

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Scranton, PA
Minutes
August 13, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Department of Aging

Legislative members

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

Valerie Barowski for Representative Matthew Baker, Chair of House Health Committee

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

Constituent representatives:

Dr. Carrie DeLone, Physician General and Dept. of Health representative

Dan Ferguson for George Gunn, Assisted Living representative

Michael Ellenbogen, Person with AD representative

Cynthia Lambert, Family member representative

Heidi Owen, Hospice representative

Kelly Carney, Alzheimer's disease research representative

Jill Schwartz, Caregiver representative

Pennsylvania Department of Aging Staff in attendance:

Rebekah Ludwick

Paul McCarty

Steven Horner

Christina Reese

Lisa Bain, consultant

Members of the public in attendance:

Dr. Mary-Beth Krogh-Jespersion

Carolyn Tenaglia, Regional Ombudsman

Sharon Palmenta

Beatrice Mallory

Lora Doebler, DOH

Kathi Lynn, Columbia Montour Aging Office, Inc.

Carolyn Lindeman

Leah Kithcart, Alzheimer's Association

Jessica Engle, Home Instead

Georgiana Ehrlich

Veronica Comfort, PA Council on Aging

Robin LoDolce, Pike County AAA

Trula Hollywood, Luzerne/Wyoming Counties AAA

Maryanne McHale
Mary O'Donnell, Telespond Senior Services
Mary Acker, Telespond Senior Services
Tracy Hunt, Allied Services
Patty Fretz, Monroe County AAA
Linda Korgeski, Serving Seniors, Inc.
Jennifer Adrian, Lackawanna County AAA
Janine Starinsky., Oakwood Terrace
Barbara O'Neill
Pearl Race
Rodney Race
Kim Munsy, Lehigh County Aging & Adults Services
Jasper Sturgis, Wayne County AAA
Cara Scheetz, LVHN
May Gaffney, Center for Independent Living
Susan Charnigo
Debra Kane
Keyshana Harris, DOH
Cindy Klenk for Senator John Blake (Lackawanna- 22nd District)
Melissa Bottorf, Marshall, Parker & Weber
Nick Lutz, Marshall, Parker & Weber
Herb Hauser, University of Scranton
Stephanie Lewis, Quality Health
Linda Arcurie, VNA Hospice
Carl Frels
Maggy Bushwick
Ed Ryan, Lackawanna Link
Jeff Dauber, Alzheimer's Association
Lotte Powell
Fran Ferguson
Valorie H, PA Link ADRC
Clayton Jacobs, Alzheimer's Association
Bill Goldsworth, Office of the Governor, Northeast Region
Pat Rumberger, North'd Co. AAA
Karen Leonovich, North'd Co. AAA
Donna M. Quinn, Alzheimer's Telespond
Catherine Hood, New Lifestyle Medical Day Care
Jim Poplockia
Betty Poplockia
Becky Jacobs, CareGivers America
Kersha DiRienzo, VNA, Lackawanna County
Linda Acurie, VNA of Lackawanna County
Victoria Ferrance
MaryLou Knabel, Allied Services
Marissa Nelons, LSA (interpreter)
Nancy Onuschak, Columbia Montour Aging Office

Ethel Thomas
Representative Eddie Pashinski (Luzerne- 121st District)
Lorrie Williams, The Greater C' dale TMCA
Donna Doherty, Traditional HH
Representative Marty Flynn (Lackawanna- 113th District)
Thom Welby, Office of Representative Marty Flynn
Dr. Mario Cornacchione, NEPA Memory & Alzheimer's Center
**List may not be complete*

Minutes prepared by Lisa J. Bain

- I. Welcome
 - a. Dr. Mary-Beth Krogh-Jesperson, Chancellor of Penn State Worthington-Scranton, welcomed participants and the PA AD planning committee
 - b. Secretary of Aging Brian Duke, welcomed participants, honored guests, the PDA team, and leaders of AAAs. He provided a brief introduction about the rationale for this committee. We are facing a crisis in PA as the incidence of AD is rising in line with aging population. In response to the crisis, the Governor signed an executive order in 2013 that led to the formation of a committee to create a comprehensive plan of action. For the next 6 months, the committee will examine needs and research trends, study existing resources, and develop effective response strategies; then deliver recommendations to the Governor.

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 (ADRD) and complete this by Feb, 2014. This is the third regional meeting. In PA, an estimated 400,000 citizens are living with ADRD. 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 ADRD. 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.

- 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. We will use feedback from these regional meetings to help us identify and evaluate how to optimize existing resource; enhance public awareness; improve education, information, and the referral process; promote brain health; support public-private partnerships; and improve supports for people with AD and caregivers.

- b. WG #2 – Healthcare delivery and workforce (Heidi Owen, Chair). The 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 met twice and are also taking in information from the public to establish a vision. We will then establish goals and objectives, and strategies. We are focusing on three major components: 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, and will be seeking additional expertise from advisors.

- c. WG #3 – Research and Metrics (Carrie DeLone, Chair). Goal is to improve the quality of information available regarding ADRD. We will examine the needs of patients, look at trends in research and how to share research results with caretakers. We will also track the economic impact of ADRD and the potential impact of interventions. We plan to set up a database of evidence-based interventions and information, and will also review policy development to ensure that policies address social and cultural diversity and bioethics and work for all people in the Commonwealth.

- III. Showed video from the Alzheimer's Association that provides background on AD and outlines the challenges we face.
- IV. Public comments. Committee members are here to listen.

- a. Kersha DiRienzo, VNA of Lackawanna County; has personal experience with parents and grandparents with AD who are in denial, which makes it difficult to plan. Very stressful for elderly spouse of person with AD. VNA is a charitable healthcare organization that provides hospice and home health to community regardless of ability to pay. It was started in Scranton to address and fund unmet health needs. The number of patients and families needing our services has tripled in the past 2 ½ years. We need care-specific training for staff in order to be better prepared to meet the needs of patients and families.
- b. Linda Acurie, VNA of Lackawanna County, and granddaughter of woman with AD who lives with Linda's family. At VNA, we receive many phone calls from caregivers who are in a state of crisis. We use resources in place to guide people but need additional resources. Everyone seems to be looking for a one-stop-shop – a place they can call and get ahold of a nurse or social worker who can talk, come to the house for an assessment, help fill out paperwork, provide referrals, etc. We also need a 24/7 day care center, low-cost home care, and perhaps a geriatric nurse practitioner to provide assistance with hands-on caregiving. Money/subsidies are needed; people cannot afford these services.
- c. Janine Starinsky, executive director, licensed personal care home administrator, certified dementia practitioner at Oakwood Terrace, non-profit Alzheimer's-specific personal care home in NE section of Moosic, PA; and granddaughter of woman diagnosed with AD 25 years ago (now deceased). Ms. Starinsky recommended that the committee address problems with State regulations, which were updated in 2011 but require further changes. For example, for personal care homes (PCH), the State only requires 16-18 hours of training, and 2 aides for every 24 residents in dementia care. Ms. Starinsky said that there are only 22 AL communities in PA, as well as 1200 licensed PCHs that serve 47,000 residents, and 710 nursing homes with nearly 89,000 beds. The median cost for a PCH is \$39,000 per year. When a patient can no longer pay the costs at a private-pay PCH, they are sent to a nursing home and the State (Medicaid/Medicare) picks up the \$99,000 per year cost (although she said the State underfunds nursing homes by an average of \$9,500 per Medicaid resident). In short, the State could support two residents in PCH for the same cost as one in nursing home.

She also addressed concerns about paying for long term care. Annual spending in long term care has reached nearly \$275 billion in the US, not counting uncompensated care. Of that, 47% is paid by Medicaid, 23% by Medicare, and 23% by families out of pocket. At private-pay homes such as Oakwood, the cost is \$80-\$90/day, which is out of reach for many people. While some people have LTC insurance, the premiums are high and also out of reach for many people.

- d. Carl Frels, son of a woman who died from complications of dementia, speaking on behalf of the Deaf community through a sign language interpreter. There are approximately 210,000 Deaf and hard-of-hearing individuals age 65 or older in PA, yet there is only one deaf care home for senior citizens, and it only accepts 40

residents. Deaf people have their own culture and language and may feel isolated from the hearing community. There is a need to create an environment that meets the needs of Deaf people, where staff, nurses, chefs, social workers, etc., are fluent in ASL. This would reduce frustration among the Deaf residents and stimulate brain function. Mr. Frels said the Planning Committee should include one or more Deaf representatives, since hearing people may not understand the needs of the Deaf. Resources for the Deaf can be found at Gallaudet University and at three regional DOH offices in PA, and at the Pennsylvania School for the Deaf.

- e. Lottie Powell, caregiver of mother who has AD, father with other health problems. The primary obstacle she has encountered is with the legal system. Mother had fear of independence being lost and became belligerent as the disease progressed, but legal constraints prevented physicians from discussing her case with the family. Ms. Powell feels that the legal system is more concerned with protecting the rights of patients than with the well-being of patients. Doctor's offices are afraid to communicate with caregivers even if patient has dementia. An obstacle is guardianship vs. power of attorney. After signing PoA, mother went to a second attorney and had it undone. She suggests that within 30 days of diagnosis, guardianship should be made available to family. Also, doctors, state police, bankers, family members, etc. need to be educated about dementia. She also suggested a registry for 911, more support groups, a mentoring program, and financial advocates for families.
- f. Representative Eddie Pashinski, caregiver. People in government may not understand the disease in all its complexities. Government must play a role, which comes down to money. Father is now in a dementia care unit that costs \$98,000 per year. "So it's totally impossible for regular folks." Need phased-in help for families, e.g. a home health advisor. Helping families take care of people longer would ultimately cost less to the State.

Second issue: this is now a business, which equals jobs. In PA there are 14 State schools as well as community colleges that could begin training people – providing a direct path from college to a job. Investing in these programs would help keep our citizens productive.

- g. Representative Marty Flynn. The "three Rs" today: research, resources, and respite care. Delaying the onset of dementia by 5 years could result in huge cost savings. The financial cost to the business community from lost productivity and stress-related illness among workers is huge. The State plan should help protect the livelihood of family caregivers and recognize the challenges caregivers face, providing training, financial help, support groups, professional nursing assistance, and respite care. Keeping seniors socially active is important; state funding is needed to provide quality programs for seniors. Need to work with businesses and employers to accommodate caregivers. Also need to encourage health care workers to specialize in geriatrics.

- h. Dr. Mario Cornacchione, geriatrician and director of Northeast PA Alzheimer's Center. There are only 1500 board-certified geriatricians in the US. AD is a family system disease. To deal with the shortage of geriatricians, suggests: increase training of primary care physicians to provide comprehensive care for people with dementia and their families including social services for families, e.g. to help management medications and deal with behavioral problems; provide more adult day care; develop (and funding) behavioral health practitioners to go into the home and teach behavioral management to families.

Dr. Cornacchione no longer evaluates patients, in part because Medicare reimbursement does not support the amount of time patients and families need for a thorough evaluation.

- i. Carolyn Tenaglia, regional ombudsman in NE region of PA. Ombudsmen are resident advocates, working with providers to make sure residents in long term care are receiving the quality of care they need and deserve and their rights and dignity are being respected.

Problems she sees include inadequate staffing levels in nursing homes as the acuity level of patients has increased. Facilities may discharge patients because they cannot meet their needs, putting more burden on families. Medical directors as well as other staff need more training and resources in dementia care.

In terms of long term care, a culture change is needed. Nursing homes were set up on a hospital-type model but have evolved to person-centered care using more non-pharmacological and non-restrain-based approaches, but providers may not understand how to provide these services and meet regulations. Options for people who cannot pay for PCH have been reduced; we need to find ways to help people pay for personal care.

We also need more resources for community education to prevent elder abuse, Elders with AD who live in long term care are the most vulnerable group. Ombudsman program needs more support to address this.

- j. Pearl Race, retired RN and formerly caregiver to mother who had dementia with mini-strokes. Volunteers at foodbank and sees many seniors and people on disability. Suggests that younger, able-bodied people on disability may be able to help by being forced to volunteer at adult day care centers.
- k. Susan Charnigo, working mother and caregiver to her mother who was diagnosed with AD 7 years ago. She had a swift decline, was cared for at home as long as possible, then moved to dementia unit in assisted living facility and then to nursing home. Family had to educate themselves and advocate for her. Many of the healthcare professionals had no idea how to care for person with AD. Nursing home was resistant to engaging hospice services, but eventually relented and

hospice was called in. Ms. Charnigo asks the committee to do all they can to support caregivers, encourage medical research, and teach medical professionals.

- l. Cara Sheetz, director of geriatrics at Lehigh Valley Network and daughter of man with AD, whose primary caregiver is Cara's 74-year-old mother. Emphasized the need for more geriatricians. By 2030 we will need 30,000 geriatricians but interest in the field is dwindling in part because of low salaries combined with huge medical school bills. Also need financial assistance for home-care; caring for individuals with dementia is exhausting and leads to health problems in caregivers. Another big worry is driving concerns – families don't want to be the "bad guy" even when elders are unsafe drivers.
- m. Clayton Jacobs, Alzheimer's Association. Association advocates legislative changes; in the meantime works to enhance care and support and increase awareness. Greater Pennsylvania Chapter serves 59 counties in PA with information, referral, support groups, research. We provide direct services to 45,000 people in PA but much more financial support from the State is needed for the 400,000 people in PA with a dementia diagnosis. People with AD and their families need: improved dementia friendly providers, better access to supportive services, improved early diagnosis, improved public awareness, robust early stage services. In order to provide better services and care, we need improved data collection and increased research funding.
- n. Mary O'Donnell, PADSA – PA Adult Day Service Association in Lackawanna County. Encourages emphasis on home and community-based services. Adult day service provides a cost effective care option and respite for caregivers. Medical community also needs more resources and training. Need more funding for Options program, which is available to more people than the Waiver program.
- o. Donna Quinn, daughter of woman with AD who receives Adult Day Services at Telespond. Mother loves going there, she thinks she has a job and feels important and useful. Funding for this program is needed.
- p. Beatrice Mallory, Marketing Specialist for multicultural communities, veterans, and wounded warrior, and has had several family members with AD. Addressed technical areas, in particular, lack of PA specific data about prevalence of AD and comorbidities in minority communities. African Americans and Hispanics are much more likely to be diagnosed with cognitive impairment and/or AD than whites; large proportion may be driven by diabetes. We need more research, more racial and ethnic minorities participating in clinical trials, cultural competency in care. Some private-sector organizations (e.g. Kaiser) are doing research relevant to minority communities. Other helpful resources include Office of Minority Health at DHHS, Minority Quality Forum in D.C., National Hispanic Medical Association, National Medical Association (Black physician group), Office of Diversity and Inclusion at the Alzheimer's Association (director, Marshawn Brown). Suggests committee engage consumer marketers who specialize in

reaching out to minority communities. Also recommends a state-wide level task force on culture and diversity to advise workgroups.

- V. Wrap up – Secretary Duke. Thanks to all who offered testimony. Next steps:
- a. Next regional meeting 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.