

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Minutes
June 7, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Department of Aging

Legislative members

Senator Bob Mensch, Chair of Senate Aging and Youth Committee

Abdoul Barry for Representative Florindo Fabrizio, Minority Chair of the House Health Committee

Valerie Borowski for Representative Matt Baker, Chair of the House Health Committee

Mike Deery for Senator Leanna Washington, Minority Chair of Senate Aging and Youth Committee

Representative Pam DeLissio for Representative Steve Samuelson, Minority Chair of House Aging and Older Services Committee

Representative Tim Hennessey, Chair of House Aging and Older Services Committee

Constituent representatives:

Dr. John Trojanowski, AD Researcher representative

Robert Marino, Statewide Alzheimer's Association representative

Cynthia Lambert, Family member representative

Cheryl Martin, Department of Public Welfare representative

Heidi Owen, Hospice representative

George Gunn, Assisted Living representative

Michael Ellenbogen, Person with AD representative

Robin Mozley, Senior Care representative

Jill Schwartz, Caregiver representative

Dr. Stuart Shapiro, Nursing Facility representative

Lauren Merlie for Dr. Carrie DeLone, Department of Health representative

Beth Herold, Area Agency on Aging representative

Vicki Hoak for Susan Heinle, Homecare representative

Dr. Charles Reynolds, Medical Care Provider Community representative

Others in attendance:

Todd Shamash, Deputy Chief of Staff, Governor Corbett's office

Shannon Royer, Deputy Secretary, Department of State

Dr. Ronald C. Petersen, Director, Mayo Alzheimer's Disease Research Center

Lisa Bain

Linda Drummond

Tina Hess

Owen Lavery

Gail Hamlin

Debra Heller

Sharon Schwartz

Erin Raub
Amal Mahroubi
Leah Kithcart
Judy Patrick
Melissa Myers
Nicole Gear
Peg Glessner
Maha Shafgat
Kevin Tucker
Judy Eschberger

Pennsylvania Department of Aging Staff in attendance:

Amy Comarnitsky
Paul McCarty
Kelly O'Donnell
Steven Horner
Kellie Kask
Becky Ludwick
Christina Reese
Laura Conrad
Dwayne Heckert
David Gingerich
Dr. Ken Brubaker
Tom Snedden

Planning Committee members not in attendance:

Kelly Carney, AD Researcher
David Leader, Personal Care Home Industry
Senator Shirley Kitchen, Minority Chair of Senate Public Health and Welfare Committee
(Clarissa Freeman, representing Senator Kitchen arrived late)
Senator Pat Vance, Chair of Senate Public Health and Welfare Committee (arrived late)

Minutes prepared by Lisa J. Bain

- I. Welcome: Secretary of Aging Brian Duke, Chair, welcomed participants, noting that the committee has representation from all corners of the State, representing stakeholders across the delivery continuum, the legislature, patients, advocacy organizations, policy makers, and researchers.
- II. The Governor's Charge: Todd Shamash, Deputy Chief of Staff, welcomed participants on behalf of Governor Tom Corbett. In signing the executive order, Governor Corbett noted that Pennsylvania has one of the largest elderly populations in the nation. He expressed his hope that the State Plan would achieve coordination of programs across the state, with a focus on how Alzheimer's disease (AD) affects communities, families, the health care system, and other State resources.

- III. Shannon Royer, Deputy Secretary, Department of State, administered the Oath of Office for all Committee Members.
- IV. Introduction: The incidence of AD is rising in Pennsylvania in line with the aging of the population. An estimated 400,000 people in PA live with AD or other dementias. Our task is to first understand the enormity of the crisis, research trends, and available resources; and then develop an effect response strategy that will help identify and remove barriers and increase public awareness.
- V. Presentation about the National Plan to Address Alzheimer's Disease by Dr. Ronald C. Petersen, Chair of the Advisory Council on Alzheimer's Research and Care Services, which provides comments and recommendations to the Secretary of Health and Human Services on the National Plan.

The National Alzheimer's Project Act (NAPA) was passed in 2010 and signed into law in 2011. The first iteration of a National Plan was presented to the Secretary, HHS, in May 2012 and will be updated annually for 15 years. The Advisory Council consists of 14 federal and 12 non-federal members involved in AD research and care. The Plan consists of 5 goals:

1. Prevent and effectively treat AD by 2025
2. Enhance care quality and efficiency
3. Expand supports for people with AD and their families
4. Enhance public awareness and engagement
5. Improve data to track progress.

A summit in May 2013 came up with six groups of recommendations regarding research necessary to achieve these goals.

Since the plan was developed, there has been a fair amount of progress creating tools and mechanisms to ensure success. However, this is contingent on resources, and while there have been some new funding opportunities totaling about \$73 Million in federal grants, the Advisory Council recommended that the federal budget for AD should be increased to about \$2 billion/year. This compares to current annual budgets of \$6 billion for cancer and \$3 billion for HIV/AIDS.

In addition, 40 states are developing their own plans. State plans are available for review at http://act.alz.org/site/PageNavigator/state_plans.html. Dr. Petersen participated in drafting the Minnesota plan. The MN plan outlines five interconnected goals: 1) identify and invest in promising approaches, 2) increase detection and improve care, 3) sustain caregivers, 4) equip communities, and 5) raise awareness and reduce stigma. After introducing their State plan, the MN team set up a group called ACT on Alzheimer's (www.actonalz.org) to implement the plan. This group is volunteer-driven, consisting of a leadership council, management steering committee, and operations group.

Dr. Petersen noted that there are 10-12 recommendations within the National Plan that have roles for states. For example, there is a recommendation that each state develops a lead agency or lead person that is responsible for the disease in the state. He also suggested that the Committee review these recommendations and create an inventory of resources and research efforts in Pennsylvania to see how we can contribute to the National effort. For example, one of the recommendations is to reduce rehospitalization, which has been addressed by Dr. Mary Naylor at the University of Pennsylvania.

Committee members suggested other areas that may be relevant for the PA state plan, including end of life care, palliative, and supportive medicine; training of dementia-capable care providers across all levels; and the economic opportunities for the state in addressing dementia care needs as well as the economic cost of not doing anything. For example, Dr. Trojanowski mentioned the development of a radiopharmaceutical called Amyvid, which is used to image amyloid in the brain. The compound was developed at Penn with investments from the State of Pennsylvania (Ben Franklin funds), spun off into a company that provided some 60 jobs in the Philadelphia area, and was eventually sold to Eli Lilly, producing even more jobs. The compound recently received FDA approval.

- VI. Member introductions: See list above for attending members and the constituencies they represent. Many members noted that they have or have had family members with dementia. Members also noted the following issues that they hope the State Plan will address:
- a. Address specific concerns of people with dementias other than AD. For example, Frontotemporal Degeneration (FTD) affects younger people who may have different issues.
 - b. Appreciate the heterogeneity of AD and related disorders and consider multi-pronged approaches to treatment.
 - c. Identify and develop an inventory of dementia capable services and those that have been particularly successful in the State. This should include home and community-based options, as well as affordable personal care facilities.
 - d. Identify more accurately the number of individuals in the State with AD and other dementias and the number of caregivers affected.
 - e. Facilitate early diagnosis and early intervention for dementia.
 - f. Develop seamless care programs across the continuum of the illness that are person-centered, well-coordinated, and integrate services for mental health as well as physical health.
 - g. Develop more sustained mechanisms to support caregivers. Representative Tim Hennessey mentioned that the Family Caregiver Act, passed two years ago, increased the monthly reimbursement rate for caregivers, allowed reimbursement for non-family caregivers, and removed the requirement that caregivers live in the same house.
 - h. Provide family members and caregivers (family and professional) with information about available resources and guidelines for providing care. Possibly

a “how-to” type book for families. For example, Susan Heinle has developed an Alzheimer's credentialing program.

- i. Ensure that resources, educational programs, and research opportunities are available across the state, including in smaller and rural communities.
- j. Evaluate the effectiveness of the long-term living system in the State.
- k. Inventory and develop programs to provide dementia-sensitive targeted training at all levels, including public service, as a step towards establishment of dementia enabled communities. For example, George Gunn reported that ACTS Retirement-Life Communities established a Corporate University to provide educational programs to train staff with the latest understanding of the impact of dementia on elders and family members.
- l. Assess public awareness of dementia.
- m. Address legal issues related to employment, benefits, driving laws, financial issues, and living wills.
- n. Train first responders in the needs of people with dementia.
- o. Encourage research and provide funding for research.
- p. Work with companies to create work environments where people with dementia can feel productive.
- q. Develop dementia-friendly communities.
- r. Develop strategies to promote cognitive health across the lifespan.
- s. Address issues of depression in the elderly.

VII. Other issues raised by members of the public:

- a. Provide resources for people with intellectual and developmental disabilities who develop dementia.
- b. Address gaps in adult day services.
- c. Address issues of diversity and inclusion across all programs.

VIII. Next steps:

- a. To meet the requirements of the executive order, the Committee will establish working groups (WGs). Various stakeholders will be invited to join the WG discussions. Committee members are asked to suggest names of individuals who could provide expertise to the WGs.
- b. A series of regional meetings will be held across the Commonwealth. The first regional meeting for south-central PA will be held July 15 in Harrisburg. News of upcoming meetings will be available on the website, www.aging.state.pa.us. WGs will run concurrently with regional meetings.
- c. We will collect public input from these meetings as well as through other means. Interested parties are encouraged to provide feedback through the website, by phone: 717-425-5515, email: alzstateplan@pa.gov or by mail: 555 Walnut St., 5th floor, Harrisburg, PA 17101-1919.
- d. The committee will regroup in the fall to plan the next steps toward development of the State Plan.