

Pennsylvania Alzheimer's Disease Planning Committee Public Meeting
Philadelphia, PA
Minutes
August 15, 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

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

Mike Deery for Senator LeAnna Washington, Minority Chair of Aging and Youth Committee

Constituent representatives:

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

Bob Marino, Statewide Alzheimer's Association representative

Michael Ellenbogen, Person with AD representative

Cynthia Lambert, Family member representative

Heidi Owen, Hospice representative

Kelly Carney, Alzheimer's disease researcher representative

Jill Schwartz, Caregiver representative

Stuart Shapiro, Nursing facility representative

John Trojanowski, Alzheimer's disease researcher representative

Pennsylvania Department of Aging Staff in attendance:

Rebekah Ludwick

Paul McCarty

Steven Horner

Terry Brown

Tom Snedden

Christina Reese

Lisa Bain, consultant

Members of the public in attendance:

Kathy Fisher, Watermark

Wendy Campbell, Alzheimer's Association

Mark Saltis

Lisa Salley

Arlen Larue for Representative Vanessa Brown (Philadelphia- 190th District)

Representative Mark Cohen (Philadelphia- 202nd District)

Sonya Thomas

Dan Haimowitz

Don I. Trachtenberg
David Irwin, UPenn
H.S. Parker
Representative Katharine Watson (Bucks- 144th District)
Karen Hirschman, UPSON
Iba Michiyo, UPenn
Debra Broccardi, Abramson Home Care
Virginia Lee, UPenn
Jennifer McBride, UPenn
Liz Murphy, Manor Care Arden Courts, Yardley
Kathy Monroe, Berks AAA
Sara Wright, Hospice Community Care
Coleen Kayden, Med Information Services
G. Hutchinson
G. Cummings Alzheimer's Association
Sallie Parker, PCOA
Denise Steward, Del. Co. AAA
Claire Day, Alzheimer's Association
Phillip Le, Alzheimer's Association
T. Grundy, Senior Community Services
Silvia Porta, UPenn
Kerry Brown, Alzheimer's Association
Julie Thomas, Alzheimer's Association
Christopher Masah, Alzheimer's Association
David Lusk, Alzheimer's Association
Holly Lange, PCA
Kellie Butsack, Alzheimer's Association
Dan Drake, UPenn LIFE Program
S. Reaman, PCOA
Steven Arnold, UPenn
Kurt Brunden, UPenn
Joe Lukach, Ralston Cneter
Dene Liott, PCOA
Harry DeLorenzo, PCOA
Donna Towers, PCOA
Celeste Faust, Mont Cty AAA
Gladys Dueñas, Philadelphia College of Pharmacy
David Hoffman
Cynthia Wishkovsky, Journey's Way
Susanne Bolude, CNDR
Mitchel Kling, UPenn
Maryann Knab, Representative Watson's office
Linda Zadorozny, Alzheimer's Association Advocacy Committee
Andrew Jannetta, UPenn
Ben Liu, UPenn
Kevin Raibel, CNDR

Tim Lyden, Lilly USA
Marybeth Howlett, Avid Pharmaceuticals/Lilly
Howard Hurtig, UPenn
Linda Gambone, Community Health and Deantl Care
Kathleen Moyer, PCOA
Page Huey
Barbara Taittinger
Kevin Jameson
Margaret Cronan
Linda Somits, Bayada
Bin Zhang, UPenn
Colin Bredenberg, UPenn
T Schuck, UPenn
Abby Lerner
Jodie Daniels, Chestnut Knoll
Leslie Green, Administration for Community Living
Sean Hennessy, UPenn
Matt Sharpe, AFTD
Mary Austin, New Courtland
Tom Carroll, Home Helper
Mary Tong, UPenn
Alice Chen-Plotkin, UPenn
Heshie Zinman, LGBTEI
M. Barnes-Hopkins, Around the Clock Home Health
Joann Bush, Better Home Care
Ray Jannelli
Carmen Torres
Jerry Schellenberg, UPenn
Jason Karlawish, UPenn and Penn Memory Center
Daniel Weintraub, UPenn
**List may not be complete*

Minutes prepared by Lisa J. Bain

I. Welcome

- a. Secretary of Aging Brian Duke, welcomed participants, including Sallie Parker, chair of the Pennsylvania Council on Aging, and Representative Kathy Watson. 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 fourth 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 have met twice, reviewed other state plans, the National Plan, and other resources. We will also be using feedback from regional meetings to help guide our recommendations.
 - b. WG #2 – Healthcare delivery and workforce (Heidi Owen, Chair). This WG has met twice and is also taking in information from the public to establish a vision, goals, objectives, and strategies. 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 are focusing on three major visions: 1) Development of a comprehensive continuum of care, 2) Workforce development and retention, 3) Caregivers and community support for the

dementia friendly communities. We are still discussing how to incorporate other components. 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, looking at trends in research and how to share research results with caretakers. We are looking at ways to improve volunteerism and improve the diversity of participants in clinical studies. We are also looking at how best to share results and trends in prevention, awareness, hospitalizations, caregiver needs, economics of AD (both the economic impact of ADRD and the potential impact of interventions.) We will also review policy development to improve outcomes for patients and caregivers.

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. Representative Kathy Watson. Came to Harrisburg in 2001 and asked to be on Aging and Older Adult Services Committee. Found out that no one seemed to know much about AD, nothing had been done to address it, and no one was thinking ahead. Bob Marino (Alzheimer's Association) said we need a state plan, which was the genesis for the bill. Asks the committee to provide a blueprint that the legislature will be able to use and find creative ways to do things that may not require government money. Pledges to work to turn report into action.
- b. Dr. John Trojanowski (Committee member), UPenn. In 2012 we convened the Marian S. Ware Alzheimer's Summit with the goal of creating crosscutting recommendations for a range of stakeholders. We focused on four areas: clinical care and health services research, biomarkers, drug development, and health economics, policy, and ethics. Developed a set of high level recommendations with the overall goals of identifying and developing new treatments, improving efficiency and knowledge gained from clinical trials, enabling better patient care through early identification of those at risk, and providing high quality, cost effective, and ethical care across the trajectory of the illness.
- c. Dr. Steven Arnold, UPenn and Penn Memory Center. Focused comments on the early diagnosis of ADRD. AD is a long, slowly emerging process. Cognitive decline emerges from accumulating disease in brain and provides many intervention opportunities with public health impact: prevention, disease modifying, and symptomatic treatment. Risk factor recognition and management may decrease the prevalence of later life AD. There are many modifiable risks: physical inactivity, low mental and social stimulation and isolation probably promote and accelerate dementia and degeneration in later

life. There are many causes/types of dementia – a thorough evaluation using a variety of diagnostic tools can improve treatment care and planning, allow time for legal, financial and life planning for person with AD and family caregivers, and enable participation in clinical studies.

- d. Dr. Howard Hurtig, UPenn. Discussed the public health challenge of Parkinsonism combined with cognitive impairment, which he said produces more disability than AD. As with AD, there is a lack of disease modifying therapies. A major focus at Penn is to create biomarkers that will spur the development of new therapies. He provided an overview of Parkinson disease (PD) and PD with dementia (PDD). Most people with PD develop significant cognitive impairment. They have a distinctive pathology that overlaps with AD pathology. A related condition is Dementia with Lewy Bodies (DLB), which has an early onset of both cognitive impairment and motor signs. DLB and PDD combined make up the second most common cause of dementia in Western societies. There are many unmet needs with regard to caring for people with PDD and DLB – better drugs, education and support of caregivers, broad-based educational programs emphasizing exercise in people with neurologic disease, improved and expanded access to State sponsored medication programs to assist low income people.
- e. Dr. Jerry Schellenberg, UPenn. Discussed the genetics of AD. Genetics enables understanding of disease mechanisms and provides molecular insight into the cause of disease, which can lead to new interventions. International genetic research has identified several genes that increase risk of AD and will soon publish 14 new genes. NIH now has a project underway that will sequence the genomes of 6,000 individuals with AD and compare to the genomes of 6,000 persons with AD. With this project, researchers hope to identify all genes that influence AD risk and identify new drug targets.
- f. Dr. Karen Hirschman, UPenn School of Nursing. Discussed NIH-funded study to examine transitional care for older adults with cognitive impairment and family caregivers. Overarching goal of this study is to improve the care experiences, health, and quality of life of cognitively impaired older adults and caregivers while reducing total health-care costs. The transitional care model (TCM) incorporates advanced-practice nurse-coordinated evidence-based approaches in multiple settings (e.g., hospital plus home care with multiple providers), engages patients and caregivers, assures continuity of care, and bridges care between hospital and community. Results of the study show TCM compared to traditional hospitalization model reduces percent of rehospitalization and death. Suggests that a system change is needed that considers needs of cognitively impaired along a continuum, prioritizes care continuity, and places emphasis on patient/family caregiver engagement and aligning services with their changing needs.

- g. Dr. Jason Karlawish, UPenn and Penn Memory Center. Addressed how to improve the financial security and autonomy of older adults living with cognitive impairment. People who lack the ability to perform or make decisions about how to manage instrumental activities of daily living (IADL), such as managing money are vulnerable to abuse. This is of particular concern for older adults, where private wealth is concentrated, because if their funds are depleted they may not have time to make up losses. Thus impairments in cognition are among the leading risk factors for abuse and exploitation. The financial services industry needs guidance for how to deal with this as they are on the front lines. The State plan should address this since much of the monitoring of elder abuse and financial exploitation rests with the state. The Federal Elder Justice Act has opportunities for state and federal action. Suggests two actions:
 - i. Bureau of Advocacy, Protection and Education, State Long Term Care Ombudsman and the PA AAAs develop training in assessing older adults cognition and their ability to make a decision.
 - ii. Department of Banking and Securities, Attorney General and other State depts. and agencies review and propose revisions to laws and regulations in order to assure older adults are protected from financial fraud and exploitation.

- h. Dr. Alice Chen-Plotkin, UPenn. Discussed biomarkers in brain disease. Biomarkers are substitute indicators of disease and things that may serve as measures of risk, helping with diagnosis or prognosis, understanding the disease process, clinical trials and drug development. They are key to tracking progression and suggesting appropriate therapy.

- i. Dr. Dave Irwin, neurologist at UPenn. Discussed Frontotemporal Lobar Degeneration (FTLD), a common type of younger onset dementia that is often misdiagnosed. Lack of definitive diagnosis and lack of awareness among health care professionals contributes to caregiver stress. In addition, caregivers are often spouses who have occupational demands and non-adult children to care for. Proposed solutions:
 - i. Optimize access to resources.
 - ii. Create new resources including online information source for caregivers and healthcare professionals.
 - iii. Establish a state-wide population registry for epidemiologic data and natural history of disease.
 - iv. Additional funding for support services (e.g., companions, health aides) to prevent morbidity and institutionalization.

- j. Dr. Mitchell Kling, psychiatrist at UPenn and VAMC. Addressed preventable causes of ADRD. Up to 50% of cases of dementia are attributable to modifiable risk factors: diabetes, mid-life hypertension, obesity, depression, physical inactivity, smoking, low education. If we were able to reduce these risk factors by 10% in PA, could potentially prevent over 10,000 cases and save \$470.5

million; a 25% reduction could potentially prevent over 27,000 cases and save \$1.26 billion. Recommends:

- i. Include estimates of 40-65 year olds with hypertension, diabetes, obesity, smoking, and depression in projections of future AD burden in PA.
 - ii. Incorporate information on cardiovascular, metabolic, and psychiatric risk factors for AD into educational programs.
 - iii. Coordinate efforts with other PA health programs (e.g. heart disease) to emphasize added impact of prevention on AD risk.
 - iv. Expand educational efforts on health-related behaviors to reduce AD risk.
 - v. Increase public education funding in PA to improve overall educational level and increase “brain reserve” in population.
- k. Gladys Dueñas, pharmacist at Philadelphia College of Pharmacy and daughter of man with AD. Need to make sure patients are taking appropriate medications and are getting the most out of their medications.
- l. Dr. Dan Haimowitz, geriatrician in private practice in Levittown. Aunt and godmother recently died with AD. Most important factors are communication and education. There is a lack of trained geriatricians and families may have trouble finding physicians experienced with AD. Neurologists may not feel comfortable with all of the issues families have. Recommendations:
- i. It would benefit the State to figure out how to attract more geriatricians, perhaps with loan forgiveness.
 - ii. Consider mandating that primary care organizations develop mandatory training and education programs.
 - iii. Create up to date, county-specific clearinghouse of caregiver resources, including respite care.
 - iv. Expand geriatric assessment programs.
 - v. Fund programs that help elders live independently.
 - vi. Town meetings may be useful for educating public.
 - vii. Collaborate with other organizations.
- m. Dene Liott, caregiver for 15 years to mother with AD. Dementia came on gradually, starting with forgetfulness, confusion. Eventually had to take her keys, lock doors, disconnect stove. Later she forgot how to walk and became confined to bed. Waiver program provided us with a caregiver so we were able to keep mother at home. Also used hospice. Recommendations:
- i. Families need access to memory care campuses so patients can stay home.
 - ii. Toll-free number for information.
 - iii. Outreach to public to raise awareness.
- n. Holly Lange, Philadelphia Corporation for Aging and caregiver for grandmother who died of AD. We are the AAA for Philadelphia, providing services and support for 100,000 persons with AD and their caregivers. We provide home care (e.g., personal care, adult day care, home delivered meals) to 20,000 individuals; support family caregiver program funded by PDA, and have 10,000

people in Waiver program. Studies show that nationwide, 14% of individuals age 71 and older have AD and 10% have dementia. There are an estimated 667,000 caregivers in PA. Many studies have shown a higher prevalence of dementia in minority communities. Lack of education plays into that but 20% of minorities live in poverty, so education improvements may be out of reach. Also, cultural beliefs may impact willingness to seek help. Recommendations:

- i. Dedicate additional funding to home and community based services for people with ADRD.
 - ii. Increase funding for family caregiver support program to provide respite care, counseling, and support groups.
 - iii. Conduct outreach campaigns, focusing on symptoms, treatment, resources.
 - iv. Continue to provide Medicaid-funded state services for nursing-home-eligible people who are cared for at home.
 - v. Provide adequate funding for interpretation and translation services – 20% of Waiver clients in Philadelphia do not speak English.
 - vi. Provide culturally sensitive training for health-care workers and social workers.
 - vii. Relax estate recovery rules to expand eligibility for Waivers.
 - viii. Require behavioral health program funded by DPW to dedicate funds and resources to meet needs of people with ADRD.
 - ix. Provide funding to conduct training of health care workers on different types of dementia, treatment, and resources.
 - x. Continue to support programs such as senior community centers that educate seniors and encourage adoption of preventive exercise and health lifestyle programs.
- o. Heshie Zinman, chair of Lesbian, Gay, Bisexual, Transgender (LGBT) Elder Initiative. Members of LGBT community face unique emotional, physical, and financial challenges. Access is limited; services are not culturally sensitive, sometimes they are hostile and stigmatizing. Family structure is different and we do not have equal benefits. Up to 70% of LGBT older adults live alone, 90% do not have children. Because of stigma, prejudice, and intolerance, many do not seek care and guardianship, advance directives, and other legal documents may be ignored or challenged. Need culturally sensitive approaches that maximize independence and dignity with respect to design of legal, social, and health care supports. Asks committee to recognize and address the needs of the LGBT community as the population with greatest need by amending the State plan, initiating a program to achieve LGBT culturally competent aging network by 2020, and ending legal discrimination in employment, housing, and public accommodations, and advocate for ending legal discrimination of same sex partners by giving them the right of marriage.
- p. Cynthia Wishkovsky, VP of Aging Services of Journeys Way in NE Philadelphia, which provides community-based services to 4,000 older people. We see people along spectrum of dementia. It's a challenge to get services

because programs exist on a thread since there is no reimbursement for most services. Specific issues to address:

- i. Age restriction of 60 and over for Medicaid waiver – causes financial and emotional burden for family members.
 - ii. Assessment issues are highly weighted to deal with functionality (ADLs), but many persons with dementia present with different kinds of impairments. Thus they may not score high enough to get services.
 - iii. The existing transportation system in Philadelphia does not work with our families.
- q. Tom Carroll, Home Helpers in Media, a provider for the Waiver program. ADRD takes a heavier toll on caregivers than patients. Need more support services for family and professional caregivers. Demand is growing but burnout and stress make it difficult to retain workforce. Recommends:
- i. Include funding for enhanced dementia training for caregivers. Training should educate and empower caregivers and must be flexible (e.g., offered at different times) and affordable. It should not be an added burden.
 - ii. Develop a network of training for professional caregivers that could become part of a peer training/peer support group.
 - iii. Implement creative ways to help agencies educate, recruit, and train caregivers.
- r. Wendy Campbell, Delaware Valley Chapter of the Alzheimer's Association and the Public Policy Coalition. Described the programs and services provided by the Association for patients, family members, caregivers, others (e.g., police, fire, EMT drivers). Chapter has over 28,000 registered advocates. Association addresses many concerns raised by others, e.g., transportation, safety, workforce development, training for workforce, statistical reporting, elder abuse, etc. Emphasized that the State plan should have a timeline and renewal built into it and reviewed on periodic basis; must have mechanism to continue beyond current Secretary and legislature.
- s. Carmen Torres, 52 year-old woman living with early onset AD. Former police officer; retired after 30 years because of disease. Supports research to find a treatment that will help her and millions of others affected. Lives alone; has two daughters but they have families of their own. Fearful of what will happen when she needs more help. Will she be able to afford it? How will she feel? Worries about becoming dependent on others. Asks committee to address issues of younger people with AD and make certain they can get the care they need.
- t. Jodie Daniels, administrator of provider organizations (nursing homes and personal care homes) and caregiver to mother with AD over 10 years; also has run support groups, talked to spouses, etc. Emotional and psychological impact are great. Patients and families have difficulty navigating a system that they don't want to think about. Need better education of public to prepare them if a

family member develops ADRD. Grieving process is never ending as disease progresses. Family members and professional develop compassion fatigue.

- u. David Hoffman, attorney and consultant who focuses on compliance issues. Addressed issue of elder abuse. In 3 international studies, the overall rates of elder abuse ranged from 34-62%. The need to educate caregivers is critical. State should mandate as a condition of payment, training for all caregivers whether in long term care facility or receiving benefits under State program. Training should include understanding dementia and how it progresses and differs from delirium, behavioral ways to intervene without medication, communication issues of persons with dementia, appropriate activities for individuals with dementia, recognizing and treating pain and documenting responses to treatment, care planning that monitors progression and modifies interventions as needed. Program should also include how caregivers can monitor their own behavior and self-identify when they are becoming a risk factor for abuse. A full educated caregiver lessens the likelihood of abuse.
- v. Coleen Kayden, practicing pharmacist. Addresses issue of over medication. Many elderly patients take multiple medications and there can be adverse repercussions. Drug related adverse events are responsible for 10% of hospital admissions of older adults. Pharmacists can help avoid these problems. Three recommendations:
 - i. Recognize the importance of providing tools to help with medication compliance and adherence (e.g., prepackaging doses) and find a way to compensate pharmacists for the time required to manage this program, which improves safety, quality, and is cost effective.
 - ii. Support broad-based medication review of patient profiles, moving beyond that associated with Medicare Part D. Reward high-level engagement in pharmacist-patient-physician contract and stop creating business contracts that pay the lowest rates and ignore dispensing issues. Kaiser foundation released a report in June that said the U.S. spends \$200 billion/year for medical care stemming from improper use of drugs.
 - iii. Embrace the idea of integrated care teams including an embedded pharmacist. Can save significant amounts of money.
- w. Sara Wright, palliative medicine consultant, geriatric nurse practitioner, certified in hospice and palliative care. Close to 1 million people need services but they are not available in many communities (e.g., Berks County, where she lives). Need to remove stigma from dementia. Also may consider student loan forgiveness for college graduates who choose to work in dementia care.
- x. Linda Zadorozny, caregiver, trained support group facilitator, pension administrator for 3rd party provider. Addressed need for more day care facilities geared towards dementia. Mother's life cut short by caring for father with dementia. Dementia units in assisted living facilities need more levels. As pension administrator, need guidance about what to do when dementia is

suspected and family wants to make a change. Education needed beyond caregivers, to include banking and pension personnel. Also need improved public awareness; suggests developing awareness programs for places where people are waiting, e.g., when renewing their driver's licenses or waiting in an airport.

- y. Liz Murphy, RN and licensed nursing home administrator with Arden Courts Memory Care Communities.
 - i. Unmet needs of Pennsylvanians include assessment of early onset and other dementias, lack of home and community based options, and the need for hospice care for people with advanced ADRD. Suggests early identification could be remedied through the use of robust screening and assessment tools available to friends and family members, in combination with an aggressive educational campaign. Also suggests a public private partnership with advocacy organizations and long term care providers to address these issues.
 - ii. Resource needs of PA caregivers – a single portal with comprehensive information on caring for people with AD is needed. Another major need is creating an environment to attract individuals to become caregivers.
 - iii. Regulatory requirements do not allow staff to use emerging best practices. Urges committee to establish a feedback process for providers and regulators to meet and identify challenges and solutions, either regulatory revision or education.

- z. Kevin Jameson, caregiver to wife who now resides in nursing home and is immobile. Established the Dementia Society (dementiasociety.org) as an umbrella organization to educate people regarding early warning signs, preventive measures and how to be an advocate; address issues of stigma; provide counseling and caregiver support; provide dementia training to frontline workers.

- aa. Dr. Don Trachtenberg – caregiver for 13+ years to wife of 52 years. Was lucky enough to have insurance. Provided homecare with help of two licensed CNAs. Finally she ended up in a skilled nursing unit. As member of a support group, he has seen what others go through as a result of not knowing how to navigate the system and not having enough money. Suggests getting rid of the word “dementia” and replacing it with “neurocognitive disorder,” since this would be less stigmatizing.

- bb. Matt Sharpe, program coordinator for the Association for Frontotemporal Degeneration (AFTD). AFTD affects people under the age of 65 as often as those over 65. Recommends including an easy mechanism for people under the age of retirement to access the services they need.

- cc. Dr. Daniel Weintraub, geriatric psychiatrist at Penn. Psychiatric aspects can be the driving problem in terms of caregiver burden, nursing home placement and

quality of life. We do not have good evidence-based treatments for psychiatric problems, and some of the meds that are available have side effects especially in elderly patients. Non-pharmacologic approaches may work but need additional research. Penn has a Behavioral Health Lab (BHL) that provides telephone care management and other support services across the State. Another innovative program at the VA uses telehealth to help provide psychiatric care for people with PD who live in remote areas.

- V. Wrap up – Secretary Duke. Thanks to all who offered testimony. He urged individuals who did not have a chance to speak to submit written comments.

- VI. Next steps:
 - a. Next regional meeting 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.