Meeting title: Dementia Action Collaborative Date: September 7, 2016

Location: Tukwila Community Center 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 Interagency Council on Health Disparaties |
| **√** | 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 | **Alzheimer’s Assoc WA**Volunteer |
| **√** | Bob **Le Roy** | **Alzheimer’s Assoc** **WA** LTSS Chair | **√** | Peter Newbould | **Alzheimer’s Assoc 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 | **√** | Christine Seymour | Hearing Loss Assoc |
| **√** | 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 | **√** | Joel **Loiacono** | Alzheimer’s **Assoc WA** |
| **√** | Bill Moss | Chair | **√** | **Jullie** Gray | Aging Wisdom |
| **√** | Marigrace Becker | UW Medicine Memory & Brain Wellness Center | **√** | Porshe Everson | Facilitator |
| **√** | Sumi Jayadev | UW Medical Ctr – ADRC | **√** | Myriam Marquez | Consumer |
| **√** | Leslie Emerick | WA State Hospice & Palliative Care | **√** | Tatiana Sadak | UW School of Nursing |
| **√** | Kathleen Macaul | AARP | **√** | Debbie Hunter | Caregiver |
| **√** | Jason McGill | Governor’s Office | **√** | Kara Lewis | WA Dental Service |
| **√** | Bruce Smith | Regence | **√** | Alison Boll | Aging & Disability Services |
| **√** | Jennifer Minich | Legistlative Asst/K Keiser |  |  |  |

AGENDA

|  |  |
| --- | --- |
| **Topic** | **Key Points and/or Decisions Made**  |
| 1. Welcome and introductions
 | **Key Points*** Bill Moss thanked the subcommittees for all of your work done to date
* Members and subcommittee members introduced themselves
* Meeting goals
	+ Review recommendations in motion
	+ Agree and improve on processes for internal and external communications
	+ Determine common messages and action steps moving into 2017
* We are working collectively on 11 recommendations. There has been a lot of progress since April coming up with recommendations we can move forward with, with the constraints we have
 |
| 1. The messiness and joys of collaborative work
 | **Key Points*** Table groups discussed working collaboratively
* What’s working in terms of getting collaborative work done?
	+ Strong leadership
	+ Draft of roadmap product is being useful already
	+ Having the right group – content and expertise along with shared ownership
	+ Speaking up when you can help – you don’t have to be the expert to contribute
	+ Identifying problems
	+ Diversity of subcommittee members and the level of volunteerism
* What challenges are you facing in working collaboratively?
	+ Lack of communication to the broader team about progress
	+ Everyone needs to take time to read what’s shared to be able to contribute
	+ Finding a common message – balancing amount of research to the target audience
	+ Time and distance. Calling into lengthy meetings is challenging
	+ Using inclusive language – identifying key partners from diverse communities
* Group norms were reviewed from April (see pre-read)
 |
| 1. Progress reports – Recommendations in Motion
 | **Key Points**Each working group reviewed their work to date by presenting:* Why the recommendation is important in big picture
* What will be completed this year? Ultimately?
* High level steps
* Any challenge or question for full group

**Public Awareness 1.A.1. –** Establish a workgroup to develop a single web-based “point of access” portal* The team is working on a DAC website. By the end of December, they will have a plan for how site will be developed and become operational (content, marketing, upkeep).
* They researched what sites people are using, what content people are interested in. They used the survey comments/suggestions from the 2015 ADWG Public Survey rather than moving forward with their own survey.
* They will be looking at analytics re: website name and address, but realized they don’t have the expertise needed to do all of it themselves. This will be included in their plan.
* DSHS has a site called Community Living Connections (CLC) which has pages for Alzheimer’s and dementia. The team is planning to enhance this website based on survey input and link to other pages and sites. DSHS uses a contracted vendor, and has a site administrator.
* By year end, this group will develop a website enhancement plan, will develop a marketing plan & will develop a sustainability plan for the website to include establishing a workgroup to oversee content, utilizing help from other subcommittees.
* Question for, and feedback from, the larger group –
	+ What content from the various project teams we want to put on the website? Initially content may be more simple .pdf files, but in future years can make content more interactive. Also think about sustainability of anything you want to post to the site.
	+ Look into translating content into other languages (this is a feature of the CLC site)
	+ Figure out how we can connect with other websites in marketing plan – have cross-referrals to CLC site
	+ Review utilization data of CLC site – how many hits it gets
	+ Be sure that any videos have captioning. Make sure content is accessible for folks with different disabilities.
	+ Have a placeholder for questions.

**Public Awareness 1.F.1.** – Inform & educate the public about healthy aging including links between brain health and nutrition, exercise, stress, management and oral health/periodontal disease* Group secured a grant to fund the implementation of two or more specific action items in the federal CDC Healthy Brain Initiative. The funding was for $25,000 for work to be completed by August 2017
* The two action items chosen from the healthy brain initiative are:
	+ Identify and promote culturally-appropriate strategies designed to increase public awareness about dementia to reduce conflicting messages, decrease stigma, and promote early diagnosis
	+ Coordinate national and state efforts to disseminate evidence-based messages about risk reduction for preserving cognitive health
	+ The work of these initiatives will be in conjunction with other organizations (refer to handout)
* By end of December, the team plans to have 6 focus groups completed and data analyzed. For DOH, will have literature review completed and research how and where to disseminate information to target audience (African American Women). See implementation plan in handouts for details.
* This group will be careful not to use any information that blames individuals for their dementia. They are looking for long term studies and research that back their findings, and will link with others, where possible, with information about brain health.
* Questions for the group:
	+ Do you know of any research or random controlled trials that could help?

**Public Awareness 2.C.1 –** Review emerging models/movements of livable, age-friendly and dementia-friendly communities and determine elements most critical to developing dementia-friendly communities in WA state* Dementia-friendly communities are about maintaining connections so all of us feel we belong. This is important because it means life can and does continue after diagnosis.
* This year, the team will complete:
	+ A fact sheet with critical elements/defining success factors of a dementia-friendly community and what would make it work in Washington. They are working to define their target audience.
	+ The team also had excitement and passion around creating a recommendation for how to integrate age-friendly and livable communities and dementia-friendly communities (e.g. initiatives recently begun in Puyallup and King County)
	+ Complete an inventory of dementia-friendly programs in Washington and determine gaps. Look for opportunities to connect and network with players already involved in this work
	+ Plan for how to work with a state-wide system (e.g. integrate with museums, parks, libraries). They will start with libraries.
* Questions for, and feedback from,the large group:
	+ Who do you think is the best target audience to distribute fact sheet to initially?
		- Faith communities
		- Senior Centers
		- Any consumer-facing organizations
		- Association of Washington Cities. Consider holding a nomination for dementia-friendly cities
		- State public works association, local planner association, state building council
		- Minority commissions. See [www.healthequity.wa.gov](http://www.healthequity.wa.gov)
	+ Other thoughts on the uniqueness of Washington and dementia-friendly communities?

**3.B.1. Public Awareness -** Compile and make accessible educational materials about ways to improve safety for people with dementia. * The team looked at the best of information that is out there now that is free to use and disseminate to families, then they narrowed down to the most credible and relevant.
* The recommendation specifically called out falls prevention, wandering, disaster preparedness, and home safety assessments – the team added driving because of the ADWG public survey. For each category, there will be a high-level fact sheet that would be available online, and a lengthier document for those who want more detail.
* Questions for, and feedback from, the large group
	+ Thoughts on where to house the toolkit and printability?
		- Would like a one-page checklist that directs me to select the areas that are of most interest to me/my family and that would then direct me where to go for detailed info
		- A mechanism where providers could assign these as readings for patients’ families, or print for them
		- Raise awareness to have providers link to the website where this is housed
		- Provide to first responders
		- Create a .pdf that links to website for further resources. Have someone available to answer questions
		- University of Michigan’s Red Book would be a good format
		- Use with ombudsman programs throughout the state – use the printed version to disseminate
	+ Let the team know if you have other ideas on resources, formatting, etc.

**4.A.1. Long term Services & Supports** – Create a Washington-specific Road Map for family caregivers providing information about what to expect over time to help plan for the future. * The caregiver roadmap is meant to fill a need for a resource people can go to for more information about what to expect and resources at each stage of dementia
* The caregiver roadmap draft is broken down by categories within 5 stages. The format includes what to expect, what you can do, important steps, and decision points. Each stage will also include a picture of a caregiver and their story.
* The roadmap will include a high-level introduction and links to references, an explanation of acronyms, and key search words. Will likely be a booklet around 10-pages in length.
* Questions for, and feedback from, the large group
	+ Are we on the right path – Yes!
	+ What’s missing?
		- Include that everyone is different and reaches the various stages at different times
		- Need to have a circular life path – not good to have a road to nowhere
		- Steer away from a linear orientation – focus on living in the moment (e.g. pull over at a rest stop – pause and focus on the journey)
		- Connect with the safety project team
	+ What modalities would be best?
		- Think about funding opportunities to print and market the roadmap. Could be used across the country
		- Have printouts for clinicians as well as an online version with local resources
		- When online, access hyperlinks throughout the document
 |
| 1. Working Lunch
 | **Key Points*** Peter Newbould gave an update on the BRFSS (Behaviour Risk Factors Survey) telephone survey from (Recommendation 2.A.2). In 2016, the survey included a cognitive module. In 2017, we are aiming to have a caregiver module (not limited to dementia). We’re hoping for a positive response and will learn this month if this is approved.

The Caregiver module has 9 questions about biggest care needs and the impact of providing care on the caregiver him/herself. The data obtained will help quantify the contributions of caregivers and identify gaps in supports needed. * A video called “Our Time Has Come 2016” from UW Memory and Brain Health was shown ([watch on YouTube](https://www.youtube.com/watch?v=Cg0qGBAGJhQ))
 |
| 1. Progress reports – Recommendations in Motion, Continued
 | **Key Points****4.C.2. – Long Term Services & Supports** - Expand and promote implementation of early stage memory loss groups for people with cognitive impairment/dementia and their care partners* Goal was to do an inventory of current early stage supports and identify gaps. With early diagnosis, there is more opportunity for early planning and support, but can also have increased anxiety attached. The team is promoting a message of hope and empowerment focused on 3 entry points – 1) support, 2) advocacy, 3) dementia-friendly community activities
* The group will be seeding upcoming Alzheimer’s Town Halls with questions around early state memory loss groups and what is needed in different communities state-wide.
* End of year goals are to take a snapshot of what’s happening now state-wide of early-stage memory loss groups, both evidence-based and informal support. The team will look at rural and diverse communities and look at providing guidance for forming support groups.
* Questions for, and feedback from, the large group:
	+ Email cara@elderwise.org her if you have ideas about who may not be in the snapshot and needs to be brought into the fold
		- What will we call these groups? People in early stages don’t recognize they have dementia. Use ‘memory loss’?
		- Look at ways we can have organizations themselves link to the CLC website
		- PSAs would be very helpful if we could get funding, to reduce the stigma of dementia

**4.F.1 and F.G.1** – **Long Term Services & Supports**Identify and engage leaders and organizations of diverse populations to explore needs for education and support AND F.G.1 – Engage tribal representatives to explore the needs of tribal families caring for propel with dementia to develop culturally relevant supports and services. * The group is conducting outreach (key informant interviews) to Native American and Alaska Native population. Their plan is to not talk about diagnoses, but rather whether people are noticing memory loss. They are hoping to ~~will~~ finish the interviews ~~survey~~ in November using plain-spoken language. After Native American population, the team plans to ~~will~~ reach out to African American and Latino populations.
* Completion dates are to be determined
* Questions for, and feedback from, the large group:
	+ Does the phased approach make sense? Yes
	+ Any suggestions on leaders or organizations within their groups to recommend?
		- SeaMar

**5.A.1. Health-Medical** – Convene an expert panel to identify and endorse a set of evidence-based standards for diagnosis, treatment, supportive care, and advance planning for people with dementia* The team’s goal was to have a mechanism to provide and promote standards, not to reinvent the wheel
* The team is hoping to be able to partner with the Bree Collaborataive’s expert panel. Senator Kaiser’s office wrote a letter of support for Bree meeting. In the July meeting, it was moved forward as one of 6 possible topics. On Sept 21, they will select 3 of those 6 and we’ll know if we have a pathway with Bree, or if we need to come up with and convene a process to work with our own panel of experts.
* Questions for the large group
	+ Who else needs to be part of this subject matter expert group (e.g. professionals associated with hearing loss, providers/populations outside of I-5 corridor)
	+ How to maintain once the Bree work ends?
	+ If chosen, Bree will need to form a workgroup of what to propose to the larger Bree, then it would go forward as a funded part of the Bree’s work and process. In this case the Health-Medical subcommittee will recommend subject matter experts, some of whom hopefully cross-over with DAC.

**5.B.2 – Health Medical** – Identify and recommend several validated, brief cognitive screening tools* There is an ask for these screenings within the provider community.
* The team is looking at 3-4 measures that would fit within a family practice setting and not be culturally biased.
* They are identifying what’s out there now, looking at how to involve the caregiver, who performs the screenings and what happens after the results.
* The outcome is to collate the tools and research that are already out there. They will also look at what other states are doing and how they’ve integrated.
* By end of the year, they will create position paper or report. The work is being done at UW and Virginia Mason. They’d like to train healthcare assistants, aides, receptionists, etc. in addition to clinicians, especially in smaller populations
* Questions for, and input from, the large group:
	+ How do we contact stakeholders and get the tools and training out to smaller practices and hospitals?
		- Dept of Health can be area of dissemination as well as State Medical Association and Hospital Association
	+ Is there a tool families can administer themselves?
		- Yes, and need to think about what they do afterwards
		- Include case managers, care managers, or any professionals that go into the home
		- Reach out to tribal communities
		- Expand assessment tools to dental providers
	+ How do we ensure clinicians are using the tools or that people are asking for them?
		- Put the seed in medical schools and nursing programs
		- SHAG buildings – can they create a program for those who are and aren’t diagnosed?

**5.E.1 – Health Medical** – Promote understanding and effective use of Medicare Annual Wellness Visit (MAWV) which includes cognitive screening* This was put out as part of the ACA, but didn’t have any guidance about how to use it, the cognitive screening tools or parameters
* The team looked at what guidance had already been put out there, including what other states are doing. Qualis did data gathering and found that about 12 percent of Washington State Medicare beneficiaries are using their MAWV visit (up about 1 percent from last year). Regence has been using financial incentives to promote within their system, with some success. We don’t know what percentage of these are including the cognitive screening as part of this visit.
* Cognitive screening could also be as part of an office visit or part of another type of annual visit. Clinical training of providers and education of consumers is needed regardless of the venue of the screening
* First, the team will help educate people about what the screening could be, and then look at how to weave it into additional materials next year. Educate consumer group (Medicare beneficiaries) about what’s available and how to have the conversation with their physician, and educate clinicians/physicians. Will likely encourage them to have people on their team do the screenings rather than doing themselves.
* Because work on the cognitive screening recommendation needs to be done first, along with work on the recommendation for Standards, this recommendation will proceed over time, but not have a product until later in 2017.
* Questions for, and input from, the large group
	+ Thoughts on the approach or how to empower providers/consumers?
		- Target adult family homes, assisted living facilities, SHAG, etc
		- Identify champions who can say getting tested is a positive thing, and primary care providers who can serve as champions to their peers
		- Before the screening, build relationship with the individual, ask questions about their functioning, and build trust.
		- Need to educate public that annual wellness visit is not the same as an annual checkup with a doctor. We need to promote screenings outside of the annual wellness visit as well.

**6.A.2. Long Term Services & Support –** Identify and promote existing models of care coordination services for individuals living in the community and their family caregivers* There are many opportunities to access care coordination. The team’s goal is to create an explanatory grid of care coordination models exist currently and help people understand what care coordination is. Are there opportunities to introduce a new model for dementia?
* Availability of care coordination depends on financials, location, and health plan. The grid is also broken down by different ways care coordination could be promoted
* By end of year, the team will have the format for the grid completed. They’ll complete the grid itself by spring/early summer 2017
* This work will be integrated into the Roadmap
* Feedback on the grid from the large group:
	+ Sustainability – how will this be kept up to date? This will be in a later phase
	+ This would be good content for a MHA program
	+ Case management for insurance is very different from others like Sound options or City of Seattle. The team should think about how to articulate the differences to families so they’re getting someone who’ll advocate for them in an unbiased way. Would like to see a recommendation of what kind of case management is needed for those who receive the diagnosis.
 |
| 1. DAC Communication Planning
 | **Key Points*** Proposed DAC Communications Plan was sent ahead to DAC for review: No suggestions/edits made. Discussion followed on some of the points.
* Internal communications – how is it going and what could be improved?
	+ Going well
	+ Make phone meetings shorter (1 to 1.5 hr max)
	+ Follow up lists (“Action Steps” on the meeting minutes) after meetings of decisions and commitments made are helpful
	+ If sending items out for review – specify if you need everyone’s input, or just provide input if you have time
	+ Read what is sent ahead or out for review
* External communications
	+ Tailor message to specific stakeholder groups
	+ Prioritize stakeholder groups
	+ Think about what people want to hear, not just what you want to say
	+ Determine the goal of the communication to the specific audience
	+ Have talking points and mission statement whenever meeting with a group
	+ Tailor the tools/modalities used to your audience
	+ Think about what the public wants to know – about the work of the DAC, or about what’s out there
* Small groups considered messages for specific target audiences. We want common, consistent branding, but specific messaging.
	+ the legislature
	+ clinicians
	+ caregivers
	+ media
	+ first responders / law enforcement
	+ senior centers
	+ faith communities
	+ Other groups:
		- interested stakeholders within dementia community
		- private sector funders/foundations
		- the organizations we work for
		- case managers- those we’re doing inventories of services
		- community groups – rotary, clubs, business people
* Tables selected topics above in bold and provided their notes to Lynne Korte. These will be reviewed by the Communications Team for action.
* We are forming a DAC Communications Team to further flesh out our Communications Plan and Next Steps. First tasks will be to decide about the DAC logo/branding. And, to put together a communications plan for the 2017 leg session and advocacy days. The Team will ideally include Lynne, Cheryl and at least one representative from each subcommittee.
 |
| 1. Advocacy Plans
 | **Key Points*** Progress was shared with the Joint Legislative Executive Committee on Aging (JLEC) in June 2016 – the presentation given is in your meeting folders.

Upcoming opportunities for community engagement* W4A – Age Wave forums invite candidates for state elected office to participate in discussion on a variety of issues. There are 7 forums in Sept and October. All are encouraged to attend and make sure you ask questions about memory loss/dementia.
* Alzheimer’s Assoc has a series of 14 Town Halls being held Oct – Nov. An update on some legislative priorities, will be given, but more importantly will be giving updates on the DAC progress and plan. We want to gather public input on our work and ask if we’re on the right track.
* We’ve asked for time on both the Senate and House Health Committees. Think about a double-sided, single sheet that lists DAC accomplishments to date and pick one from each area to report on.
* We probably won’t ask for legislative funding this year, but show what we’ve been able to do thus far without funding. We want to brand DAC as the continuation of the plan so legislators can feel good that they voted for the plan.
 |
| 1. Subcommittee Meetup
 | **Key Points**Subcommittees met briefly to share thoughts and reactions to the feedback received on their plans, decide on next meetings, and determine who from their group would serve on the communications team.  |
| 1. Public Comment
 | **Key Points**Three members of the public provided comment:* Madeline Frailey from Port Orchard, caregiver for husband who has late stage dementia spoke about HB 2835 – the Purple Card. This card is something caregivers or loved ones can present to others who are interacting with the person with dementia letting them know they suffer from memory loss.
* Claudia Donnelly from Renton. Her mom had dementia. She is working to protect Alzheimer’s patients from abuse by guardians. There are state laws on the books, but her mom was forced into a facility against her wishes. She is concerned because judges can currently cancel POAs. She feels we don’t need more studies; we need guardian monitoring now.
* Trang Tu – is the caregiver for mother who is mid-stage Alzheimer’s and lives with her. She shared the many cultural barriers they’ve faced (including a geriatric assessment that had cultural and language biases, meal programs that couldn’t be culturally adapted, utility rebates that don’t accommodate family situations, the huge gap in home caregivers who speak Vietnamese) and urged the committee to continue to look at how we serve diverse communities. We should consider both stand-alone diversity recommendations and be sure diversity is integrated across all of our recommendations.
 |
| **ACTION ITEMS** |
| **ACTION STEPS**  | **ASSIGNEE** | **DUE DATE** |
| Next year, there will be 2 full DAC meetings (March and September 2017) and subcommittee meetings as determined by subcommittee Chairs . **The next FULL DAC meeting will be held March 9, 2017.** This will be in Lacey as it will be legislative session, and some members may need to be near Olympia.  | All DAC members and subcommittee members | Put the date of MARCH 9, 2017 on your calendars NOW |
| Lynne shared that the DAC Steering group decided to extend the terms of appointed DAC committee members from April 2017 to 2018. **If you *don’t want to serve on DAC*** through CY 2018, PLEASE let Lynne know.  | All DAC members | Oct 30, 2016 |
| We will be convening a DAC Communications Team. We will set up a conference call to get this team together in a few weeks.  | Lynne to arrange conference call  | Sept 30, 2016 |
| If you have any ideas to improve the process and/or communications, or if there is anything we need to be better ambassadors, please let Lynne know. We all need to be leaders in our communities. | All DAC members and subcommittee members | Sept 30, 2016 |
| Attend upcoming subcommittee meetings as scheduled and continue work on recommendations in motion  | All DAC members and subcommittee members | Put dates on calendars as soon as received from your Chair |