

Pennsylvania (PA) Alzheimer's Disease (AD) Public Meeting
Harrisburg, PA
Minutes
October 25, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, PA Department of Aging

Legislative members

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

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

Deborah Toomey for Shirley Kitchen, Minority Chair of Senate Public Health and Welfare Committee

Steve Samuelson, Minority Chair of House Aging and Older Adult Services Committee

Constituent representatives:

Kelly Carney, AD research representative

Dr. Carrie DeLone, Physician General and PA Department of Health representative

Michael Ellenbogen, Person with AD representative

George Gunn, Assisted Living representative

Susan Heinle, Homecare representative

Cynthia Lambert, Family member representative

David Leader, Personal Care Home Industry representative

Cheryl Martin, Department of Public Welfare representative

Bob Marino, Alzheimer's Association representative

Dr. Charles Reynolds, Medical Care Provider Community representative

Jill Schwartz, Caregiver representative

Dr. Stuart Shapiro, Nursing Facility representative

Kathy Jedrziwski for Dr. John Trojanowski, AD Researcher Representative

Pennsylvania Department of Aging Staff in attendance:

Dr. Ken Brubaker

Amy Comarnitsky

Rebekah Ludwick

Paul McCarty

Steven Horner

Kelly O'Donnell

Dan Smedley, intern

Tom Snedden

Lisa Bain, consultant

Others

Erin Raub, House of Representatives Aging Committee

Leah Kithcart, Alzheimer's Association
Kevin Tucker, Alzheimer's Association
Gail Roddie-Hamlin, Alzheimer's Association
Melissa Myers, PA House of Representatives

Not in attendance

Matthew Baker, Chair of the House Health Committee
Beth Herold, Area Agency on Aging representative
Senator Bob Mensch, Chair of Senate Aging and Youth Committee
Robin Mozley, Senior Care representative
Heidi Owen, Hospice representative
Maura Pelinsky, Adult Day representative
Senator Pat Vance, Chair of Senate Public Health and Welfare Committee
Senator Leanna Washington, Minority Chair of Senate Aging and Youth Committee

Members of the public in attendance (apologies to those not listed, some names were difficult to read)

Judy Patrick, DPW-OLTL
Marjorie Hughes
Katie Warner, Alzheimer's Association
Megan Smith, Alzheimer's Association
Ryan Pysker, Alzheimer's Association
Anne Henry, DPW OLTL
Shannon Baker, DPW OLTL
Lisa McGrordy, DPW OLTL

Minutes prepared by Lisa J. Bain

- I. Welcome (Brian Duke)
- II. Guest speaker – Katie Maslow, scholar in residence at the Institute of Medicine. Introduced by Paul McCarty. All committee members received a copy of her white paper: “Translating Innovation to Impact: Evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community.”
 - a. Comments on our recommendations: Wishes we would be more explicit and emphasize that there are things to be done for people with Alzheimer’s disease and related dementias (ADRD). The report looked at 44 U.S. randomized clinical trials that looked at interventions and care practices. They tell us that there are things we can do. A major problem, however, is that people with dementia and family members believe that there is nothing to be done.
 - b. Most interventions were for caregivers and resulted in decreased depression and anxiety as well as increased self-efficacy (feeling capable). Interventions for people with dementia showed not that they change the course of the disease but that they change the experience. With counseling, people

- showed decreased depression, less shame, more able to manage, and more comfortable with their caregiver.
- c. A lot has been learned about differences between care settings. Mary Naylor at Penn has a wonderful intervention for transitional care. Wishes we would say more explicitly that care settings matter and interventions are available, including home-based interventions and caregiver support programs (e.g., national family caregiver support, Savvy Caregiver, Cleveland managed care project). These are evidence-based interventions.
 - d. Why don't people know about these programs? As a society we don't put as much focus on care as we do on cure. Promoting these programs is first step to getting coverage by Medicare.
 - e. Practices that work include educational interventions in which caregivers learn about the stages of ADRD as well as ways to manage problematic behaviors. E.g. Mary Middleman's NYU caregiver intervention.
 - f. Kelly Carney asked about the difficulty of bringing evidence based practices into the real-world setting. Katie said there has been a lot of translational research done through the congressionally mandated AD supportive services program. She suggests including recommendations about partnerships with academic organizations and service organizations in the State plan. This will push it forward.
 - g. Steve Samuelson asked if there is a central government or private organization that keeps an updated list of programs. Katie said this is not available in a way that the public, payers, or policy makers could easily find. A clearinghouse for this information would also be good to include in the State plan.
 - h. Regard dementia friendly communities, Katie suggested looking at Minnesota's Act on Alzheimer's – including state legislation. Minnesota has 4 communities trying to become dementia friendly. San Francisco is the first city that has its own dementia plan. St Louis is trying to build something around early detection and diagnosis. Many of the things people are trying are not evidence-based, so it's hard to pull out the relevant variables.
 - i. Over last decade, American Medical Association and other organizations developed 10 quality measures for physician care for AD and dementia. Centers for Medicare & Medicaid Services (CMS) put 9 of those into the physician quality reporting system, which provides incentives. The one left out was about palliative and end of life care. National Quality Forum reviews and vets measures that government must follow. CMS has told them to open another committee review looking for ADRD quality measures. This process creates the opportunity for new measures to be proposed and perhaps endorsed.
 - j. Regarding screening – the United States Preventive Services Task Force decided in 2003 that there is no reason to screen for cognitive impairment because there is nothing to be done. This has been a setback and needs to be changed.
 - k. Stuart Shapiro asked, what three things family caregivers can do to prevent the progression of the disease. Katie said that while there is currently no way

to prevent progression, there are interventions and medications that will help. She suggested finding a savvy caregiver program or an early stage program; meet a mentor; ask what problems do you want to solve and what would make your life better. There has been poor translation of how interventions can help. Communicating better is an important message we can give.

- l. George Gunn described program at the Friendship House (dementia care component in 23 continuing care retirement communities) - Memory box into which residents put 3-5 memorable items. Helps them remember it's their room. Another important message to caregivers is to meet the residents where they are rather than constantly correcting them. Katie agreed, adding that studies show that when family caregivers are able to not argue, they tend to be less depressed and sometimes irritating behaviors stop.

III. Workgroup (WG) updates

- a. WG1 – Prevention and Outreach (Chip Reynolds):
 - i. One area of focus is on promoting healthy brain and cognitive fitness into later years, even though science does not confirm that this helps.
 - ii. WG is also addressing the importance of regular screening for cognitive fitness and depression since many underlying problems can be corrected.
 - iii. Support further education for clinicians across the spectrum of care.
 - iv. Outreach and support to family caregivers
- b. WG2 – Healthcare delivery and workforce (Kelly Carney). Four general themes; we are fleshing out strategies and goals :
 - i. Developing and sustaining a comprehensive continuum of care.
 - ii. Encouraging innovation in terms of funding.
 - iii. Workforce recruitment and retention
 - iv. Dementia friendly communities.
- c. WG3 – Research and Metrics (Carrie DeLone):
 - i. Supporting research
 - ii. Getting more patients involved in research studies, including educating providers about how to get patients into trials and making sure individuals have the information they need.
 - iii. Collecting data about prevalence, incidence, and best practices.
 - iv. Information sharing – will recommend an annual conference.
 - v. What can be done from policy perspective to help people remain in home as long as possible.

IV. Secretary Duke said the workgroups will continue their work.

- a. Next meeting is November 21.
- b. Secretary Duke also noted that November is Alzheimer's Awareness Month. On Nov. 18th at 1:00, a resolution cosponsored by Representatives Hennessey and Watson will be read. People are encouraged to come to the public gallery. Also, at 11:30 that day, we will be giving legislators and staff an update on the work of the planning committee.

V. Public comments:

- a. Lisa McGrordy, works for the Office of Long-Term Living, but speaking here as a citizen who cared for mother in law for three years. She can relate to feelings of hopelessness. It is difficult to get coverage for supports. She asked about studies tracking the physical health of caregivers and family members in relation to the supports the patient gets.

Katie said that most studies are not long enough but some have looked at caregivers over time. These studies show that taking care of someone with dementia is more difficult than caring for an older person with other conditions. One problem that makes it difficult to study the impact on caregivers is that if the caregiver's health suffers a great deal, someone else may take over the care of the person with dementia.

- b. Tim Hennessey suggested that the medical community move away from the word dementia as it demonizes the condition. Suggests using a word that is less derogatory/offensive.
- i. Katie said people vary in terms of whether they hate the term "Alzheimer's" or "dementia" more, but agrees language is important. Beyond language, what is the problem and what is the cause? It's not just a medical but a societal issue.
 - ii. Chip noted that in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition, the preferred term is neurocognitive impairment (minor to major).
 - iii. Michael Ellenbogen, however, said that he does not find the term dementia offensive. "What is offensive is that people don't know the true meaning." People need to be educated about what it means to have this disease.
 - iv. Chip commented that this addresses the issue of stigma.
 - v. Katie agreed, noting that we place a high emphasis on cognition as if that is the only thing that matters in AD. She said we need to understand more about what Alzheimer's is and what dementia means, but also that people are more than their cognition; that they have strengths they can use to help them remain able and contribute to society.