medicare and Medicaid Services

HOW DEMENTIA AFFECTS VIRGINIA

caring for children age 18 or younger (Alzheimer's Association, 2019a). Many caregivers will provide care for more than one person living with dementia over their lifetime, for example providing care for a parent and later a spouse.

The cost of care for people living with dementia is significantly higher than that for others: Medicare costs for beneficiaries living with Alzheimer's disease or a related disorder are estimated to be three times higher than for other beneficiaries in the same age group. The Alzheimer's Association (2019a) estimates the average lifetime cost of care for an individual living with dementia at \$350,174. Medicare and Medicaid cover two-thirds of the total \$290 billion spent in America each year on dementia care costs, with personal resources required to cover a further 22% (Alzheimer's Association, 2019a).

Varied Prevalence of Dementia

The prevalence of dementia varies among populations for reasons that are not entirely understood:

- Women make up more than 60% of the total number of people age 65 or over living with dementia, and estimates suggest 16% of women age 71 or over have Alzheimer's disease or another form of dementia compared to 11% of men (Alzheimer's Association, 2019a).
- Older African-Americans are twice as likely to have Alzheimer's disease or another form of dementia than are whites, and older Hispanics are one and one-half times as likely to have dementia. Asian-Americans typically have the lowest prevalence of dementia. These differences are likely due to differences in health, lifestyle and socioeconomic risk factors (Alzheimer's Association, 2019a).
- Individuals living with developmental

disabilities (DD) are increasingly living longer lives, though life expectancy remains lower than for the general population. Individuals with Down syndrome are at highest risk for developing Alzheimer's disease or a related dementia, and typically develop it in their 50s or earlier. For other individuals with DD, prevalence is thought to be higher than for the general population, although with a similar age of onset and time course. (Pritchett, 2017)

Addressing Stigma for Better Outcomes

Stigma surrounding Alzheimer's disease and other forms of cognitive impairment is widespread and problematic, and does not just affect people living with the disease. The National Plan to Address Alzheimer's Disease (US Department of Health and Human Services, 2018) notes that stigma and misperceptions affect the care and degree of social interaction experienced by people living with dementia and their families and care partners. Concerns related to stigma may leave people reluctant to discuss their cognitive health with providers and delay diagnosis and treatment (Alzheimer's Association, 2019c).

This stigma is in part due to a lack of knowledge and awareness about dementia. Although dementia is not a normal part of aging, increasing understanding and acceptance of dementia should improve the quality of life for people living with the condition and their caregivers.

The Dementia State Plan 2020-2024 contains several recommendations intended to increase public awareness and understanding of Alzheimer's disease and dementia. From public health campaigns to the promotion of dementia-friendly communities, these involve educating people about the disease, its early warning signs and risk prevention, as well as the importance of early diagnosis and planning for future needs.

HOW DEMENTIA AFFECTS VIRGINIA

Dementia Requires Public Health Approach

Dementia is the sixth leading cause of death in the United States, with one person diagnosed roughly every sixty seconds. Distressingly, it is the only one of the leading causes of death that has no effective treatment or cure. It remains one of the most stigmatized conditions affecting Americans, with a lack of awareness and understanding contributing to low rates of diagnosis, difficulties accessing services and supports when they are needed, and a failure to prepare for the long-term impact on individuals and families.

Years of study and research have increased understanding about the mechanisms of diseases like Alzheimer's disease, and awareness and knowledge of risk factors associated with dementia. This has fostered a more systematic approach to the disease. Applying a traditional three-phase public health model to the challenge of dementia offers promise. Phase one involves the identification of risk factors, and community-wide proactive

messaging and education about them to modify behaviors and reduce stigma. The second phase focuses on the early diagnosis of those with cognitive impairment so co-morbid conditions can be well-managed, and so available and future dementia medications can be used as appropriate. Finally, the third phase, for those living with dementia, involves the earlier implementation of active management strategies to benefit the person and any caregivers through improved quality of life and timely use of available resources.

Throughout the Dementia State Plan 2020-2024, goals and recommendations have been reviewed through the lens of this public health approach. The Commission has utilized the Healthy Brain Initiative 2018-2023 Road Map (Alzheimer's Association & Centers for Disease Control, 2018) as a guide to the practical steps that can be taken to achieve better outcomes.

Dementia Caregiving in Virginia

465,000

caregivers

529 million

hours of unpaid care

\$6.7 billion

value of unpaid care

\$317 million

higher health care costs for caregivers than non-caregivers

(Alzheimer's Association, 2019a)

ACCOMPLISHMENTS 2015-2019

Overarching Accomplishments

- In 2018, Virginia passed SB305 to require the Virginia Department of Health to include messaging about dementia and risk factors for cognitive decline in public health campaigns.
- In 2017, The Virginia Department of Health, supported by the Dementia Services Coordinator, launched HealthyBrainVA.com, an information site on brain health that is a centerpiece of dementia-related public health initiatives.
- Over the four years to 2019, Virginia's General Assembly increased funding for the Public Guardianship Program to \$4.7 million, more than double the \$2.1 million available in 2015. This resulted in a 73% increase in the number of slots available for those needing a public guardian to 1,049.
- A workshop to kick off Dementia Friendly Virginia was held in April 2018 in Richmond. This workshop has led to the growth of multiple dementia friendly community initiatives across the state. Going forward, their efforts will be supported by the DSC and LeadingAge Virginia. One of the key components of Dementia Friendly Communities is workforce training in basic awareness and understanding of dementia and some of the issues that relate to people living with dementia in the community.

Data and Research Accomplishments

- In 2015, Virginia included the Cognitive Decline module in the annual BRFSS survey.
- In 2015, Virginia included the Caregiver module in the annual BRFSS survey.
- In 2016, Virginia was awarded \$900,000 from the Administration for Community Living to expand availability of the Chronic Disease Self-Management Education program to the entire state. One goal of the grant was to expand delivery of the program to include individuals living with early stage dementia and their caregivers, with the Alzheimer's Association assisting with referrals and outreach.
- In 2015, Virginia's General Assembly adopted changes to the legal framework surrounding research to make it easier for individuals living with dementia to participate in research and clinical trials when they themselves are not able to provide informed consent.
- The Virginia Neuroscience Initiative (VNI) has come together to help foster links between researchers and institutions and to promote collaboration on research efforts between five medical centers and seven research universities. The VNI includes an Alzheimer's disease interest group.

Coordinated Care Accomplishments

- In 2015, Virginia received a three-year federal Administration for Community Living Alzheimer's Disease Initiative—Specialized Supportive Services (ADI-SSS) grant of \$970,000 to devise and implement a model program of care coordination (Care Coordination Program) for individuals living with dementia, and to adapt and implement a model program for individuals at risk of developing dementia to learn strategies to maintain independence for a longer period of time. This project also served as a model collaboration between an Area Agency on Aging and a local health system. The program served more than 200 individuals living with dementia and their care partners.
- In 2018, the Care Coordination Program received a Commonwealth Council on Aging's Best-Practice Award and a National Association of Area Agencies on Aging (n4a) Innovations in Aging Award.
- In 2016, Virginia received an 18-month federal Administration for Community Living Alzheimer's

ACCOMPLISHMENTS 2015-2019

Disease Supportive Services Program (ADSSP) grant to expand the FAMILIES program (supporting family caregivers) from pilot regions around Charlottesville and Williamsburg to the entire Commonwealth. This included training additional counselors and offering the program via telehealth. More than 130 people enrolled, well above the target of 100.

- In 2018, Virginia received funding from the Virginia Center on Aging Geriatric Training and Education initiative to train an additional 15 counselors for the FAMILIES program of counseling support for caregivers. This funding will sustain the FAMILIES program across the Commonwealth into the next decade.
- In 2018, three-year Alzheimer's Disease Program Initiatives grants from the Administration for Community Living were awarded to UVA's Memory and Aging Care Clinic and to Riverside Center for Excellence in Aging and Lifelong Health. Among other goals, both programs will improve and support care coordination for people living with dementia utilizing the Benjamin Rose Institute (BRI) Care Consultation program.
- In 2018, Virginia received \$281,817 in federal funding to support the Virginia Lifespan Respite Voucher Program for three years to serve more than 450 family caregivers, including those caring for people living with dementia.

Training and Workforce Development Accomplishments

- An additional project under the 2015 ADI-SSS grant was Virginia's Microlearning for Dementia pilot project. This produced five modules to train the primary care workforce in having difficult conversations around dementia with their patients. These are now available on AlzPossible.org and Virginia Navigator.
- Virginia devised and made available dementia capability training modules for Options Counselors, Care Transitions Coaches, Information and Referral Specialists. Links to these modules are available on AlzPossible.org.
- The DSC supported training for State Police and EMT personnel. Virginia is allocating \$50,000 annually to train first responders on Alzheimer's disease and dementia, helping to develop an eight-hour, dementia-specific training module.
- The DSC supported the training of Dementia Friends Champions by LeadingAge Virginia.
- Virginia has continued an open and informal discussion on dementia services and training needs through the interdisciplinary, multi-agency Virginia Geriatric Mental Health Partnership (GMHP). The GMHP has created and disseminated more than 20 webinars to train community-based staff and providers as well as family caregivers under its Mental Health and Aging Training Initiative.

OVERVIEW OF DEMENTIA STATE PLAN

GOAL 1: Coordinate quality dementia services in the Commonwealth to ensure dementia capability

- A. Support and maintain a Dementia Services Coordinator (DSC) who oversees Virginia’s dementia capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.
- B. Expand availability and access of dementia-capable Medicaid and other state-level administered services.
- C. Review all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements.

GOAL 2: Use dementia-related data to improve public health outcomes

- A. Collect and monitor data related to dementia’s impact on the people of the Commonwealth.
- B. Collaborate with related public health efforts and encourage possible risk-reduction strategies.

GOAL 3: Increase awareness and create dementia-specific training

- A. Provide standardized dementia-specific training to individuals in the medical, health, and social services fields and require demonstrated competency.
- B. Provide dementia-specific training to professional first responders (police, fire, EMS and search and rescue personnel), financial services personnel, and the legal profession.
- C. Support caregivers, family members and people living with dementia by providing educational information about dementia and available resources and services.

GOAL 4: Provide access to quality coordinated care for individuals living with dementia in the most integrated setting

- A. Create a statewide network of interdisciplinary memory assessment centers with specialized, dementia-capable services for individuals living with dementia and their care partners from assessment and diagnosis through end-of-life.
- B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals living with dementia and care partners during the disease trajectory.
- C. Identify and coordinate supports for informal and family care partners to enhance well-being.

GOAL 5: Expand resources for dementia-specific translational research and evidence-based practices

- A. Support ARDRAF, especially projects that have a specific emphasis on “methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth” (§ 51.5-153).
- B. Provide support to researchers and interested stakeholders across the Commonwealth through data sources and networking opportunities.
- C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.

DEMENTIA STATE PLAN

GOAL 1

Coordinate quality dementia services in the Commonwealth to ensure dementia capability.

- A. Support and maintain a Dementia Services Coordinator (DSC) who oversees Virginia's dementia capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.
 1. The DSC shall disseminate information on systems, services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, the academic community, individuals living with dementia and their family caregivers, advocacy associations, and the general public.
 2. The DSC shall coordinate services and activities of state and local agencies, service providers, advocacy groups, first responders and law enforcement, as well as other entities throughout the state that engage the person living with dementia and their care partners, including the Alzheimer's Association, the Area Agencies on Aging, and state and local Departments of Health.
 3. The DSC shall coordinate and provide support for Commission activities.
 4. The DSC shall continue to identify interdisciplinary memory assessment centers, share information about them with consumers, and provide professional development opportunities for center staff.
 5. The DSC shall coordinate with LeadingAge Virginia to support and encourage Dementia Friendly America initiatives in counties and communities across the state.
- B. Expand availability and access of dementia-capable Medicaid and other state-level administered services.
 1. Increase respite services for caregivers of people living with dementia.
 2. Expand the accessibility and availability of adult day services, the Commonwealth Coordinated Care Plus (CCC+) waiver, hospice and palliative programs, and Program of the All-inclusive Care for the Elderly (PACE).
 3. Increase funding for home and community based services (HCBS).
 4. Increase the payment rate of Auxiliary Grant to cover the actual cost of care in an assisted living facility or other supported housing.
 5. Promote the awareness and use of Virginia's Long-Term Care Partnership Insurance Program.
 6. Increase funding for Virginia's State Long-term Care Ombudsman Program.
 7. Monitor and support the dementia capability of care coordination services provided under the CCC+ waiver.
 8. Continue to evaluate and improve Virginia's advance directive, emergency custody order (ECO), temporary detention order (TDO), and commitment laws to more easily allow persons living with dementia to access needed and appropriate behavioral health services.

DEMENTIA STATE PLAN

(Goal 1 cont.)

9. Ensure the demand for public guardians is fully met.
 10. Create a student loan forgiveness program or tuition assistance for medical and nursing students specializing in geriatrics.
 11. Review state legislation and regulations for licensing of professions, facilities and providers.
 - a. Review licensing and survey standards or protocols for long-term facilities and identify opportunities to improve dementia capability and quality through actions such as acuity-based staffing.
 - b. As regulations are open for review, advocate and recommend that expected dementia care practice components be standard for assessments, service delivery, and training and oversight of medical and health professionals and paraprofessionals engaged in caregiving.
 - c. Increase the availability of information on licensed professions, facilities and providers for consumers, including information on dementia-specific training and programming.
- C. Review all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements.
1. Integrate the Alzheimer’s Association Dementia Care Practice Recommendations into the development, delivery and evaluation of services provided in Virginia, including the development and implementation of the Commonwealth’s Four-Year Plan for Aging Services.
 2. Partner with the Department for Aging and Rehabilitative Services (DARS) Adult Protective Services Division, the Virginia League of Social Service Executives, Virginia’s Area Agencies on Aging, the Virginia Department of Behavioral Health and Developmental Services (DBHDS), Community Services Boards, and the Geriatric Mental Health Partnership (GMHP) to identify solutions and promote best practices for providing crisis stabilization for individuals living with dementia who are experiencing challenging dementia-related behaviors.
 3. Review the overlapping requirements for the licensing of residential facilities, assisted living facilities, and nursing facilities to further clarify the different levels of services and clarify the differences in admission disclosure documents.
 4. Ensure that Virginia’s No Wrong Door (formerly known as Aging and Disability Resource Connectors) network is dementia capable, with a specific focus on education and training for information and referral specialists, options counselors, and care transitions coaches.
 5. Incorporate dementia education into developmental disability (DD) services and provider training, and review waiver regulations and policies to accommodate the growing population of individuals with DD, including Down syndrome, and dementia who are served through state-based programs.
 6. Conduct veteran-specific outreach efforts in partnership with the Virginia Department of Veterans Services and through the Virginia Veterans Care Centers.

DEMENTIA STATE PLAN

GOAL 2

Use dementia-related data to improve public health outcomes.

- A. Collect and monitor data related to dementia's impact on the people of the Commonwealth.
 1. Coordinate statewide data collection and regularly share the findings through [AlzPossible.org](https://www.alzpossible.org), which serves as a clearinghouse of links to state or federal agencies or entities with relevant, up-to-date, and available data on dementia. Such data findings should include the results of the BRFSS Caregiver and Cognitive Decline modules, Medicare data on beneficiaries and on individuals who are dually eligible for Medicare and Medicaid, and data from sources including No Wrong Door, Adult Protective Services, DBHDS, DMAS and the Virginia Crime Information Network (VCIN).
 2. Coordinate with state licensing agencies to collect data on dementia prevalence, trends, and the characteristics of professions, facilities and providers.
 - a. Consider the extent to which internal agency policies could mandate data collection that captures the presence or absence of Alzheimer's disease and dementia.
 - b. Consider potential financial incentives for entities that fully complete forms or assessments.
 3. The DSC should collect and monitor data with the following themes in mind:
 - a. The prevalence of dementia-related diseases across the Commonwealth, including by locality, across rural and urban communities, gender, ethnic and racial minorities, younger onset, individuals with DD, and other special populations or unique characteristics.
 - b. The availability of dementia-related services and supports.
 - c. The availability of diagnostic and assessment services for Alzheimer's and dementia.
 - d. The number and location of Virginians who are currently providing care to a family member or friend with dementia.
 - e. The cost of caring for persons with dementia.
 - f. The prevalence of dementia among incarcerated populations.
 4. With collected data, apply the findings to policy development and implementation so that such policies can target geographic areas and populations with identified unmet or higher needs.
- B. Collaborate with related public health efforts and encourage possible risk-reduction strategies.
 1. Use the BRFSS to collect health outcomes data for persons with Alzheimer's disease and dementia and their care partners in Virginia, and analyze and apply the findings to improve dementia capability.
 2. Collaborate with related public health efforts (e.g. diet, exercise, co-morbid conditions, etc.) to improve treatment adherence and encourage possible risk-reduction strategies.
 - a. Promote awareness of the importance of controlling vascular risk factors to reduce dementia risk.

DEMENTIA STATE PLAN

(Goal 2 cont.)

- b. Promote efforts to improve treatment adherence among those experiencing subjective cognitive decline (SCD) living with at least one chronic condition.
3. Encourage participation in the Chronic Disease Self-Management Education (CDSME) program by persons experiencing subjective cognitive decline, persons living with dementia and caregivers. Continue to expand this program to make it available in all areas of the Commonwealth.
4. In collaboration with the Virginia Department of Health (VDH) and local health departments, integrate dementia and brain health into public health strategies and reports.
 - a. Promote awareness of the benefits of consulting health care providers about brain health for people experiencing subjective cognitive decline.
 - b. Educate public health and healthcare professionals on sources and uses of reliable information about brain health and dementia prevalence.

GOAL 3

Increase awareness and create dementia-specific training.

- A. Provide standardized dementia-specific training to individuals in the medical, health and social services fields and require demonstrated competency.
 1. Develop or collect and deliver dementia-specific, evidence-based trainings that include an emphasis on the differences between dementias and their disease trajectories, management of co-morbid conditions, dementia-related behaviors, referral protocols and resources, non-pharmacological interventions, care planning and advance directives, and the needs of and supports for family and informal care partners, among others.
 - a. Such dementia-specific, evidence-based trainings should be part of regular offerings and required demonstrated competencies for medical and health professions, including physicians, physician assistants, nurses of all licensing levels, gerontologists, psychologists, occupational, physical, and speech therapists, pharmacists, rehabilitation counselors, and social workers, and other health and social services professionals across all professional care settings including emergency room, other acute care and home-care settings.
 - b. Integrate the dementia-specific, evidence-based training modules into the existing trainings offered through VDH, Virginia Department of Social Services (DSS), DARS, DBHDS, and their local entities and contractors, including Area Agencies on Aging, Community Services Boards, local health departments and local departments of social services.
 - c. Integrate the dementia-specific, evidence-based training modules into the curriculums and training strategies for long-term care facilities and HCBS providers.
 - d. Promote the integration of dementia-specific, evidence-based training modules into the curriculums and training strategies for care coordinators in the CCC+ network.
 2. Promote the continued and expanded use of the Advanced Nurse Aide Certification and encourage employers to reward such additional education with increased salaries.

DEMENTIA STATE PLAN

(Goal 3 cont.)

3. Develop or catalog and deliver a portable certification program for direct-care staff with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals living with Alzheimer’s disease or related dementias. This content should include evidence-based, non-pharmacological strategies for addressing dementia-related behaviors.
 4. Coordinate training opportunities with the GMHP, particularly with regard to overlapping issues such as cognitive impairment and mental health, substance use, and polypharmacy.
- B. Provide dementia specific training to professional first responders (police, fire, EMS and search and rescue personnel), financial services personnel, and the legal profession.
1. Develop or catalog and deliver dementia-specific, professionally-endorsed trainings with dedicated funding that include an emphasis on challenging dementia-related behaviors, detention orders, driving safety, wandering issues and resources, advance directives and other legal tools, and risks and signs for abuse, neglect, and financial exploitation, among others.
 - a. In partnership with the Virginia Department of Criminal Justice Services (DCJS), Virginia State Police (VSP), Virginia Department for Emergency Management, (VDEM) and Virginia Department of Corrections, continue to develop relationships and implement coordinated, dementia-specific, evidence-based trainings with state and local first responders (police, fire, EMS, and search and rescue personnel), emergency and disaster response personnel, and correctional personnel.
 - b. In partnership with DCJS, VSP and VDEM, continue work with first responders (police, fire, EMS and Search & Rescue personnel) to ensure a coordinated protocol for swift and appropriate action upon report of a missing adult with dementia, to include the appropriate use of Senior Alert, Project Lifesaver, and other wandering prevention and response tools.
 - c. In partnership with statewide and local legal organizations and associations, implement dementia-specific, professionally-endorsed trainings for general practice attorneys, prosecutors, judges, magistrates, victim advocates, and court clerks.
 - d. In partnership with the VSP, Virginia State Corporation Commission and industry representatives, implement dementia-specific, professionally-endorsed trainings for financial services personnel, including bank tellers, accountants, financial advisers, loan officers and collectors.
 2. Coordinate dementia-specific outreach and training efforts with the Virginia Office of the Attorney General and its Senior-focused Triad and SALT (Seniors and Law Enforcement Together) initiatives.
- C. Support care partners, family members and people living with dementia by providing educational information about dementia and available resources and services.
1. Expand [AlzPossible.org](https://www.alzpossible.org) resources and its library of free, quality trainings and online materials available to address dementia care and research needs in Virginia, to include:
 - a. Dementia and caregiving data for tracking trends in the Commonwealth.

DEMENTIA STATE PLAN

(Goal 3 cont.)

- b. Interdisciplinary memory assessment centers.
 - c. Best practices for dementia assessment and diagnosis, care and caregiving support and a clearinghouse of evidence-based and evidence-informed dementia care interventions and therapies not involving medications.
 - d. Cognitive assessment instruments.
 - e. A comprehensive listing of available, evidence-based and evidence-informed trainings for professional care staff.
 - f. A listing and explanation of services provided by state agencies related to dementia and caregiving.
 - g. The stages of Alzheimer's disease and common services associated with each.
 - h. Train-the-trainer outreach program for faith-based and other organizations to assist families with a member living with dementia in legal and financial awareness.
2. In partnership with the Alzheimer's Association and other state agencies and their contractors, train and link informal or family care partners to information and education about dementia and the caregiving process, including staying healthy, coordinating legal and financial issues, and locating and using respite care services, among other topics.
 3. Develop or collect and deliver a statewide, culturally-appropriate awareness strategy that has tailored components for the unique needs of rural communities, racial and ethnic minorities, non-English speaking individuals, veterans, individuals with younger-onset Alzheimer's disease, individuals with developmental disabilities, members of the LGBT community, and individuals with traumatic brain injuries (TBI). As appropriate, such a strategy could be in partnership with faith-based communities and the Alzheimer's Association to increase the availability and use of education materials tailored to these groups.
 4. With appropriate stakeholders, develop or collect and implement an evidence-based protocol for appropriate interaction with individuals living with dementia, with specific information on dementia-related behaviors.
 5. Develop or collect and deliver person-centered training for family care partners that incorporates evidence-based strategies for addressing dementia-related behaviors. These strategies often include understanding that the behavior is an attempt at communication, identifying the cause of the behavior, and using knowledge of the person to deliver individualized support.
 6. Advocate for and increase awareness and inclusion of advance directives and end-of-life planning, including knowledge of Virginia-specific laws governing such practices, in routine care for all older adults, with particular emphasis on individuals with Alzheimer's disease and dementia and caregivers.
 7. Increase awareness of the Annual Wellness Visit, which includes an assessment of cognitive function, offered to Medicare beneficiaries.
 8. Incorporate dementia awareness and information about resources into the Commonwealth of Virginia employee wellness program.

DEMENTIA STATE PLAN

GOAL 4

Provide access to quality coordinated care for individuals with dementia in the most integrated setting.

- A. Create a statewide network of interdisciplinary memory assessment centers with specialized, dementia-capable services for individuals living with dementia and their care partners from assessment and diagnosis through end-of-life.
 1. Promote a statewide network of memory assessment centers that use an interdisciplinary team approach to assess and treat persons with dementia.
 2. Identify the typical pathways to assistance for individuals living with dementia, possibly through a study, and develop a system of entry based on coordinated memory assessment centers for individuals living with dementia and their care partners.
 3. Within the interdisciplinary memory assessment centers and community partners, establish and fund dementia coordination centers that are staffed by credentialed patient navigators who can help persons living with dementia and their care partners and offer such services as:
 - a. Assessing and developing care plans in conjunction with the person living with dementia, their care partners and family.
 - b. Identifying and making referrals or arranging appropriate clinical care.
 - c. Identifying and making referrals or arranging long-term care services and programs, including home and community based supports, PACE programs, long-term care facilities, and hospice and palliative programs.
 - d. Identifying and making referrals or arranging supportive services, such as transportation, meals, home modifications, respite care, counseling, and support groups.
 - e. Educating the persons living with dementia and their care partners about their disease, interactions with other chronic conditions, care options, driving assessments, and legal and financial issues including end-of-life wishes and advance directives.
 - f. Accessing public and private benefit programs and assisting with insurance claims.
 4. Integrate data collection and track health outcomes and service utilization of persons living with dementia and care partners in the memory assessment center network to analyze prevalence and trends, effectiveness, and cost, including money saved through coordinated care.
- B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals living with dementia and care partners during the disease trajectory.
 1. Standardize the protocol followed after an individual receives a diagnosis of Alzheimer's disease or a related disorder, to include referrals for further evaluation by an interdisciplinary team with expertise in cognitive impairment and dementia at a memory assessment center, and referrals to appropriate services including the Alzheimer's Association and the local Area Agency on Aging.

DEMENTIA STATE PLAN

(Goal 4 cont.)

2. Track health outcomes and service utilization of persons living with dementia and care partners to assess and analyze effectiveness and cost, including money saved through coordinated care.
 3. With appropriate stakeholders, identify current protocols, and develop and implement improved protocols for appropriate placement options and available community resources based on the stages of Alzheimer's disease and related disorders.
 4. Support systems that promote integrated care between primary, acute and long-term care settings and the transitions between them, with an emphasis on minimizing transitions, repeat hospitalizations, and emergency department visits, and on improving medication reconciliation.
 5. Identify and remove barriers for community integration for persons living with dementia in part by promoting and supporting dementia friendly communities.
 6. In coordination with Area Agencies on Aging and Community Services Boards, establish cross-setting teams and provide supports to long-term care facilities and family care partners to respond to changed behaviors in a safe and appropriate manner.
 7. Promote research participation and university-community partnerships to address community needs and promote mutually beneficial participatory research opportunities in diagnosis, treatment, long-term services and supports, and caregiver supports.
 8. Promote geriatric emergency departments in hospitals that include trained staff and a thorough evaluation of adults presenting with possible delirium or dementia to assure safety and best outcomes for individuals.
 9. Advocate for accessible and innovative transportation systems including new models of transport options.
 10. Promote and advocate for long-term care services modeled after Culture Change (including Green Houses, Eden Alternatives, Household Models, etc.) and other related initiatives that establish person-centered, home-like environments.
 11. Increase opportunities and reduce barriers to the widespread and successful use of telemedicine and telehealth services that meet the needs of individuals living with dementia and caregivers, particularly in rural areas.
- C. Identify and coordinate supports for informal and family care partners to enhance well-being.
1. Identify, promote awareness and work to enhance the sustainability of successful, evidence-based programs (e.g., FAMILIES) that support family care partners through education, counseling, referrals, respite, and other related supports.
 2. Offer business and individual tax incentives to support family care partners with the purchase of locator devices, respite care services, and other related expenses.
 3. Encourage the development and implementation of employee assistance programs identify the needs of care partners and resources available to support them, which may include educational materials, onsite respite care and support groups.
 4. Provide information about long-term care insurance policies and other related programs that help offset the financial costs associated with long-term care.

DEMENTIA STATE PLAN

GOAL 5

Expand resources for dementia-specific translational research and evidence-based practices.

Support ARDRAF, especially projects that have a specific emphasis on “methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth” (§ 51.5-153).

- ☒ Support an increased focus and balance on translational projects, to include those that:
 - ☒ Utilize epidemiological methods.
 - ☒ Advance translational or clinical methods that identify evidence-based practices for service delivery and take them from bench to bedside.
 - ...☒ Identify costs associated with the delivery of programs and services to individuals living with dementia and care partners.
 - ☒ Develop both high-tech and low-tech assistive devices that adapt everyday environments for people living with dementia.
 - ☒ Assess the quality of services and facilities for individuals living with dementia and their care partners.
- ☒ Explore projects that attempt to better understand Alzheimer’s disease and dementias in rural communities, racial and ethnic minorities, non-English speaking individuals, veterans, individuals with younger-onset Alzheimer’s disease, individuals with developmental disabilities, members of the LGBT community, individuals with TBI, and individuals experiencing dementia-related behaviors and co-occurring serious mental illness.
- ☒ Disseminate research findings, especially translational research findings, on [AlzPossible.org](https://www.alzpossible.org).
- ☒ Provide support to researchers and interested stakeholders across the Commonwealth through data sources and networking opportunities.
 - ☒ Develop a research consortium network and provide networking opportunities for researchers and interested stakeholders in Virginia.
 - ☒ Periodically disseminate information about studies in need of participants and funding opportunities, which may include federal grant opportunities from the US National Institutes of Health as well as from the Alzheimer’s Disease Programs Initiative (ADPI) within the Administration for Community Living and the US Centers for Medicare and Medicaid Services Innovation grants, Civil Money Penalty funding and pilot demonstrations.
 - ☒ Use [AlzPossible.org](https://www.alzpossible.org) and the International Alzheimer’s Disease Research Portfolio (IADRP) on iadrp.nia.nih.gov to link researchers interested in dementia research.
 - ☒ Direct researchers to dementia and caregiving-related data sources so that they can better write research funding applications.

DEMENTIA STATE PLAN

(Goal 5 cont.)

- C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.
1. Promote training for gatekeepers (primary care providers, physicians, nurses, office managers, and other health professionals) on dementia and the value of research participation.
 2. Develop incentives, such as research partnering and communication of study results, for medical and health professionals who encourage research participation in the community.
 - a. Explore options to further support participant recruitment and participation in research studies in Virginia, specifically with populations marked by higher risk of dementia such as ethnic and racial minority populations and individuals with intellectual and developmental disabilities, and with rural and underserved communities, individuals with younger onset Alzheimer’s disease, and other special populations or unique characteristics.
 - b. Foster university-community partnerships to further research and development, address community needs, and promote mutually beneficial participatory research opportunities.
 - c. Develop and share resources to support Review Boards in developing consistent methods for assessing and approving dementia and caregiving research studies, to include information on understanding and confirming with informed consent allowances as outlined in § 32.1-162.16 through § 32.1-162.20.
 - d. Use [AlzPossible.org](https://www.alzpossible.org) to link to additional resources related to research.
 - e. Promote awareness and use of existing mechanisms to link potential participants with research opportunities (e.g., ClinicalTrials.gov and TrialMatch).
 3. Further dementia capability with the use of evidence-based practices, and use [AlzPossible.org](https://www.alzpossible.org) as a resource to evaluate and share dementia-capable services, evidence-based practices, and risk-reduction strategies.
 - a. With additional study and subsequent positive outcomes, identify opportunities for continued and expanded use of evidence-informed programs in Virginia, including the shift of quality evidence-informed programs into evidence-based programs.
 - b. Examine the effectiveness of common methods used to disseminate and translate evidence-based practices, and apply the results in Virginia.
 - c. Implement promising practices and programs statewide and promote the incorporation of evidence-based practices into existing programs that are merely evidence-informed at the present time.

DEMENTIA STATE PLAN

Development Process

The Commonwealth of Virginia's Alzheimer's Disease and Related Disorders Commission was established in 1982. The Commission serves as an advisory board in the executive branch of Virginia's state government and aims to assist people living with Alzheimer's disease and related disorders and their care partners.

Under the Code of Virginia § 51.5-154, the Commission has the power and duty to:

1. Examine the needs of persons with Alzheimer's disease and related disorders, as well as the needs of their caregivers, and ways that state government can most effectively and efficiently assist in meeting those needs;
2. Develop and promote strategies to encourage brain health and reduce cognitive decline;
3. Advise the Governor and General Assembly on policy, funding, regulatory, and other issues related to persons living with Alzheimer's disease and related disorders and their caregivers;
4. Develop the Commonwealth's plan for meeting the needs of people living with Alzheimer's disease and related disorders and their caregivers, and advocate for such plan;
5. Submit to the Governor, General Assembly, and Department by October 1 of each year an electronic report regarding the activities and recommendations of the Commission, which shall be posted on the Department's website; and
6. Establish priorities for programs among state agencies related to Alzheimer's disease and related disorders and criteria to evaluate these programs.

To guide the process, a Dementia State Plan Work Group, chaired by Laura Bowser, was appointed. As was the case in the development of Virginia's 2011 and 2015 Dementia State Plans, the Work Group reviewed state plans from other states, particularly those created in recent years, reviewed accomplishments achieved under the previous Plan, and considered changes in the legal and regulatory environment. Once a draft of the updated Dementia State Plan was in place, Commission members hosted five public listening sessions around the Commonwealth: in Big Stone Gap, Norfolk, Roanoke, McLean and Richmond. These sessions were attended by over 100 people. Additionally, the DSC conducted electronic outreach to members of the Virginia Neuroscience Initiative and received comments from professionals and family caregivers via mail, telephone and email through DARS.

Once input was gathered, the Commission drafted the Dementia State Plan. The Commission intends that this will be a living document always responsive to the needs of Virginians. The intent is to update it every four years to ensure that it is adaptive to changing circumstances, and that it makes use of cutting-edge research and standards.

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GLOSSARY

ARDRAF: In 1982, the Virginia General Assembly established a research award fund entitled the Alzheimer’s and Related Diseases Research Award Fund (ARDRAF). “The awards shall be given annually to scientists in Virginia in order to support research into the causes of Alzheimer’s disease and related disorders, methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the of the Commonwealth.”

Auxiliary Grant (AG): An AG is an income supplement for individuals who receive Supplemental Security Income (SSI) and certain other aged, blind, or disabled individuals who reside in a licensed living facility or an approved adult foster care home.

Behavioral Risk Factor Surveillance System (BRFSS): The Virginia BRFSS is an annual survey of Virginia’s adult population about individual behaviors that relate to chronic disease and injury. The BRFSS is the primary source of state-based information on health risk behaviors among adult populations.

Care Partner/Caregiver: The terms care partner and caregiver refer to anyone who supports another person who is, in some degree, incapacitated and needs help. Informal care partner/caregiver and family care partner/caregiver are terms that refer to unpaid individuals such as family members, friends and neighbors who provide support. These individuals can be primary or secondary care partners, full time or part time, and can live with or apart from the person being supported.

Commonwealth Coordinated Care Plus (CCC+) Medicaid Waiver: The CCC+ Waiver provides services to older adults and individuals with physical disabilities living in a community setting to prevent the premature institutionalization of seniors and physically-disabled individuals. The waiver allows for consumer direction of personal assistance services and respite care services, meaning they can choose who provides the service. Spouses and legal guardians may not be hired, but adult children, friends and other select relatives can be compensated for their care activities. Services include medical and behavioral health, adult day health care, personal care assistance, respite care, assistive technology, home and vehicle modifications, personal emergency response systems (PERS), skilled private duty nursing and transition services.

Culture Change: Culture change is the common name given to the national movement for the transformation of older adult services, based on person-directed values and practices where the voices of older adults and those working with them are considered and respected. Core person-directed values are choice, dignity, respect, self-determination and purposeful living.

Cultural Competence: Cultural competence is the application of skills and knowledge to effectively deliver services to culturally diverse individuals by tailoring programs and interventions to their behaviors, beliefs, values and linguistic needs. Professionals who exhibit cultural competence work successfully with persons from varying cultures because they demonstrate understanding and respect of their unique background, keeping in mind these differences when providing education and planning, implementing and evaluating programs.

Dementia Capable: Dementia capable means being skilled in identifying people with possible dementia and working effectively with them and their care partners, being knowledgeable about the kinds of services needed, and being able to inform or refer to agencies and individuals that provide such services. It typically includes increasing the knowledge and skills of those who care for or interact with people living with dementia and their supporters, identifying gaps in services and providing long-term services and supports to meet the needs of people living with dementia and their care partners. (Alzheimer’s Association, 2016).

GLOSSARY

Dementia Friendly: Often used in the context of community, dementia friendly indicates a community that makes intentional changes to ensure their safety and accessibility for people living with dementia, as well as to support people living with dementia to remain engaged and participate in the life of the community (Alzheimer's Association, 2016).

Dementia-related behaviors: Used to describe a large group of symptoms associated with Alzheimer's disease and related disorders including sleep disturbances, agitation (physical or verbal aggression, general emotional distress, restlessness, pacing, shredding paper or tissues and/or yelling), delusions (firmly held belief in things that are not real) and hallucinations (seeing, hearing or feeling things that are not there). These symptoms may be caused by things like pain, drug interactions, or changes in the environment or routine among others. It is important to try non-pharmacologic strategies to address behaviors before adding medications. (Alzheimer's Association, 2019b).

Evidence-Based: Based on research. Evidence-based programming translates tested program models or interventions into practical, effective programs that can provide proven health benefits to participants. When an evidence-based program is implemented, there is proof that the program works.

Evidence-Informed: Reflects the deliberate and systematic use of the best available evidence. This is combined with a distillation of the experience of experts where that evidence is not available, to inform clinical decision-making and evaluation, program development and policy creation.

Formal/Professional Care Partner/Caregiver: Professionals or paraprofessionals who are paid in exchange for providing care.

Home and Community Based Services (HCBS): Assistance provided to individuals so they can remain in their homes and communities. Services could include case management, homemaker services, home health, adult day services, personal care, respite care, as well as other related activities.

Hospice Care: Hospice care is designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home, such as freestanding facilities, nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs, as well as medical symptoms as part of treating the whole person.

Informal Care Partner/Caregiver: Individuals, usually family members, friends, neighbors or volunteers who provide unpaid support and care.

Interdisciplinary Memory Assessment Center: These centers have multi-disciplinary teams that provide a comprehensive dementia assessment and diagnosis, continuing care for individuals diagnosed with dementia, access to support groups, and opportunities to join clinical trials.

Long-Term Care (LTC): encompasses a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community (e.g., adult day services), in assisted living or in nursing homes. People may need long-term care at any age.

Medicaid: Medicaid is health insurance available to certain people and families who have limited income and resources. Eligibility may also depend on how old you are and whether you are pregnant, whether you are blind or have other disabilities, and whether you are a US citizen or a lawfully admitted

GLOSSARY

immigrant. People with Medicaid may also get coverage for services such as nursing home care and home and community based services.

Medicaid Waivers: Medicaid Waivers were developed to encourage people with disabilities and the elderly to access services in their homes and communities. Medicaid is a joint federal-state program. Through Medicaid Waivers, states can “waive” certain requirements including the requirement that individuals live in institutions in order to receive Medicaid funding. Medicaid Waivers provide funding to provide people who are eligible for long-term care in institutions such as hospitals, nursing facilities, and intermediate-care facilities to access home and community-based services.

Medicare: Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD). The different parts of Medicare help cover specific services. Part A covers inpatient hospital stays, short-term care in a skilled nursing facility, hospice care and some short-term home health care. Part B covers certain doctors’ services, outpatient care, medical supplies and preventive services. Part C (Medicare Advantage Plans) is a type of Medicare health plan offered by private companies that contract with Medicare to provide all Part A and Part B benefits. Part D plans offered by private companies cover prescription drugs. Through the Virginia Insurance Counseling and Assistance Program, Virginia offers free, unbiased, confidential counseling on Medicare and related insurance programs (call 800-552-3402 for more information).

Person-Centered Care: It empowers staff to be a resident advocate and honors each person’s dignity, rights, self-respect, and independence. It allows individuals to make choices, and requires staff to respect the wishes of the individual receiving services. It requires involving the person in decision making to provide the person with control of their own life.

Program of All-Inclusive Care for the Elderly (PACE): PACE provides the following services: adult day care, physical, occupational and recreational therapies, meals, nutritional counseling, social work, personal care, home health care, necessary prescription drugs, social services, medical specialties, respite care and hospital and nursing home care when necessary. Recipients must be at least 55 years of age, live in the PACE service area, be screened by a care team and found to meet the nursing facility level of care, and be able to live safely in a community setting at time of enrollment.

Respite Care: Respite care is the provision of relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned breaks for family and other unpaid care partners. There is much evidence demonstrating the benefits of respite for both the care recipient and care partners.

Skilled Nursing Facility: Skilled nursing facilities, also known as nursing homes, provide housing, meals, skilled and intensive medical care, personal care, social services, and social activities to people who have physical or behavioral conditions that prevent them from living alone. Medicare and private insurance typically cover short-term nursing home stays for skilled care needs, but they do not cover long-term stays.

Subjective Cognitive Decline: Self-reported memory problems that have been getting worse over the previous twelve months. Subjective cognitive decline is a risk factor for developing mild cognitive impairment or dementia, but does not necessarily develop into those conditions. People experiencing subjective cognitive decline should discuss their concerns with a healthcare provider. The BRFSS Cognitive Decline module provides data on the prevalence and impact of subjective cognitive decline.

Translational Research: Taking the findings from basic science and applying them to enhance the health of humans, particularly through the development and implementation of treatment options.

REFERENCES

- Alzheimer's Association and Centers for Disease Control and Prevention (2018). Healthy Brain Initiative, State and Local Public health partnerships to address dementia: The 2018-2023 road map. Chicago, IL: Alzheimer's Association.
- Alzheimer's Association (2016). A public health approach to Alzheimer's and other dementia: Module 4 Dementia capable systems and dementia friendly communities [PDF file]. Retrieved February 25, 2019, from <https://www.cdc.gov/aging/aginginfo/pdfs/ALZ-Module4-Dementia-Capable-Systems-Dementia-Friendly-Communities.pdf>
- Alzheimer's Association (2018). Cognitive decline in Virginia [PDF file]. Retrieved March 12, 2019 from <https://www.alz.org/media/Documents/virginia-brfss-cognitive-decline-2015.pdf>
- Alzheimer's Association (2019a). 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 15, 321-387.
- Alzheimer's Association (2019b). Dementia-related behaviors. Retrieved September 6, 2019, from <https://www.alz.org/media/Documents/alzheimers-dementia-related-behaviors-ts.pdf>
- Alzheimer's Association (2019c). Overcoming stigma. Retrieved March 14, 2019, from <https://www.alz.org/help-support/i-have-alz/overcoming-stigma>
- Alzheimer's Association (2019d). What is Alzheimer's? Retrieved February 5, 2019, from <https://www.alz.org/alzheimers-dementia/what-is-dementia>
- Centers for Disease Control and Prevention (2018). Virginia Caregiving [PDF file]. Retrieved March 12, 2019 from <https://www.cdc.gov/aging/data/pdf/2015-brfss-virginia-caregiving-h.pdf>
- Kaspar, J.D., Freedman, V.A., Spillman, B.C., & Wolff, J.L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*, 34, 1642-1649. <https://doi.org/10.1377/hlthaff.2015.0536>
- Langa, K.M., Larson, E.B., Crimmins, E.M., Faul, J.D., Levine, D.A., Kabeto, M.U., & Weir, D.R. (2017). A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Internal Medicine*, 177, 51-58.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S.G., Huntley, J., Ames, D., Ballard, C., ..., Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet Commissions*, 390, 2673-2734.
- National Institute on Aging (2017). Cost-effective Early Detection of Cognitive Decline, Meeting October 25, 2017 [PDF file]. Retrieved February 5, 2019, from <https://www.nia.nih.gov/sites/default/files/2018-01/final-cognitive-decline-summary.pdf>
- Pritchett, G.D. (2017). Assessment and diagnosis of dementia in individuals with intellectual disability: A toolkit for clinicians and caseworkers [PDF file]. Retrieved on February 28, 2019, from <http://www.wai.wisc.edu/pdf/IDDtoolkit.pdf>
- United States Centers for Medicare and Medicaid Services (2015). Retrieved on February 28, 2019, from https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Medicare_Beneficiary_Characteristics.html
- United States Department of Health and Human Services (2018). National plan to address Alzheimer's disease: 2018 update [PDF file]. Retrieved on March 14, 2019, from <https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf>
- Williamson, J.D., Pajewski, N.M., Auchus, A.P., Bryan, R.N., Chelune, G., Cheung, A.K., Cleveland, M.L., ..., Wright, C.B. (2019). Effect of intensive vs standard blood pressure control on probable dementia: A randomized clinical trial. *JAMA*, 321, 553-561. <https://doi.org/10.1001/jama.2018.21442>