Dementia Action Collaborative

Meeting title: Dementia Action Collaborative
Date: March 9, 2017
Location: Lacey ALTSA
Time: 9:30 AM – 3:30 PM

ATTENDEES

√	Attendee	Role	√	Attendee	Role
√	Aziz Aladin	Developmental Disabilities Council		Maureen Linehan	Aging & Disability Svcs
	Marietta Bobba	Tribal Affairs – ALTSA		Emma Medicine White Crow	Governor's Council on Health Disparates
√	Kim Boon	NW Regional Council	√	LeighBeth Merrick	Leading Age Washington
√	Susan Engels	State Unit on Aging ALTSA	√	Mary Lynn Pannen	Sound Options
√	Erik Erickson	WA Home Care Coalition	√	Mimi Pattison	Franciscan Hospice & Palliative Care
√	John Ficker	Adult Family Home Council	√	Gerald (Jerry) Reilly	ElderCare Alliance
√	Patricia Hunter	WA Longterm Care Ombuds		Lauri St Ours	WA Health Care Association
√	Todd Larson	Family Caregiver		Steve Tharinger	24th Legislative District Representative
√	Cara Lauer	Elderwise	√	Cindy Balbuena	Alz WA Volunteer
√	Bob LeRoy	Alzheimers of WA / LTSS Chair	√	Peter Newbould	Alz WA
√	Lynne Korte	Project Coordinator		Karen Winston	Aging & Disability Services / observer
	Christine Kubiak	Resdential Care Services DSHS	√	Hillarie Hauptman	ALTSA
√	Marci Getz	WA State Dept of Health	√	Arlene Johnson (phone)	Family Caregiver
	Kathy Lofy	WA State Dept of Health		The Honorable Karen Keiser	WA State Senate
√	Marty Richards	Caregiver/Social Worker	√	Cheryl Townsend-Winter	State Council on Aging
√	Kristoffer Rhoads	UW Medicine Memory & Brain Wellness Center		Julie Gray	Aging Wisdom
√	Bill Moss/Bea Rector	Chair	√	Porshe Everson	Facilitator
√	Marigrace Becker	UW Medicine Memory & Brain Wellness Center	√	Myriam Marquez	Consumer
	Sumi Jayadev	UW Medical Ctr – ADRC	√	Tatiana Sadak	UW School of Nursing
√	Leslie Emerick	WA State Hospice & Palliative Care		Debbie Hunter	Caregiver
√	Kathleen Macaul	AARP	√	Carla Calogero	Elderlaw – WA State Bar
	Jason McGill	Governor's Office		Alison Boll	Aging & Disability Services
√	Bruce Smith	Regence	√	Aime Fink	Sno Co Longterm Care
√	Robert Wellington	Consumer	√	Amanda Avalos	Health Care Authority
√	Myriam Marquez	Consumer	√	Nancy Isenberg	Virginia Mason
√	Jan Higman	Alzheimer Society WA	√	Basia Belza	UW HPRC-HBRN
√	Diana Thompson	Hearing Loss Assoc		**Members of the Public**:Donna Phillips, Cathy Knight, Kari Lase, Scott Bloom, Colleen Keltz	
√	Dave Budd	Full Life Care			

AGENDA

Topic	Key Points and/or Decisions Made
1. Welcome and introductions	• Bill Moss welcomed the group and encouraged us to keep up the momentum. We've accomplished a lot already and have informed our legislators of our progress.
2. Big picture dementia updates	**New Medicaid Waiver – Susan Engels** • Two programs that have been in the works for a couple of years got approved last January. We'll be standing up these two new programs: 1) Medicaid Alternative Care (MAC) – for individuals eligible for Medicaid. Will provide a new choice for family caregivers – they can now receive supportive services for themselves in lieu of the full package of personal care services offered through CFC/Copes waivers (e.g., education/training, counseling, respite care, equipment/supplies). There will be no cost and no estate recovery for the services 2) A new eligibility group, the first in the nation, Tailored Supports for Older Adults (TSOA) will include people who have not yet spent down to Medicaid eligibility, but are within 300% poverty level and up to $53K in resources (or $106 K for a couple). This program will give them access to care coordination and hopefully help them avoid or delay the need to go onto Medicaid. • More than half of current care receivers either have a dementia diagnosis or symptoms. • The program has a 6 month benefit cap of $3,300, with an average monthly benefit of up to $550. Recipients can use the benefit to receive training, advice, equipment, or ongoing services, including respite, and health maintenance for the care giver. **Dementia Specialty Training Rollout – Lorrie Mahar** • In 2014, a consultant was hired to perform a gap analysis of current training across the State. With this information, a new course was created that is rolling out now to community instructors - Dementia-Capable Caregiver course. This is a basic training, but two additional levels will also be created. This basic training now includes: trauma-informed care, communication skills, managing

behaviors, medication and alternative therapies, more effective self care for caregivers, and issues relating to sexuality. A new requirement has been added requiring community instructors take an adult ed course before they can teach this course. All assisted living courses should be trained by the end of the year.

New Medicare benefit/dementia care planning – Bob LeRoy

- One of the major elements of the HOPE Act was a modification of Medicare reimbursement to compensate doctors for taking more time for meeting with patients with dementia to discuss care planning and care coordination.
- Late last year, CMS adopted a new billing code. Effective Jan 1, 2017, clinicians can now be reimbursed in alignment with the HOPE Act. We have a real opportunity to educate physicians on how to use this code.

Legislative/advocacy activities – Bob LeRoy

- On the Federal level, our priority is to drive more dollars towards Alzheimer's research. Funding has nearly doubled, but the challenge is that we have less than $1B per year which is about half of what the experts tell us is needed.
- Twelve members of WA Alz Assoc will be going to DC this month to "hike the hill". They will attend the annual dinner and present lifetime the achievement award to Maria Shriver, and volunteer of the year award to (Myriam Marquez.
- At the State level, we have two priorities: 1) extend the JLEC. There is broad consensus to continue this work either through another budget proviso, or through new legislation sponsored by Senator Barbara Bailey, and 2) secure funding for 4 FT staff – one for each key State organization, to coordinate with DAC and among/across agencies. We have early bipartisan support for this via budget proviso.

Update on potential federal legislation – Bill Moss

- With the House Bill to repeal the ACA, we'd lose our match for personal care. We get $80-100 M in enhanced match per year for personal care currently. The Bill extends Medicaid expansion through 2020, but does this essentially

	by gutting Medicaid – making it harder for people to obtain services. - Washington's rate of uninsured under the ACA has dropped from 14.5% in 2012 to 7.3% in 2015%. This bill would do significant damage. Long term services and supports is 6% of State operating budget, so these cuts would significantly impact us. Bill encourages us to send a letter to the congressional delegation and/or phone our Federal legislators. - 1115 waiver – the funding mechanism may be impacted, but not sure yet about how that will impact initiatives 1, 2 and 3. - Bill will share a fact sheet with the group with information to help facilitate our conversations/activism with legislators. DAC Planning for 2017 – Bill Moss - In 2016, we decided to focus on priorities that did not need money. DAC members have contributed over 5,000 volunteer hours. For 2017, if there are things we can do that are not hugely expensive, we can consider them. Don't let money be an inhibiting factor. We'll look at what funding would look like – public/private, or both. If this would be part of the ALTSA budget development process, it will need to be approved through DSHS and ultimately OFM. If funding requires legislation, we need to have language in place by June. If advocacy-based, it could be longer term.
3. Projects review & accomplishments	**Public awareness / community readiness - Cheryl** 1A1: Establish a work group to launch a web-based portal - The team evaluated websites to find the best platform and decided on the Community Living Connections (CLC) page. They then determined and prioritized 12 enhancements and a check off sheet for leads to use. Each priority will need a lead. - They are starting to look at analytics needed. This will lead to a marketing plan and a goal of implementing 2-4 enhancements this year.

- Subject matter experts are needed to write web content. The first need is an expert on In-home and outside-home care options. *If interested, let Cheryl and Lynne know.*

1F1: Inform and Educate public about healthy aging

- Using a $25K grant, the team set to work on two bodies of work:

  1) Working with NAPCA to develop and disseminate information about cognitive health such as how to message to loved ones and caregivers about getting involved earlier and providing care? They modeled from work done at the University of Pennsylvania, and, in Seattle, worked with Japanese and Chinese individuals via 6 focus groups consisting of 47 total participants. The next step is to find students at UW to analyze data and write action briefs to encourage those from other cultures to participate.

  2) Increase knowledge of ways to reduce cognitive decline. Messages will apply to all, but the team started by started by targeting African American women, and focused on brain health, not dementia specifically. Next steps are to select and review messages, determine if IRB approval is needed, and look at Pew research data to understand where people are getting their information to ensure we're reaching the target audience. The team will be updating the Dept of Health website. *If DAC members have suggestions of who to talk to, especially in eastern WA, please let Marci/team know*

3.B.1: Safety toolkit

- The published toolkit addresses the safety concerns that were of highest interest from survey. It's available on DAC website. All information is credible and free. Think about how this can be disseminated through your websites, networks, etc. *If you see a new, credible safety resources, let Lynne know for consideration in future updates.*

Long Term Supports and Services - Bob

4.C.2 and 4.E.1– Expand and promote early stage groups, linked with 4.F.1 and 4.G.1 engaging leaders of diverse/tribal populations.

	• The team has developed a pretty complete inventory of programs currently being offered. They are developing strategies and guidance that can be shared with communities in outlying areas, and will begin doing outreach to underserved populations in SE Washington for early stage programs. • 4.F.1/4.G.1 – Team has sent letters and surveys in the form of a "Dear Tribal" letter to Native American populations. The next steps will be to pull together the information gathered. They are looking to add a few members of this group to help. 6.A.2 – Care Coordination • The team created a resource document that defines care coordination and why it's important. Next, they broke out a grid by sector – what's available through Medicaid, private pay, hospital systems, etc. Their draft is 95% complete. When completed, they will send to DAC for review and input. The goal is to have this information be embedded in the Caregiver Roadmap, housed on organizations' websites, and made available in hard copy. **Health and Medical - Kris** 5.B.2 – Identify and recommend best practices for cognitive screenings in family care settings. • The team has drafted a position paper which is about 95% complete. Next, the full H-M subcommittee will review, and then will go to the full DAC for input. The emphasis is not to be prescriptive about what specific tool to use, but rather to describe all the important considerations and how to integrate screenings into workflow. 5.E.I – Promote Medicare Annual Wellness visit. • This work was deferred until this year. Some foundational research was needed first, including Bree Collaborative work. Preliminary investigations into utilization rates show that they are very low currently. The team is looking for a lead who knows how this would work in a family care setting.
4. Cross-cutting conversations	• The room was split into 3 groups. Each group heard from 3 sets of leaders on the topics below to share reactions, feedback, and suggestions:

	○ Dementia-friendly communities ○ Road Map for dementia caregivers ○ Expert panel/Bree Collaborative: Identify Evidence-based standards
5. Action Planning	• Moving forward, we will begin considering mid-term recommendations as well as what else we can accomplish in the near-term. **Kris – Health/Wellness:** ○ In goal 5, several things will fall out of Bree collaborative. Following up with annual visit results will be important. The team has identified extra folks to work on this. ○ The team will dig into goal 7 - Promote research related to causes and interventions for dementia. They can take on 7.B.1 (identifying organizations involved in providing dementia-related services) this year by looking at what's being done, and linking with other associations ○ They will also explore recommendations 5.G.1 (increasing awareness among primary care clinicians of avoidable cases of ER visits and hospitalizations) and, 5.F.1/ 5.F.2/5.F.3 (increasing awareness of challenges associated with dementia) in September. **Bob – LTSS** • The team is interested in next creating a version of the roadmap for folks who live alone. They would like to add Myriam to the team. "Living with Memory Loss – A Basic Guide" is a resource that's available. It's on Memory and Brain Wellness Center website. • Making the roadmap interactive and available online is the next step in its evolution. The team would like to find some private funding. This will make it easier to, in turn, secure State funding. The dedicated staff we've asked for could work on keeping up the Roadmap. • There is interest in helping families who need to pay privately know how to hire a caregiver and keep legal with IRS rules, how to be watchful of abuse. This could fall

	under 4.A.2 (providing information and assistance to caregivers). **Cheryl – Public Awareness** • The team has identified two continuations of work they've been doing: 2.D.2 (work with HBRN) and 1.E.3 (promoting the website) • They identified four recs to consider for 2017: ○ 1.A.3 – offering materials and information to underserved populations. They would need money to set up an Eastern WA team. Six short-term recommendations are ones that State agencies may be able to help implement. They would need a project team under Public Awareness to do this. Could be a huge success story. ○ I.E.I – engage a PR professional to advise on a campaign. There would be costs involved, but the investment could make everything we're doing more successful. ○ 2.D.3 – promote implementation of programs for people with dementia and their caregivers. This team may need help/collaboration from the LTSS Early Stage team for this one. They are writing a proposal to Robert Wood Johnson to develop an outcomes framework for our initiatives. If RWJ won't fund, they'll look elsewhere. ○ 1.B.1 – promoting positive images. *Next steps – committees will be meeting again by mid April.*
6. Upping our Communications	• The full group discussed social media, including potential hashtags for our efforts (maybe something with a positive spin) and how to spread our message. • A flip chart was started for participants to list organizations they recommend following. These were added to the list: ○ @Alz_WA (Twitter) ○ Leading Age Washington ○ Alzheimer's Society of Washington (Instagram) ○ @AlzsocietyWA (Twitter)

	• The group brainstormed things to do in social media, including: ○ Search Facebook for Alzheimer's; like/share reputable posts ○ Add DAC to LinkedIn profile ○ Share relevant news stories on social media ○ Create a DAC Facebook page – Mary Grace will think about this ○ Add DAC participation on personal LinkedIn profiles ○ Take advantage of already existing hashtags relating to the work we're doing – e.g. #dealingwithdementia
7. What if?	• Table groups engaged in conversation around specific funding opportunities for the recommendations we're working on, and what activities are best for public funding; which for private funding. ○ Each AHC (9 of them) will be putting in an application for projects with the Health Care Authority. ○ For affordable communities of health – make sure we have a DAC representative on each one ○ PR firm – public/private ○ Publishing copies of roadmap/online version – pub/private/in-kind ○ Research for dementia-friendly – pub/private/Alz Assoc? ○ Student scholarships to work at agencies ○ Seed grants for dementia friendly programs ○ Have a DAC catalog for ways people can contribute (e.g. buy X many roadmaps for $X) ○ Philanthropists e.g. Paul Allen brain institute ○ For 1.A.3 – Eastern WA team – Bill Moss may be able to help ○ Contact John Shirife (King 5 News) advocate for dementia ○ Products that support caregivers – find corporate sponsors

	○ Deloitte has cutting edge FMLA policies and Employee Assistance Programs ○ Foundations e.g. Group Health Foundation, family foundations ○ AARP/Rick Steves spokesman ○ Legislators with personal dementia connection ○ Veteran's Administration newsletters, getting someone from VA from the DAC ○ Consider 501c status for DAC? ○ Convention or web series for clinicians to share ideas and innovative pilots – public/private, or tag on to existing standing meetings ○ Echo platform/telehealth for case consultation for rural providers- public funding ○ Communication to clinicians, caregivers, consumers – a team of experts to bring info out to communities ○ Reach out to tech sector for sponsorship/investment in online version of Roadmap and tech support, then to the legislature to match private funding ○ Resources to find foundations: Philanthropy NW, Secy of State, and WA State Foundation Book
8. 15% Solutions	• Individually, participants took time to consider what small steps they can take/commit to. They then shared their ideas in pairs.
9. Wrap Up/Next Steps	• Lynne reviewed action steps (see below). Bea thanked the group for time and contributions, and encourages team to think through what it will take to help them accomplish their goals.

ACTION ITEMS

ACTION STEPS	ASSIGNEE	DUE DATE
Convene subcommittees. Decide what we can commit to, and what could be done if we had more time.	Bob, Cheryl, Kris	4/15/17

Consider scheduling remaining dates through the summer (subcommittees)	Bob, Cheryl, Kris	4/30/17
Update and submit existing implementation plans	Team Leads	4/25/17
Create and submit implementation plans for new recommendations	Team Leads	8/31/17
Next full DAC meeting in Tukwila – note date change	All	~~9/14/17~~ **9/27/2017**