



Delaware State Plan to Address Alzheimer's Disease and Related Disorders



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Introduction

The *Delaware State Plan to Address Alzheimer's Disease and Related Disorders* is a joint project of the Alzheimer's Association Delaware Valley Chapter and the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD). 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 represents a major step forward in bringing together advocates, caregivers, and professionals from healthcare, education, and social services to identify ways to more effectively address current and future needs related to Alzheimer's disease. Individuals with diverse backgrounds and areas of expertise converged to offer their energy and talents in the development of the plan.

The plan identifies 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.

The same level of collaboration among individuals and organizations that went into developing the plan is anticipated as Delaware moves forward with the plan's implementation. As part of the process of creating the plan, it became clear that many Alzheimer's-related resources already exist in Delaware and that the greatest impact will be derived from coordinating, combining, or leveraging those resources where most needed. Actions identified in the plan will be addressed through partnerships and the focused use of existing resources.

Project partners have already expressed eagerness to begin working on various tasks identified in the plan, and these efforts will begin immediately upon the plan's completion. The Alzheimer's Association Delaware Valley Chapter and DSAAPD will coordinate implementation activities and will track progress in meeting goals and objectives outlined in the plan. Given the high level of interest and commitment among individuals and organizations involved in the process thus far, it is expected that the plan can achieve results that will have a significant and positive impact on Delaware's caregivers, service professionals, and population living with Alzheimer's disease.

* The term "Alzheimer's disease" used in this plan refers to Alzheimer's disease and related disorders. Consistent with the definition used in the national Alzheimer's plan, related disorders include frontotemporal, Lewy body, mixed, and vascular dementia.

Impact of Alzheimer's Disease

The impact of Alzheimer's disease is far-reaching. It is estimated that over five million* Americans currently have the disease. While many cases of early-onset Alzheimer's disease exist (there are approximately 200,000 cases of persons under age 65 with the disease today), the majority of persons with the disease are aged 65 and over. Among Americans aged 65 and over, 1 in 9 persons is currently living with Alzheimer's, and among those aged 85 and over, the ratio is 1 in 3. In 2010, over 83,000 Americans died of Alzheimer's disease, making it the country's sixth leading cause of death. Unlike some of the other top causes of death in this country, at this time there is no proven way to prevent it, cure it, or consistently slow its progression. Moreover, the incidence of Alzheimer's disease is skyrocketing in proportion to the growth in the older population. It has been estimated that by 2050, nearly 16 million Americans will have Alzheimer's disease.

My mom and dad were married for 46 years when my dad passed away with Alzheimer's. They did not get to enjoy their golden years as they had intended to but my mom did what she set out to do which was to take care of my dad until the end. My mom was the most courageous woman who ever walked this earth and she was not afraid to be my dad's voice so he would get the proper care he so deserved! Alzheimer's stole my dad from me and I worry every day that it will steal me from my only daughter. - Paula

In Delaware, the incidence of the disease is equally daunting. It was estimated that in 2010, 14,000 Delawareans aged 65 and older were living with Alzheimer's disease. This number does not include the many thousands more with younger-onset Alzheimer's disease or those with related dementias. According to

the Alzheimer's Association Delaware Valley Chapter, approximately 26,000 Delawareans are living with Alzheimer's disease or a related disorder. As would be expected, the number of people with Alzheimer's disease in Delaware has grown since the State, like the rest of the country, is in the midst of an unprecedented growth in the older population. Between 2000 and 2025, the number of persons aged 65 and over with Alzheimer's disease in Delaware is expected to grow by 33% (from 12,000 people to 16,000 people).

The prevalence of Alzheimer's disease has a significant impact on the health care system and on health care costs. It is estimated that in 2013, the direct costs of caring for Americans with Alzheimer's disease will total

I was a caregiver for my mother who had Alzheimer's disease. I feel there is a need for more support and education for caregivers. When my mother received the diagnosis, I received little to no information from my mother's doctor. I felt like caregiving was sink or swim. - Joyce

* Prevalence and cost data have been provided by the Alzheimer's Association (www.alz.org).

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As I'm finding out just about every day, the State of Delaware has so many programs out there that most people either do not know about or do not take advantage of. My mother had Alzheimer's, and the first source, besides the computer, was turning to the Alzheimer's Association of Delaware to give me a better understanding. It would be great to educate all Delawareans of the great resources that we have right in our own backyard. - Rich

\$203 billion, including \$35 billion and \$107 billion in costs to Medicaid and Medicare respectively. The average per-person costs for Medicare beneficiaries with Alzheimer's and other dementias are three times higher than for those without those conditions. For Medicaid, the cost differential is staggering: the average per-person Medicaid spending for seniors with Alzheimer's and other dementias is 19 times higher than the average per-person costs for all other seniors.

The growth in the incidence of Alzheimer's disease has important implications for health care providers. The expansion of the older population nationally and in Delaware has created an increased demand for health care services, including importantly, the demand for long term care services. Nursing homes, assisted living facilities, home health agencies, personal assistance services agencies, adult day services agencies and other providers require staff to support a growing population with long term care service needs. Beyond that, all health care providers must rely increasingly on

the availability of a workforce that has been trained to support the specific care needs of individuals with Alzheimer's disease and related disorders.

The impact of Alzheimer's disease is experienced perhaps most intensely by family caregivers. As a group, family members caring for persons with Alzheimer's disease tend to experience a tremendous amount of emotional stress and often sacrifice their own physical well-being. In addition many family caregivers carry an economic burden related to their caregiving.

It has been estimated that in the U.S. in 2012, 15.4 million informal caregivers (family and friends) provided over 17 billion hours of unpaid care to persons with Alzheimer's disease and other dementias. More than 60 percent of caregivers rated the emotional stress high or very high, and over one-third reported symptoms of depression. The physical and emotional stress of caregiving resulted in an additional \$9.1 million in health care expenditures in 2012 for caregivers themselves. In addition, caregivers have other out-of-pocket expenditures. Long-distance caregivers (those who live

When my wife first showed signs of memory problems, she was 53 years old. A year later she was diagnosed as having Alzheimer's disease. That was 10 years ago and she now lives in a nursing home, under Medicaid coverage, at the young age of sixty-three. This disease has taken our retirement years from both of us. She can't enjoy her grandchildren, vacations, traveling, family get-togethers or anything else that she loved. My request: support efforts to get funding for research and more public awareness about this disease. - Anon

I prepared a wonderful meal for Mom and she said that my sister Alice had prepared the meal and how good it was. My heart dropped because I knew that I was the better cook and that my sister had passed away years ago. I decided to go along with Mom's comment and agreed that Alice had indeed cooked a good meal. I know that that is not the comment I would have gotten if she was not affected by Alzheimer's but it did make me sad. - Helen

an hour or more away) tend to incur about twice as many out-of-pocket costs.

Delaware is home to a very large number of caregivers. In 2012, approximately 51,000 Delawareans provided 58 million hours of unpaid care to persons with Alzheimer's disease or other dementias. Additional health care costs for Delaware's caregivers in 2012 were an estimated \$37 million dollars.

Throughout the development of this plan Delaware caregivers freely expressed, many times in heartbreaking detail, how the realities of the disease have affected them and their families. For these caregivers, statistics about prevalence and other demographic realities do not begin to portray the loss and grief that they experience. Some of their words are shared here to illustrate the human impact of Alzheimer's disease in Delaware.

Methodology

The process of the development of the *Delaware State Plan to Address Alzheimer's Disease and Related Disorders* was initiated in early 2012. The Alzheimer's Association Delaware Valley Chapter coordinated a meeting with Governor Jack Markell, Secretary of the Department of Health and Social Services Rita Landgraf, and Director of the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) Bill Love. During the meeting, there was a consensus about the importance of mapping out a strategy to address Alzheimer's disease in Delaware, and a decision was made to begin working on the development of an Alzheimer's State Plan.

The Alzheimer's Association and DSAAPD established a task force, comprised of caregivers, advocates, and professionals representing a broad range of organizations. (A list of task force members is included in Appendix A.) The task force met in September and December 2012 to review background information and establish the foundation of the plan. With support from DSAAPD staff, the task force created an initial draft of the plan's goals, objectives, and strategies.

Following the December 2012 meeting of the task force, five working groups were formed, each of which was co-chaired by two members of the task force and included additional persons recommended by the chairs. (See Appendix B.) Working group topics included the following:

- Caregiver support
- Public awareness and outreach
- Improving service delivery
- Improving and expanding the state's home and community-based infrastructure
- Training and professional development

The working groups were charged with reviewing and making recommendations about the initial draft of the goals, objectives, and strategies. The groups met and had follow-up phone conferences between January and April 2013 and then submitted their recommendations to the task force.

The task force held a third meeting in April 2013 to review working group recommendations, to suggest further revisions, and discuss plans for upcoming town hall meetings to get public input into the plan. On May 1, 2013 the goals, objectives and strategies were re-drafted to incorporate working group and task force member recommendations and were ready for public review.

Three town hall meetings were scheduled in June 2013 to provide the general public the opportunity to offer input into the plan. The town hall meetings were advertised via a statewide press release as well as an announcement on DSAAPD's website. The goals, objectives and strategies document was made available in advance of the town hall meetings via web download. (Individuals who needed or preferred the document in another format were encouraged to contact DSAAPD for assistance.) In addition, individuals who were not able to

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attend the town hall meetings or who preferred to make comments outside of the meetings were informed that comments would be accepted by phone, mail, e-mail or fax until mid-July 2013.

One town hall meeting was conducted in each of Delaware's three counties. The meeting schedule was as follows:

- June 24, 2013
6:00 PM to 8:00 PM
John H. Ammon Medical Education Center
Newark, Delaware
- June 25, 2013
6:00 PM to 8:00 PM
Alzheimer's Association Julie H.C. Bailey Training Center
Smyrna, Delaware
- June 26, 2013
6:00 PM to 7:45 PM
Brandywine Assisted Living at Fenwick Island
Selbyville, Delaware

As part of each of the meetings, persons in attendance were provided with background information and copies of the plan's goals, objectives and strategies document. It was explained that feedback on the plan would be welcomed during the town hall meetings or any time until the mid-July deadline. Individuals were then offered the opportunity to make comments or suggestions, ask questions, or share other information related to the plan. Discussion was recorded at each meeting by DSAAPD staff.

A fourth meeting of the task force was held in July 2013. During this meeting, task force members were provided with a compilation of the feedback received during and after the town hall meetings and a revised draft of the goals, objectives, and strategies that incorporated the public input. The task force also was given an outline of additional content areas, including appendices, to be included in the plan. Task force members provided final feedback on the goals, objectives, and strategies and offered guidance on the construction of the completed version of the plan.

The plan was completed in December 2013 after final review and input from members of the task force.

Goals, Objectives, and Strategies

Goal # 1: Promote public awareness of Alzheimer's disease

Objective 1.1 Build on existing public and private partnerships to support a comprehensive public education campaign using reliable and evidence-based Alzheimer's related educational messages

Strategy 1.1.1 Develop and implement a high impact campaign across Delaware to disseminate information on Alzheimer's disease, services available, and community resources available for support (e.g., meetings with editorial board of the News Journal, Governor's weekly radio message, op-ed's, etc.)

Strategy 1.1.2 Explore and identify reliable and evidence-based messages on Alzheimer's disease working in close collaboration with the Alzheimer's Association

Strategy 1.1.3 Disseminate messages using a variety of forums, such as community events, health fairs, speaking engagements, public service announcements, and web-based social media

Strategy 1.1.4 Coordinate with community partners to promote outreach to rural communities, minority populations, and non-English speaking persons (e.g., Latin American Community Center, La Red Health Center, and other organizations that will facilitate the dissemination of information to Spanish-speaking communities)

Strategy 1.1.5 Build strong partnerships with the health care community (e.g., Medical Society of Delaware) and develop avenues for reaching physicians and others in health care on best practices and emerging issues in treatment and support for individuals with Alzheimer's disease

Objective 1.2 Expand available materials and links to resources related to Alzheimer's disease

Strategy 1.2.1 Expand resources related to Alzheimer's disease listed in future editions of DSAAPD's *Guide to Services for Older Delawareans and Persons with Physical Disabilities*

Strategy 1.2.2 Expand information on DSAAPD's websites (intranet and internet) for staff, other professionals, and the general public

Objective 1.3 Explore opportunities to expand dissemination of educational materials that foster increased public awareness of Alzheimer's disease

Strategy 1.3.1 Identify and engage the support of non-traditional partners to expand dissemination of educational materials (e.g., the faith-based community, AARP, employers, Delaware Restaurant Association, libraries, Social

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- Security offices, Division of Motor Vehicles, and others points of heavy community traffic)
- Strategy 1.3.2 Promote efforts to prevent, detect, and address abuse, neglect, mistreatment, and exploitation of persons with Alzheimer's disease

Goal # 2: Improve the delivery of services to persons with Alzheimer's disease

Objective 2.1 Promote early detection of Alzheimer's disease so individuals can participate in decision making about living options and financial and legal matters

- Strategy 2.1.1 See Strategy 1.1.3 (Disseminate messages using a variety of forums, such as community events, health fairs, speaking engagements, public service announcements, and web-based social media)
- Strategy 2.1.2 Advocate for the inclusion of Alzheimer's disease as a focus area in the Division of Public Health's Health Promotion and Disease Prevention Section

Objective 2.2 Identify barriers to services for persons with Alzheimer's disease

- Strategy 2.2.1 Perform a service needs assessment, at each stage of the disease that includes caregivers as well as persons with Alzheimer's disease and other dementias
- Strategy 2.2.2 Survey community and facility based long term care* service providers as they serve people with Alzheimer's at each stage of the disease
- Strategy 2.2.3 Identify Alzheimer's-related service and educational challenges faced in locations with large numbers of older individuals residing in rural areas, including access to emergency psychiatric care, and recommend targeted actions to effectively address these challenges

Objective 2.3 Address the barriers to services for persons with Alzheimer's disease

- Strategy 2.3.1 Designate a staff person within the Division of Services for Aging and Adults with Physical Disabilities with expertise in Alzheimer's disease and other dementias, such as a nurse, to be available for consultation by other long term care service providers
- Strategy 2.3.2 Create a mobile interdisciplinary team with expertise in Alzheimer's disease and other dementias and behavioral issues to be available for consultation to long term care service providers
- Strategy 2.3.3 Improve access to home and community-based services by disseminating information on services to the medical and health care

* See glossary in Appendix C

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- community, academic community, primary family caregivers, advocacy associations, and the general public
- Strategy 2.3.4 Provide training in Alzheimer’s disease and other dementias to DSAAPD case managers, ADRC call center staff, and front line staff across the aging and disability network

Objective 2.4 Promote the expansion of available services for persons with Alzheimer’s disease

- Strategy 2.4.1 Increase the availability of supportive services through administrative streamlining to improve access to services and expand the use of self-direction*
- Strategy 2.4.2 Explore replicating the nursing home rate setting structure so that community-based providers receive higher reimbursement for individuals with higher level of care
- Strategy 2.4.3 Explore a rate setting structure that empowers providers to supplement services for the purposes of crisis management and seek authorization for payment retroactively
- Strategy 2.4.4 Explore the use of volunteer respite providers through a variety of sources including nursing programs, volunteer organizations, community organizations, and faith-based groups
- Strategy 2.4.5 Explore options for the provision of emergency respite services

Objective 2.5 Advocate for the improvement of delivery of services for persons with Alzheimer’s disease

- Strategy 2.5.1 Promote the use of Telehealth* to bring Alzheimer’s expertise to sites that lack specialized skills or advanced training to maximize the availability of medical, preventative, and home-based support services
- Strategy 2.5.2 Increase awareness in Delaware of “universal design,”* assistive technologies, and livable communities to promote opportunities for aging in place
- Strategy 2.5.3 Educate employers about the issues facing caregivers and encourage them to establish workplace policies such as flextime, telecommuting, referral services, and on-site support programs
- Strategy 2.5.4 Advocate for alternative home and community-based programs of care such as Programs of All-Inclusive Care for the Elderly (PACE)*
- Strategy 2.5.5 Advocate for an increase in salary for direct service providers

* See glossary in Appendix C

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Strategy 2.5.6 Explore options and advocate for regulatory changes that would empower health care providers to deliver the most appropriate interventions for persons with Alzheimer's disease

Goal # 3: Strengthen the support of caregivers of persons with Alzheimer's disease

Objective 3.1 Identify and expand the availability of, and participation in, educational programs for caregivers, other stakeholders, and community partners

Strategy 3.1.1 Perform an environmental scan of all caregiver training and resources currently available

Strategy 3.1.2 Create a robust online "Toolkit" for placement on the Delaware Aging and Disability Resource Center (ADRC) and Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) websites containing practical tips, educational materials, and links to educational programs for use by caregivers; ADRC call center staff; and others; and include "Toolkit" information in DSAAPD's *Guide to Services for Older Delawareans and Persons with Disabilities*

Strategy 3.1.3 Coordinate with the Alzheimer's Association and other public and private community partners to link caregivers to community-based and online educational programs for caregivers through the Delaware ADRC and DSAAPD websites, Caregiver Resource Centers, pamphlets, brochures, and other promotional outreach

Strategy 3.1.4 Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings, including programs offered in Spanish

Strategy 3.1.5 Encourage caregivers to learn about the financial and legal impact of Alzheimer's disease and the importance of obtaining financial and legal advice as a planning tool

Strategy 3.1.6 Encourage caregivers to learn about and actively engage in discussion surrounding end-of-life issues

Strategy 3.1.7 Identify caregiving as a health risk factor and promote self-care and frequent breaks for caregivers

Strategy 3.1.8 Promote the use of available emergency preparedness tools among caregivers

Objective 3.2 Increase and enhance supports available for caregivers of persons with Alzheimer's disease across the continuum of care and through all stages of the disease

Strategy 3.2.1 Promote and link caregivers to the Delaware ADRC, local Caregiver Resource Centers, and the Alzheimer's Association for help in

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- understanding Alzheimer's disease, navigating the long term care system, sorting through service options, and accessing relevant supports, including caregiver assessments; care consultation; counseling; care management; respite care; support groups; assistive technologies; future care needs; and other effective interventions
- Strategy 3.2.2 Explore options to increase support for diverse caregivers, including those caring for persons with early-onset Alzheimer's disease
- Strategy 3.2.3 Promote and encourage referrals to the Delaware ADRC by physicians, healthcare and service providers, faith-based organizations, and other community partners
- Strategy 3.2.4 Provide ongoing training to Delaware ADRC call center staff, Options Counselors, and other information and referral specialists on resources available for caregivers
- Strategy 3.2.5 Explore options to enlist the faith-based community as a key resource that can reach out to and support caregivers; including promoting partnerships in developing programs to train volunteers
- Strategy 3.2.6 Build strong partnerships with the health care community and develop avenues to promote caregiving as a health risk factor, and encourage health care professionals to acknowledge and address the issue

Objective 3.3 Participate in, and support, advocacy efforts on behalf of caregivers

- Strategy 3.3.1 See Strategy 2.5.3 (Educate employers about the issues facing caregivers and encourage them to establish workplace policies such as flextime, telecommuting, referral services, and on-site support programs)
- Strategy 3.3.2 Establish a legislative agenda to address caregiver issues

Goal # 4: Achieve an Alzheimer's-competent workforce in the State of Delaware

Objective 4.1 Improve Alzheimer's disease competency among health care and social service providers

- Strategy 4.1.1 Disseminate evidence-based guidelines for Alzheimer's disease management to primary care providers to improve early diagnostic evaluation, treatment, care coordination, and follow-up support of patients
- Strategy 4.1.2 Coordinate with professional societies and other organizations to create and implement strategies to maximize the dissemination of appropriate continuing education on Alzheimer's disease for physicians, nurses, and other health professionals
- Strategy 4.1.3 Establish and/or strengthen, as appropriate, dementia specific training for all staff of any state-licensed entity in the health care continuum that serves individuals with Alzheimer's disease and other dementias,

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including, but not limited to nursing homes, acute care facilities, community residential care facilities, home health agencies, hospice, or adult day care programs

- Strategy 4.1.4 Incorporate specific needs of ethnically diverse population groups into existing and emerging training programs for healthcare and social services providers, with attention across the continuum of care
- Strategy 4.1.5 Develop strategies to train professionals who provide services to persons with mental illness and developmental disabilities to recognize and address Alzheimer's disease within their consumer populations
- Strategy 4.1.6 Partner with a geriatric education center to provide increased Alzheimer's disease related training to primary care providers serving areas in Delaware with large numbers of older residents
- Strategy 4.1.7 Provide guidance to care providers, care managers, and advocates on the Medicare benefit that reimburses for an annual cognitive exam and on the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care consultation that educate and support family caregivers, guide future decisions, and enhance the quality of medical care and support services
- Strategy 4.1.8 See Strategy 2.3.4 (Provide training in Alzheimer's disease and other dementias to DSAAPD case managers, ADRC call center staff, and front line staff across the aging and disability network)

Objective 4.2 Provide training of professionals in other, non-health care fields that interact increasingly with persons who have dementia, including Alzheimer's disease

- Strategy 4.2.1 Partner with the Alzheimer's Association and others to provide comprehensive Alzheimer's dementia training to first responders, law enforcement, EMTs, fire fighters, emergency preparedness, and search and rescue officials, and others
- Strategy 4.2.2 Partner with state regulators, court administrators, and the Delaware Bar Association for training on legal issues facing persons with Alzheimer's disease, including training on the roles of guardians and surrogate decision makers

Objective 4.3 Increase access to training resources related to Alzheimer's disease

- Strategy 4.3.1 Increase the spectrum of educational resources available on Alzheimer's disease for health care and social service professionals through clearinghouse development, website links on online continuing education-related training/resources meeting professional licensure requirements, and coordination with service-providing agencies/facilities required to provide dementia-specific training
- Strategy 4.3.2 Establish a formal network of providers of Alzheimer's training in Delaware to increase the availability of quality continuing education and

other training on Alzheimer's disease and to serve as consultants on the ongoing development and/or refinement of competency-based models of Alzheimer's training

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]

Objective 5.1 Catalyze the creation of a virtual Delaware Center for Alzheimer's and Related Dementias (a private, public, and academic partnership) to support data collection, analysis, and dissemination as well as basic, translational and clinical* research activities in the state and region

Strategy 5.1.1 Study the features of similar entities that have been created in the state and region

Strategy 5.1.2 Facilitate the establishment of a private, public, academic partnership to efficiently support data and research infrastructure related to Alzheimer's and dementia in the state and region in a way that partners the research, clinical, patient, and caregiver communities while serving as a meaningful resource for the public

Objective 5.2 Improve data collection and quality assurance measures, analysis, dissemination, and impact

Strategy 5.2.1 Study other states' relevant infrastructure for data and quality assurance measures collection and analysis

Strategy 5.2.2 Identify existing sources of data and quality assurance measures (e.g., U.S. Decennial Census and/or American Community Survey, Alzheimer's Association, Minimum Data Set (MDS) 3.0, Behavioral Risk Factor Surveillance System (BRFS), and others)

Strategy 5.2.3 Explore the need for new data and quality assurance measures as a partnership with Alzheimer's Association, Delaware Department of Health and Social Services (DHSS), University of Delaware, Delaware State University, and others

Strategy 5.2.4 Coalesce the variety of data and quality assurance sources, analysis, and dissemination in a way that improves access and impact of these measures

Objective 5.3 Improve the support infrastructure for basic, translational, and clinical Alzheimer's and dementia research

* See glossary in Appendix C

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- Strategy 5.3.1 Study other states' relevant infrastructure for supporting basic, translational, and clinical Alzheimer's and dementia research
- Strategy 5.3.2 Identify and engage the relevant members of the research community and stakeholders
- Strategy 5.3.3 Explore ways to improve the research infrastructure for supporting basic, translational, and clinical research in the state and region
- Strategy 5.3.4 Develop a plan for improving the state's relevant infrastructure for supporting basic, translational, and clinical Alzheimer's and dementia research

Appendices

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Appendix A: List of Task Force Members

Henry Alisa

Alzheimer's Caregiver; Alzheimer's Association Delaware Valley Chapter

Rudy Bailey

Division of Services for Aging and Adults with Physical Disabilities

Lisa Barchi

Department of Justice

Lisa Bond

Division of Services for Aging and Adults with Physical Disabilities

Dr. Patricia Curtin, MD, FACP, CMD

Christiana Care Health System

Patricia Days-Wilmer

Adult Protective Services Program

Kelvin Lee, PhD

University of Delaware

Bill Love (Co-Chair)

Division of Services for Aging and Adults with Physical Disabilities

Joe McCaffrey

Alzheimer's Caregiver

Katie Macklin (Co-Chair)

Alzheimer's Association Delaware Valley Chapter

Kathryn Murray

Alzheimer's Advocate

A. Sue Ruff

The Lorelton; Delaware Aging Network (DAN)

Yrene Waldron

Delaware Health Care Facilities Association

Denise Weeks-Tappan

Division of Services for Aging and Adults with Physical Disabilities

Appendix B: List of Working Group Members

Working Group #1: Caregiver support

Henry Alisa, Alzheimer's Caregiver; Alzheimer's Association Delaware Valley Chapter (Co-Chair)
Bob Bird, Home Instead
Ruby Holdeman, Home Instead
Lori Kaczmarczyk, Division of Services for Aging and Adults with Physical Disabilities
Joe McCafferty, Alzheimer's Caregiver
Cindy Mitchell, CHEER
LaVaida Owens-White, Parish Nurse Association
Beth Seeds, CHEER
Joanna Shea, Division of Services for Aging and Adults with Physical Disabilities
Yrene Waldron, Delaware Health Care Facilities Association
Denise Weeks-Tappan, Div. of Services for Aging and Adults with Physical Disabilities (Co-Chair)

Working Group #2: Public awareness and outreach

Susanne Abate, Al DuPont Hospital for Children
Jill Fredel, Department of Health and Social Services
Bill Love, Division of Services for Aging and Adults with Physical Disabilities (Co-Chair)
Kathryn Murray, Alzheimer's Advocate (Co-Chair)
Joanna Shea, Division of Services for Aging and Adults with Disabilities

Working Group #3: Improving service delivery

Lisa Bond, Division of Services for Aging and Adults with Physical Disabilities (Co-Chair)
Linda Brittingham, Christiana Care Health System
Patricia Days-Wilmer, Adult Protective Services
Bill Dunn, Community Legal Aid Society, Inc.
James Reynolds, Senior Partner, Inc.
A. Sue Ruff, The Lorelton; Delaware Aging Network (DAN) (Co-Chair)
Donna Stowell, Elwyn Delaware

Working Group #4: Improving and expanding the state's home and community-based infrastructure

Katie Macklin, Alzheimer's Association Delaware Valley Chapter (Co-Chair)
Kelvin Lee, Ph. D., University of Delaware (Co-Chair)
Melissa Harrington, Delaware State University

Working Group #5: Training and Professional Development

Christine Arenson, Thomas Jefferson University
Rudy Bailey, Division of Services for Aging and Adults with Physical Disabilities (Co-Chair)
Bob Bird, Home Instead
Patricia Curtin, M.D., Christiana Care Health System (Co-Chair)
Tim Gibbs, Academy of Medicine
Ruby Holdeman, Home Instead
Jessica Hedden, Medical Society of Delaware
Bernice Hughes, Division of Services for Aging and Adults with Physical Disabilities
Katie Macklin, Alzheimer's Association
Paul Schwab, Alzheimer's Advocate
Kelly Snyder, Christiana Care Health System
Linda Sydnor, Christiana Care Health System

Appendix C: Glossary

Basic, clinical, and translational research

Basic Research is investigation and analysis focused on a better or fuller understanding of a subject, phenomenon, or a basic law of nature instead of on a specific practical application of the results.

Source: <http://www.businessdictionary.com/definition/basic-research.html>

Clinical research is medical research that involves carefully conducted investigations that ultimately uncover better ways to treat, prevent, diagnose, and understand human disease. Clinical research includes trials that test new treatments and therapies as well as long-term natural history studies, which provide valuable information about how disease and health progress.

Translational research means research that applies discoveries generated in the laboratory to studies in humans (bench to bedside), or that speeds the adoption of best practices into community settings (bedside to practice). Phases of translational research include:

T1 – First phase of translational research, or “Bench to Bedside,” moves a **basic** discovery into a clinical application

T2 – “Bedside to Practice” research provides evidence of the value of taking the **basic** discovery in the clinical setting

T3 – Research that moves the evidence-based guidelines developed in phase 2 into health practice

T4 – Research to evaluate the “real world” health outcomes of the original T1 development

Source: <http://www.michr.umich.edu/about/clinicaltranslationalresearch>

Long-Term Care

Long-term care is a range of services and supports to meet personal care needs. Most long-term care is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called Activities of Daily Living (ADLs), such as:

- Bathing
- Dressing
- Using the toilet
- Transferring (to or from bed or chair)
- Caring for incontinence
- Eating

Other common long-term care services and supports provide assistance with everyday tasks, sometimes called Instrumental Activities of Daily Living (IADLs) including:

- Doing housework
- Managing money
- Taking medication
- Preparing and cleaning up after meals
- Shopping for groceries or clothes

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- Using the telephone or other communication devices
- Caring for pets
- Responding to emergency alerts such as fire alarms

Source: <http://longtermcare.gov/the-basics/what-is-long-term-care/>

Programs of All-Inclusive Care for the Elderly (PACE)

The Program of All-Inclusive Care for the Elderly (PACE) provides comprehensive long term services and supports to Medicaid and Medicare enrollees. An interdisciplinary team of health professionals provides individuals with coordinated care. For most participants, the comprehensive service package enables them to receive care at home rather than receive care in a nursing home.

Financing for the program is capped, which allows providers to deliver all services participants need rather than limit them to those reimbursable under Medicare and Medicaid fee-for-service plans. The PACE model of care is established as a provider in the Medicare program and enables states to provide PACE services to Medicaid beneficiaries as a state option.

Source: <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Program-of-All-Inclusive-Care-for-the-Elderly-PACE/Program-of-All-Inclusive-Care-for-the-Elderly-PACE.html>

Self-Directed Services

Self-directed services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services.

Source: <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>

Telehealth

Telehealth is the use of technology to deliver health care, health information or health education at a distance.

Some common applications of telehealth include the use of video-conferencing for real-time patient-provider consultations such as with tele-psychiatry; the use of video-streaming to provide patient and provider education; the use of mobile devices to monitor and transmit patient data to caregivers and health care providers (commonly referred to as remote patient monitoring); and the electronic transmission of pre-recorded videos and digital images (like x-rays) between health care providers.

Source: <http://www.matrc.org/what-is-telehealth>

Universal Design

Universal Design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

Source: <http://www.nahb.org/generic.aspx?genericContentID=89934>

Appendix D: Resources

Alzheimer's Association

Phone: 1.800.272.3900

TDD: 1.866.403.3073

Email: info@alz.org

Website: <http://www.alz.org/>

Alzheimer's Association Delaware Valley Chapter

Website: <http://www.alz.org/desjsepa/>

Delaware Regional Office

240 North James Street Suite 100A

Newport, DE 19804

(302) 633.4420

Sussex County Branch Office

108 North Bedford Street

P.O. Box 625 (Mailing Address)

Georgetown, DE 19947

(302) 854.9788

Julie H. C. Bailey Training Center

100 S. Main Street, Suite 211

Smyrna, DE 19977

(302) 514.6510

(at the Health and Wellness Center, Entrance C)

Delaware Aging and Disability Resource Center

Phone: 1.800-223.9074

TDD: 302.391.3505 or 302.424.7141

E-mail: DelawareADRC@state.de.us

Website: <http://www.delawareadrc.com/>

Appendix E: Contact Information

Division of Services for Aging and Adults with Physical Disabilities
Herman M. Holloway, Sr. Campus
Main Administration Building, First Floor Annex
1901 N. DuPont Highway
New Castle, DE 19720

Phone: 1.800.223.9074

TDD: 302.391.3505 or 302.424.7141

Fax: 302.255.4445

Email: DelawareADRC@state.de.us

Website: <http://www.dhss.delaware.gov/dsaapd>