**MINUTES** – **Attendance and Notes below**

* + Meeting title: Dementia Action Collaborative Meeting
* Date: Feb 15, 2023
* Location: Virtual/Zoom Meeting | Time: 9 am – 12:30 pm

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| **Governor Appointed DAC Members** (Note: Voluntary Members listed at back) |
|  | Craig Bill, Gov Office of Indian Affairs | X | Maureen Linehan, Consumer/Family CG |  | TBD: EMS representative |
| X | Lori Brown, W4A | X | Shannon Manion, DDA |  | TBD: Behavioral Health provider |
| X | Georgiann Dustin, SCOA | X | Angela Macey-Cushman, Elderlaw attorney |  | TBD: Health Care serving BIPOC |
| X | Brad Forbes, Alzheimer’s Association | X | Alyssa Odegaard, Leading Age |  | TBD: Nurse with dementia SME |
| X | Barak Gaster, UW Medicine | X | Carolyn Parsey, UW MBWC |  |  |
| X | Dan Gray, Dementia Support NW | X | Amy Person, WA DOH |  |  |
| X | Jaime Hernandez, Consumer/Family CG | X | Bea Rector, ALTSA |  |  |
| X | Patricia Hunter, LTC Ombuds | X | Kristoffer Rhoads, UW MBWC |  |  |
|  | Amber Leaders, Governor’s Office |  | Don Smith, Workforce Board |  |  |
| X | Sylvia Lee-Thompson, Consumer |  | Judy Zerzan-Thul, MD/WA HCA |  |  |

**Minutes**

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| **Topic** | **Key Points and/or Decisions Made**  |
| **Welcome and Overview of the Day** | Porsche Everson welcomed participants and presented an overview of the day’s agenda, DAC members and attendees introduced themselves.Bea-Alise Rector - Assistant Secretary of DSHS, Co-Chair- Excited to work on updating WA State Plans. Thanked everyone for their time and attention.Brad Forbes - Co-Chair and Director of Public Policy at Alzheimer’s Association - WA - Thanked and welcomed everyone for coming. Porsche led the group through introductions of governor-appointed and subcommittee members including 1 word to describe each person today.**ACTION** – A quorum was confirmed; Call for approval of minutes 12/14/2022. The minutes were approved by Governor Appointees of the DAC. |
| **Safety in Dementia** | **Maggie Christofferson, Community Outreach Manager from the Alzheimer’s Association WA** presented information on Safety in Dementia.* The most common safety issues are wandering, driving, firearms in the house, EMS and First responder training.
* Wandering happens when a person living with dementia becomes lost or confused because they do not recognize familiar places and faces.
	+ Support options include: MedicAlert Foundation, Education Presentations (6 different options), Care Consultations, Support Groups
* Firearms can be an issue if someone living with dementia has access to firearms and fails to recognize people they know and mischaracterizes them as an intruder or a threat.
	+ Support options include: education programs, care consultants, safety center topic sheets from alz.org.
* Driving is a big concern because it requires quick reaction to a large variety of circumstances.
	+ Support options include educating families on what signs to look for, and how to move forward if you see the signs. The Alzheimer's Association’s safety center has resources like a contract, or scripted conversation for families.
* EMS and First Responder Training can be an issue because emergencies are especially upsetting and confusing for people living with dementia making for potentially volatile situations if responders are not trained on how to successfully navigate the situation.
	+ Support options include training and topic sheets, as well as targeted training sessions for search and rescue and first responders.
* Barak asked for the highlights of first responder training
	+ Joel shared that a lot of it is communication tips - How to approach the person, using a calm voice, clear, easy to understand words, simple instructions.
* Porsche asked for people to post gaps that they saw in the safety issues In the CHAT:
	+ Cooking/Kitchen safety
	+ Kitchen appliances / other fire hazards in the home
	+ In addition to the common First Responders training, also Mental Health "first responders"
	+ The other nuance is history of DV and how that impacts the caregiver/care receiver dynamic
	+ Not just "go talk to your PCP" but tools for PCPs about what they should do when these issues are raise
	+ Falls - Lori Brown
	+ Medications, and other things in the environment
	+ Financial safety/scams
	+ Social Isolation, Sleep
	+ Bathroom/bathing/showering
	+ Keeping track of Meds
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| **Approaches related to safe returns** | **Carrie Gordon - Washington State Patrol, Missing Person Alert Coordinator** presented information on safe returns using the silver alert system.* Silver Alert can be used to find someone over 60 years old who could not return to safety without help. (Not dementia-specific)
* This is an investigation-driven system, it has to come from law enforcement (not families) and requires a vehicle association to post it to the highways and cell phone alerts.
* Families who are concerned can report missing people directly to their local law enforcement agency. If someone contacts them, they will assist them with contacting the proper local authorities.
* Phone alerts can be geographically targeted for on-foot alerts, but it’s not being used in Washington State yet, but is coming soon. The alerts will also include hyperlinks to open the digital poster showing the missing person.
* Patricia Hunter asked about whether they could use billboards if someone wandering might be using public transportation. Likely no, unless the specific vehicle could be identified.

**Dan Gray - Dementia Support Northwest, Project Lifesaver** presented information on safe returns using Project Lifesaver.* This system reduces search time for people who wander with many types of cognitive challenges. Project Lifesaver’s average return time is 30 minutes from alert to when a person is found.
* One of the drawbacks is that different systems have different radio frequencies so alerts aren’t available across platforms.
* These programs take a lot of people (volunteers) to maintain in high-density areas.
* If a search is initiated, the info is released to the signal up to about a mile away. Radio signal tracking time is shorter than GPS and it’s preferable to other systems due to no requirement for human interaction to receive the message.
* Questions:
	+ How often batteries need to be replaced. It’s recommended to do every 2 months and have a designated person to be assigned to keep batteries replaced.
	+ How is Project Lifesaver is funded. There are grants and scholarships typically plus volunteer time.
	+ Has been any research done with people with dementia and how they feel about the program? It depends on the person, but they have a great staff member who works with individuals on getting them to feel comfortable and that the tracking device is less intrusive.
* To see more information, including where Project Lifesaver is currently operative in WA state: <https://projectlifesaver.org/about-us/where-we-are/>
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| **Subcommittee Breakouts** | **Lynne Korte** presented information on what resources already exist around safety.* Dementia Safety Info Kit
* Community Health Worker training
* Dementia Road Map
* Early legal and financial planning
* Adult protective services
* Started toolkit for educating & collaborating w/ EMS – not completed due to pandemic
* Assistive technology/devices funds available

**BREAKOUTS discussion:** ***What can we do to support safety issues with dementia? Consider what actions in your topic area might help?******Few comments on discussion upon return (what subcommittee identified) -*** **Kris Rhoads - DAC Health-Medical*** Pragmatic tools are needed most
* During the breakout time, additional safety concerns were discussed, and the group brainstormed ideas for a safety tips and actions for Primary Care to utilize.

**Cheryl Townsend-Winter, DAC Public Awareness-Community Readiness*** Creating more awareness around existing tools
* Speakers Bureau around safety
* Booklet about safety, similar to the roadmap
* Include the voices of newly-diagnosed people to get their input

During the breakout time the group discussed safety concerns and how they can better be addressed by the Public Awareness-Community Readiness subcommittee:* Safety issue-Angel Sense is a company many of her clients with children with autism use. Not hearing as much about this company in the dementia world: [Angel Sense](https://www.angelsense.com/?utm_source=bing&utm_campaign=sch_branded_US&msclkid=a4c18d0ae24517ec351aeee7c0d32a3b) – the device to track is attached to a person’s clothes, can track to the square foot where someone is. It is expensive, but is less expensive than assisted living.
* We have already developed this toolkit: new goal may be to have someone doing outreach-like a speakers’ bureau-they would be able to get this information into the right hands-5 or 10 minute presentation. Marketing standpoint, developing a nice polished toolkit, like the Dementia Road Map-people are more likely to pick it up and look at it.
* Including the voices of people newly diagnosed with dementia regarding the topic of tracking devices.

**Maureen Linehan, DAC Long Term Services and Support**During the breakout time the group discussed safety concerns and how they can better addressed by LTC services.* Requiring Safety to be one of the CEUs, requiring agencies to train their staff on safety, getting stuck outside of their home in a courtyard/garden at their memory care community. There’s increased risk of falls in the outdoor environments, so there should be better awareness and training for staff to support people using those areas. And also ID for people in senior living.
* More community outreach to inform the general public about the existing supports. Both agencies and family caregivers directly.
* Updating the data links and having more awareness of the safety resources in your area. DAC should help people get a one-stop-shop within existing resources.
* Trying to make sure Project Lifesaver could be available state-wide. Also consider auto-locking door systems for wanderers.

**Resources Shared in Chat:*** <https://topics.alz.org/?ids=WANDERING_PREP&cid=999&src=alz>
* <https://topics.alz.org/?ids=MEDIC_SAFETY&cid=999&src=alz>
* <https://dementiaenquirers.org.uk/> & <https://www.youtube.com/watch?v=b0YOgiGZjZw>
* <https://topics.alz.org/?ids=FIREARM_SAFETY&cid=999&src=alz>
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| **DAC Consumer Survey Results** | **Lynne Korte** presented the findings of the DAC Consumer Survey.* 1,618 people responded, 113 with memory loss or dementia.
* How difficult was obtaining a diagnosis from a provider?
	+ 50% said it was somewhat or very difficult, this is up from 2016 where 39% found it somewhat or very difficult.
* What kind of information did you get after a diagnosis?
	+ 22% say no information was shared
	+ Increase in people reporting there was some verbal discussion with provider at diagnosis 54% vs. 42% (2016)
* Best places to raise awareness?
	+ Health care providers > Aging services > Social media (rising since 2016) > PSA or TV > Websites
* Is assistive tech helpful?
	+ 70% said it’s useful.
	+ From Family or Friends: The most helpful areas or to track location/wandering, fall detection, staying connected, meds help, monitor appliances
	+ From PLWD: Staying connected, reminders for meds, detect falls, track location, access online training & education
	+ The concerns are centered around being unaware of options (PLWD) or issues of/with using it or scams (families/friends).
* Overall/Top Most critical issues that should be addressed in next 5 years:
	+ Increased home care supports
	+ Financial help with care costs
	+ Promote quality in LTC care services
	+ Family caregiver supports
	+ Increase residential care availability
	+ PLWD top things were increasing awareness in the public, home supports and diagnostic services

**Subcommittee BREAKOUTS discussion on survey data –** * **Brief summary of thoughts/suggestions**

**Long Term Supports & Services*** The group discussed that many services and supports that most people are looking for are available but people have difficulty accessing them due to lack of awareness and complicated systems.
* Can strengthen and utilize non-services-based community supports such as faith communities, accessible housing, community activities, intergenerational supports, etc.
* Raise LTC planning awareness and assistance.

**Public Awareness-Community Readiness** * Subcommittee discussed how the responses to Question 4 from the survey could inform our future work. (Q: *In your opinion which of the following would be the BEST places or ways to raise public awareness about dementia in your community?).*
* Social media was highly suggested-could use funding for social media advertising, so people can easily locate DAC created materials and information.
* Given health care professionals are who people want to hear from, possibly create a campaign focused on health care professionals, so they are more knowledgeable regarding dementia and the resources available.
* How do we support Senior Centers, given they are a place where people learn about resources?
* In addition to primary care providers, ensure the other members of a clients care team are knowledgeable about dementia.
* It is important to have a functional website.
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| **Currently available systems/Health Care** | **Judy Zerzan-Thul, MD - HCA** presented via video with Q&A support from Jamie Teuteberg.The video was played: * HCA cares for 2.6 million Washingtonians, about 2 million Medicaid beneficiaries
* They provide healthcare insurance for retirees, and many other categories of care including helping people meet their social needs.
* Areas for improvement:
	+ Value-based purchasing
	+ Policy
	+ Accountable Communities of Health
	+ PEBB, SEBB, Managed Care contracts
	+ Benefit coverage options
* HCA Intersections with Dementia
	+ Coordinate services with healthcare and LTC
	+ Care coordination and primary care
	+ How do we pay for things differently to get better outcomes and healthier communities?
		- Focus on high-value care and eliminate waste
		- Pay for the care we want to have and is more wholistic
	+ HCA is working on Primary Care System Transformation through a strategy of Comprehensive System Alignment to make it easier for PCPs to provide the kind of care that is most effective.
	+ Goal of 12% of spending on primary care.
* They have many collaborators and partners. Many state agencies, but also industry associations and insurance plans.
* Challenges, gaps and opportunities include that there are many competing priorities, funding is a challenge, there are always new treatments available, contracts may be hard to change or add. A Community Health Worker grant is an opportunity (but it’s currently targeted toward kids.)
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| **Strategies to rectify disparate effects of dementia** | **Porsche Everson -** facilitated a discussion on how to promote equity and reduce disparate effects. * Porsche facilitated a Polleverywhere survey to collect responses on how to illustrate the DAC’s commitment to improving equity.
* PULSE-CHECK/POLL - The majority of the group voted to thread equity throughout by adding language into each of the goals.
* The comments include recommendations for partnering and bridging gaps and actively recruiting under-represented voices.
* Recommendation to include evidence-based programs and gathering and evaluating the data while working toward the goals.
* The Alzheimer’s Association has invested a lot of effort in this area and they have a lot of supportive data that they can provide as a resource.
* Idea of having a designated equity representative on each subcommittee.
* Would be great for each subcommittee to have a list of questions to ask themselves each time they make a new decision or propose new work. Diversity and inclusion is important, but it shouldn’t be just assigned just to people in diverse communities.
* WA Office of Equity may be a good resource.
* ALTSA EDAI Administrator/Specialists involved in the DAC’s subcommittee work.
* Porsche Everson shared that diverse purchasing practices are examples of how a simple change in a standard business process can make a big impact.
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| **Family Caregiver Perspective** | **Jaime Hernandez - Consumer/Family Caregiver** shared his story of caring for his wife, Lois in Washington State.* Lois is currently 78 years old and living with dementia in the later stages.
* She’s living in a Memory Care facility and has been enrolled in hospice for 12 months.
* Diagnosed with Alzheimer’s 6 years ago, but 1-2 years prior she was having noticeable memory impacts.
* Jaime has experienced a radical change in the life he shared with Lois and their children have pulled away somewhat. He has had to watch her continue to decline over time.
* When he had a camera in her room he would watch it at all times to feel a sense of control.
* The uncertainty of the progression of the condition is very difficult, especially the unknown of what the final conditions might be.
* Cost of care is a concern ongoing as well.
* Jaime and Lois do feel close when he visits her. He also has learned about the importance of taking care of himself to extend health and his kids have adopted healthy practices also.
* Working with Dr. Sadak has been a super important resource and support in navigating this journey.
* Getting together with other care partners periodically has been very helpful.
* Educational programs, like those from the Alzheimer’s Association have helped Jaime to feel more prepared.
* Jaime is grateful that Lois has had this time in relatively good, not painful health. He appreciates that they can spend time together connecting even non-verbally.
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| **Public Comment & DAC Announcements** | **Porsche Everson** facilitated the public comment and community events segment. * Brad Forbes updated the group on the Dementia Resource Catalyst request being spearheaded by W4A/Alzheimer’s Association. The first two are moving along, and additional funding is being requested.
* Alyssa Odegaard share that the Specialized Dementia Care Program (SDCP) dementia reimbursement rate update is included in a larger ask around rate increases. LeadingAge is working to increase rates and change how it’s structured (creates an ‘add on’ to a base rate for specialized dementia care expectations) so that this SDCP rate will continue to rise with the base rate.
* Barak Gaster shared that the Cognition in Primary Care dementia care training for Primary Care Practitioners will be provided again next month, and registration is now open to providers beyond the UW system. Sign Up here: <https://familymedicine.uw.edu/cpc/>
* Alzheimer’s Association Support Groups: <https://www.alz.org/alzwa/helping_you/support_groups>
* Alzheimer’s Association Journey Conference for Caregivers on March 25: <https://www.alz.org/alzwa/helping_you/conferences>
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| **Next Steps/Wrap up** | * March, April & May meetings will be to set priorities for setting the next priorities
* May - The Subcommittees will refine recommendations and present to the full DAC on **June 22**
* **Health-Medical Subcommittee:** 3/8, 10-11:30am
* **Public Awareness-Community Readiness:** 3/7, 2-4pm
* **LTSS:** 3/22 from 9-11am
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| **ACTION ITEMS** |
| Save subcommittee dates above in your calendars | ALL members | Now |
| Confirm you have April 26 and June 22 also saved on your calendars | ALL members | Now |
| Suggestion to set aside some time before each DAC meeting to do the pre-reviews/reading | ALL members | Before each meeting |
| Submit your feedback and updates on the Dementia Road Map<https://www.surveymonkey.com/r/2D6TTZ5>  | All members | End of February |
| When received, please help us disseminate outreach materials around listening session in March | DAC Staff | With follow ups |

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| **DAC Voluntary Subcommittee/Team Members** | **Guest Speakers & Public**  |
|  | Aziz Aladin, WA Developmental Disabilities Council | X | Mikaela Louie, Family Caregiver | X | Maggie Christopherson |
| X | Dana Allard-Webb, SUA/ALTSA |  | Cathy MacCaul, AARP | X | Jillian Morris |
| X | Marigrace Becker, UW-MBWC | X | Carrie McBride, NW Hospice Assoc |  | Maggie Ramirez |
| X | Basia Belza, UW HBRN |  | Vicki McNeally, WHCA |  |  |
|  | Alison Boll, ADS/King |  | Phung Nguyen, King ADS |  |  |
| X | Kristen Childress, ARNP, UW-Nursing |  | Mary Pat O’Leary, King ADS |  |  |
|  | Chastity Charette | X | Mimi Pattison, MD/Franciscan Hospice  |  |  |
|  | Karen Cordero, AFH Council |  | Cheri Perazzoli, Hearing Loss Assoc |  |  |
|  | Katie Denmark, Alzheimer’s Assoc |  | Marty Richards, LICSW |  |  |
| X | Leslie Emerick, WA State Hospice and Palliative Care Organization | X | Carrie Rubenstein, MD/UW |  |  |
|  | Eric Erickson, Home Care |  | Tatiana Sadak, UW Nursing |  |  |
|  | John Ficker, AFH Council |  | Allyson Schrier/UW, Dept of Neurology |  |  |
|  | Aime Fink, SUA/ALTSA |  | Lauri St Ours, WHCA | **Staff/Facilitation** |
| X | Jullie Gray, Aging Wisdom | X | Breanne Swanson, AAA/SW WA AAA | X | Susan Engels, Office Chief, SUA |
|  | Meredith Grigg, Northwest Justice Project |  | Rep. Steve Tharinger, WA State Representative | X | Porsche Everson, Relevant Strategies |
| X | Debra Hoeman, RCS | X | Michael Terasaki, WA Pro Bono Council |  |  |
| X | Jaime Hernandez, Family Caregiver | X | Diana Thompson, Hearing Loss Assoc | X | Marci Getz, WA DOH |
| X | Debbie Hunter, Family Caregiver | X | Ron Vivion, formerly SCOA | X | Lynne Korte, ALTSA/DSHS |
| X | Nancy Isenberg, Swedish | X | Jessica Welsch, Alzheimer’s Assoc | X | Joe Murphy, ALTSA/DSHS |
| X | Kathy Jacobi Hansen, Alzheimer’s Assoc | X | Jim Wilgus, Alzheimer’s Assoc | X | Jamie Teuteberg, HCA |
| X | Cathy Knight, W4A | X | Karen Winston, King ADS |  |  |
| X | Todd Larson, Family Caregiver | X | Cheryl Townsend Winter, DDS |  |  |
| X | Joel Loiacono, Alz. Association | X |  Anshul Noori, Gentle Generations |  |  |