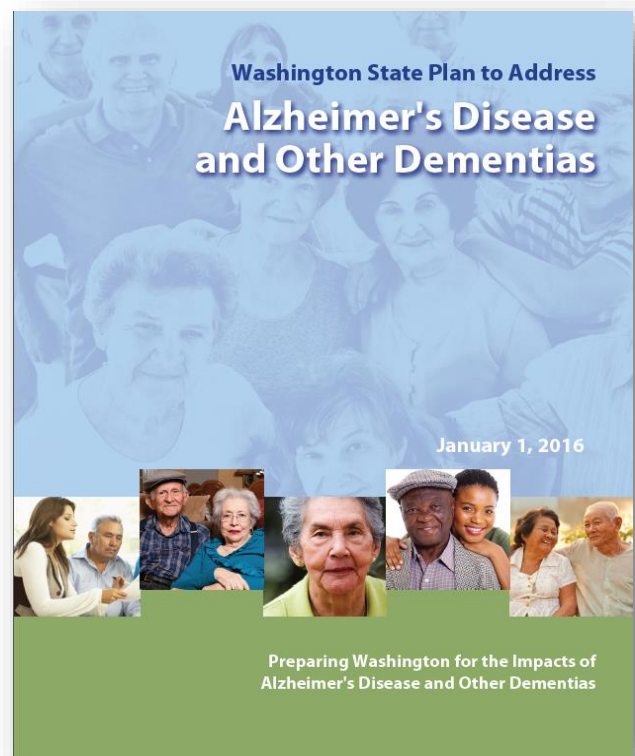

Dementia Action Collaborative

Progress Update: April 2016 to December 2019



Introduction

In 2014, legislation established an Alzheimer's Disease Working Group (ADWG) to create a state plan to address Alzheimer's disease. This plan, released in January 2016 identifies goals, strategies and recommendations as a starting point to prepare for the future. The ADWG developed the first [Washington State Plan to Address Alzheimer's Disease and Other Dementias](#) as a public-private partnership. The plan's implementation – including action planning, next steps, and policy changes – depends upon the participation and contributions of a broad group of committed partners.

What is the Dementia Action Collaborative?

Members of the ADWG called for the formation of a next generation workgroup to implement the plan. This group is now known as the Dementia Action Collaborative (DAC) - a voluntary statewide collaboration of partners committed to preparing our state for the future. The DAC includes a range of appointed members – people with dementia, family caregivers, representatives of advocacy groups, the aging network, Alzheimer's organizations, long-term care providers, health care professionals, legislators and governmental agencies. The DAC has four subcommittees: Public Awareness/Community Readiness, Health and Medical, Long Term Supports and Services, and Advocacy.

What are the goals of the plan?

The purpose of the plan is to promote strategic actions that will prepare Washington State for the future.

The high-level goals are shown at right. See [State Plan](#) for more detail on specific strategies and recommendations.

What's been accomplished so far?

The DAC focused first on actions that could be accomplished through heightened collaboration and existing resources. This report shares activity and accomplishments through 2019.



NOTE: Throughout this document a recommendation with an open box (☐) has been initiated and is 'in process'; a recommendation with a checked box (☒) is considered completed.

Goal 1: Increase public awareness, engagement and education

☑ **Recommendation 1.A.1:** Establish a work group to develop, launch, and oversee a single web-based “point of access” portal/website linking to a comprehensive statewide array of credible and validated information, resources and supports.

☐ **Connects with Recommendation 1.E.3:** Publicize and promote the online point-of-access portal (See 1.A.1), as well as other points of access (e.g., dementia care navigators, toll free number) for services and supports for persons with dementia and their family caregivers. Utilize social media to build public awareness of available resources.

Year End Accomplishments 2018/2019:

- Elected to enhance a statewide website, Community Living Connections (CLC), which had an AD/dementia page and the capacity to link users to local services. Aging and Long Term Support Administration maintains this website under contract with a private vendor. Based on the ADWG survey, the team identified enhancements and then coordinated with the CLC program manager to improve webpage content.
- A new URL (memorylossinfo.org) was established, and a Communication Plan to disseminate its availability is underway. The new URL was included in a reprint of the Dementia Road Map and used in many community presentations.
- The team is creating a sustainability plan to keep content of web page updated.

Status: 1.A.1 Completed; 1.E.3 Promotion will be ongoing.

Next Steps:

- Review web page analytics to inform future dissemination plans.
- Use the Communications Plan to disseminate the new URL, and emerging sustainability plan to keep it updated.

Project Team: Carrie McBride, Debbie Hunter, Joel Loiacono, Ron Vivion, Cheryl Townsend Winter

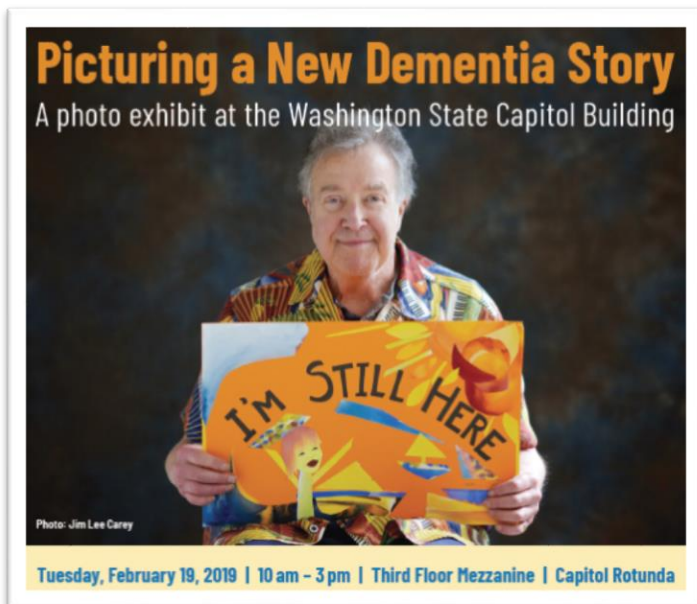
☑ **Recommendation 1.B.1:** Promote positive images and messages of persons with dementia and their caregivers to combat stigma and increase societal acceptance and integration

Year End Accomplishments 2019:

Developed and produced four action projects:

- a) Dementia Friends pilot in three counties with concurrent evaluation. See Rec 1.E.2 for more.
- b) Busting Dementia Stigma – Creation and dissemination of a children’s book list showing criteria and examples of books that offer positive images of people with dementia.
- c) Photo/Art Exhibit at State Capitol/Olympia in conjunction with Alzheimer’s Advocacy Day.
- d) Let’s Talk Dementia mini-video series on the value of diagnosis and living with dementia.

Project Team: Team Lead: Marigrace Becker Members: Alisa Tirado Strayer, Hilarie Hauptman, Lynne Korte, Cathy MacCaul, Marty Richards



"Picturing a New Dementia Story" at the State Capitol reached more than 90 + personal viewers. A related marketing online story reached 2000+ people. Those who attended had meaningful conversations and responses related to the exhibit -

"Nice during advocacy day to balance the message. It's not all about crises – but hearing a message that's positive and hopeful is important."

"Images of hope within the challenge ...there's joy here..."

"Busting Dementia Stigma – One Children's Book at a Time" was shared in person and online (reaching 2000+) through the American Library Association, Washington Library Association, UW Memory and Brain Wellness Center and the Department of Health.

"I especially love the guidelines for inclusion as that will be so helpful going forward, whether or not the specific titles are on hand. GREAT WORK!"

"Let's Talk Dementia" Mini-Video Series

People with dementia and their family care partners discuss living with dementia and the value of early diagnosis. To date, we know of 1,500 views through ALTA, more from other partners.



View DAC materials:

www.dshs.wa.gov/altsa/dementia-action-collaborative

□ Recommendation 1.B.2: Promote models of stigma-free, dementia-friendly communities, places and events (e.g., Alzheimer’s Cafes) to combat stigma and increase societal acceptance and integration. See Rec 4.E.1 later in this document for related activity.

□ Recommendation 1.C.1: Educate the public about the importance and advantages of getting an early diagnosis and what to ask their health provider, including asking for a cognitive assessment when memory and/or cognitive processing issues become a concern.

Year End Accomplishments:

- Achieved funding per budget proviso for the Department of Health, in the amount of \$150,000 per year. Proviso funding is to be used to develop public awareness campaign strategies regarding dementia and the value and importance of early detection, diagnosis and planning for the public, including racial and ethnic groups at increased risk in 2-4 targeted areas of the state.
- Investigations are underway regarding evidence-based messages & public awareness strategies.
- While locales are yet to be determined, considering a pilot project with health system to disseminate messaging and/or targeting similar areas as ECHO program participants.

Status: In progress

Next Steps:

- January: Continued investigation of campaign strategies, including literature review.
- June: Campaign content and strategies developed.
- July – December: Launch digital campaign.

□ Recommendation 1.D.1: Educate the public about the need for advance care and end-of-life planning, before cognitive function declines, consistent with the Bree Collaborative End of Life Care Recommendations.

□ Connects with Recommendation 1.D.2: Educate the public and caregivers about the need for legal and financial planning – and the importance of obtaining legal and financial advice as a planning tool.

□ Connects with Recommendation 3.C.1: Make more readily available appropriate forms for legal planning such as Durable Power of Attorney for Health Care, Durable Power of Attorney for Finances, Advance Directives, and information about a Physical Order for Life Sustaining Treatment (POLST) at no cost to consumers through public libraries, resource centers, online, and other appropriate locations.

Year End Accomplishments 2018/2019:

- Included messaging about legal and advance care planning within content of Dementia Road Map, Dementia Capable Approaches training and Community Health Worker trainings.

- Completed content development for a dementia-focused legal/advance care planning toolkit.
- Filmed videos to engage consumers with the “Living with Dementia Mental Health Advance Directive”
- Achieved funding per budget proviso for ALTSA, in the amount of \$167,000 per year. Proviso funding is to be used to contract with a legal organization to provide educational materials and attorney training, and to coordinate pro bono legal services that support legal and advance care planning.
- ALTSA conducted Request for Information and identified a contractor, Northwest Justice Project to implement budget proviso. As of December, their hiring process is underway.

Status: In progress

Next Steps:

- March: Dementia legal toolkit for full DAC review, printed by end of June.
- June – December: Market and offer Continuing Legal Education program for attorneys.
- June – December: Establish pool of pro bono attorneys to help with legal and advance care planning in local areas.

Project Team: Lead: Carla Calogero Members: Caroline Wood, Katie Denmark, Bruce Smith, Debbie Hunter, Myriam Marquez, Lisa Ellen Brodoff, Marie Eaton, Meredith Grigg, Lori Ichimura, Hilarie Hauptman, Lynne Korte

□ Recommendation 1.E.2: Raise awareness of dementia and available resources by engaging public and private ‘champions’, including faith, business community leaders/corporate and non-profit partners, educators, and health professionals, to assist in developing, implementing and leveraging education and outreach campaigns. Expand the reach of campaigns by identifying and engaging partners that may not be a part of the traditional information service system such as Chambers of Commerce, Employee Assistance Programs, community college and university students.

Year End Accomplishments:

- Elected to utilize the global awareness program, Dementia Friends, for this purpose as it is intended to raise awareness and combat stigma.
- Engaged University of Washington graduate student and advisors to conduct evaluation of pilot project in three counties – Jefferson, King and Yakima.
- Recruited/trained 15 champions (trainers) who between them provided Dementia Friends Information Sessions for 200+ people in the three counties. Session are 60-90 minutes in length. (Note: 22% of participants were people of color, and 47% lived in a rural area).

Status: In progress

Next Steps:

- January: create an action brief summarizing the pilot program and recent evaluation. And, continue planning a 2-year pilot expansion of Dementia Friends, to include 3 new regions/sectors per year, with at least one of these each year being particularly focused on a diverse community.
- February: Develop structure for expansion, identifying partner organizations in three areas who will provide a Master Champion.
- March: Work with DNP student to create Master Champion toolkit.

Challenge: Due to lack of funding stream to administer this program, the project team is starting small with expansion in order to determine support needs and feasibility for ongoing implementation and sustainability.

Project Team: Lead: Marigrace Becker Members: Alisa Tirado Strayer, Basia Belza, Lynne Korte



Key Messages of Dementia Friends

1. Dementia is not a normal part of aging. Not everyone who grows old will develop dementia.
2. Dementia is caused by diseases of the brain. The most common is Alzheimer's.
3. Dementia is not just about having memory problems. It can affect thinking, communication and doing everyday tasks.
4. It is possible to have a good quality of life with dementia.
5. There's more to the person than the dementia. People with dementia are a valuable part of the community.

Dementia Friends Evaluation

The Dementia Friends (DF) program was offered in three Washington counties – Jefferson, King, and Yakima. We trained 15 Dementia Champions who offered DF Information Sessions to 200+ attendees.

We evaluated the program using three surveys of DF Information Session attendees: a survey both before and after the DF Information session, as well as a survey one month later.

What did we learn?

After attending a Dementia Friends session, attendees had an increase in comfort around people with dementia and in knowledge about dementia. This was still the case one month after the information session.

□ **Recommendation 1.F.1:** Inform and educate the public about healthy aging, including links between brain health and nutrition, exercise, stress management and oral health/periodontal disease.

□ **Recommendation 1.F.3:** Inform and educate the public about the connections between chronic disease (diabetes, heart disease, hypertension, oral health/periodontal disease, sleep disorders, etc.) and dementia. These connect with Rec 2.D.2.

Year End Accomplishments:

- Updated DOH webpage on dementia. See this at: <https://www.doh.wa.gov/YouandYourFamily/HealthyAging/AlzheimersDiseaseandDementia>
- Formed DOH Healthy Aging Workgroup. With representation from multiple public health programs, the workgroup reviewed the [Healthy Brain Initiative Road Map - 25 Actions for state and local public health agencies](#), and identified 88 potential new opportunities for activities to integrate aspects of dementia into their work.
- Coordinated digital campaigns, headed by DOH, HCA and AL TSA, integrated messages on brain health and dementia, and/or the link between chronic conditions and dementia during awareness months related to stroke, heart disease and family caregivers. These campaigns targeted public health, health care and related stakeholders linked to agency social media platforms.

Status: In progress

Next steps:

- Work with DOH program staff to support integration of identified HBI Road Map activities.
- Work with DSHS-AL TSA and HCA to see where we can collaborate on HBI Road Map activities.
- Coordinate digital awareness campaigns as opportunities arise.

Project Team: Marci Getz, Janna Bardi, Lynne Korte, Jamie Teuteberg

Goal 2: Prepare communities for significant growth in the dementia population

□ **Recommendation 2.A.2:** Implement the Behavioral Risk Factor Surveillance System (BRFSS) cognitive and caregiver modules at least once every three years.

Year End Accomplishments 2018/2019:

- BRFSS Cognitive Module was fielded in 2016. Applied to DOH to include full BRFSS Caregiver Module, but request denied due to large number of questions.
- One question related to prevalence of caregiving was included in 2017 BRFSS (ALISA/Older Americans Act funds).
- Applied for and achieved inclusion of Cognitive Decline Module in 2020 BRFSS Survey.
- **Status:** In progress

Next Steps:

- January - March: Analyze the 2017 Caregiver question data.
- January - May: Work with DOH to request inclusion of Caregiver Module (in 2021 or 2022).

Project Team: Peter Newbould, Marci Getz, Susan Engels, Lynne Korte

□ **Recommendation 2.B.1:** Integrate goals and objectives related to cognitive impairment, memory loss and dementia into local and state governmental agencies' strategic plans. Such plans include state and area plans on aging, coordinated chronic disease management, falls prevention and emergency preparedness, transportation, and the Washington State Plan for Healthy Communities.

Year End Accomplishments 2018/2019:

- Developed list of state/local/regional agencies with information about strategic plan timing, contact person, URL to their strategic plan & any notations on anything currently related to dementia in those plans. Prioritized agencies assigned for follow up.
- Developed a Project Brief for use with agency contacts.
- ALISA included Alzheimer's and other dementias/Dementia Action Collaborative as a strategic focus area in its [State Plan on Aging](#) for 2018-2022.
- DOH is working to get healthy aging, Alzheimer's disease and other dementias into the State Health Improvement Plan (SHIP).

Status: In progress

Project Team: Lynne Korte, Kim Boon, Marci Getz, Jamie Teuteberg, Cheryl Townsend Winter

☑ Recommendation 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 Washington State.

Year End Accomplishments 2018/2019:

- Disseminated [Dementia Friendly Communities fact sheet](#) developed in 2016 to more than 16 statewide groups/associations.
- Created and presented workshop on dementia-friendly library practices to Washington State Library Association for second year, and at Washington State Physical Therapy Association Conference.
- Engaged with recreation associations and YMCA's as a new statewide association, including a group of King County YMCA directors.
- Conducted statewide survey investigating specific interests in dementia-friendly topics and networking, with more than 200 responses – leading to development of first statewide networking event (webinar) scheduled for 2018.
- In partnership with LTSS project team offered quarterly dementia-friendly program webinars with follow-up networking opportunities, in partnership with DAC early stage programs team which attracted 392 registrants. See Recs 4C2/4E1.
- Presented at Washington State Recreation Professionals Association Conference.
- Determine plans for a Dementia Friendly conference/summit in 2020. See Rec 2.C.2.

Status: Completed, some ongoing effort.

Next Steps:

- January - March: Determine plans for additional dementia-friendly guidance documents and program webinars.
- June - December: Plan Dementia Friends training and sessions in three new areas.
- September: Host Dementia Friendly Summit/Conference. See 2.C.2.

Challenge: This effort may also take some funding to provide support necessary to expand beyond current state.

Project Team: Lead: Marigrace Becker; Members: Hilarie Hauptman, Cathy Knight, Lynne Korte, Cathy MacCaul, Marty Richards, Jon Rudicil

□ **Recommendation 2.C.2:** Encourage and incentivize local communities to become more dementia-friendly.

Year End Accomplishments:

- ALTSA provided funds to UW Memory and Brain Wellness Center to plan and implement a Dementia Friendly Summit/Conference for 2020.
- UW convened a project team from various geographic area and sectors to help plan event.
- Established timeline, goals, agenda and potential dates for event.

Next Steps:

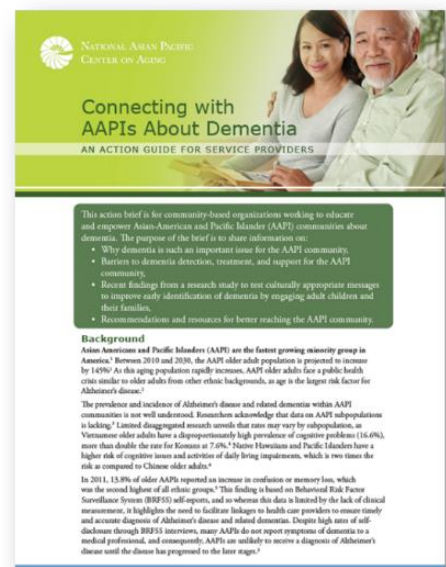
- January: Finalize date and location.
- January – June: Continue planning and begin outreach/marketing.
- September: Host Dementia Friendly Summit/Conference.

Project Team: Lead: Marigrace Becker; Members: Corrie Blythe, Kim Boon, David Brown, Joann Clemo, Debbie Hunter, Cheri Knighton, Lynne Korte, Christina Marneris, Karen Winston, Cathy MacCaul, Michael Woo

□ **Recommendation 2.D.2:** Work with the UW Healthy Brain Research Network (HBRN) and other partners to develop evidence-based public messages around promoting healthy aging and brain health, while ensuring messages are culturally/ethnically appropriate and designed to reach statewide populations including persons with limited English. See also Recs 1.F.1/1.F.3.

Year End Accomplishments 2018:

- In 2018, disseminated evidence-based messages about preserving brain health and useful resources to African Americans through “Memory Sundays”, via Seattle area churches in partnership with nonprofit Center for Multi-Cultural Health.
- Produced & disseminated hand fans (with information on resources for families) through churches.
- Six focus groups were conducted in 2016/17 with Chinese and Japanese adults with older relatives via the National Asian Pacific Center on Aging (NAPCA) partnering with the UW Healthy Brain Research Network to consider the acceptability of messages concerned about cognitive health. This year, the Action Guides were presented to more than 800 area providers in more than



46 organizations. See the NAPCA created Action Guides for Service Providers and Policy Makers:

<http://depts.washington.edu/hprc/resources/products-tools/aapi-dementia-action-guide/>

- The two efforts above were featured in the new *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* which can be seen at <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>
- DOH webpage on dementia went live. See this at: <https://www.doh.wa.gov/YouandYourFamily/HealthyAging/AlzheimersDiseaseandDementia>

Status: Ongoing

Next Steps:

- Continue efforts to connect brain health and healthy aging in Washington State Health Improvement Plan.
- Seek and promote opportunities to develop and share culturally appropriate messaging.

Project Team: Team lead: Marci Getz and Basia Belza; Members: Lynne Korte, Myriam Marquez, Kathy Lofy, Ingrid Ulrey, K'aimi Sinclair

Goal 3: Ensure well-being and safety of people living with dementia and their family

☑ **Recommendation 3.A.1:** Incorporate content about dementia (warning signs, the importance of early detection and diagnosis), the heightened risk of abuse, neglect, and exploitation; and about community resources into the Community Health Worker training.

Year End Accomplishments 2018:

- Engaged Department of Health (DOH) program manager for Community Health Worker (CHW) training in 2017 to determine need for, potential formats, and costs of such a training.
- Identified funding to develop a training module for CHWs through ALTSA's federal Dementia Capable Systems grant and Older Americans Act.
- Developed contract with DOH, and online training system developer (Talance) to complete work, utilizing subject matter experts to determine content for self-paced online training module on Memory Loss and Dementia for CHWs.
- DOH completed and launched the self-paced, optional Memory Loss and Dementia training module to CHWs statewide in June and December 2018.
- Going forward, the Memory Loss and Dementia training module will be scheduled and available two times a year for CHWs statewide who have completed the core CHW training.



Status: Completed

Project Team: Scott Carlson, Lynne Korte, Joanne Maher

☑ **Recommendation 3.B.1:** Compile and make accessible educational materials about ways to improve safety for people with dementia. Information may address fall prevention, wandering, disaster preparedness, and home safety assessments.

Year End Accomplishments 2017/2019:

- In 2016/17, investigated what is currently available re: safety for dementia that is targeted to families living with dementia, prioritized most relevant, and determined criteria for inclusion in an "info kit". Finalized online [Dementia Safety Info Kit](#) (a compilation



of best, credible documents available via PDF and websites).

- Disseminated through DAC partners, re: awareness of these materials.
- Disseminated online and paper versions at conferences, trainings and meetings.
- Reviewed and updated content February 2019.

Status: Completed

Next Steps:

- Review/update once per year.
- Disseminate as possible via partners and webpages.

Project Team: Lynne Korte, Bob Wellington, Dave Budd

□ Recommendation 3.B.3: Promote and disseminate training for first responders about dementia.

Information may address: recognizing signs and symptoms, communication skills, understanding behaviors including wandering, community resources, and red flags of neglect and abuse.

Year End Accomplishments:

- Formed project team and developed implementation plan.
- Investigated what is available as resources/training nationally and in Washington.
- Identified Washington programs that are doing training on dementia for first responders.
- Sought out information on return of investment.
- Decided to develop Info/Toolkit targeting Fire Department/EMS, AAAs and partner organizations.

Next Steps:

- February: Develop outline for an Informational Toolkit
- May: Draft of Info/Toolkit
- September: Finalize Info/Toolkit

Status: In progress

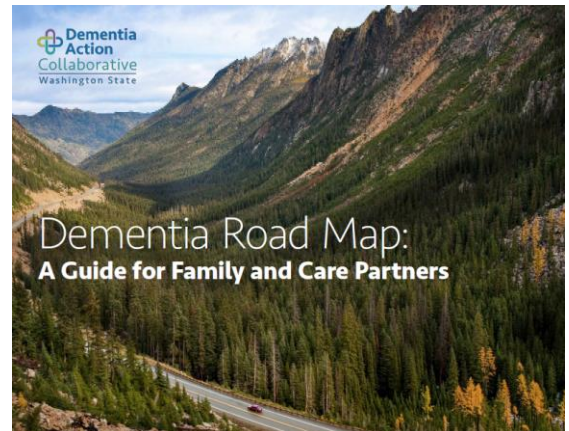
Project Team: Lori Brown, Maureen Linehan, Kim Boon, Susan Engels, Karen Heeney, Lynne Korte, Joanne Maher, Jon Rudicil

Goal 4: Ensure access to comprehensive supports for family caregivers

☑ **Recommendation 4.A.1:** Create a Washington State-specific “roadmap” for family caregivers providing information about what to expect over time to help plan for the future.

Year End Accomplishments 2018/2019:

- Disseminated the [Dementia Road Map: A Guide for Family and Care Partners](#) widely through DAC network for placement on websites.
- Used Older Americans Act funds and Alzheimer’s Association support to print.
- Have disseminated 70,000 booklets to organizations and caregivers across Washington State.
- AL TSA provided funding to the Alzheimer’s Association for translation into Spanish.
- Developed new system for managing distribution through the Department of Enterprise Systems. See box below for ordering instructions.
- Completed translation and printing of Spanish language translation – available in print through inquirywa@alz.org.
- Granted permission for other states, including Oregon, to adapt document for their use.



Status: Completed

Timeline:

- January: Inform prior users of new dissemination system. Outreach regarding new Spanish version.
- February: Review costs and experience of Spanish language translation, and consider other possible translations.
- June: Review content of Dementia Road Map, updating links as needed prior to next printing.

Greatest Challenge: Sustainability of Dementia Roadmap in printed and online versions, cost of translations/printing.

Project Team: Lead: Todd Larson; Members: Cindy Balbuena, Kim Boon, Erik Erickson, Lynne Korte, Jerry Reilly, Carrie McBride, Lauri St. Ours, Rep. Steve Tharinger

You can find this publication and more online:
www.dshs.wa.gov/altsa/dementia-action-collaborative

ORDERING INSTRUCTIONS:

For individuals requesting 1–5 copies, email:
Dementiaroadmap@dshs.wa.gov

For more than five copies, follow the instructions below:

1. Go to <http://myprint.wa.gov>
2. If it is your first time ordering, you will need to register
 - Click on the **Login** link in the upper right corner of webpage
 - In the pop-up box, click **Register**
3. Once you have registered and/or logged in, put the title (Dementia Road Map) in the search box and click **Enter**
4. Choose item that fits your type of organization
5. Enter quantity and click **Begin**
6. Choose **Due Date** (ship date) in upper left corner of checkout page
7. Click **Proceed to Checkout** and follow onsite instructions

To request this publication in Spanish, email:
inquirywa@alz.org

□ **Recommendations 4.A.2:** Provide dementia-specific information and assistance for family caregivers of people living with dementia.

□ **Connects with Recommendation 6.A.4:** Provide dementia-capable information and assistance for people living with dementia to help them remain in the community.

Year End Accomplishments 2019:

- Completed 3-year federal Administration for Community Living Grant on Dementia Capable Systems, in partnership with five Area Agencies on Aging (AAAs), the Alzheimer's Association and the Department of Health and submitted final report.
- This grant developed and piloted Dementia Capable Approaches in Person Centered Support and Counseling training which focuses on providing dementia knowledge and skills for Information & Assistance and Family Caregiver Program staff in Area Agencies on Aging (AAAs).
- At grant's end, this training was made available on an online/ongoing basis, within the Relias Learning Management System for all AAAs that would like to use it to improve dementia-capability.

Status: Ongoing

Challenges:

- While AAAs provide general information, assistance and support, we know that people with dementia need more and different services. AAAs do not have adequate resources to provide the specialty supports and services to address the complex and heightened needs created by dementia, which might include support for individuals with dementia living alone, with safety/behavioral needs or transitioning between care settings.

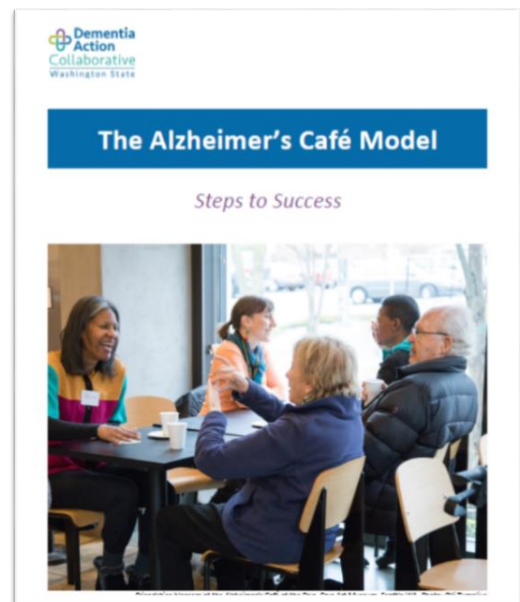
Project team: Lynne Korte and five AAAs – Aging & Adult Care of Central Washington, Aging & Long Term Care of Eastern Washington, Area Agency on Aging and Disabilities of Southwest Washington Aging & Disability Services/King County, Southeast Washington Aging and Long Term Care

□ **Recommendations 4.C.2:** Expand and promote implementation of early stage memory loss groups for people with cognitive impairment/dementia and their care partners.

□ **Connects with Recommendation 4.E.1:** Develop information about models of social engagement such as Alzheimer's Cafes, Zoo Walks, Museum/Arts ("here:now") programs, etc.

Year End Accomplishments 2018:

- Piloted an evidence-informed early stage memory loss (ESML) model developed by the University of Washington (UW) called Staying Connected in five Area Agencies on Aging, with federal grant funding. Developed contract with Alzheimer's Association to continue offering leader training for this program.
- Identified programs that might be expanded through collaboration and within existing resources, e.g., Alzheimer's Cafes, Walking Programs, and developed plan for promoting these models through networking opportunities.
- Developed guidance documents for "Starting an Alzheimer's Café" and "Dementia Friendly Walking Groups". <https://www.dshs.wa.gov/altsa/dementia-action-collaborative>
- Offered four dementia-friendly program webinars with follow-up networking opportunities, in partnership with DAC early stage programs team which attracted nearly 400 registrants from across the state.
- Monitored uptake of Alzheimer's/Memory Cafes in Washington. Since time of our work mentioned above, the number of Café's listed at increased from 15 to 35.



Status: In process

Next Steps:

- Monitor uptake of early stage and social engagement programs and promote interest during meetings, conferences, etc.
- Work with LTSS joint team to develop new guidance materials to develop music-related engagement programs.

Challenge: Beyond Puget Sound, there is a lack of capacity in partners and funding to increase community awareness and in communities to begin or sustain early stage support and/or social engagement programs. May require additional funding to support more development.

Project Team: Lynne Korte, Marigrace Becker, Cayce Cheairs, Jan Higman, Cathy Knight, Bob Le Roy, Kenna Little, Christina Marneris, Cheryl Townsend-Winter

□ **Recommendation 4.F.1:** Identify and engage leaders and organizations of diverse populations to explore needs for education and support.

☑ **Recommendation 4.G.1:** Engage tribal representatives to explore the needs of tribal families caring for people with dementia to develop culturally relevant supports and services.

Year End Accomplishments 2018/2019:

- Created and distributed “Dear Tribal” letter, identified tribal points-of-contact and developed set of outreach questions in 2016. Initiated outreach, beginning with Native Americans, with a plan to next focus on African American and Hispanic.
- Attained feedback from tribal representatives in the Title VI program, and through conversations and written input to surveys at tribal events. This revealed a need for education around dementia.
- ALISA hosted Savvy Caregiver in Indian Country training – a native specific training on dementia – four times between 2017-2019: 14 Washington tribes have representatives who have completed the training. See box below.
- DAC partners provided speakers on dementia at the Money Follows the Person Tribal Summits in 2017 and 2019.
- Engaged full DAC in September 2018 to discuss how to address diverse communities and health disparities within entirety of AD Plan implementation.
- Developed dedicated DAC workgroup to integrate work on disparities within DAC initiatives.
- Included speaker on dementia/disparities in African American communities at April DAC meeting, and speaker on dementia/disparities in LGBTQ community at September DAC meeting.

Status: Ongoing

Next Steps:

- Diversity/Disparities in Dementia workgroup to meet at least quarterly.
- April: Finalize a “disparities in dementia” fact sheet.

Challenge: Doing outreach and relationship building takes significant planning, linking and in-person relationship building. This will be an ongoing process and need to involve all subcommittees.

Project Team: Basia Belza, Marietta Bobba, Kim Boon, Marci Getz, Lynne Korte, Maureen Linehan, Carolyn Parsey, Ka’imi Sinclair, Jamie Teuteberg

Earlier Team: Bob LeRoy, Aziz Aladin, Emma Medicine White Crow, Marietta Bobba, Yolanda Lovato, Karen Winston, Shelly Zylstra

Savvy Caregiver in Indian Country

Savvy Caregiver is an evidence-based program for those caring for a family member with Alzheimer’s or other dementia. It is a psychoeducational, 12-hour training with manual and videos. The program is broken into separate sections that focus on knowledge of Alzheimer’s and dementia, caregiver skills, and how to better manage stress related to caregiving (Hepburn, et al. 2007).

The National Indian Council on Aging (NICOA) adapted the original program for use in Indian Country under the name Savvy Caregiver in Indian Country.

□ **Recommendation 4.H.3:** Educate professionals working with families of people with younger-onset Alzheimer's, including those in the developmental disabilities system, about the special challenges, issues and resources available for support.

Year End Accomplishments 2018/2019:

- The Developmental Disabilities Council partnered with Developmental Disabilities Administration (DDA), the Alzheimer's Association, ALTSA and others to sponsor a forum at the SeaTac Conference Center on Intellectual/Developmental Disabilities and Dementia featuring national experts Drs. Seth Keller and Matt Janicki.
- Part-time DAC staff, Kim Boon (shared between DDA and ALTSA) was hired and began to provide support for this and related recommendations.
- Investigated what is available as trainings for families related to developmental disabilities and dementia.
- Gathered input around training needs of families from stakeholders, including: Developmental Disabilities Council, Informing Families Advisory group, DDA training unit, Community Residential Services Association and SEIU.
- Developed survey to gather information more directly from families in the parent-to-parent coalition.

Status: In progress

Next Steps:

- January - June: Develop training curriculum for professionals working with families of younger onset Alzheimer's in the developmental disabilities system.
- March – June: Determine the who and how of training implementation.
- July – December: Begin to implement training.

Project Team: Aziz Aladin, Sarah Blanchette, Kim Boon, Karen Cordero, Kenna Little, Advisors: Linda Gil, Shannon Manion

Goal 5: Identify dementia early and provide dementia-capable evidence-based health care

- ☑ **Recommendation 5.A.1:** 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.
- ☑ **Recommendation 5.E.3:** Request and encourage the Dr. Robert Bree Collaborative to address cognitive impairment and dementia care.

Year End Accomplishments 2017:

- Engaged the Dr. Robert Bree Collaborative in 2016 as the optimal venue through which to convene an expert panel to identify/endorse guidelines.
- DAC members identified potential content experts for the Bree dementia workgroup which convened between January and October, populated by several members of the DAC as well as other local, state and national experts in dementia care.
- The [Bree Alzheimer's Disease and Other Dementias Report and Recommendations](#) was finalized and submitted to the Health Care Authority in November 2017.
- Also developed a Clinical Provider Practice Tool that echoes and refers back to the Bree Report, available at: <https://www.dshs.wa.gov/altsa/dementia-action-collaborative>



Status: Completed

Project Team: Lead: Kris Rhoads Members: Amanda Avalos, Nancy Isenberg, Lynne Korte, Bruce Smith

- ☐ **Recommendation 5.B.1:** Encourage regular screening of cognitive status for older adults in primary care settings, considering cognitive status as a 'vital sign', similar to tracking blood pressure in heart disease.

Year End Accomplishments:

- Twenty-four (24) provider and community presentations related to dissemination and provider/system education around screening, case detection and other recommendations outlined in Bree document.
- Integration of screening into a 3-hour dementia in primary care CME conducted by Barak Gaster, MD at the UW with expansion of training to UW Neighborhood Clinics as well as medical education for students, residents and fellows.
- Plan to include screening as a foundational module in the Project ECHO Dementia curriculum.

Status: Ongoing

Next Steps:

- January & Ongoing: Dissemination and implementation.

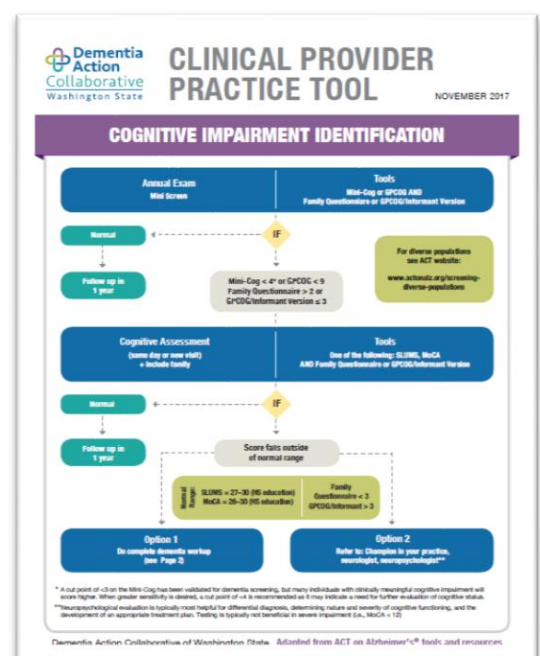
Challenges: Increasing impact and reaching a broader audience. Identification of organizational champions in health care to move implementation work forward.

Project Team: Kris Rhoads, Nancy Isenberg, Lynne Korte, Carolyn Parsey, Tatiana Sadak, Jamie Teuteberg

☑ **Recommendation 5.B.2:** Identify/recommend several validated, brief cognitive screening tools.

Year End Accomplishments 2017:

- Completed a literature review on available screening measures, review of practice parameters and recommendations, best practice models and some preliminary examination of current practice parameters in 2016.
- Completed a position paper entitled [Brief Cognitive Screening Tools for Primary Care Practice](#) outlining recommended tools, clinical pathways and opportunities for screening.
- Developed a graphic/flow chart that outlines clinical pathways and tools for screening, diagnosis and support to individuals and families throughout the process. This Clinical Provider Practice Tool, available at: <https://www.dshs.wa.gov/altsa/dementia-action-collaborative>



Status: Completed

Challenges: Dissemination and implementation in medical systems as well as more rural practices will take additional resources.

Project Team: Team lead: Kris Rhoads Members: Nancy Isenberg, Lynne Korte

□ Recommendation 5.B.3: Promote timely assessment and disclosure of cognitive impairment and/or diagnosis of dementia through the identification of a diagnostic pathway for use in primary care settings.

Year End Accomplishments:

- Twenty-four (24) provider presentations disseminating the Bree recommendations, screening paper, and Clinical Provider Practice Tool.
- Secured funding to develop and implement Project ECHO Dementia. See 5.C.6 below.

Status: Ongoing

Next Steps:

- January & Ongoing: Dissemination and implementation.

Challenges: Identification of organizational champions in health care to move implementation work, increasing reach and impact.

Project Team: Kris Rhoads, Lynne Korte, Nancy Isenberg, Tatiana Sadak, Bruce Smith

□ Recommendation 5.C.6: Promote use of tele-health by aligning with efforts of the statewide tele-health workgroup convened by DOH. Utilize such technology to provide care directly for individuals with dementia and/or to support a consultative role with providers and care teams such as the Impact model or the Echo model.

Year End Accomplishments:

- Achieved funding per budget proviso for the University of Washington Memory and Brain Wellness Center, in the amount of \$497,000 per biennium. Proviso funding is to be used to create a telemedicine program to disseminate dementia care best practices to primary care.
- Program manager position created with an offer extended in December.
- Co-directors Drs. Kris Rhoads and Nancy Isenberg attended 3-day ECHO Immersion Training at the University of New Mexico.
- Identified IT staff, ECHO mentor, and expert clinical panel members.
- Began ongoing recruitment of spoke provider sites, including leadership and provider champions, in Port Angeles (North Sound Health Care), Yakima (Memorial Hospital), Spokane (Providence and Multicare), Columbia County (Dayton Medical Center), Tri-Cities (Kadlec), and Bellingham (PeaceHealth).
- Secured a dedicated location for the Zoom Room/technological hub, with ongoing collaboration with the UW regarding IT/tech needs and building renovations.

Next Steps:

- January & Ongoing: Spoke site recruitment, with a goal of 12 sites identified for launch.
- February: finalize curriculum and complete CME application
- March: Immersion training for program manager and expert panel
- May: completion of building renovations and move in, ECHO launch

Challenges: Potential spoke site providers are already overburdened and short on time and have been hesitant to add on another commitment. Similarly, leadership within these systems, while supportive and appreciative of the value of the work, are also increasingly limited in terms of what they can carve out of remunerative clinical time for their providers.

Project Team: Kris Rhoads, Nancy Isenberg, Jamie Teuteberg

□ Recommendation 5.E.1: Promote understanding and effective utilization of (a) Medicare Annual Wellness Visit (MAWV) which includes objective cognitive assessment/screening; and (b) Complex care management (CCM) codes for care coordination services, and advance care planning codes for individuals at end of life.

Year End Accomplishments:

- Twenty-four (24) provider and community presentations related to dissemination and provider/system education around implementing the visit, opportunity for screening and case detection, billing codes and other recommendations outlined in Bree document.
- Ongoing work at multiple health care systems to increase uptake and implementation of the MAWV and referral pathways, including at the UW Medical Center, Harborview, Virginia Mason Medical Center, and Kaiser Permanente.
- Refined data and improved understanding around current practices regarding billing codes and documentation needs.
- Expanded and refined data around utilization rates across the state as well as different organizations.

Status: Ongoing

Next Steps:

- January – March: Continue to refine objective numbers around utilization rates
- January - December: Provider and systems education events
- May – July: creation of a provider educational video

Project Team: Lead: Jamie Teuteberg Team: Andrea Sawczuk, Leslie Emerick, Charissa Fotinos, Tatiana Sadak, Lynne Korte

□ Recommendation 5.E.2: Advocate for the development of, and promote use of, billing codes and reimbursement for care that improves the health and lives of older adults.

Year End Accomplishments 2018:

- Dissemination of finalized billing code information in the Bree recommendations.
- Identification of best practices and information graphics from Alzheimer's Association and related organizations.

Status: Ongoing

Next Steps:

- January & Ongoing: Data collection around current utilization practice, practice change

Challenges: Getting data from state level and individual organizations around current billing practices.

Project Team: Jamie Teuteberg, Kris Rhoads, Nancy Isenberg

Goal 6: Ensure dementia-capable long-term services and support are available in the setting of choice

☑ Recommendation 6.A.1: DDA, AL TSA, HCA, and DOH should each designate an Alzheimer's program coordinator to improve communication and collaboration among these agencies.

Year End Accomplishments 2018:

- DAC advocates requested and received funding through budget proviso for part-time staff at each of the above agencies.
- The above agencies subsequently hired staff who will work with one another, the DAC program manager and the DAC Chair and Subcommittee Chairs to:
 - 1) Integrate goals and objectives related to dementia into agency strategic plans.
 - 2) Identify recommendations in their respective areas which could be implemented through heightened collaboration and existing resources.
 - 3) Identify high-value recommendations and related funding requirements for upcoming biennial budgets.
 - 4) Coordinate the work of implementing the selected recommendations.

Status: Completed

Project Team: Alzheimer's Association, AARP, W4A, Senior Lobby

☑ Recommendation 6.A.2: Identify and promote existing models of care coordination services for individuals living in the community and their family caregivers, such as Health Homes, geriatric care managers, and Alzheimer’s Association Care Navigators.

Year End Accomplishments 2017:

- Developed consensus on what is meant by care coordination, and completed an inventory detailing existing care coordination resources.
- Compiled document summarizing care coordination models to be referenced moving forward.

Status: Completed.

Ongoing Work:

- Promote care coordination models within existing resources as possible.

Project Team: Lead: Leigh Beth Merrick; Members: Susan Engels, John Ficker, Julie Gray, Maureen Linehan, Mary Lynn Pannen, Mimi Pattison

☐ Recommendation 6.A.4: Provide dementia-capable information and assistance for people living with dementia to help them remain in the community. See 4.A.2.

☐ Recommendation 6.B.2: Evaluate the potential for specialized dementia care services in adult family homes to determine cost-effectiveness, standards, training, services, rates, and oversight needs.

Year End Accomplishments:

- The Adult Family Home Council worked to pass SSB 5672 aimed at improving services for specific population living in adult family homes, including for people with dementia.
- ALTSA hosted input sessions to gather input from AFH providers, consumers and other stakeholders on the enhancements or additional services needed for AFHs that are dedicated to the care of people with dementia.

Status: In progress

Next Steps:

- ALTSA will develop recommendations for new or enhanced services for individuals living in adult family homes dedicated solely to the care of individuals with dementia.

Project Team: John Ficker (AFH Council), Alec Graham, Barb Hanneman, Natalie Lehl (ALTSA staff)

☑ Recommendation 6.C.1: Enhance Dementia Specialty Training available to LTSS workers for all settings.

Year End Accomplishments 2017:

- After working with stakeholders to garner input, ALTSA finalized an enhanced Dementia Specialty Training in 2016.
- Rolled out new training to residential long-term care settings.

Status: Completed

Project Team: Lorrie Mahar, Angela Regensburg (ALTSA staff)

☑ Recommendation 6.D.1: Support a study commissioned by the State on public/private long-term care financing models and subsequent efforts to improve the financing for public LTSS.

Year End Accomplishments:

- SSB 6052 was passed in the 2015 legislative session directing DSHS-ALTSA to contract for a feasibility study of policy options to finance long-term services and supports.
- Study findings were included in a report to the legislature in 2017.
- The Long-Term Care Trust Act failed in 2018 but passed in 2019, making Washington the first state to launch a long-term care insurance benefit for all eligible Washington employees.

Next Steps:

- Early planning is underway and will include coordination of multiple agencies, including DSHS-ALTSA and HCA.
- Working Washingtonians will begin paying premiums in 2022.
- Benefits begin for qualified beneficiaries in 2025.

Project Team: Bea Rector (ALTSA) and partner agency staff.

☑ Recommendation 6.D.2: Identify tools and strategies to more effectively coordinate current systems and seek federal funding opportunities to help meet the costs of financing care, such as the Medicaid Transformation Waiver.

Year End Accomplishments 2017:

- Health Care Authority (HCA), Aging and Long Term Support Administration (ALTSA) and Area Agencies on Aging (AAAs) worked together, and with Centers for Medicare and Medicaid (CMS), to plan processes and procedures that support implementation of a new Medicaid Transformation Demonstration, a federally funded project that assists older adults, including those living with dementia, by financing long term supports and services that help them to live at home.

- Launched 2 new programs – Medicaid Alternative Care and Tailored Supports for Older Adults which offer a wide range of services and supports such as housekeeping and errands, specialized medical equipment, training opportunities, adult day services, support groups and counseling as a new alternative to traditional services for Medicaid recipients over 55 and to a new eligibility group of those older adults at risk of spending down to Medicaid.
- Employed an outreach campaign to raise awareness among families about these new programs.

Status: In process (5-year demonstration)

Ongoing Work:

- Promote awareness about these new programs for long-term supports and services.
- Evaluate outcomes of this demonstration to document return on investment.

Project Team: Bea Rector, Susan Engels, Kim Boon, Adrienne Cotton, AAA directors and staff

□ Recommendation 6.E.3: Convene a workgroup to define and promote dementia care quality standards and outcome measures for Washington long term care settings, to include standards for settings advertising themselves as “memory care” and/or “specialized dementia care”.

Year End Accomplishments:

- Convened a workgroup with consistent broad representation including provider associations, State Ombuds, Alzheimer’s Association, family caregivers, DSHS Residential Care Services and Home and Community Services, geriatric care managers and medical professional.
- Investigated complex subject with three meetings to date spent understanding current rules and regulations, and the work of other legislatively mandated workgroups concerning adult family homes and assisted living.
- Investigated other state’s initiatives focusing on “memory care/specialized dementia care”.
- Have requested data from the AGs office, Ombuds and RCS about dementia-related complaints.

Status: In progress

Next Steps:

- January – March: Complete gathering of background information and chart a course forward.
- January – March: Consider if a survey of consumers/family member who are using or seeking services may be needed to better clarify concerns and issues.
- April – June: Further define the issue so as to better craft a solution/recommendation.

Project Team: Leads: Maureen Linehan/Alyssa Schnitzius Members: Kim Boon, Jeanette Childress, Erica Farrell, John Ficker, Candace Goehring, Kim Henderson, Patricia Hunter, Lynne Korte, Joel Loiacono, Cathy McAvoy, Mary Lynn Pannen, Lauri St. Ours, Libby Wagner

Goal 7: Promote innovation and research related to causes of and effective interventions for dementia

□ Recommendation 7.B.1: Identify organizations/institutions in WA involved in providing dementia related psychosocial and medical services, and connect them with AD research to promote research awareness and strategic alliances.

Year End Accomplishment:

- Continued compilation of state/local/regional research efforts.
- Creation and launch of a virtual quarterly Alzheimer's Research Network meeting with attendees from around the state.

Status: In progress

Next Steps:

- January - March: Ongoing Alzheimer's Research Network virtual meetings.
- September: planning for a statewide research symposium to be held in late 2020 (Rec 7C3).

Ongoing Work:

- Follow through with current agency contacts, and determine best method for keeping this list up-to-date.
- Connecting healthcare providers with research opportunity information.

Greatest Challenge: Identifying research organizations outside University of Washington system or those indicated on the Alzheimer's Association Trial Match platform.

Project Team: Suman Jayadev, Carolyn Parsey, Jamie Teuteburg

□ Recommendation 7.C.1: Educate the public, including people with cognitive impairment, on the availability, purpose, and value of research and encourage participation in a broad spectrum of dementia research (i.e., research on finding a cure, prevention, improving the quality of life for individuals and caregivers).

Year End Accomplishment:

- Ongoing partnership with UW Alzheimer's Disease Research Center, VA, Alzheimer's Association and WSU colleagues to complete over 30 community talks, social media and presentations around Alzheimer's research.

Status: In progress

2020 Timeline:

- January - March: Determine next action steps around archiving a publically available repository of video and slide presentations.
- January - September: Enhance partnerships with Institute for Translational Health Sciences to support dissemination and assessment of impact, particularly within underserved populations.

- February - planning for a statewide research symposium to be held in late 2020.

Ongoing Work:

- Increase connectivity with community stakeholders and representative organizations from underserved populations.
- Improve connections with media, social media and other visible outlets.
- Improve ability to reach the public through other medical providers and systems.

Greatest Challenge: Increasing impact beyond the audience present. Measuring impact of community education events and presentations in terms of interest and willingness to participate in research.

Project Team: Andrea Sawczuk, Suman Jayadev, Carolyn Parsey, Jamie Teuteberg, Kris Rhoads

For more information on DAC activities and products:

Go to the DAC webpage: <https://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan>

With Appreciation

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