

THE DELAWARE STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE AND RELATED DEMENTIAS 2016 Progress Report In December 2013, the Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), in conjunction with the Alzheimer's Association Delaware Valley Chapter, released the <u>Delaware State Plan to Address Alzheimer's Disease and Related Disorders</u>. The plan was developed out of recognition of the enormous social, emotional, and economic impact of Alzheimer's disease and the need to find creative approaches to support the many people impacted in Delaware.

The plan identified five goals, each with accompanying objectives and strategies. Broadly speaking, the plan outlines actions to: increase awareness of and understanding about Alzheimer's disease; bring focused attention to the development of long term care services for persons with Alzheimer's disease; strengthen support for caregivers; improve the capacity of Delaware's workforce to respond to the needs of persons with Alzheimer's disease; and increase Delaware's capacity for Alzheimer's disease-related research and data collection.

Through the Delaware Alzheimer Disease Initiative Steering Committee, five workgroups, corresponding with the five goals of the Plan, were developed. Members of the Steering Committee chair each. The Steering Committee consists of the following individuals:

- Henry Alisa, Caregiver
- Bob Bird, <u>Home Instead</u>
- Patricia Curtain, M.D., Christiana Care Health System
- Michael Gitcho, Ph.D., <u>Delaware State University</u>
- Joan Gleckel, Psychiatric Nurse Consultant
- Kelvin Lee, Ph.D., University of Delaware
- Denise Lyons, MSN, <u>Christiana Care Health System</u>
- Katie Macklin, <u>Alzheimer's Association Delaware Valley Chapter</u> (co-chair)
- Barbara McCaffery, Division of Services for Aging and Adults with Physical Disabilities
- Cindy Mercer, Division of Services for Aging and Adults with Physical Disabilities (co-chair)
- Veronica Rempusheski, <u>University of Delaware</u>
- Pat Risher, <u>AARP</u>

This is the 2016 Progress Report of the activities of the workgroups.



Alzheimer's Disease is the 6th Leading Cause of Death in the United States.

1 in 3 seniors dies with Alzheimer's or another dementia.

More than 5 million Americans are living with Alzheimer's.

Alzheimer's Association 2016 Alzheimer's Disease Facts and Figures

GOAL #1

PROMOTE PUBLIC AWARENESS OF ALZHEIMER'S DISEASE

This workgroup consists of several active members. The group is working with nontraditional partners to let people know about the warning signs of Alzheimer's. Evidence based messaging has also been used throughout the state, including the Alzheimer's Association facts and figures report, which was included in the 2016 <u>Guide to Services for Older Delawareans and</u> Persons with Disabilities.

The workgroup also developed the <u>Alzheimer's Toolkit</u> to promote resources and services. The toolkit, housed on the DSAAPD website, has been advertised statewide. The workgroup is now developing a pamphlet to be shared widely.

Alzheimer's Toolkit



GOAL #2 IMPROVE THE DELIVERY OF SERVICES TO PERSONS WITH ALZHEIMER'S DISEASE

This workgroup consists of 22 active members from a cross-section of the aging system. The workgroup drafted a letter to the Division of Public Health (DPH) Director to include Alzheimer's disease as a focus area in the Health Promotion and Disease Prevention Section. While the response was positive, the Director asked for more specific things DPH can do to promote Alzheimer's disease. The group is now working on identifying what those specific things are.

The workgroup has met with several agencies throughout Delaware that work with people diagnosed with Alzheimer's disease and related dementias in order to discuss roadblocks of service delivery. One of the main concerns is that while plenty of information is available to the public, service providers face challenges in reaching the public, especially in rural areas. The workgroup is looking at nontraditional partners, like casinos, to get the information to the public. Delaware's federal representation has expressed interest in overcoming this challenge.

DSAAPD, through the urging of this workgroup, has designated two registered nurses with expertise in Alzheimer's disease and related dementias to be available for consultation to other long-term care service providers. The RN's will be the point people for resources.

GOAL #3

STRENGTHEN THE SUPPORT OF CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE

This workgroup consists of 20 active members, including caregivers of those diagnosed with dementia, religious leaders, and staff from organizations working with caregivers. The workgroup completed a review of currently available resources and audited DSAAPD's <u>Guide to Services for Older</u> <u>Delawareans and Persons with Disabilities</u> and the <u>Alzheimer's Toolkit</u>. Both of these resources have caregiver sections. The workgroup made recommendations on what to add to the Guide and Toolkit and accessibility of those resources.

The group then identified the need for a consolidated resource, including a multi-purpose brochure or pamphlet, that would be available to caregivers and those diagnosed with dementia. The workgroup will work with the Public Awareness workgroup to develop this. One way to reach caregivers is to have the information available at pharmacies and doctor's offices. The group is also looking at non-traditional partners, like financial institutions, to have information about Alzheimer's disease resources available to customers.

The workgroup is now researching specific needs of diverse caregivers and ways to address those needs. One recommendation is for the Delaware Ecumenical Council and other faith-based partners to collaborate with the Alzheimer's Association to break down the barrier of denial about Alzheimer's disease because it is often seen as taboo. A subcommittee has been formed to address this.

GOAL #4 ACHIEVE AN ALZHEIMER'S-COMPETENT WORKFORCE IN THE STATE OF DELAWARE

This workgroup consists of 24 active members, from a cross-section of the aging system. The workgroup completed an inventory of dementia trainings given to staff, as well as to clients, at all senior centers in Delaware. The workgroup also did an informal environmental scan of dementia trainings provided to healthcare providers throughout the state and then compiled a listing of required dementia lessons available for CNA's in Delaware. This cataloguing was to see what training was currently available and where Delaware's professionals need more training.

A focus of this workgroup has also been on working with underserved populations, like those who have Down's syndrome and dementia. Trainings are being identified that will enhance service delivery to these populations. The workgroup is collaborating with the disabilities community and Public Health on this in pushing for more training opportunities.

Three dementia competency trainings, one a train-the-trainer, were held. The trainings were a collaboration between DSAAPD, the Alzheimer's Association and the Division of Substance Abuse and Mental Health. More multi-professional trainings are being developed and conducted throughout the state. Professionals include health care, first responders, retail, and anyone who may deliver a service to someone diagnosed with dementia.

GOAL #5

IMPROVE AND EXPAND DELAWARE'S ALZHEIMER'S AND DEMENTIA-RELATED INFRASTRUCTURE (DATA, QUALITY ASSURANCE, RESEARCH) BY SUPPORTING THE CREATION OF A DELAWARE CENTER FOR ALZHEIMER'S AND RELATED DEMENTIAS [DECARD])

This workgroup consists of five members, including Delaware's major colleges and universities. The workgroup is in the process of establishing the Delaware Center for Alzheimer's and Related Dementias (DECARD). The group foresees DECARD to be a virtual hub of information for Alzheimer's information in Delaware. A website has been purchased and is being developed.

The workgroup was also instrumental in getting the cognitive impairments module added to the Behavioral Risk Factor Surveillance System (BRFSS) in Delaware. BRFSS is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Delaware will use the cognitive module to inform how the state addresses dementia and other cognitive impairments in the future.

Need Help or More Information about Alzheimer's? Contact the <u>Delaware Aging and Disability Resource Center (ADRC)</u> or the <u>Alzheimer's Association Delaware Valley Chapter</u>.

WANT TO GET INVOLVED? BE A PART OF THIS DYNAMIC EFFORT ACROSS DELAWARE! EVERYONE IS WELCOME TO JOIN.

Would you like to join Delaware's efforts to support people with Alzheimer's disease and related disorders (ADRD)? Committees to advance the <u>State Plan to Address ADRD</u> are now accepting new members.

Most groups meet once a month during the workday and a call-in option is available if you cannot make the meetings in person.

If you are interested, please contact the <u>Delaware Aging and Disability Resource Center (ADRC)</u> and ask to speak with the Alzheimer's State Plan Committee volunteer coordinator.

If you cannot commit to a workgroup, but want to remain informed, follow the progress of the State Plan by visiting <u>DSAAPD's webpage</u> devoted to updates on the Division's dementia related activities.

