

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Pittsburgh, PA
Minutes
September 17, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Department of Aging

Legislative members

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

Constituent representatives:

Kelly Carney, Alzheimer's disease researcher representative
Michael Ellenbogen, Person with AD representative
Jen Martchek for George Gunn, Assisted Living representative
Beth Herold, Area Agency on Aging representative
Cheryl Martin, DPW representative
Robin Mozley, Senior Center representative
Heidi Owen, Hospice representative
Maura Pelinsky, Adult Day representative
Charles Reynolds, Medical Care Provider Comm. Representative

Pennsylvania Department of Aging Staff in attendance:

Rebekah Ludwick
Paul McCarty
Steven Horner
Christina Reese
Donna Reinaker, PCOA
Lisa Bain, consultant

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

Joan Rogers, AAA and UPitt
Pam Toto, UPitt
Ed Ricci, UPitt
Leslie Dunn, UPitt
Hal English, State Representative – 30th district
John Lovelace, UPMC
Tanya Fabian, UPMC
Christine Ruby, UPMC
Rich Schulz, UPitt
Orla Nugent, PCoA
Jack
Anne Newman, UPitt
Tiara Chadran, UPitt

Korie Krull, UPitt
Erin Bittman, UPitt
Cathi Sweeney, AIUCP
Beverly Sullivan, PCoA
Andy
Chris Williams, UPitt
David Lusk, Alzheimer's Association
Jack Lusk
Lalith Kumar-Solai, UPMC
Heather Sedlacko, Valley Care Association
Mina Chen, UPitt
Kaila B., UPitt
Robert Johnson, Governor's Office, Southwest Region
Thomas Lauritzen, Washington County Adult Day Care
Betty Robison, Aging Institute, UPMC
Madeleine Bourgeois, UPitt
Kristen West, UPitt
Judy Cameron, UPitt
Caterina Rosales, UPitt
Beth Mulvaney, UPitt/caregiver
Robert Boothe, Bayada
Cheryl Daver, Bayada Home Health Care
Gwen Ogle, PCoA
Rima Elattajje, UPitt
Carol Hennesery
Nadine Simon, PCoA
Denise Hodes, UPMC Senior Care
Beth Deely
Annie Harder, UPitt
Joanne Graffte, Laurel Highlands Alzheimer Foundation
Lynda Tyri, Family Links
Ines Boisrond, Community Human Services
Valerie Kay
Betsy Momich, Alzheimer's Association Board
Leah Kithcart, Alzheimer's Association
Lynn Collins, LIFE Pittsburgh
Nicole Fowler, UPitt
Thomas Laton, UPMC
Saskia Berrios-Thomas, UPitt
Lori O'Brien, JAA
Anthony Turo, Ursuline Sr. Svcg PCoA
Brenda Selkeleti, Allegheny County AAA
Gail Roddie-Hamlin, Alzheimer's Association
Mildred Morrison, Allegheny County AAA
Derek Uber, Highmark Health Services
Joe Elliott, Allegheny County DHA

Jenny Wolskbain, IWB Consulting
Danielle Holt, Community Human Services
George Gesser, CTA Stephen Foster
Patricia Lesnoski, Anova Hospice
Hillary M., Rosecrest Assisted
Cindy Cameron, Laurel Highlands Alzheimer Foundation
Martha Ligas, Americorps Intern at Ursuline Senior Services
Jason Flatt, UPitt
Ransom Towsley, Presbyterian Senior Care
Natalie Ernecoff, UPitt Public Health
Dan Miller, State Representative
Andrea Rosso, UPitt
Dorothy Gordon, NHS Allegheny Valley School
Michael Zigmund, UPitt
Neil Resnick, UPitt
Julie Jedlick, Seton Center
Patty Lemro, Vincentian Home
Angela Grimm, Alzheimer's Association
Nancy Riggle, Alzheimer's Association
Carol Erzen, NHS Allegheny Valley School
Sue Schmidt, Merion Manor
Ron Budash, Laurel Highlands Alzheimer Foundation
Margaret Hutchinson, Laurel Highlands Alzheimer Foundation
Govy Rothstar, Pittsburgh Post-Gazette
Denise R. Vincentian Home
Mary Lou Harjer, LIFE/Lutheran Senior Life
Carrie Chiusano, Presbyterian Senior Care
Taafoi Kamara, Aging Institute
Lois Lutz, Alzheimer's Association
Margie Zelenak, UPMC
Erin Raub, House Aging Committee
Ray DuCoeur, Westmoreland County AAA
Russell Gorzlazyk, AAA
Marie Goff, Laurel Highlands Alzheimer Foundation
Deborah Sauder Franzen
Beverly DiSabato, Sarah Care Adult Day Services
Jason Yest, UPitt
Shravani Chamyula UPitt
Rich Moryzc, UPitt
Diane Cunningham, Home Instead Senior Care
Juliet Adedimab, UPitt
Rebecca May-Cole, PBHAC
Howard Degenholtz, UPitt
Stephanie Simmons, Sarah Care
Oscar Lopez, UPitt
Leslie Grenfell, Southwestern PA AAA

**List may not be complete*

Minutes prepared by Lisa J. Bain

I. Welcome

- a. Dr. Charles Reynolds, UPMC Endowed Professor in Geriatric Psychiatry, introduced Brian Duke, Secretary of Aging.
- b. Secretary Duke welcomed everyone and described the “Healthy PA” plan introduced yesterday by Governor Corbett to achieve 3 goals: 1) improve access 2) improve quality and 3) provide affordability. He also described the crisis in PA brought on by the increasing numbers of persons with AD and the large elderly population. This 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 sixth and final 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.

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

- c. WG # 1 – Prevention and outreach (Dr. Charles Reynolds, Chair). WG1 has established 5 main themes:
 - 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.
- d. WG #2 – Healthcare delivery and workforce (Heidi Owen, Chair). 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.
 - e. WG #3 – Research and Metrics (Brian Duke). Chair is Dr. Carrie DeLone, Physician General for the Commonwealth. Goal is to improve the quality of information available, 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.
- II. Showed video from the Alzheimer’s Association that provides background on AD and outlines the challenges we face.
- III. Testimony from members of the public.
 - a. Dr. Neil Resnick, Chief of Academic Division of Geriatric Medicine, UPMC. Dr. Resnick focused on the desperate need to increase the number of geriatricians. Elderly patients often have multiple conditions and take many meds, which makes their care complicated. Also, aging robs older people of resilience, and this can result in delirium, which more than doubles the risk of dementia. Team approach is needed including physicians, nurse practitioners, pharmacists, etc. the proportion of physicians and other professionals with even minimal training is tiny. Suggests:
 - i. Consider ways to increase the number of geriatricians. Geriatricians are among most satisfied of all physicians, yet less than .5% of med school graduates express interest in geriatrics. Investigate broadening loan forgiveness to include those going into geriatrics, similar to what has been done in South Carolina and other states.
 - ii. Develop programs to train PCPs and non-physicians.
 - iii. Develop improvements at the system level, e.g., help with diagnostic management, coordinating programs and services.
 - iv. Improve home health programs and all inclusive care for the elderly
 - b. Carol Erzen, Director of training and staff development for NHS Allegheny Valley School, which provides residential care for individuals with intellectual and developmental disabilities (IDD). People with Down syndrome (DS) have a

much higher risk of developing dementia; by middle age nearly all adults with DS have protein deposits in the brain consistent with AD. These individuals and their families have an increased need for support. Recommendations:

- i. Increased funding to improve training, retrain staff to provide 1:1 care
 - ii. Review and revise state laws regarding advanced care planning to insure that they work for individuals with IDD.
 - iii. Increase research on treatment of AD in individuals with IDD.
 - iv. Disseminate research findings.
 - v. Acknowledge IDD as a vulnerable subpopulation.
- c. Rich Schulz, Professor of psychiatry at UPMC. Research shows that caregiving is a public health issue, increasing levels of depression, illness, mortality. Those who provide high levels of care such as for people with AD are at high risk; other risk factors include lower income, older age, low education, female gender, lack of choice, living with recipient. Intervention for caregivers is needed. Recommendations:
- i. Identify and implement best practice models (has been done effectively in other states), e.g., identifying caregivers at risk for adverse outcomes and implementing tailored, evidence-based solutions to address caregiver needs.
 - ii. Explore technology-based solutions to address caregiver needs.
- d. Beverly Sullivan, Administrator of Beaver County Office on Aging and caregiver to mother for five years. Family planned ahead, but still struggled with complicated needs of mother. Heavy burden on family, although not eligible for financial assistance because not low income. Hired private pay caregivers. Day care can be helpful for some families, but if family caregivers go to work every day, it can be difficult to get person ready and transport to day care before going to work. Transportation to day care is needed.
- e. Robert Boothe and Cheryl Daver, Bayada Home Health Care. Bayada provides services so patients can live in home. Funding is needed to provide education for informal and professional caregivers so that they will be prepared to care for clients with AD.
- f. Beverly DiSabato, Sarah Care Adult Day Care. ADCs promote concept of aging in place, and are also in unique position to provide care to family caregivers. ADCs cost about 40% as much as nursing home placement and provides safe, structured environment, meets nutritional and medical needs, and provides social connection. Sarah Care meets expanded criteria for enhanced waiver – open at least 11 hours a day at least 5 days a week, employs RNs, provides bathing services, has care plan on every client documented every 14 days, staff to client ration of 1:5 or better. Most Sarah Care clients have AD. Requests the committee consider:
- i. Addressing funding eligibility issues that currently take as long as three months before eligibility is considered.

- ii. Increase funding- limited dollars mean clients can usually only receive care 2 days per week
 - iii. Expand transportation in rural areas
 - iv. Expand dementia training for staff; consider non-mandatory dementia certification
 - v. Encourage collaboration with other aging providers, e.g., in home services get client ready to go to ADC.
 - vi. Address needs of individuals with early onset AD who often have younger families and children at home.
- g. Stephanie Simmons, daughter of Sarah Cares client. Tried home care but difficult to find reliable caregivers. At Sarah Care she has 6 days of consistent care. Mom is more interactive and more social, her health has improved and she has had fewer hospitalizations. “I can go to work and my mind is at rest”.
- Suggestions:
- i. Longer hours
 - ii. Short term respite care (i.e. weekends).
- h. Deb Franzen, caregiver. Addressed the issues of guardianship and abuse. Tells story of her mother who had to go from PA to Ohio to get rehab after a broken hip. A woman from church went to an attorney and had mother declared incompetent and took over guardianship. Suggests that committee look into the definition for abuse and how to better protect vulnerable individuals.
- i. Marie Goff, Laurel Highland chapter of Alzheimer Foundation in Johnstown. Money raised by foundation is used to provide educational materials, speakers, early dementia screening, free hours of respite care, local professional caregiving services. Identified the following needs:
- i. Respite care – more options and get it covered by Medicare?
 - ii. Information provided at doctors’ offices
 - iii. Screening for elderly patients
 - iv. Early diagnosis
 - v. Info on how to deal with combative patients
 - vi. Caregiver training
- j. Gail Roddie-Hamlin, President of Alzheimer's Association Greater PA Chapter, which serves 59 of 67 PA counties, providing face-to-face and teleconference support groups, helpline in 170 languages and dialects, educational programs. More is needed:
- i. Wandering – safe return program of Alzheimer's Association
 - ii. Technology and social networking communities
 - iii. Early stage outreach
 - iv. Diversity and inclusion.

- k. Thomas Lauritzen, caregiver to mother-in-law who has moderate dementia and has lived with Mr. Lauritzen and wife for 6 years. Mother-in-law goes to adult day care center 4 hours/day, 5 days/week. Issues to address:
 - i. Prevention
 - ii. Training program for caregivers; UPMC has a good program.
 - iii. Transportation to ADC necessary in order to keep patient at home.
 - iv. Short term respite care – what is available now is cost prohibitive, but of great value to caregivers.

- l. John Lovelace, President of Government Programs at UPMC health plan. Addressed issues related to Medicare. UPMC is working on creative supports for caregivers including respite opportunities; also instituting screening at annual Medicare wellness visit, which requires advanced training for PCPs. We are working with the Aging Institute at Pitt to create curriculum for physicians to help them better assess needs of families and caregivers. Also working with providers and families on issues related to palliative and end-of-life care. Also working to help patients and families use resources more effectively.

- m. Howard Degenholtz, Associate Professor of Health Policy and Management, School of Public Health, UPMC; also part of Aging Institute dementia workgroup. Led study to inform the AI and UPMC about the challenges faced by caregivers of people with dementia. Three themes emerged (full report will be posted on line):
 - i. Real need for education of general public and those directly touched by AD.
 - ii. Need for support to decipher complex legal, financial, and insurance issues.
 - iii. Stress and burden of caring for person with AD leads caregivers to become socially isolated.

- n. Gwen Ogle, PCoA and caregiver to husband who was diagnosed at age 60. Despite history of work in aging, was totally unprepared to become a caregiver. Identified several needs:
 - i. Educate families.
 - ii. Provide care for those with moderate incomes, e.g. by providing Medicare subsidy for Adult Day Care.
 - iii. Improve transportation so people can take advantage of Adult Day Care.

- o. Dr. Oscar Lopez, Director of ADRC at UPitt. Discussed the experience of other places in the world. Has been working with a center in Barcelona that has developed integrated clinic that takes care of all patient needs, i.e., Adult Day Care, day hospital, cognitive stimulation in context of active research program. Also has a well-developed system for screening. Byproduct is that it relieves burden on caregivers and delays nursing home admissions.

- p. Leslie Grenfell, Executive Director of AAA Southwestern PA.
Recommendations:
- i. Expand family caregiver program that is supported through the AAAs. Currently lacks sufficient funding to support all who are in need, including those with early onset.
 - ii. Expand statewide respite care program, including help for moderate income people.
 - iii. Expand availability and accessibility of home- and community-based programs (e.g., ADCs) to ensure availability and eliminate waiting lists.
 1. Provide transportation in rural parts of PA.
 - iv. Develop public awareness campaign.
 - v. Convene annual AD State summit to enable Commonwealth to continue the process started by this planning committee – reviewing priorities, learning about cutting edge research, providing opportunities to hear about what is available in terms of services and training.
- q. Betsy Momich, Board member of Alzheimer's Association and caregiver to mother with AD. We have a large family, and also hired caregiver, yet despite a lot of organization and help, it was very stressful. Emphasized:
- i. Need to raise awareness, change peoples' perception about AD and dementia.
 - ii. Need to become desperate about finding cures and drugs that slow progression.
 - iii. Need better home care options.
- r. Ransom Towsley, Senior Director of Community Services, Presbyterian SeniorCare and caregiver for father with AD. Emphasized that AD is not the only form of dementia and recommended that we use the term "AD and related dementias" (ADRD) to be as inclusive as possible. Different terminology affects service delivery and funding. ADRD results in higher rates of institutionalization and hospitalization, higher costs, takes more resources than other chronic diseases, and robs people of their ability to self-manage and overloads caregivers with stress. Recommends committee explore systems of better home management of medical and psychiatric comorbidities in these areas:
- i. Support of caregiver
 1. Assessment and providing support by using caregiver burden assessment, e.g., the California caregiver resource center uniform comprehensive assessment tool, which has 10 components.
 2. Long term supports including respite and adult day services.
 - ii. Management of comorbidities of person with dementia – additional assessment to identify other remedial medical, behavioral and environmental factors that place client at risk of short or long term institutional services.
 1. Assessment would look at cognitive/behavioral health needs.
 2. Keep an eye on medication and functional rehab issues.

- iii. Disease management and education, end of life counseling.
 - iv. Avoidance of acute care and hospitalization by supporting primary care practices. These can have debilitating effect on person with dementia. Explore models such as ACE program in Cleveland.
 - v. Care management and access to community-based long term supports and services should be integrated into primary care practice.
- s. Jack Lusk, caregiver to wife since 2008. (his son, David Lusk, read his comments). In June 2013, wife moved to nursing home. Supports increased research to find cures/treatments.
- t. Betty Robison, gerontology educator. Discussed two programs:
- i. “Ageless Wisdom” program at Aging Institute, which focuses on caregivers in the home. Program utilizes experiential training in a 2-4 hour format. Have also developed a “train the trainer” manual to provide training to nursing assistants and other workers.
 - ii. “I’m Still Here” dementia training program that can be tailored to different audiences. Piloting this program and plan to develop “train the trainer” modules for this as well.
- u. Rebecca May-Cole, PA Behavioral Health and Aging Coalition. Up to 90% of individuals with dementia experience behavioral and psychological symptoms including hallucinations, delusions, depression, anxiety, wandering, verbal agitation, physical aggression, disinhibition, emotional changes, etc. These symptoms are often treatable but because people do not know how to manage, they often result in premature institutionalization. Nursing homes, however, may deny entrance because they do not feel capable of managing behaviors. Especially difficult to find treatment and assistance for people with early onset dementias. Increases family stress. Needs:
- i. More assistance to family caregivers.
 - ii. Education of professionals about these symptoms and management strategies.
 - iii. Encourage more professionals to enter this field.
- v. Ed Ricci, Professor in the Graduate School of Public Health at UPMC. Also chair of advisory council to Allegheny County AAA and caregiver to wife. \$50 million goes to our county for community oriented programs to keep seniors in their homes. Even with those resources, stress is overwhelming to family caregivers and we do not have full continuum of services for patient/caregiver dyad. We need to improve the system of care by making it more comprehensive, responsive, and coordinated. Also need to empower caregivers and inform the community so they can be supportive. Recommendations:
- i. Fully examine and support efforts of the Department of Health to promote widespread adoption of the patient-centered medical home for chronically ill patients.

- ii. Healthcare providers should view patients as a dyad; support for caregiver of equal importance to patient.
 - iii. Incorporate palliative care into treatment plan.
 - iv. Encourage employers to support family caregivers with work flexibility.
 - v. Develop/expand programs to support and inform caregivers about medical, legal, and stress management issues.
- w. Tanya Fabian, UPitt School of Pharmacy. Pharmacists play a key role in optimizing medical management of patients. Most people 65 and older received 3-5 medications; that doubles in long term care settings. Medical safety is a huge concern, with multiple providers, conditions, etc. Pharmacist can help manage medication challenges and are among most trusted and accessible health care providers, but are underutilized. Three main barriers to overcome:
- i. Training health care force in geriatric mental health.
 - ii. Funding education for pharmacists to rapidly expand workforce.
 - iii. In order to sustain services, obtain provider status so we can practice at high level.
 - iv. Develop policies for pharmacists to advance roles of pharmacists by recognizing them as integral to the health care team.
- x. Christine Ruby, Clinical Pharmacist at Senior Care Institute, UPitt. Across the state there are inadequate numbers of clinics with a team approach to caring for patients with dementia. Pharmacists are uniquely equipped to address many of the challenges of managing these patients, including avoiding unsafe medications and drug-drug interactions, identifying appropriate treatments, dealing with transitions, educating patients and families. Lack of reimbursement is a major barrier. Policy changes are needed to allow for advanced roles for pharmacists.

IV. Wrap up

- a. Secretary Duke thanked all participants for their statements.
- 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. If people wish to share additional comments, we will continue to collect public input through the website, www.aging.state.pa.us; 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.