

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
State College, PA
Minutes
August 8, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Department of Aging

Legislative members

Geri Sarfert for Senator Bob Mensch, Chair of Senate Aging and Youth Committee

Melissa Myers for Representative Steve Samuelson, Minority Chair of House Aging and Older Services Committee

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

Constituent representatives:

Robert Wargo for George Gunn, Assisted Living representative

Michael Ellenbogen, Person with AD representative

Heidi Owen, Hospice representative

Maura Pelinsky, Adult Day representative

Kelly Carney, Alzheimer's disease research representative

Pennsylvania Department of Aging Staff in attendance:

Wes Culp

Rebekah Ludwick

Paul McCarty

Steven Horner

Kellie Kask

Tom Snedden

Donna Reinaker, PCOA

Members of the public in attendance:

Jane Taylor, Centre County Office of Aging

Donna M. Ayers

Steven Zarit, PSU

Gwen McGhan, PSU

Evelyn Bellinger, Nittany Valley Medical Associates

Dan Lago, CCA Council

Carol Gold, PSU

Keith Eldred

Janet Eldred

Martin Sliwinski, PSU

Katie Kensinger, Home Nursing Agency

Nancy Dotts, Clearfield County AAA

Jackie Anderson, Clearfield County AAA

Brian Anderson

Rev. Robert J. Way
Joy Bodnar, Foxdale Village
Augusta Wargo, Juniata Valley SC
Marie Bumbarg, Juniata Valley SC
Rosemary Frank, past caregiver of spouse
Briana Sprague, Center for Healthy Aging
Nikki Hill, School of Nurisng
Karla Shaffer, Aging Services, Inc.
Liz Plozner, CRPR Senior Center
Kathy Gillespie, CCAAA
Jean Rodkey
Valerie Swales Darrow, CCAAA
Annie Livergood, CCAAA
Amanda LeGars, CCAAA
Dennis Shea, PSU Health and Human Development
Judy Geschwindner, Centre County AAA
Jane Hauck, Juniata Valley Senior Center
Bethany Rietscher, Aging Services, Indiana County
Ezeduba Eze, Brookline Village
Cindy Moyes, The Arc of Centre Co.
Amy Bennett, The Arc of Centre Co.
Linda Drummond, Rehab & Community Providers Association
Robert K. Wargo, PCoA
Judy Sarett
Debbie Sanders, Union-Snyder AA, Inc.
Denise Corcoran, ARCU
Janie Provan, Brookline
Anne Campbell, Brookline
Sandy Schuckers, Centre County Office of Aging
JoAnn Holobinko, Clearfield Area Agency on Aging
Leah Kithkart, Alzheimer's Association
Bill Orzechowski, OHS Aging
Stephanie Probert, Centre Home Care
Marcia Stewart, Lewistown Hospital
Jolene Hulson, Foxdale Village
**List may not be complete*

Minutes prepared by Lisa J. Bain

- I. Welcome
Amy Lorek from Center for Healthy Aging at Penn State's College of Health and Human Development welcomed participants to Penn State.
Secretary of Aging Brian Duke, welcomed participants.
 - a. Secretary Duke provided a brief introduction about the rationale for this committee: We are facing a crisis as the incidence of AD is rising in line with the aging population. We are the 4th grayest state in the U.S. based on the percentage

of population over age 60. By 2030, it is estimated that 1 in 4 Pennsylvanians will be over the age of 60. Committee has been tasked, via executive order signed by Governor Corbett, with developing a comprehensive state plan of action to address the growing crisis of AD and related dementias (ARD) and complete this by Feb, 2014. The first regional meeting was held in Harrisburg; this is the second regional meeting. In PA, an estimated 400,000 citizens are living with ARD. PA Department of Health estimates over 35,000 deaths in PA have been caused by AD over a 10-year period, a 71% increase in the death rate due to AD. The cost of caring for those with AD nationally is estimated at over \$200 billion in direct costs. Impact on unpaid caregivers also needs to be considered. Approximate ratio is 1-4 family caregivers for each person living with AD. In 2012, estimated these caregivers provide more than 750 million hours of care to those with ARD. These statistics show what we are facing in Commonwealth. We must first understand the enormity of the crisis. We look forward to hearing from the public.

Solutions will come from many sectors – public, private, etc. Our committee’s charge of the next 6 months – examine needs, research trends, study existing resources in PA, develop an effective response strategy to the rising numbers of those living with ARD, and deliver final recommendations to Governor Corbett.

The committee will play a significant role in bringing public awareness to this crisis and how we as a commonwealth should address the many issues before us.

- b. The plan for this meeting is to share information and update the public on our workgroups, and more importantly to listen to concerns of the public.
- II. Three workgroups have been created to address the many topics. Brief updates from these WGs:
- a. WG # 1 – Prevention and outreach (Steve Horner). Chair is Dr. Charles (Chip) Reynolds. Goal of this group is to increase awareness of AD among the public; study existing resources for addressing needs of families and persons with AD; better inform, educate, and equip the public and health care providers about AD; provide recommendations to assist unpaid caregivers; promote activities that would promote and improve brain health; improve public safety and address safety related needs; provide recommendations regarding legal protection of persons with AD; establish and maintain a clearinghouse of information; provide technical assistance and consultation to agencies about available resources, programs and services. We will be looking at public awareness, training and education, caregiving, brain health and healthy aging, safety, legal issues, technical assistance, consultation, social and cultural diversity, and dementia friendly communities.

WG#1 also includes George Gunn, Representative Matthew Baker, Michael Ellenbogen, Senator Shirley Kitchen, Representative Steve Samuelson, Dr. Stuart

Shapiro, and Maura Pelinsky. We have met twice so far. We are trying to prioritize and determine how to strategically address the issues listed above. We are starting to review what a consultant has done looking at a comprehensive review of other state plans, the recently updated National Plan, and other resources. We are looking at how to optimize existing resources and improve and coordinate ongoing activities; enhancing public awareness engagement; improving education across the board for individuals with AD, caregivers, families and providers; supporting public private partnerships; and improving and expanding supports for individuals with AD and their families.

- b. WG #2 – Healthcare delivery and workforce (Heidi Owen, Chair). Our key features that we have focused on in our first two meetings are: early detection and diagnosis, care and case management, healthcare system capacity, workforce development, retention of workforce, home and community based services, long term care services and supports, social and cultural diversity, finance, palliative care, medical home and accountable care organizations (ACOs), technology and telemedicine, bioethics, and dementia friendly communities.

We have looked at the scope of services and decided to start by defining a vision, establish goals and objectives, and strategies. We have developed 3 strategies and a fourth we will possibly include. The three so far: 1) Development of a comprehensive continuum of care, 2) Workforce development and retention, 3) Caregivers and community support for the dementia friendly communities. We plan to meet by teleconference every 2 weeks for an hour.

- c. WG #3 – Research and Metrics (Brian Duke). Chair is the newly appointed physician general for the Commonwealth, Dr. Carrie DeLone. Goal is to look at improving quality of information available. We will look at collaborative ways to share research results and information, examine the needs and research the trends of Pennsylvania’s Alzheimer’s population, look at recommendations to increase research, look at cost effective approaches, make recommendations on improved data collection and repositories, analyze data on AD especially with a focus on the implications for public health, make recommendations about how the government evaluates and adopts policies to assist persons with AD and their families.

The group has met twice by conference call and is reviewing what a consultant produced, comparing these areas of focus with the National Plan, the Ware Symposium, which was held at the University of Pennsylvania. We are refining our goals. General topic areas will include a broad area defined under the terms “research collaborative”, an effort that will be looking at data, another effort looking at the efficacy of interventions, and one that will look at the continuum of disease and policy. Will continue to fill in these recommendations.

- III. Showed video from the Alzheimer’s Association that provides background on AD and outlines the challenges we face.

- IV. Public comments. This is the most important part of the meeting, where the committee gets a chance to listen. Speakers include experts from Penn State, providers, caregivers, people from senior community centers, Area Agencies on Aging (AAAs), and others. Some people have signed up; if you would like to speak but have not signed up, please speak to PDA staff. We know we have great resources in PA, including two NIA-funded AD research centers and leading thinkers in terms of family caregiving and support.
- a. Steve Zarit, professor and head of the Department of Human Development and Family Studies at Penn State. Dr. Zarit addressed issues related to caregiver stress. The Alzheimer's Association estimates that 15 million people in the U.S. give unpaid help to persons with dementia. Research shows that this kind of caregiving is highly stressful: caregivers have higher rates of stress-related illnesses and depression, higher rates of mortality. The well-being of the patient depends on the family, and the health and well-being of the family depends on the types of supports we can put into place. Research shows that caregivers benefit from professional and comprehensive help, including short-term counseling and structured support groups provided by people with appropriate training. Research also shows that caregivers benefit from breaks provided through respite services and adult day care. For example, Dr. Zarit's research has shown that adult day care reduces stress both in terms of how caregivers feel and through objective measurement of stress biomarkers. He concluded that there is both an ethical and practical (i.e., cost saving) obligation to address the stress of caregiving. Not only is it the right thing to do, but it will help prevent stress-related illnesses among caregivers and enable caregivers to keep their loved ones at home for a longer period of time.
 - b. Jane Taylor, Centre County Area Office of Aging, one of 52 AAAs that serve 67 counties in PA. This agency identifies resources to help people remain in the community, completes assessments to determine individual needs, and operates a protective services program. Ms. Taylor raised several points:
 - i. Advocates for protocol changes in recommendations for medical exam to include early screening of people with cognitive complaints. This would allow individuals to be more fully involved in planning for the future.
 - ii. Another tool for early screening could be coordinated with PennDOT and used at the time of driver's license renewal. Hartford has some excellent driving tools. Also could provide information on transportation alternatives and contacting a doctor for more information at this time.
 - iii. Early support is not readily available in the publicly funded sector, i.e., technologies and services that could enable person to remain safely at home. PDA policy is that these types of interventions are only available to people who are nursing-facility eligible, but could be expanded to those with earlier stages of cognitive impairment.
 - iv. Caregiver support program is available but the law limits utilization with an aggregate cap of \$300/month on the agency side. Personal care homes can provide this type of support but are very expensive.

- v. Education is needed for caregivers, paid providers, and other professionals on how to assist people with AD. Curriculum development for certified nurse aides, home health providers, facility administrators, law enforcement, and others should include information about how to reduce agitation and confusion.
 - vi. The biggest challenge is getting information to people who need it. Suggest adding a tag line with PDA website to lottery ads. Website could then provide links to educational materials. PR campaign must be continual. Suggest partnering with public television, call-in shows, other media partners.
- c. Linda Drummond, Rehabilitation and Community Partners Association. Provides human services in substance abuse, mental health, intellectual disability (replaces terminology mental retardation), development disabilities and children's behavioral health and medical rehabilitation. Recommends that the committee consider the needs of the intellectual and developmental disabilities communities who are aging with ADRD. Changes in behaviors and service needs are often not recognized in this population. Individuals with Down syndrome (DS) can start with ADRD in late 30s and 40s; they can also have premature aging, including physical changes. AD is more common in those with DS – up to 25% of those with DS over the age of 35 show signs of AD or dementia. In PA, DPW data indicates there are over 48,800 individuals in community services and of those almost 27,000 are aged 30 and older, so this is a big population. PA also has an intellectual disability waiting list of 15,000 people, approximately 800 of those are family caregivers are age 60 and older, so this is another group that needs support and services. Recommends including this population and their specialized service needs in the State plan, including specialized staff training, home modifications, assistive technology to allow these individuals to live as independently as possible in community or with family.
- d. Amy Bennett, the Arc of Centre County. One of first intellectual disability/Alzheimer's specialized licensed homes in State of PA; and Cindy Mayes, director of long term planning and Nittany Employment Services. A year or two ago we had folks we were serving since late childhood who were diagnosed with AD, so we had to learn how to support these individuals. This was a clear unmet need. We could not find any home in the State that provides services to this unique population. So we set up model at one of our homes. We received support (\$6,000) from Centre County United Way. The PA Alzheimer's Association did not have any information or trainers specific to this population; however the Alzheimer's Association in Northeast New York was able to help us. Gretchen Moore Simmons pointed us to a model in Schenectady, NY, which was a day program that devoted two rooms to this population. Also Dr. Kathy Bishop at Rochester University worked with us to adapt our facility. Dr. Daniel George at PSU also has extensive knowledge of ID and AD. The language of today: memory support, dementia friendly communities, dementia friendly neighborhoods. We reached out to contractors and businesses (e.g., Lowes) to get

funding to modify an existing home and create the “Forever Home”. In the year ahead we will be working on the programmatic piece. Staff needs new approaches and special training to work with this population.

- e. Debbie Sanders, Union/Snyder Health Coordinator and RN, also a caregiver to mother in-law for 10 years (ending in 2006). Family physician had little knowledge of AD and ignored family concerns. Family also needed education, information, resources, caregiver support, respite care, family restrooms in public places (supports legislation to that effect), legal counsel, AD-trained hospital staff including in emergency department. End-of-life care in the nursing home was also problematic (they wanted to use feeding tube), despite presence of living will. People need to know that you can have hospice care for someone with AD and can have it in nursing home. Physical presence of someone from the Alzheimer's Association would have been helpful in addition to online resources. There is a tremendous need for day care that is in facilities close to home, with longer hours, and ability to care for people with complex needs. Another population we are beginning to see is Vietnam Veterans with PTSD. Funding is needed for day care.

Additional comments from colleagues (submitted written comments via e-mail):
A family physician cited need for a centralized information repository for educational information about diagnosis, different ways disease progresses, listing of available support agencies, evidence-based treatments, what resources are needed, attendants, financial resources to pay for drugs and home health aides, support groups and family counseling. Create incentives for providers to develop expertise and provide care to these people.

- f. Daniel Lago, Central Regional Council on Aging and PhD in human development and family studies. Mother had AD; she stopped being anxious and became affectionate although confused during this time. Entitlement programs cannot be financially sustained; also there has been a federal retreat from Older Americans Act programs. Lottery funding inadequate to meet needs. People above poverty level get almost no help from AAAs. Marketing is targeted narrowly, framed as a monolithic problem, while it actually involves multiple chronic conditions that add to cost of treating patients.
 - i. Suggests “Angie’s List” type of database for dementia family caregiver support information with review and ranking of providers, especially community-based care.
 - ii. Supports increases in family caregiver program; PA needs to review regulations and approaches that Department of Aging uses to implement that program. The cap is too small, assurances are burdensome.
 - iii. Recommends education partnerships between schools and provider organizations for intergenerational cognitive enhancement programs.
 - iv. Redefine adult education with dementia prevention as focus.
 - v. Encourage more discussions of advanced directives.

- g. Marcia Stewart, Director of Case Management at Lewistown Hospital. Works with patients and families when patient needs a long term care dementia bed. In past year, 9 residents have needed to be transferred to a different county. Driving time for family members ranged from 45 minutes to 2 ½ hours one way. There is a huge need for people who need this level of care. Recommend that the need be assessed and work towards helping facilities build more residential long term care facilities for those patients that need them.
- h. Jean Rodkey, caregiver of mother who has AD. Many problems: it's a logistical nightmare to get her in day care, because they are too far away; lack of support from community and extended family; limited resources; people (even doctors) have poor understanding of AD; costs are too high for services since mother is not destitute. However, AAAs have provided good support.
- i. Kathy Gillespie, Director of Clearfield County AAA (new to position). Has worked as social worker in long term care facilities, skilled nursing facilities, and personal care homes. Major problem is lack of education and training for professional caregivers of those who are cognitively impaired. Recommends committee consider funding to expand direct care services to include case management, so families and caregivers know what steps to take; and care management.
- j. Dr. Martin Sliwinski, Director of Center for Healthy Aging at PSU. Developing strategic and sustainable programs for AD prevention and promoting brain health should be central to attaining goals. Dementia evolves over the course of decades, causing demonstrable memory impairments 5-7 years prior to diagnosis. During this pre-diagnostic period, individuals with mild cognitive impairments may withdraw from precisely those kinds of activities that promote brain health and possibly slow progression, and they may become more socially isolated. We need to identify those at highest risk. Risk factors have been identified that increase risk of AD and many of these are modifiable. A strong case can be made that funding prevention program that target these factors will be cost effective. First we need baseline information on risk levels in individuals and communities. Dr. Sliwinski believes that targeting lifestyles, health behaviors, and social isolation should have demonstrable and rapid effects on dementia risk.
- k. Dr. Carol Gold, Coordinator of the Geriatric Education Center of PA, which is funded by HRSA to work on Alzheimer's issues at community level. Important to remember that many dementia diagnoses are mixed and often have a component of vascular problems. For instance, there is an increased risk of dementia in those with diabetes, obesity, high cholesterol. African Americans and Latino populations are at elevated risk of ADRD. Educating people about healthier lifestyles at a younger age may prevent many cases of dementia. Recent studies in England and Denmark indicated that the rates of dementia have slowed in older people, possibly due to higher educational levels, later retirement from work (increased cognitive engagement). Recommends that a significant amount of

money be targeted for in-home services for those with dementia. We also need to address needs of those with early onset dementia, and ethnically diverse populations. Important to help dementia patients with psychiatric illnesses such as psychoses or depression.

- l. JoAnn Holobinko, RN, Clearfield County AAA. Speaking as a daughter of a woman with vascular dementia diagnosis. She formerly was a resident of Colonial Courtyard, which burned down and everyone in facility got out safely but lost everything. Need support to find appropriate housing, especially in rural areas. For family members to support residents, housing needs to be located nearby.
- m. Reverend Robert Way. Mother has had dementia for over 15 years. She got increasingly angry and belligerent as disease progressed. Doctors' and hospital staff inexperience with AD delays diagnosis, ability to get insurance coverage, and receive appropriate care.
- n. Jane Hauck, Juniata Valley Senior Center. Husband with AD for about 10 years, also has diabetes. He lives at home. Cost of medication is extreme. Centers need to be well educated.
- o. Joy Bodnar, Director of Health Care Services at Foxdale Village. Conducted a study on caregiver stress in Ohio. Developed multi-level dementia special care units in rural central PA, established support group for family members, provided training for staff. Helped design and develop two new memory support neighborhoods at Foxdale. Supports what others have said, emphasizing the need for expansion of family support services. There is extensive research on long term services and support (LTSS); AD patients are among those most in need of LTSS, in order to keep patients in homes and out of long term care facilities, thereby reducing significant costs to families and reducing Medicaid-based costs that are borne by taxpayers. A 2011 report ("On the Verge") released by AARP Public Policy Institute, showed that PA is ranked 46th out of 50 in terms of the percent of family caregivers getting needed support.
 - i. Suggests learning from other states and adopting policies from some of the higher ranked states. Also encourages committee to look at work Oregon has done to shift Medicaid dollars to alternative services other than nursing care.
 - ii. Encourages committee to examine another report (2012) from National Advisory Council on Alzheimer's Research, Care, and Services. This report makes 10 recommendations targeted to increasing support for patients and family members. One is to assess caregiver health and mental health regularly. Another is to include information on AD in curriculum of any profession and career track involved in providing LTSS, including physician education. Incentives for geriatric training deserve consideration.
 - iii. Asks the committee to formulate recommendations without regard to whether they are politically palatable to any party.

- p. Rosemary Frank, caregiver for husband who had Lewy Body Dementia. Emphasized need for education of physicians, public (i.e, family restrooms), spouses/caregivers, pharmacies. Recommends committee secure funding for outreach to doctors, public, etc. Better information provides better care and less stress on caregivers.
 - q. Judy Zarett, speech-language pathologist. Represents a long term care facility. We have a course that you walk and hold onto, so even those with cognitive disability can walk every day. Even small amounts of exercise can stimulate brain cells and help repair cognitive loss. There are also some new, very effective drugs, and diets that can be helpful.
 - r. Michael Ellenbogen (Committee member). Lives with AD. Frustrated by lack of people with AD speaking up; they may not be able to speak, write, or even drive to get to events like this and announcements may be difficult to understand. Stigma also prevents people from speaking out. Was diagnosed with young onset AD in 2008. Living with AD means he has trouble making decisions; has lost processing ability so can no longer pursue hobbies or use technologies that previously he enjoyed; cannot filter out loud noises; cannot write or speak as I could previously; worries about challenges ahead. Sees a lack of public commitment to address AD. Sees wife becoming stressed and overwhelmed.
 - s. Leah Kithcart, Greater PA Chapter Alzheimer's Association. Thanks everyone who came today. We are committed to making sure PA has a comprehensive plan to address ADRD. Special thanks to Secretary Duke and Chairman Hennessey for their leadership.
- V. Wrap up – Secretary Duke. Thanks to all who offered testimony.
- VI. Next steps
- a. Next regional August 13th in Scranton, August 15th in Philadelphia, September 16th in Clarion with a specific focus on living with Alzheimer's in rural communities, September 17th in Pittsburgh.
 - b. Directions and news will be available on the website, www.aging.state.pa.us. WGs will run concurrently with regional meetings.
 - c. Committee will regroup in the fall in Harrisburg to develop a framework with the objective of having a final plan completed by February, 2014.
 - d. We will collect public input from these meetings as well as through other means, best to get comments to us by September/October, although we will take comments through February. Interested parties are encouraged to provide feedback through the website, by phone, 717-425-5115, or by mail: 555 Walnut St., 5th floor, Harrisburg, PA 17101-1919. In addition we have developed a tool with the Alzheimer's Association to collect feedback. This is available on the website as the Alzheimer's Disease Survey.