



Alzheimer's Disease Working Group

Meeting title: Alzheimer's Disease Working Group Meeting
 Location: Tukwila Community Center, Tukwila, WA

Date: 11/12/2014
 Time: 10 a.m. – 3 p.m.

ATTENDEES

√	Attendee	Role	√	Attendee	Role
√	Bill Moss	Chairperson	√	Emma Medicine White Crow (phone)	Member
√	Lynne Korte	Project Manager	√	Tara Jo Heinecke/K.Keiser	Observer for member
√	Steve Tharinger	Member	√	Luisa Parada Estrada	Member
√	Tom Montine	Member	√	Joshua Chatman	Member
√	Patricia Hunter	Member	√	Dave Budd	Member
√	Leslie Emerick/M.Pattison	Observer for member	√	Marty Richards	Member
√	Kristoffer Rhoads	Member	√	Tatiana Sadak	Member
√	Christopher Henderson	Member	√	Jason McGill (phone)	Member
	David Maltman	Member	√	Bob LeRoy	Member
	Kathy Sitker	Member	√	Lauri St. Ours	Member
√	Manuela Prieto	Member	√	Sarah Miller	Member
	John Ficker	Member	√	Eric Erickson	Member
√	Bill Baker	Member	√	Debbie Hunter	Member
√	Todd Larson	Member	√	Arlene Johnson (phone)	Member
√	Myriam Marquez	Member	√	Robert Wellington	Member
√	Peggy Quan	Member		Jerry Reilly	Member
√	Maureen Linehan	Member	√	Cheryl Townsend-Winter	Member
√	Porsche Everson	Facilitator	√	Kathy Lofy	Guest Speaker
√	Charissa Fotinos	Guest Speaker	√	David Mancuso, PhD	Guest speaker
√	Bea Rector	Guest Speaker	√	Hilarie Hauptman	DSHS Staff
√	Susan Engels	DSHS Staff	√	Colette Rush	DSHS Staff
√	Joel Loiacono	Alzheimer's Association Staff	√	Beth Harvey	Alzheimer's Association Staff
√	Peter Newbould	Alzheimer's Association Staff	√	Karen Lewis	Observer
√	Diana Thompson	Observer	√	Cherie Perazzoli	Observer
√	Amanda Avalos	Observer			

Alzheimer's Disease Working Group

AGENDA

Topic	Key Points and/or Decisions Made
<p>1. Welcome</p> <p>Bill Moss, Porsche Everson, Lynne Korte</p>	<ul style="list-style-type: none"> • Today's meeting goals – <ul style="list-style-type: none"> ○ Review state statistics and projections related to Alzheimer's, and become aware of the strengths and limitations of that data. ○ Understand the currently available systems and supports for people with Alzheimer's and their care partners. ○ Obtain feedback on report structure and organization.
<p>2. What Does the Data Say?</p> <p>David Mancuso, PhD</p>	<ul style="list-style-type: none"> • Presentation focus on on information pulled from academic literature on prevalence of Alzheimer's and looking out 10 to 25 years. • Approaches to estimation – overview of studies used in this research <ul style="list-style-type: none"> ○ Data on disease prevalence <ul style="list-style-type: none"> ▪ Aging, Demographics and Memory Study (Plassman et al 2007) ▪ Chicago Health and Aging Project (Hebert et al 2003; 2013) ○ US Census data (American Community Survey) ○ Explanation of differences in AD prevalence rates <ul style="list-style-type: none"> ▪ Diagnostic differences ▪ Whether a clinician participated in study or results were self-reported • Forecasting approach <ul style="list-style-type: none"> ○ Data on future population by age (from state office of financial management – <i>Forecast of the State Population by Age and Sex</i>) ○ Prevalence studies don't include persons under the age of 65 • Projection is about 250K persons with dementia in WA by 2040 (age 65+) • 30-year increase 2010-2040 is 152%-181%, depending on study <p>Conclusion: The burden that dementia places on the population, absent interventions that reduce prevalence of the disease, is substantial.</p> <p><u>Q&A/Comments:</u></p> <ul style="list-style-type: none"> • Source studies do not include mild cognitive impairment, but there is interest in including data in future studies. • Source studies do not address changes in population demographics. • An additional study worth reviewing is the Adult Changes in Thought study being done by Group Health Cooperative and the University of Washington. • There is some data available that addresses capacity to meet needs, and the economic impact of the projected growth in incidences of Alzheimer's, particularly from a Medicaid utilization perspective. • State research could also include review of utilization of hospice services. • The definition of "Alzheimer's" in the various source studies is not identical but there is broad overlap between the definitions. • There is data available that compares the prevalence of Alzheimer's to the prevalence of other diseases; for example, diabetes occurs in about 35% of those aged 65+, vs. dementia occurring in about 33% of those aged 85+. • It's possible that the studies take into account people with dementia who don't disclose their diagnosis; that could explain the range of projections of rate of increase.

3. Towards a Comprehensive Approach: Systems that Impact People with Alzheimer's or Related Dementia

Kathy Lofy, Charissa Fotinos, Bea Rector

Kathy Lofy – Public Health System overview:

- About improving the health of everyone in Washington
- Public health system has 3 levels
 - Federal – Centers for Disease Control – providers of technical expertise; provides funding (about half of state public health budget).
 - State – Dept of Health – technical expertise; policy work; convening/coordinating.
 - 35 local health departments – primarily follow the county lines – implementation of programs and policies.
 - WA has a decentralized system – much is done at the local level; all independent.
 - Other partners – tribes, other state agencies, nonprofit organizations.
- 3 primary goals of WA DOH
 - Protect people from communicable diseases and other health threats
 - Prevent illness/injury, promote ongoing wellness
 - Improve access to healthcare
- 4 divisions
 - Disease Control and Health Statistics (communicable disease control etc)
 - Health Systems and Quality Assurance
 - Environmental Public Health (drinking water etc)
 - Prevention and Community Health (immunizations, MCH, smoking cessation, etc)
- How public health intersects with dementia
 - Identify trends and high risk populations
 - Death records, CHARS data
 - BRFSS cognitive impairment and caregiver modules
 - Educate community health workers, home health workers and first responders
 - Promote cognitive brain health
 - Promote early detection and diagnosis
 - Promote safety

Charissa Fotinos- Health Care Authority overview:

- \$13 billion budget
 - Medicaid (biggest part of budget)
 - Public Employee Benefit Board
- Purchaser of health care
 - Move from fee for service to managed care
- Key Medicaid programs: Health Homes, Health Path (King/Snohomish Counties only), Managed Care
 - Aged, Blind, Disabled – at higher risk
- Why these programs?
 - Focused on chronic conditions
 - Dually diagnosed individuals
 - Care coordination and case management
 - Transition planning
 - Family support
 - Referral to community services
 - Disease management/education

Alzheimer's Disease Working Group

- Role of HCA
 - Policy Evidence Reviews – evidence-based assessments; influences decisions about what treatments are covered and what aren't. Medications to treat persons with dementia coming available – will be expensive – must be shown to work.
 - Convener – medical associations etc.
 - Purchaser of health care – major player in this area – pay for performance. Can set performance goals for providers they contract with.
 - Health information exchange – ensuring that providers communicate with each other w/r/t a patient's care. All Medicaid patients in system by next July? Info will be available to providers, mental health professionals, etc.
 - EDIE – emergency room records
 - Healthier Washington – possible \$90 million CMS grant – 'communities of health' – regionally based.
- HCA collaborations
 - BREE Collaborative – evidence based care
 - Other state agencies
 - State Hospital Association
 - State Medical Society
 - Insurance plans
 - Specialty societies
 - WA Health Alliance
- Intersect with dementia
 - Purchasers of care for patients
 - Develop coverage policies
 - Value based purchasing
 - Health Path/Health Homes
 - Performance based measures
 - Data integration
 - Coordinated services and supports
 - Dual eligibles
 - Care transitions

Bea Rector – Long Term Support Services overview

- LTSS
 - Assistance with daily living tasks
 - Health related tasks
 - Most likely provided in home
 - Most likely provided by family members (unpaid)
 - Also provided in licensed or certified facilities or institutions
 - Most is unpaid, then Medicaid, then Medicare, then private insurance, then out of pocket
- Government structure includes Administration for Community Living (federal); CMS (federal); Washington State Legislature
 - Very complex structure in terms of funding streams, target populations and rules
 - DSHS/AL TSA role is to integrate as much as possible, and push out to consumers
- AL TSA role is to promote, plan, develop and provide long-term care services responsive to the needs of elderly persons and those with disabilities, and

	<p>their families.</p> <ul style="list-style-type: none"> ○ System design: <ul style="list-style-type: none"> ▪ Maximize health and independence ▪ Promote dignity and quality of life ▪ Provide options in receiving care ▪ Ensure quality care through oversight and enforcement ▪ Moving toward measurable outcomes ○ Array of choices (vs continuum) – home, assisted living, nursing home <ul style="list-style-type: none"> ● Area Agencies on Aging <ul style="list-style-type: none"> ○ Established by federal Older Americans Act to help elders stay in their homes ○ 13 AAAs in WA State <ul style="list-style-type: none"> ▪ Information and assistance - “Community Living Connections” ▪ Family Caregiver Support Program ▪ Case management for clients 18+ receiving Medicaid-funded in-home personal care ● AL TSA <ul style="list-style-type: none"> ○ 3 regions of Home and Community Services <ul style="list-style-type: none"> ▪ Medicaid eligibility assessment ▪ Coordinate with LTSS network ▪ Protect vulnerable adults ○ 3 regions of Residential Care Services <ul style="list-style-type: none"> ▪ Licensing and oversight of adult family homes, assisted living/nursing/care facilities, certified residential programs ● LTSS intersection with dementia <ul style="list-style-type: none"> ○ Information and assistance ○ Protect vulnerable adults ○ Quality care measures ○ Dementia training for LTSS workers ○ Home and community based services ○ Identify/promote effective LTSS from early to end stage ○ Health promotion-healthy brain ○ Family caregiver support ○ Promote advanced care planning ○ Health and long term care transitions <p><u>Challenges and opportunities:</u></p> <p>Bea Rector:</p> <ul style="list-style-type: none"> ● Strong system of services and supports. ● Opportunity to build dementia capacity, to support pre-planning. ● Know a lot about successful interventions but have not been able to bring those to scale in WA state. <p>Charissa Fotinos:</p> <ul style="list-style-type: none"> ● HCA can do more measurement, reporting on measures via contracting. ● Improved training of health care community in early diagnosis, management ● Better coordinate – take better advantage of surveillance data, pay attention to disparities, work with LTSS to better understand available
--	--

Alzheimer's Disease Working Group

	<p>supports and services.</p> <p>Kathy Lofy:</p> <ul style="list-style-type: none"> • Challenge is lack of dedicated staff working on dementia. • Opportunities: <ul style="list-style-type: none"> ○ Better use of surveillance data. ○ Make use of 'healthy living' programs to help improve cognitive function. ○ Extend healthy living programs into the aging population. <p><u>Q&A/Comments:</u></p> <ul style="list-style-type: none"> • HCA does not have cost data for persons with dementia at this time. • The WA State Innovations Plan does not specifically address enhancing services for persons with dementia and caregivers; the intent of plan is not so much to specifically allocate funds but rather to help healthcare systems adapt to conditions they need to. The goal is care coordination that responds to whatever need is presented. • There is a program in the Public Health System to train community health workers that currently does not include dementia, but it could. A module is being developed at this time – more info coming in 2015. • The BREE Collaborative just voted on topics they want to evaluate this year but unknown if the misuse of antipsychotics is one of the selected topics. • There is a need for a diagnosis module – this is a continuing issue with physicians • Another major issue is people in the middle stages of dementia with catastrophic behavioral incidents. • Regarding access to care for persons with younger-onset dementia: Medicaid eligibility for LTSS is 18+; eligibility under Older Americans/Senior Services is 60+. Eligibility is also possible on a functional basis (high cost-high risk). • Not clear if there is a current or potential role for HCA, PHS or LTSS to play in the realm of pre-planning. • Recommend that ADWG look at BREE Collaborative latest work on end of life recommendations.
<p>4. Review of Guiding Principles</p> <p>Porsche Everson</p>	<p>As revised based on feedback at September ADWG meeting:</p> <ul style="list-style-type: none"> • Alzheimer's includes other dementias: Consistent with national and other state plans, "Alzheimer's" is considered to also include other forms of dementia. • Public-private framework: The plan will not be a "state government only" plan, but rather a framework of what public-private partners in Washington can do collectively. • Build upon other work: We will build upon what's being done nationally, and on what's working in Washington State and other areas (e.g., National Alzheimer's Disease Plan, CHC Healthy Brain Initiative, other states and nations.) • Person and family centered: The plan will be developed with the needs of persons with Alzheimer's, their care partners, family members, and guardians at the forefront; this includes sensitivity to cultural values and beliefs. • Life course approach: We are in this together, from before diagnosis through end-of-life care. Our plan recognizes that we can do something at every stage to help individual and the state to address this disease holistically.

<p>5. What's Unique About Washington State?</p> <p>Porsche Everson</p>	<ul style="list-style-type: none"> • Progressive • High use of technology • Independent minded • Person-centered services • Innovative in projects/ideas • Statewide common DSHS system • Commitment to home and community based services • Great adult day service programs • Top coffee drinking state? • High military population • Older people are moving here • Large population of immigrants • High diversity of languages • Ethnic/racial diversity - Multiculturalism • Many tribes • Huge east/west divide – East: rural, conservative, poorer; West: urban, progressive, wealthier • Isolated communities • Hanford impact? • One of highest prescription drug abuse among youth • 60% of Vets from current wars have hearing loss • One of highest rates of MS and AD/dementia in the U.S. • 1 in 3 (vs. 1 in 6 nationwide) persons over 65 die with Alzheimer's • Regressive tax system and voters disinclined to make changes or increase taxes to pay for many services • No state income tax
<p>6. The Consumer Voice</p> <p>Bob Le Roy, Lynne Korte, Porsche Everson</p>	<p><u>Bob Le Roy – Report on Alzheimer's Association Town Halls:</u></p> <ul style="list-style-type: none"> • 11 key issues that emerged <ul style="list-style-type: none"> ○ Lack of awareness ○ Difficulty with diagnosis ○ Poor dementia care ○ Specific younger onset challenges ○ Unprepared and overwhelmed caregivers and families ○ Cost of care ○ Need for care coordination ○ Personal and public safety challenges and the need for safe and secure respite care ○ Inadequacy of Alzheimer's related statistics ○ Better reflecting the diversity of the Alzheimer's community – age, economic status, ethnic status, etc. ○ Non-pharmacological approaches to Alzheimer's treatment – diet, social engagement, exercise, etc. <p><u>Lynne Korte - Survey:</u></p> <ul style="list-style-type: none"> • State Plan in Aging Survey – please review before next subcommittee meetings • Questions related to Alzheimer's Plan effort - Ad hoc working group <ul style="list-style-type: none"> ○ Want to do a broad survey ○ Need to direct efforts to medical provider community

Alzheimer's Disease Working Group

	<ul style="list-style-type: none"> ○ Developed two surveys – one general, one to providers. ○ Each ADWG member who represents an organization, please give general surveys (green flyer) to your communications staff in order to place it on your website. Please do so within the next two weeks. ○ Provider surveys (blue flyer) – please let Lynne know if you can get this survey to groups of providers, e.g. UW, Virginia Mason, Group Health, etc. ○ Lynne will look into possibility of making surveys available in Spanish. <p><u>Porsche Everson – Listening Sessions:</u></p> <ul style="list-style-type: none"> ● Listening sessions – four around the state plus 2 online ‘webinars’. Will be open to the public. ADWG members should attend these. ● When should they be held? Before we have recommendations or after? <ul style="list-style-type: none"> ○ Comments: <ul style="list-style-type: none"> ▪ Either would be fine, but either way it would be nice to have something for people to respond to. ▪ Let participants help shape rather than just react to a completed report. ▪ Would be good to tie sessions to the surveys. ▪ Do sessions just before May ADWG meeting. ▪ Consider scheduling around the legislative session. ▪ Make use of lobby days/advocacy days to do listening sessions while legislators are in Olympia. ○ Time of day? <ul style="list-style-type: none"> ▪ Midday will draw more retirees. ▪ Variables – weather and length of day. If springtime – might have better results at the end of the day, but that can depend on the communities. ▪ 6-6:30 starting time might draw people who work during the day. ▪ Use webinars to provide scheduling flexibility.
<p>7. Inventory of Long Term Supports and Services</p> <p>Bill Moss</p>	<ul style="list-style-type: none"> ● WA has one of the best LTSS systems in the country ● Very complex system ● Everybody spends down to Medicaid – it’s just a question of when ● Information and assistance – Community Living Connections (currently in 4 of the AAAs, moving to get it statewide) <ul style="list-style-type: none"> ○ Local access point for information and referral ○ AAAs <ul style="list-style-type: none"> ▪ Awareness ▪ Access assistance ▪ Counseling/planning ▪ Care transitions ▪ Dementia-capable systems grant ● Family Caregiver support Program <ul style="list-style-type: none"> ○ Backbone of state’s system ○ Supportive services for unpaid family caregivers ○ Offers <ul style="list-style-type: none"> ▪ Education and training ▪ Consultation ▪ Counseling ▪ Access to support groups

	<ul style="list-style-type: none"> ▪ Respite care ▪ Referrals to community resources <ul style="list-style-type: none"> ○ In FCSP more than 50% of care receivers have probable or diagnosed dementia (another 30% have problems with memory). • Adult protective services – about 20K intakes per year <ul style="list-style-type: none"> ○ Home and Community Services ○ Abuse, neglect, etc. ○ Financial exploitation cases ○ Capacity – assess executive function needed to function independently • Residential Care Services – oversees licensed/certified residential facilities <ul style="list-style-type: none"> ○ Complaint resolution unit hotline
<p>8. Towards a Comprehensive Approach: Reconciling Needs with Services</p> <p>Porsche Everson</p>	<p>What are some of the most valued services currently offered? (<i>Note: Almost all of the respondents indicated that we need more of the highly valued current services. There is some overlap among the existing and missing lists</i>).</p> <p><u>Public Health/Education</u></p> <ul style="list-style-type: none"> • Alzheimer's Association • Aging in place education for legislators and decision makers • Studies, pilot programs • The Conversation Project (everyone please visit) • Healthy brain programs (public health) • Support for aging in place • First responder support • Support groups • DPOA, POLST and other care directives <p><u>Health Care</u></p> <ul style="list-style-type: none"> • Resources for comprehensive diagnostics (at centers of excellence – not statewide) • Advanced diagnostics <p><u>Long Term Supports & Services</u></p> <ul style="list-style-type: none"> • Gero-psych resources • Care management and coordination • APS – Office of Public Guardian – Ombudsman • More Medicaid beds • LTSS – look at long term care funding/financing • Adult Day Services • Respite care • Dementia specialty care • Caregiver education and training • Assisted living and adult family homes • Unified long term care support services in WA • APS dementia training • APS appointed guardians <p><u>Other</u></p>

Alzheimer's Disease Working Group

- Translation services

What would you like to see in a comprehensive and coordinated service network for PWDs? (*Note: Some of these services exist in some capacity, but service is either very limited or fragmented. There is some overlap among the existing and missing lists*).

Public Health/Education

- Minority outreach
- Better understanding of cultural differences
- Centralized online portal – one stop shop
- Community collaboration
- Increase public awareness
- Public health needs to increase healthy brain programs
- Public awareness that is multicultural
- Non-medical services (Alzheimer's Cafes etc.)
- Normalizing Alzheimer's – more café's, zoo walks, dementia friendly communities
- More non-medical opportunities (day centers, exercise, diet, etc.)
- More evidence based programs eg memory care wellness services for people with dementia
- Emergency response (natural disasters)

Health Care

- Access to home health care
- Diagnostic centers with complete wraparound services
- Education and training for medical practitioners on how to diagnose and treat dementia
- Better education for providers on full spectrum of care
- Training on diagnosis and communicating diagnosis appropriately; referral
- Standards of early diagnosis
- Roadmap for each stage of the disease
- Clinical data repository
- More time with patients
- Early access to end of life information
- Dual eligible caseworker knowledge about dementia
- Assessment of individual capacity for decision making
- More robust legal infrastructure – who makes decisions when PWD cannot?
- Better ability to recognize financial abuse

Long Term Supports and Services

- Caregiver health services and support services in rural areas
- Services for PWDs living alone
- More services in rural areas

Other

- Money – funding for needed services
- Funding for BRFSS cognitive and caregiver module
- Managed care capacity and understanding of state plan recommendations

Alzheimer's Disease Working Group

	<ul style="list-style-type: none"> Better understanding of how hearing loss and dementia are related <p>*SEE GROUP WORK GRAPHIC at end of this document.</p>
<p>9. Subcommittee Reports</p> <p>Porsche Everson, Kris Rhoads, Luisa Parada Estrada, Bob Le Roy, Marty Richards</p>	<ul style="list-style-type: none"> Health/Medical Care – Kris Rhoads <ul style="list-style-type: none"> First meeting went very well Outlined scope of prevention thru palliative care Leverage/capitalize on what's already in place e.g. toolkits for providers Public Health/Community Readiness – Luisa Parada Estrada <ul style="list-style-type: none"> Overlap with other subcommittees A lot of next steps for members Long Term Supports and Services – Bob Le Roy <ul style="list-style-type: none"> Addressed many key issues, including services and supports for caregivers Things that are actually working – leverage to full potential and use more collaboratively Included focus on long term care financing Public Awareness/Outreach and Education – Marty Richards <ul style="list-style-type: none"> Energetic committee A lot of strengths in the state – lot of resources Make people aware of the good things we do have Disconnect between providers and PWDs Concern about dementia stigma – looking for positive messaging Concern about outreach to special populations – rural, ethnic, etc. Find a spokesperson who can speak for us Look at public/private partnerships Stories from people who live with dementia
<p>10. Public Comment Period</p> <p>Porsche Everson</p>	<p><u>Diana Thompson - Hearing Loss Association of Washington and Hearing Loss Association of America; retired attorney</u></p> <ul style="list-style-type: none"> Hearing loss has been associated with cognitive impairment. 75% of older Americans have hearing loss; leads to social isolation. In process of completing a document at the request of Lynne Korte. Goal – For the state to provide to adults with hearing loss with environment/treatments to reduce cognitive decline related to hearing loss. <p><u>Cherie Perazzoli - Advocacy Director for Hearing Loss Association</u></p> <ul style="list-style-type: none"> Stigma attached to hearing loss. Takes a long time to adjust to hearing aids. Need to change culture to bring in people with hearing loss. Trying to make hearing access as recognizable as disabled access. Teach students to use a microphone, talk one at a time. Teach this to seniors so they have the skills in place before they get dementia.
<p>11. Wrap-Up and Next Steps</p> <p>Porsche Everson, Bill Moss</p>	<p><u>Porsche Everson</u></p> <ul style="list-style-type: none"> Lynne Korte's role as project coordinator is critical – contact her with any questions/concerns/followup etc. Next ADWG meeting is January 7, 2015 at Tukwila Community Center - 10 a.m. to 3:15 p.m. <p><u>Bill Moss</u> Thanks to the ADWG members for their hard work.</p>

ACTION ITEMS

ACTION	Assignee	Due Date
Get a PA system for the next ADWG meeting in January.	Lynne Korte	1/7/2014
Circulate survey flyer; post on websites if possible; notify Lynne Korte of where the flyer and/or link have been posted.	All	ASAP
Subcommittees – make a list of ideas from today's meeting to discuss at your subcommittee meetings.	All	Prior to next subcommittee meetings
Explore Spanish-language options for survey or other public input and work to develop a solution.	Bob Le Roy, Nelly Prieto	ASAP
Turn in meeting feedback and session evaluation forms today.	All	11/12/2014

*Group work – Valued/existing services (Pink) & What's needed in comprehensive, coordinated system (Yellow)

