

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Clarion, PA
Minutes
September 16, 2013

Planning committee members in attendance

Legislative members

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

Senator Bob Mensch, Chair of Senate Aging and Youth Committee

Constituent representatives:

Kelly Carney, Alzheimer's disease researcher representative

Michael Ellenbogen, Person with AD representative

John Kordish for George Gunn, Assisted Living representative

Beth Herold, Area Agency on Aging representative

Cheryl Martin, DPW representative

Heidi Owen, Hospice representative

Maura Pelinsky, Adult Day representative

Pennsylvania Department of Aging Staff in attendance:

Rebekah Ludwick

Paul McCarty

Steven Horner

Donna Reinaker, PCOA

Lisa Bain, consultant

Members of the public in attendance: (apologies for misspellings; some names were illegible and not included)

John Stroup, Clarion Hospital

Byron Quinton, Clarion Hospital

Arthur Barlow

Melanie Titzel

Nancy Florio, Brookville Hospital

Julie Beichner, Venango County AAA

Dave Steele, Office of Human Services, Inc.

Cheri Clinton, Mt. Laurel Nursing and Rehab

Audrey Kozalla, Venango County AAA

Kathy Gillespie, Clearfield County AAA

Deborah Kelly, Clarion Forest

Debbie Wisinski, Alzheimer's Association

Samantha Cassman, LINK

David Mitchell, PA Governor's Office NW Director

Doris Jean Boddorf, Jefferson County AAA

Jill Over, CFVNA

Rosemary, AAA
Sandy Day, Active Aging
Karen Miller, Active Aging
Krista Geer, Active Aging
Stephanie Wilshire, Clarion AAA
Vicki Hoak, PHA
Donna Oberlander, State Representative, 63rd district
Matt Trott, GECAC AAA
Debra Menneck, GECAC AAA
Barb Hinds, Venango County AAA
Jan Brown, Regional Ombudsman
Sandy Nangle, DuBois Village
Tammy Heine, DuBois Village
Peter M. W.
Kristi Wolbert, AAA
Don Burkett, PCoA
Lisa Davis, PA Office of Rural Health
David Venanzi, Wesbury
Leah Kithcart, Alzheimer's Association
Joseph Bechtel
Sam Bellich, Mercer County AAA
M. Gusek, LIFE
Beverly DiSabato, SarahCare Adult Day Services
**List may not be complete*

Minutes prepared by Lisa J. Bain

- I. Welcome
 - a. John Stroup, executive director of the Clarion Hospital, welcomed Representative Donna Oberlander and other visitors to the meeting, noting that rural hospitals like Clarion are struggling to determine the direction they are going in particular with regard to caring for people with AD.
 - b. CEO of the Hospital, Byron Quinton added his welcome.
 - c. Senator Mensch welcomed planning committee and others to the 5th regional meeting of the PA Alzheimer's Disease Planning Committee. Secretary Duke is traveling today with the Governor, who is making an announcement about his healthcare plan and Medicaid. Senator Mensch summarized the process the committee has undertaken to develop a statewide plan action plan. Regional meetings such as this one enable the committee to hear the concerns of residents across the State.

- II. Three workgroups have been created to address the many topics. Brief updates from these WGs:

- a. WG # 1 – Prevention and Outreach (Maura Pelinsky). Chair is Dr. Charles (Chip) Reynolds. WG1 has established 5 main goals and have begun to develop a draft plan and reach consensus about recommendations. The five goals are:
 - i. Raise dementia awareness among the public.
 - ii. Prevent and/or delay the onset of dementia by promoting brain health and prevention.
 - iii. Raise dementia awareness in the healthcare community by educating healthcare professionals at all levels of care.
 - iv. Support and provide resources for caregivers.
 - v. Build capacity to promote brain health through partnerships.

- b. WG #2 – Healthcare delivery and workforce (Heidi Owen, Chair). This WG has been tasked with considering these key features: 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. Over the last couple of weeks the WG has drilled down to 4 vision statement and will begin assigning strategies to accomplish these goals:
 - i. Pennsylvania is a place that will optimize current systems and develop new systems to provide a comprehensive continuum of care and support that responds to social and cultural diversities, with services ranging from early detection and diagnosis through the end of life.
 - ii. Pennsylvania is a place that will promote innovations in service systems and funding mechanisms that improve quality of care, enhance quality of life, create efficiencies and reduce costs of supporting individuals with dementia.
 - iii. Pennsylvania is a place that will recruit, educate and retain a competent, knowledgeable and ethical paid workforce to meet the needs of the growing population of individuals with dementia and their caregivers.
 - iv. Pennsylvania is a place that will promote and support the development of dementia friendly communities that empower individuals with dementia and their caregivers.

- c. WG #3 – Research and Metrics (Becky Ludwick). Chair of this WG is Dr. Carrie DeLone, Physician General of PA. The goals of this WG are to improve the quality of information available regarding Alzheimer's disease and other dementias (ADRD), develop collaborations to share research results, increase research and provide cost effective approaches, analyze data and AD implications on public health, improve how government evaluates and adopts policies to assist people with AD and their families. We have incorporated our issues into these main categories:
 - i. Research collaboratives – to increase provider awareness and participation and ensure the inclusion of minority and other special populations.

- ii. Efficacy of interventions database and website that is accessible to Pennsylvanians and includes a risk stratification model.
 - iii. Economic impact of ADRD.
 - iv. Promotion and participation in dementia registries.
 - v. Policy changes aimed at keeping patients at home as long as possible.
- 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. Senator Mensch questioned why, given that the incidence of other diseases is declining while AD is increasing, there is not nearly as much noise around AD.
 - a. Dr. Arthur Barlow, retired professor at Clarion University and caregiver to wife who died on July 23. Wife was in denial for a long time. When she was diagnosed, they were able to find a lot of information from the Alzheimer's Association and AAA. Recommends: 1) patience and preparation, 2) adapt as things change and be realistic, 3) find support from many sources (AAA, friends, etc.). Greatest help was hospice, which took over medical needs, provided emotional and financial support, and provided holistic care. Misconceptions about hospice (e.g., that it is only for patients facing imminent death) delayed initiation of services. They reassured the family that they would not terminate relationship as long as services improved the quality of life.
 - b. Lisa Davis, director of Pennsylvania Office of Rural Health, which is dedicated to increasing the health status and access to services of rural residents. PA is one of the most rural states in the nation; 3.5 million residents live in rural areas. Demographics differ from urban residents – they tend to be older, sicker, and poorer, and face geographical barriers. There is also a big disparity in availability of health care providers, particularly in specialty areas such as geriatrics; thus they rely much more on primary care physicians. Patient-centered treatment approach (rather than disease-centered) is important for the elderly population who often have multiple medical problems, cognitive impairment, etc. Disease-centered approach breaks down when patients transition between different care settings, and this contributes to poor outcomes and inefficiencies.
 - c. Deborah Kelly, Clarion Forest Visiting Nurses Association (VNA). Concerns of individuals in rural PA include lack of access (especially to specialists in gerontology and geriatric psychiatry) and resources and inadequate knowledge on the part of caregivers. Difficult problems become magnified in rural areas. Relayed story of family that was referred to geriatric psychiatrist in Pittsburgh but were told they had to wait 3 months for an appointment. Many families are not willing to make that journey and there is limited access to public transportation. Also, many towns of rural PA have been affected by the economic downturn and children have moved away. There is also a great need

for respite care. Adult day care (ADCs) may provide an option, but lack funding and many patients are not be able to afford to pay out of pocket.

- d. John Kordish, PA Council on Aging. Focused on difficulties facing caregivers in rural areas: Rural organizations face unique challenges from large coverage areas (e.g., delivering 10 meals may take hours rather than minutes in urban areas). Also, solutions that work well in urban areas may not work as well in rural areas, e.g., ADCs – because of sparse populations, ADCs may not be near enough to be convenient. Suggestions:
 - i. Examine existing rules and requirements and consider more flexibility
 - ii. Encourage distinct rural models of service – let marketplace show what is needed, e.g., use of technology, better ways of using vouchers, or a brand new system.
 - iii. Provide demonstration/pilot funds to support rural service options to support caregivers.
 - iv. Provide families with help in planning for long term care, guardianship issues, etc.
- e. Melanie Titzel, family caregiver to mother over 13 years. Caregivers need social support and education and need to be able to access support in a variety of settings where caregivers are already located. While caring for her mother, she was working full time and did not have time to go to support groups and seminars. Suggests that a resource person from Alzheimer's Association or AAA be made available for caregivers when the patient is at a doctor's office or church, etc. Training of HR professionals about dementia and caregiver needs could also help.
- f. Kristi Wolbert, living for 4 years with mother who has dementia. Family was in denial, especially those living out of town. Has three wonderful caregivers who come to the house Tuesday-Friday; has caregivers keep logs of what mom eats, activities, etc. Her goal is to keep mom healthy, happy, safe, clean, and fed; and to keep her out of nursing home as long as possible. Finding trustworthy caregivers is difficult and has done it mainly through church and word-of-mouth. Maintaining two homes has been complicated. Cost of care is also a concern. Recommends to other caregivers: patience, staying positive, join 'their' world.
- g. Deb Wisinski, family service coordinator at Alzheimer's Association Greater PA Chapter and AAA in Erie. The Greater PA Chapter covers 59 of 67 counties and in the past year, provided direct services to over 45,000 Pennsylvanians, but it is not nearly enough given that an estimated 400,000 Pennsylvanians have a dementia diagnosis. Families often do not know where to turn, especially in rural areas. Needs: improved data collection, better access, improved early diagnosis, increased awareness, increased research funding, more early stage services, and better understanding of best methods to deliver services.

- h. Vicki Hoak, Pennsylvania Homecare Association, which represents hospice and home care organizations across the state. Hears over and over how wonderful the hospice benefit is, yet it is a struggle to get benefits for hospice. It is often difficult to be certified by Medicare for hospice because of stringent rules. Last year, AD was one of top 3 denied diagnoses. One reason is that physicians often face a difficult task in certifying that an individual would die in 6 months. Recommends broadening the Medicare rules around hospice and home health care.

Medicaid rules (including Waiver program) for in-home care also need to be changed. Many people are not eligible to receive benefits yet would be eligible for more costly nursing home care. Also, it takes on average 3-4 months for person to become eligible to receive services in home and community, although nursing homes are allowed to begin services based on presumptive eligibility.

Urges committee to work with other committees and not create more silos.

- i. Nancy Florio, Community Relations Coordinator, Brookville Hospital Senior Transitions Unit and Geriatric Outpatient Clinic. We see patients related to behavior problems. In this region of PA, we have many resources but several facilities have closed secured units or revise admission criteria, so we do not have placements for more difficult individuals. Facilities often do not have enough staff, and those staff do not have adequate training. Nursing Aides are doing majority of care but do not get paid enough or have enough training. It has been difficult to recruit geriatric psychiatrists. Suggests:
 - i. Standardized training mandated for staff (e.g., to recognize symptoms of delirium).
 - ii. Specialized residential units with specialized services
 - iii. Peer support person to help guide through system.
- j. Julie Beichner, Venango County AAA. Addresses concerns with family caregiver support program. County has about 35-40 people in this program. Originally was \$200/month, but has been increased with federal component. Costs exceed the amount provided, yet institutional care would be far more expensive. We try to connect people with local services and do fundraising to help caregivers. Families are isolated and shut off because they are so far from others.
- k. Don Burkett, caregiver to 40-year-old autistic son; previously cared for mother with dementia. "There are two victims, maybe more when we are dealing with AD". Caregivers need help.
- l. John Stroup, executive director of Clarion Hospital. His mother is going through early stages of dementia. Families need education to know what is coming.

- m. Deborah Kelly from VNA commented that hospice is much less expensive than people going in and out of hospitals. If people could opt for a hospice-type system, where you are choosing not to pursue treatment of everything but have a team of people to work with you, the government could save money, and patients and families would be happier.
- n. Beverly DiSabato, Director of SarahCare Adult Day Services in Forest Hills; also on board of PADSA. Agrees that there are two victims. Notes that hospice can come into ADC to provide services; however, we do not have enough ADCs in rural communities. ADC in PA is much improved over last 10 years – have added an enhanced waiver program, which means that centers must have registered nurses, provide bathing services, be open 11 hours/day, care plans every 14 days, and one staff member per 5 persons. “We are like a nursing home without beds.”
- o. Shirley worked in waiver program, but it has been cut. Home health is much cheaper.
- p. Kristi Wolbert responded to Melanie’s comment about support groups. The problem is the need to hire someone to stay with mom so she can go to group. We are desperate but don’t go because of this. Then the groups are eliminated for lack of support.
- q. Nancy Florio offered a couple of ideas:
 - i. A consumer based “warm line” that people can call, staffed by volunteers who have been through similar problems.
 - ii. Caregivers health fair – activities for people with AD/dementia and at the same time, learning opportunities for caregivers.
 - iii. We often forget about caregivers – we need more cooperation among services.
- r. Deb Wisinski said the Alzheimer's Association has a 24-hour help line staffed by masters’ level clinicians. They also have early stage teleconferencing for people with disease and their loved ones and message boards.
- s. Lisa Davis – we see that different communities come up with different solutions, either with the help of or in spite of government programs. On the ground pieces are what matter.

V. Wrap up

- a. Senator Mensch said we need more community reinvolvement in all areas and not rely on government to take care of us.
- b. Heidi Owen (committee member) noted that we are seeing common themes across all regional meetings including the need for geriatric psychiatrists,

education for professional caregivers, and support and education for caregivers in the home.

- c. Kelly Carney (committee member) noted that each meeting had a particular flavor, so we are seeing the issues from a variety of perspectives.
- d. Senator Mensch noted that this meeting was perhaps the first where there was little resentment of the medical community expressed.

VI. Next steps:

- a. Next and final regional meeting September 17th in Pittsburgh.
- b. Committee will regroup in the fall in Harrisburg to develop a framework with the objective of having a final plan completed by February, 2014.
- c. 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.