

THE 2013 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: RECOMMENDATIONS AND ACTIVITIES

Pursuant to 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. The Commission advises the Commonwealth on the care of individuals with Alzheimer's disease and other dementias, and how to assist their caregivers.

Dementia State Plan and National Alzheimer's Plan

In December 2011, the Commission released the *Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers*. This plan serves to advise policy makers, legislators, other public officials, health and human services professionals, advocates, and other interested people about best practices and strategies as the Commission and all public and private partners work together to better serve individuals with dementias and their family members, friends, and care providers.

On May 15, 2012, the federal government released the country's first National Alzheimer's Plan (Plan). It is the result of a mandate in the National Alzheimer's Project Act (NAPA), which Congress passed unanimously in December 2010. The Plan, which will result in important progress when fully implemented, sets out to prevent and effectively treat Alzheimer's by 2025.

The concerted efforts of state and federal planning will provide the best chance of overcoming Alzheimer's disease and related disorders. 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 other dementias and their caregivers.

COMMISSION RECOMMENDATIONS FOR 2014 GENERAL ASSEMBLY ACTION TO IMPLEMENT THE DEMENTIA STATE PLAN

Extend the Commission's Sunset to July 1, 2021.

The number of people affected by Alzheimer's disease is expected to increase 60% by 2025 in Virginia making the Commission's continuation necessary.

The Commission, composed of 15 members and established in 1982, serves in an advisory capacity to the Governor and the Secretary of Health and Human Resources. Code of Virginia § 51.5-154, which establishes the Commission, expires July 1, 2014. In 2009, approximately 65% of residents of Virginia's nursing facilities had cognitive impairment related to dementia. Life expectancy is increasing while the prevalence of dementia increases beyond age 65. The number of people being affected by Alzheimer's disease, the most prevalent form of dementia, is growing at a faster rate than our health care system can handle. Given its accomplishments thus far and proven track record of advocacy for the needs of individuals with dementia and their caregivers, the Commission recommends extending its sunset by seven years until July 1, 2021 to enable it to carry out the goals of the Dementia State Plan and to address the challenges that lay ahead to prevent and effectively treat Alzheimer's by 2025.

ALZHEIMER'S DISEASE FACTS AND FIGURES:

Statistics published in the Alzheimer's Association's 2013: *Alzheimer's Disease Facts and Figures* found at www.alz.org document the rapidly growing Alzheimer's crisis:

- Over **5 million** Americans are living with Alzheimer's disease, and as many as **16 million** will have the disease in 2050.
- **1 in 3** older Americans dies with Alzheimer's or another dementia.
- Alzheimer's disease is the **6th** leading cause of death in the United States.
- The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$203 billion** in 2013, increasing to **\$1.2 trillion** by mid-century.

ACCOMPLISHING THE GOALS OUTLINED IN THE DEMENTIA STATE PLAN 2011-2013

- **COORDINATE CARE:** The 2013 General Assembly fully funded the Dementia Services Coordinator position in DARS to ensure a dementia-capable services system.
- **SERVICES:** Medicaid and other state-level services expanded including the DARS Virginia Lifespan Respite Voucher Grant and the increase in the Medicaid adult day care rate in 2013.
- **DATA:** Collected state-wide prevalence data from the Department of Behavioral Health and Developmental Services for 2012 and used the Behavioral Risk Factor Surveillance System (through VDH) to collect health outcomes data using the Cognitive Impairment Module in 2012.
- **TRAINING:** Commission received GTE funding in 2011 and 2012 for training webinars on dementia.
- **RESEARCH:** 2013 General Assembly provided the ARDRAF an increase of \$125,000.



Coordinate ARDRAF with Goals of the Dementia State Plan

Virginia needs to invest in the recommendations of the Dementia State Plan to ensure the Commonwealth is dementia capable.

The Alzheimer’s and Related Diseases Research Award Fund (ARDRAF) gives annual awards 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 citizens of the Commonwealth (Code of Virginia § 51.5-153). In 2013, the General Assembly increased the ARDRAF by \$125,000, an increase of over 60%. The Commission recommends coordination of ARDRAF research funding with the goals of the Dementia State Plan.

Expand State Long-Term Care Ombudsman’s Access to Records of Community Providers

The State Long-Term Care Ombudsman Program’s access to records is currently limited to institutional settings and needs to be expanded to providers of community services.

The State Long-Term Care Ombudsman Program (SLTCOP) was established through the Older Americans Act to advocate for people living in long-term care facilities. One responsibility of the SLTCOP is to respond to and resolve complaints made by, or on behalf of, these residents. As Virginia moves services for long-term care from institutional settings to the community, the role of the SLTCOP is expanding. Code of Virginia § 51.5-139 gives the SLTCOP authority over community based long-term care providers, but § 51.5-140 limits the SLTCOP’s access to records regarding long-term care provided to residents only in institutional settings, namely nursing homes, assisted living facilities, and geriatric units of state hospitals. The Commission recommends an amendment to the Code of Virginia to expand SLTCOP’s access to records of providers of community based services to fulfill their programmatic responsibilities as Virginia modernizes the system of long-term care services and supports from institutional to community based care.

Increase Funding for the Public Guardian and Conservator Program.

The aging of the population makes it imperative that Virginia fiscally support public guardianship services so that persons suffering from dementia may be free of neglect, exploitation and abuse and have a maximized quality of life.

In FY 2012, the Virginia Public Guardian and Conservator Program had a capacity to serve 601 persons in the Commonwealth. Additional public guardianship funding is needed to stabilize the program, provide for the unmet demand, including some incapacitated persons leaving state training centers under the Department of Justice Settlement and those undergoing prison reentry, and expand the program into other regions of the state. Older public guardianship programs are reaching a crisis point. Funding has not increased and yet the programs are under court order to provide services throughout the incapacitated person’s lifetime. Without an increase in funding, one or more guardianship contractors are likely to discontinue providing services. With no willing provider, the state is responsible. The unmet demand for public guardian services is projected at 1200.¹ Additional funding will help in the community placement of persons who are incapacitated. This includes expanding guardianship services in other areas of the state such as New Kent, Mecklenburg and Halifax Counties.

¹ [The Need for Public Guardians in the Commonwealth of Virginia—Final Report](#), Center for Gerontology, Virginia Polytechnic Institute and State University, Roberto, Duke, Brossoie and Teaster Report (2007) p.ii.

COMMISSION ACTIVITIES

In July 2013, the Commission welcomed **Charlotte Arbogast, MSG**, as Virginia's first Dementia Services Coordinator (DSC) who will review existing programs and work with agencies to create a dementia-capable service delivery system. Ms. Arbogast will identify gaps in Medicaid and other state services and reduce duplication of existing services and disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academia, primary caregivers, advocacy organizations and the general public. Ms. Arbogast will establish a strategy to link and coordinate services and activities of state agencies, other service providers, advocacy groups, and other entities throughout Virginia such as emergency personnel, police, universities, and attorneys. This could include partnerships with the Alzheimer's Association, Area Agencies on Aging, and other groups involved with dementia research and care. She will oversee and promote services for all types and stages of Alzheimer's and related dementias, including individuals with younger onset dementias and support the Aging and Disability Resource Centers in becoming dementia capable. Persons may contact the DSC through the VACAPI (Virginia Alzheimer's Commission AlzPossible Initiative) website (www.alzpossible.org). VACAPI is an online platform dedicated to learning, sharing, and formulating concrete solutions to the problems involved in Alzheimer's disease caregiving.

The Commission received funding in 2013 through the Virginia Center on Aging's Geriatric Training and Education Initiative (GTE) to implement a series of free webinar training events using VACAPI entitled, **SAFE@HOME**, to provide tools, environment, coordination, and management to support the delivery of educational information to Virginia professional home care services providers. The courses held were:

Balancing Maximum Independence and Home Safety for Individuals with Dementia

Live webinar held June 5, 2013

Assistive Technology for Home Safety

Live webinar held June 12, 2013

High Tech@Home: Not Your Grandma's Eldercare

Live webinar held June 19, 2013

Through VACAPI, the Commission promotes public access to the results of research being conducted in the Commonwealth and clearly demonstrates that the research is effective. The Commission also will continue to use the VACAPI website as a forum to link researchers interested in Alzheimer's disease research. VACAPI posts information on ARDRAF applications and deadlines. VACAPI links to the Alzheimer's Association TrialMatch®, a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's, caregivers, healthy volunteers and physicians with current studies.

CURRENT FOCUS

The Commission continues to partner with public and private partners throughout Virginia and at the national level to implement the Dementia State Plan and address the Alzheimer's crisis. The Commission stands ready to promote its recommendations in the coming 2014 General Assembly session, which collectively promote research to prevent and effectively treat the disease, expand support for the people with the disease, and enhance care quality and coordination. Additional information about the Commission may be found on the Commission's website, <http://www.vda.virginia.gov/alzcommission.asp>.