



- **MINUTES – Attendance and Notes below**
- Meeting title: Dementia Action Collaborative Meeting
- Date: Apr 26, 2023
- Location: Virtual/Zoom Meeting | Time: 8:30 a.m. – 12:30 p.m.

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, Elder law attorney	TBD: Health Care serving BIPOC
X	Brad Forbes, Alzheimer’s Association		Alyssa Odegaard, Leading Age	TBD: Nurse with dementia SME
X	Barak Gaster, UW Medicine		Carolyn Parsey, UW MBWC	
	Dan Gray, Dementia Support NW	X	Amy Person, WA DOH	
	Jaime Hernandez, Consumer/Family CG	X	Bea Rector, AL TSA	
	Patricia Hunter, LTC Ombuds	X	Kristoffer Rhoads, UW MBWC	
	Amber Leaders, Governor’s Office		Don Smith, Workforce Board	
X	Sylvia Lee-Thompson, Consumer	X	Judy Zerzan-Thul, MD/WA HCA	

### Minutes

Topic	Key Points and/or Decisions Made
<b>Welcome and Overview of the Day</b>	<p>Porsche Everson welcomed participants and presented an overview of the day’s agenda, DAC members and attendees introduced themselves.</p> <p>Bea-Alise Rector - Assistant Secretary of DSHS, Co-Chair- Excited to work on updating WA State Plans. Thanked everyone for their time and attention.</p> <p>Brad Forbes - Co-Chair and Director of Public Policy at Alzheimer’s Association - WA - Thanked and welcomed everyone for coming.</p> <p>Porsche led the group through introductions of governor-appointed and subcommittee members.</p> <p><b>ACTION</b> – A quorum was confirmed; Call for approval of minutes 2/15/2023. The minutes were approved by Governor Appointees of the DAC.</p>
<b>Report from Listening Sessions</b>	<p>Lynne thanked the group for sharing outreach about the six listening sessions offered. Two of these had pre-scheduled Spanish translators, one was tribal-specific all had either pre-scheduled or available as needed ASL or other translators.</p> <ul style="list-style-type: none"> <li>• We had around 400 unique registrants, 140 of whom were consumers (people living with dementia or family caregivers). Of these registrants, 251 actually attended the sessions. A disappointment was that despite efforts to reach diverse audience, attendees were not very diverse.</li> <li>• She brought attention to a summary of these sessions sent to you last week, with meeting materials – includes both themes and more detailed suggestions.</li> <li>• Overall themes were:</li> </ul>

	<ul style="list-style-type: none"> <li>• Variety of issues arising that demand more attention to aging in general, and need to create a more age-friendly state/communities, and a life-course perspective</li> <li>• Increase awareness and knowledge about dementia and dementia supports (risk reduction, dementia progression, behaviors, resources)</li> <li>• Want centralized place to access resources and supports</li> <li>• High costs of care – people need to anticipate and plan for, options for affordable care/financial assistance</li> <li>• Increase dementia-specific training for providers of all types in health and long-term care</li> <li>• Increase workforce – LTSS and Health care</li> <li>• Tribal listening session - dementia not talked much about, due to stigma and lack of awareness. Need for more awareness about dementia, service options, and more culturally tailored support services.</li> </ul>
<p><b>Cross subcommittee review/feedback on proposed recommendations</b></p> <p><b>Chairs Report back</b></p>	<ul style="list-style-type: none"> <li>• Chairs reported back after cross-committee review of proposed recommendations</li> <li>• Marci Getz/Cheryl Townsend-Winter reported that there were some great suggestions about merging ideas/priorities across different groups, group offered excellent feedback</li> <li>• Porsche reminded everyone that each subcommittee will hold one more meeting before we all reconvene again, all will have additional time to review these recommendations</li> <li>• Maureen Linehan/Joe Murphy reported discussion about expanding workforce development reference, two recommendations possibly outside scope of DAC but need to rewrite to clarify DAC role, suggestion to include eval component, legal planning toolkit group previously developed content that was not used in final product that may be used in this group’s work (glossary, caregiver resources, financial info), recommendation to translate roadmap into multi languages/need to provide culturally nuanced translations of these materials versus straight translations</li> <li>• Kris Rhodes/Jamie Teuteberg thanked everyone for providing excellent feedback, shared discussion re brain health in diverse populations, maintaining cultural competency front and center, focus on how medical providers intersect with other community professionals such as first responders, locksmiths, hair dressers, good questions about measuring certain goals and clarifying operators, ensuring central repository for research opportunities, importance of making and maintaining relationships with diverse groups</li> </ul>
<p><b>Panel: Public safety – emergency responders/law enforcement dementia-</b></p>	<ul style="list-style-type: none"> <li>• Panel: <i>Dawn Felt, DOH, Emergency Care System, EMS Education and Training Consultant; Anne Raven, Spokane Fire Department; Commander Jay Mason, Tumwater PD; Chief Wendi Steinbronn, Washougal PD; Deputy Chief Jason Viada, Port Angeles PD</i></li> <li>• Dawn Felt provided an overview of the state’s EMS system: established to reduce morbidity rate of people due to cardiac, stroke, and other</li> </ul>

<p><b>related challenges and suggestions</b></p>	<p>emergencies, goal of getting people to the right facility in a timely manner, designation of facilities to provide specific emergency care, one of first states to establish by law an emergency care system and has a well-respected system in place, shared color-coded map showing where and what level of EMS services are provided, reflected some inequity of services in more rural communities, outlined EMS provider types and regionalized trauma care map, physician medical program directors provide oversight in each county, statewide database tracks emergency responses, some challenges with completeness and quality of data, statutorily mandated steering committee reviews regional plans and proposed rules and proposed modifications, DOH EMS office’s primary role is regulation, oversight along with regional councils, licensing/certification, guidance on education and training, develops minimum standards and content for EMS education and training, provided overview of key issues/challenges for EMS</p> <ul style="list-style-type: none"> <li>• Panelists shared various stories about responses involving persons with dementia: Anne shared stories about calls regarding falls, because persons with dementia can have challenges being accurate “historians,” it is hard to assess them for severity of fall/what treatment they need, likely that they get over triaged because EMS has to err on the side of caution; Jay shared stories about calls for disorderly individuals (sometimes persons with dementia), typically male, disoriented, sometimes angry, officers try to deescalate/get additional information/return them to their residence, these calls are not uncommon; Wendy shared story about her own late mother (who had dementia), who made reports about being abused by her caregivers in memory care, was hard to assess whether it was related to her paranoia symptoms or whether it was actually occurring, had to report as a mandatory reporter, memory care home in her jurisdiction so sometimes activity that would typically be criminal in nature is not when persons with dementia are involved and intent is lacking; Jason shared scenarios in which person with dementia wanders away, Project Lifesaver helps with this when sensors are voluntarily used, Silver Alert plan in place, gap in current system of safety nets is a lack of training, knowledge gained through experience with own mother in law, convincing person to wear sensor or transponder is difficult, if caregiver has an issue and person with dementia is left alone in the home, how can we help them? If law enforcement involved in that scenario, they might not know person about to be left has dementia, needs very specific training for law enforcement, in recent years have had some update training for autism/substance abuse disorder, need something similar for dementia training, involuntary treatment act not an appropriate mechanism so we do they call? Not everyone has family in town, so what do law enforcement or responders do with remaining dementia partner?</li> <li>• Porsche added that incidents involving domestic violence and persons with dementia can also be complicated and are likely common as well</li> <li>• Panelists shared erratic driving, collisions, indecent exposure, shoplifting, suicide and homicide when guns are in the home, violence are also common, even with lack of intent those situations can be dangerous; when an emergency transfer occurs sometimes it is difficult to contact family members to inform them of transfer/location of patient</li> </ul>
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	<ul style="list-style-type: none"> <li>• Programmatic responses: <i>what might DAC consider to help with some of these issues?</i> From a statewide perspective, training module created by one of the AAAs was very helpful, gaps they identified included need for education about dementia and how to work with them, best practices, patient rights, culturally competency, working with families of persons with dementia, one option may be to make modifications to that curriculum and offer statewide, make it adaptable to include community-specific needs, EMS offered to provide any input for this training; Anne shared that in Spokane, Integrated Medical Services developed community assistance response (CARES) teams including social workers, students getting masters in SW, go out in teams of two, most of referrals from EMS system, then provide access to resources/wrap-around services, behavioral response unit has a licensed mental health care worker and paramedic often encounter persons with dementia and then make referral to a CARES team, does not fix the problem but offering resources and support to these people and their families; Jason shared need for social workers and other community members who can respond to calls that law enforcement and EMS have had to report to in the past, it will need to be a 24/7 resource, not just during business hours, many are currently in office only and not field responders; Jay emphasized need for partners in field response, ability to take into case management for these individuals, need wrap-around process to help them and their families be more successful, need to have validated regional resources to help individuals in crisis, officers can only contact them and possibly take them to the ER and that is not a viable answer; Wendy agreed that they cannot take people to jail or use Involuntary Treatment Act so we need others to step in and help with next steps in those scenarios</li> </ul>
<p><b>Subcommittee breakout on next steps</b></p>	<p><b>Notes taken in breakouts</b></p> <p>Health-Medical Subcommittee</p> <ul style="list-style-type: none"> <li>▪ How could we have a role in advocating for wearables for PLWD – especially the younger onset?</li> <li>▪ What happens when the EMS takes away the care partner and doesn't recognize the person left behind is PLWD – could we include it somewhere within the AD registry that the caregiver is caring for a person with dementia in the home and so don't leave them behind. <ul style="list-style-type: none"> <li>○ Purple angel program in Spokane addresses this – <i>information to follow</i></li> </ul> </li> <li>▪ We need to continue to work to reduce stigma associated with dementia and cognitive decline</li> <li>▪ EMTs are looking for POLST form – could we have magnet or sticker next to it that shares there is a PLWD living here</li> </ul> <p>Long-Term Services and Supports Subcommittee</p> <ul style="list-style-type: none"> <li>• Promote development of various models available across the state that allow for EMS providers to work more closely with social service providers in their areas, such as the CARES program in Spokane, Bellevue and Seattle Northshore, a database of risk kept by the Tri Cities Fire Department with</li> </ul>

	<p>referrals to the Area Agency on Aging, and Seattle Fire’s similar direct referral system to Aging and Disability Services.</p> <ul style="list-style-type: none"> <li>• The Vial of Life program may be helpful for proactive emergency preparation – if users added that a person with dementia lives there, including if it’s the family caregiver (who needs to be cared for if the other is taken to hospital).</li> <li>• Discussed the Alzheimer’s Association first responder training and agreed that any training provided must include a local component of how to access resources in that area.</li> </ul> <p>LTSS members agreed there should be a recommendation to raise awareness of existing models of collaboration such as CARES, and to support replication of these programs across the state.</p> <p>Public Awareness and Community Readiness (PA&amp;CR) Subcommittee</p> <ul style="list-style-type: none"> <li>• Acknowledgement of what the panel shared about first responders receiving calls and expectations they do something regarding a person who they have no control over.</li> <li>• Suggested adding to the Portable Orders for Life-Sustaining Treatment (POLST) form that a member of this household has dementia. POLST forms are medical order forms that tell EMS/medical staff what to do if you have a medical emergency and are unable to speak for yourself.</li> <li>• Creating or adding to a National data base that an EMT can go to, if you have been diagnosed with something, such as dementia, it would show up if the EMT typed in your name.</li> </ul>
<p><b>Panel: Mobilizing a coordinated state response</b></p>	<ul style="list-style-type: none"> <li>• Panel: <i>Amy Person, DOH, Bea Rector, DSHS  AL TSA, Judy Zerzan-Thul, HCA</i></li> <li>• Dementia-related topics that align with agency strategic priorities and are of mutual interest across sectors</li> <li>• Bea shared that many of DAC’s draft recommendations are consistent with DSHS priorities, given doubling of population of people with dementia, need to focus on healthy aging, ensure access to good quality, culturally appropriate responsive services, and are free from abuse, neglect, and exploitation, need to develop programs to serve people in own homes and communities, avoiding hospitalizations when prolonged stays can be debilitating, want to leverage work of DAC, we cannot do any of these things without adequate number of workers to provide care, need to build skilled, competent, and compassionate workforce;</li> <li>• Dr. Zerzan-Thul shared that equity and disparity work and avoidable hospital admissions are areas of overlap, agree that workforce is an issue, especially behavioral health workforce, state master plans on aging in other states have propelled some of this work forward;</li> <li>• Dr. Person shared that low hanging fruit is equity work, pillar of public health is prevention, reducing modifiable risk factors and creating healthiest environments, workforce is an area of overlap with AL TSA and HCA because one of five goals is health system and workforce transformation, DOH does some work around reducing hospitalizations but more focused on</li> </ul>

	<p>prevention, public health loves collaboration so partnering with other agencies is desired</p> <ul style="list-style-type: none"> <li>• Porsche asked the panel: <i>Clearly significant overlap here - What would you need each other to pursue deeper connections with respect to these topic areas?</i> <ul style="list-style-type: none"> <li>○ Dr. Person shared that the biggest challenge is coordinating overlap when we are not aware of the overlap, how do we coordinate and provide appropriate data so we can better mix and match our work?</li> <li>○ Bea shared that multi-sector plan on aging and difficult to discharge are priorities because shared intention and focus is imperative and multi-sector plan could do this, need to carve out dedicated time and resources, many DAC recommendations about caregivers, prevention, etc. could be leveraged and amplified.</li> <li>○ Dr. Zerzan-Thul agreed that hospitalizations, equity, and state multi-sector plans should be priorities, need to highlight urgency of aging population, first step is figuring out work connected when it is not visible, ensuring that work is synced up.</li> </ul> </li> </ul>
<p><b>Public comment &amp; DAC community announcements</b></p>	<ul style="list-style-type: none"> <li>• No public comments</li> <li>• Brad Forbes shared update re DAC legislative priorities: budget awaiting the Governor’s signature, but specialized dementia care program (special Medicaid rate for people served in assisted living facilities) \$43.43/day per person as an add-on, only half of what was requested so advocates will continue to ask for remaining amount, dementia resource catalyst program has two sites funded, requested additional two, leg agreed to fund a total of three, housed in an AAA</li> <li>• Karen Winston shared that she’s working with ALZ Assoc on multicultural caregiver resource fair on June 8 10:00 a.m. – 2:00 p.m. at Tukwila Community Center</li> <li>• Lynne Korte shared that updated Dementia Road Maps will be available soon, shipment will arrive 4/28, start ordering again as soon as 5/1</li> <li>• Diana Thompson shared 5/19 at 9:00 a.m. WA Alzheimer’s and Dementia Research Network meeting is hosting Dr. Alison Huang, presenter is from Johns Hopkins sharing the new study that links hearing loss with dementia</li> </ul> <p><b>ACTION</b> – may order updated Dementia Road Maps on or around May 1<sup>st</sup>.</p>
<p><b>Next steps and wrap up</b></p>	<ul style="list-style-type: none"> <li>• Lynne shared timeline again and emphasized what we all be doing during our May subcommittee meetings, including finalizing each subcommittees drafts of and then prioritizing recommendations, review plan sections text. May subcommittee meetings will be important.</li> <li>• June 22 8:30 a.m. – 1:00 p.m. DAC will approve plan recommendations by quorum, then need to post by July 1 for public comment.</li> <li>• Please look out for emails re upcoming meetings/requests to review.</li> <li>• Lynne thanked everyone for their attendance and commitment to these upcoming meetings</li> <li>• Health-medical: 5/10 10:00-11:30 a.m.</li> </ul>

	<ul style="list-style-type: none"> <li>• PA&amp;CR: 5/31 10:00 a.m. – 12:00 p.m.</li> <li>• LTSS: 5/16 11:00 a.m. - 1:00 p.m.</li> <li>• Bea and Brad thanked participants for their robust participation and focus.</li> <li>• Porsche also expressed her gratitude for group’s hard work and focus today</li> </ul> <p><b>ACTION</b> – plan to attend subcommittee meetings in May and full DAC meeting on June 22 – these are important meetings to get to “done”</p>
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ACTION ITEMS		
Attend upcoming subcommittee meetings in May – reading materials sent for review in-between meetings as requested	All	May 31, 2023
Plan to attend June 22 full DAC meeting	All	June 22, 2023
Watch for and review any materials sent between meetings	All	May – June, 2023
Order updated Dementia Road Maps	All	May 1, 2023

DAC Voluntary Subcommittee/Team Members				Guest Speakers & Public	
X	Aziz Aladin, WA Developmental Disabilities Council		Mikaela Louie, Family Caregiver		Maggie Christopherson
	Dana Allard-Webb, SUA/AL TSA	X	Cathy MacCaul, AARP		Jillian Morris
X	Marigrace Becker, UW-MBWC		Carrie McBride, NW Hospice Assoc		Maggie Ramirez
X	Basia Belza, UW HBRN		Vicki McNeally, WHCA		
X	Alison Boll, ADS/King	X	Phung Nguyen, King ADS		
X	Kristen Childress, ARNP, UW-Nursing	X	Mary Pat O’Leary, King ADS		
	Chastity Charette	X	Mimi Pattison, MD/Franciscan Hospice		
	Karen Cordero, AFH Council	x	Cheri Perazzoli, Hearing Loss Assoc		
X	Katie Denmark, Alzheimer’s Assoc	X	Marty Richards, LICSW		
X	Leslie Emerick, WA State Hospice and Palliative Care Organization		Carrie Rubenstein, MD/UW		
X	Eric Erickson, Home Care		Tatiana Sadak, UW Nursing		
X	John Ficker, AFH Council	X	Allyson Schrier/UW, Dept of Neurology		
	Aime Fink, SUA/AL TSA		Lauri St Ours, WHCA		
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		
	Jaime Hernandez, Family Caregiver	X	Diana Thompson, Hearing Loss Assoc	X	Marci Getz, WA DOH
	Debbie Hunter, Family Caregiver	X	Ron Vivion, formerly SCOA	X	Lynne Korte, AL TSA/DSHS
X	Nancy Isenberg, Swedish	X	Jessica Welsch, Alzheimer’s Assoc	X	Joe Murphy, AL TSA/DSHS
X	Kathy Jacobi Hansen, Alzheimer’s Assoc		Jim Wilgus, Alzheimer’s Assoc	X	Jamie Teuteberg, HCA

	Cathy Knight, W4A	X	Karen Winston, King ADS		
X	Todd Larson, Family Caregiver	X	Cheryl Townsend Winter, DDS		
	Joel Loiacono, Alz. Association		Anshul Noori, Gentle Generations		