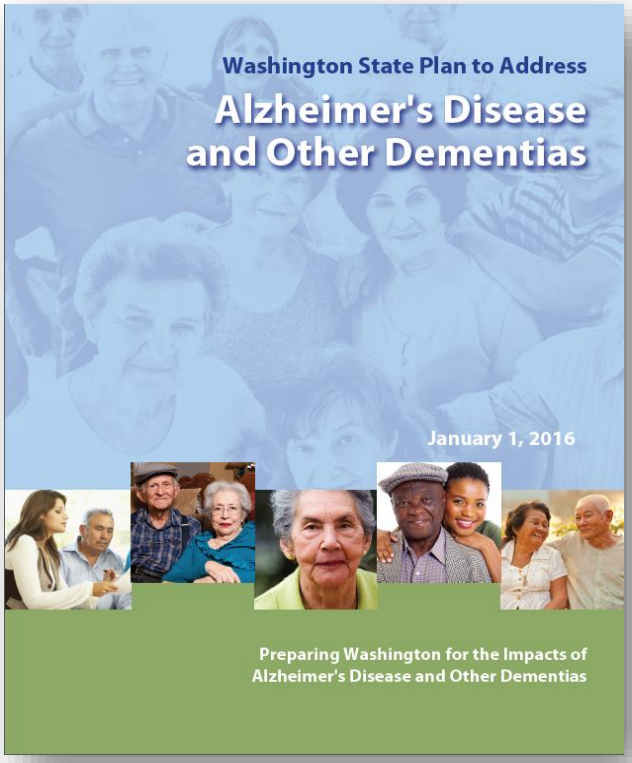
Dementia Action Collaborative

Progress Update: April 2016 to December 2021



Dementia Action Collaborative
Washington State

Bill Moss, Chair

Assistant Secretary, Aging and Long Term Support Administration

Washington State Department of Social and Health Services

Introduction

In 2014, legislation (SSB 6124) created an Alzheimer's Disease Working Group (ADWG) to develop Washington's first state plan to address Alzheimer's disease. The ADWG published the Washington State Plan to Address Alzheimer's Disease and Other Dementias in January 2016. The plan identifies goals, strategies and recommendations as a starting point to prepare for the future. The plan's implementation – including action planning, next steps, and policy changes – depends upon a broad and committed group of public and private partners.

What is the Dementia Action Collaborative?

While the legislation expired when the plan was submitted in 2016, members of the ADWG called for the formation of a next generation workgroup to implement the plan. The original group members were committed to moving the work forward and established the Dementia Action Collaborative (DAC).

The DAC includes a range of people, some who were appointed members of the ADWG and other participants who share their time on an in-kind basis to address identified priorities – and has included people with dementia and family caregivers along with representatives of advocacy groups, the aging network, Alzheimer's organizations, long-term care providers, health care professionals, legislators and governmental agencies.

As it was during the plan development phase, the DAC is guided by a Steering Team, with the ALTSA Assistant Secretary acting as Chair. The DAC collaboratively prioritizes and accomplishes it's work through four subcommittees: Public Awareness/Community Readiness, Health and Medical, Long Term Supports and Services, and Advocacy. In the last two years, even throughout the pandemic, this dedicated group contributed between 1,800 and 1,900 hours of volunteer or in-kind service each year to accomplish recommendations in the plan.

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 above. See the State Plan for more detail.

What's been accomplished?

The DAC focused first on actions that could be accomplished through heightened collaboration and existing resources, and over the last several years has put forth several moderate requests to the state legislature to fund high value priorities. This report shares activities and accomplishments from 2016 through 2021.

With gratitude and respect for our committed participants and partners, including:

We are grateful for the support we have received from the Joint Legislative and Executive Committee on Aging and Disability Issues (JLEC), and for staff support from:

NOTE: Throughout this document a recommendation with an open box (☐) has been initiated and is "in process" – some of these involve "ongoing" work (see Status section of each recommendation); 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.**

Accomplishments 2018/2019/2020/2021:

- A DAC project team elected to enhance a statewide website, Community Living Connections (CLC), which has 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 (Memorylossinfowa.org) was established, along with a Communication Plan to disseminate its availability. The new URL was in included in a reprint of the Dementia Road Map, is shared in DAC community presentations, and in 2020 a Rack Card was developed and disseminated to promote awareness of the site.
- Through 2021, nearly 6,000 Rack Cards promoting the site were distributed to community-based organizations across the state.
- In 2021, as part of the website sustainability plan, the team processed content updates and enhancements.

Memorylossinfowa.org

Status: 1.A.1 Completed; 1.E.3 Completed but promotion is ongoing.

Next Steps:

- Review web page analytics to inform future dissemination plans.
- Consider adding two new pages for the website, 'Social Engagement' and 'For Professionals'

- Continue distribution of the website promotional materials
- Consider new places to reach out with the Rack Cards
- Using the Communications Plan, determine next steps for outreach and dissemination of information about the site.

Challenges: Sustaining the site, with updates and enhancements, requires staff time at ALTSA that is not fully supported.

Project Team: Kim Boon, Carrie McBride, Marci Getz, Meredith Grigg, Debbie Hunter, Lynne Korte, Jamie Teuteberg, Ron Vivion, Cheryl Townsend Winter

☑ **Recommendation 1.A.2:** Strengthen capacity of the Washington State Information & Assistance (I & A) system by educating staff about recognizing possible dementia, making appropriate referrals by building links between relevant organizations. See also 1.E.4.

Accomplishments 2018/2021:

- ALTSA leveraged a Dementia-Capable Systems federal grant from the Administration for Community Living (ACL) to increase the dementia-capability of Washington's Aging and Disability Resource Centers (I & A, FCSP) in five Area Agencies on Aging (AAAs). Dementia capability includes:
    - Inclusion of data elements that document memory loss/dementia status, as well as service needs and referrals, in statewide data systems GetCare and TCARE®.
    - Training staff to be more dementia-capable. In this grant, more than 180 staff across five AAA public service areas received the Dementia Capable Systems Training resulting in 57% of Washington's 60+ population having access to dementia-capable staff offering Information & Assistance, Options/Person Centered Counseling and Family Caregiver Support. The training material was transitioned into an online format for optional use.
    - This grant utilized a planning/advisory team made up of the participating AAAs, and representatives of the Alzheimer's Association and the University of Washington School of Nursing. This team helped to foster relationships and improve information flow between the Alzheimer's Association and AAAs to promote cross-referrals. The Alzheimer's Association both informed and participated in some of the live trainings.
    - Access to dementia-capable home and community-based services. At grant's end in 2018, while awareness was increased in five service areas and an early-stage health promotion program called Staying Connected had been provided, the effort to expand dementia-capability efforts remain limited by the lack of sufficient staff resources at AAAs to provide ongoing dementia-capability training and funding to expand dementia-capable services.
- In 2021, DAC advocacy resulted in state funding for ALTSA to create two AAA pilot sites, each of which allow for Dementia Resource Catalyst staff to optimize and develop resources along with funding to increase the capacity to serve the dementia population in their areas i.e., to fund new or expand dementia-capable services. A subsequent request for proposal process resulted in the selection of Aging and Long Term Care of Eastern Washington (ALTCEW) and the Northwest Regional Council (NWRC) to implement this "Building Dementia Capable Communities" program. Project funding allotted for July 1, 2021 through June 30, 2023.

Status: Ongoing

Project Team: Kim Boon, Lynne Korte, Aime Fink and staff of participating AAAs

☑ 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**

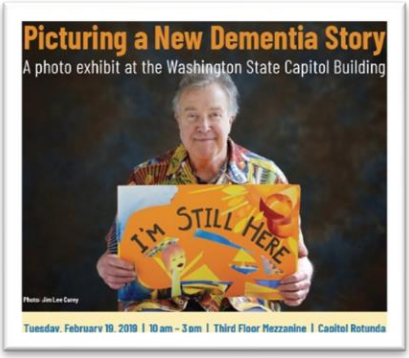
Accomplishments 2019:

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: Marigrace Becker, Alisa Tirado Strayer, Hilarie Hauptman, Lynne Korte, Cathy MacCaul, Marty Richards

MORE ON THESE PROJECTS TO PORTRAY MORE POSITIVE IMAGES AND MESSAGES:



"**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…"*

"Let's Talk Dementia" Mini-Videos
People with dementia and their family care partners discuss living with dementia and the value of early diagnosis. We know of more than 1,800 views through ALTSA, more from other partners.

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

Busting Dementia Stigma – One Children's Book at a Time

Action Collaborative Washington State

Identity and Personhood

"I'M STILL HERE." "I'M A PERSON FIRST."

Respect and Kindness

"UNDERSTAND WE'RE NO DIFFERENT FROM ANYBODY ELSE."

Person in Relationship

"WE STILL HAVE THE CAPACITY TO CHERISH AND LOVE OUR FAMILIES."

Valued Contributor

"I HAVE A LOT TO GIVE."

Life Beyond Diagnosis

"IT'S HARD, BUT WE'LL GET THROUGH IT."
"I HAVE FUN, FRIENDS, AND FAMILY, AND THAT GIVES ME JOY."

☐ **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 1.E.2, Rec 2.C.2 and 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.**

Accomplishments 2019/2020:

- Achieved funding per budget proviso for the Department of Health (DOH), in the amount of $150,000 per year. Proviso funding is intended 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.
- In 2020, The Department of Health conducted foundational work, investigating what is known around the experience of digital public awareness campaigns on dementia and other chronic illnesses, then developed and piloted a digital awareness campaign on the value of early diagnosis.
- The brief pilot Facebook campaign "Learn about memory loss" was run in King, Pierce, Chelan, and Yakima counties, where we have primary care providers participating in Project ECHO, and reached more than 50,000 people (an average of three times). Analytics showed positive engagement of the target audience with the campaign. Lessons learned from the pilot informed the expanded the campaign in 2021.
- Developed promotional tools to help community organizations spread the word about the value of early diagnosis, including a Rack Card for use in mailings or kiosks, on the topic: "Worried about memory loss?"

Learn about memory loss campaign

There are a number of reasons for memory loss - some may be reversible. The right information at the right time helps you live your best life. The ad led readers to the Alzheimer's Association website article called "Why Get Checked?"

Accomplishments 2021:

While it is important to educate the public at large regarding the value and importance of early detection, diagnosis and planning, the DAC Proviso Campaign Workgroup decided to begin the next phase of our campaign work focusing on the African American community in King and Pierce Counties. This decision was made due to the health disparities that exist in the prevalence of Alzheimer's Disease and Related Dementias (ADRD). African Americans are about two times more likely to have Alzheimer's disease than the non-Hispanic white population. Older African Americans are less likely to receive a specialized diagnostic evaluation and are diagnosed later in the course of the illness.

To ensure the most effective and culturally appropriate campaign messages and strategies were created, DOH contracted with two media consulting groups, Cascadia Consulting Group (CCG) and Desautel Hege (DH).

- CCG conducted 13 insight interviews with community leaders and subject matter experts, as well as two focus groups, in which a total of 18 Washington State residents participated, ranging in ages 39 to 80 years old.
- DH created the following web landing pages:
  - doh.wa.gov/memory
  - doh.wa.gov/memorypartnerresources
- The landing pages include resources for individuals experiencing memory loss and those that support and love them and the other provides resources for organizations to share the important materials created from this campaign.

Status: In progress

Next Steps:

- Establish contracts with three Community and Faith-Based organizations that serve King and Pierce Counites. These organizations will serve as the "trusted messengers" and share the campaign materials for African American communities created in 2021.
- Beginning January 2022 work with CCG and DH to develop a campaign reaching out to the Latino communities in Washington to promote the value and importance of early detection, diagnosis and planning. Older Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older Whites.

Project Team: Marci Getz, Janna Bardi, Kim Boon, Tara Bostock, Debbie Hunter, Lynne Korte, Carrie McBride, Janelle Okorogu, Allyson Schrier, Ka'imi Sinclair, Jamie Teuteberg, Bob Wellington, Juanita Wellington, Cheryl Townsend Winter

☐ Recommendation 1.C.2: **Provide Alzheimer's awareness, education and resource materials to public/private workplaces regarding how to recognize and related to persons with early-stage dementia or their caregivers who are their customers or employees.**

Accomplishments 2020/2021:

- Health Care Authority (HCA) Wellness Program developed and presented a workshop entitled "Promoting Brain Health in the Workplace" for wellness coordinators from state agency offices. Created and/or presented by representatives from DOH, DSHS, HCA and the Alzheimer's Association, the session covered topics of brain health, its impacts on the workplace and what workplaces can do to support a "healthy brain" work environment through health promotion, risk reduction/prevention, and supporting employees who are also family caregivers.
- Sixty-nine wellness coordinators attended the 2020 session, with positive feedback on content and potential for use in their settings. They were offered resource materials to share with their

respective agencies/offices. The state Wellness Program has the potential to reach 300,000 state employees.

- In 2021, the DAC collaborated on an Alzheimer's Association effort to reach out to businesses. This included sharing information about Dementia Action Collaborative and its array of partners and resource materials such as the *Dementia Road Map: A Guide for Family and Care Partners* and the *Dementia Legal Planning Toolkit* with event attendees. The event included 20 companies, among them Nordstrom, Salesforce, Expeditors and more.

Status: Ongoing

Project Team: Kim Concepcion, Maggie Christofferson, Marci Getz, Lynne Korte, Jamie Teuteberg, Pam Walker, Karen Wilson, Cory Townsend, Kim Boon

☐ **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.**

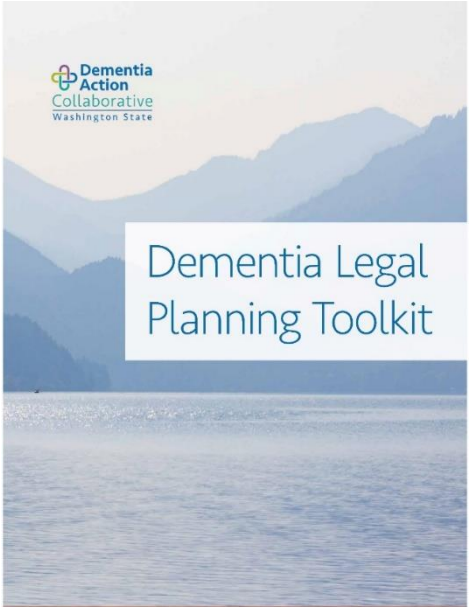
☐ **Connects with Recommendation 1.D.2: Educate the public and caregivers about the need for legal and financial planning – and the importance of obtaining legal and financial advice as a planning tool.**

☑ **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.**

Accomplishments 2018/2019/2020/2021:

- Included messaging about legal and advance care planning within content of Dementia Road Map, Dementia Capable Approaches training and Community Health Worker trainings.
- Achieved funding per budget proviso for ALTSA, in the amount of $116,000 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.
- Completed brief videos to engage consumers with the "Living with Dementia Mental Health Advance Directive."
- ALTSA finalized a contract with Northwest Justice Project (NJP) to implement budget proviso. An attorney was hired by NJP as of the end of January 2020 to be in place through June 2021.
- Completed a Dementia Legal Planning Toolkit to inform consumers about the importance of financial, legal and advance care planning at the earliest opportunity in the course of dementia.

- The NJP attorney developed content for webinars about the Dementia Legal Planning Toolkit and invited DAC members to co-present at the webinars. Four webinars occurred, with more than 300 registrants, in the fall of 2020, each with a slightly different practice areas. Two of the webinars were eligible for continuing legal education credit to encourage lawyers to learn more about dementia planning and hopefully agree to volunteer time helping people with dementia plan ahead.



- The NJP attorney and project team worked collaboratively with clinicians to incorporate updates to the Dementia Legal Planning Toolkit. An updated version was posted in October 2021. The online and downloadable PDF version of the Dementia Legal Planning Toolkit is available on the Washington Law Help website (www.washingtonlawhelp.org) and the Community Living Connections website (www.memorylossinfowa.org).
- NJP continues to distribute the Toolkit in hard copy format, including information and forms. The hard copies are sent with a letter acknowledging updates. They are available for order through a Google form - https://forms.gle/cUPXKeStQ5obr6kx6
- The NJP attorney met with the Northwest Justice Project's Pro Bono coordinator and the Washington State Pro Bono Council manager to plan strategies for recruiting pro bono attorneys to advise and assist persons with Dementia and their care partners.
- In May 2021, amidst the ongoing pandemic, NJP sponsored a virtual legal clinic in which 28 volunteer lawyers prepared power of attorney and health care directive documents for 45 clients around Washington state. The clinic was advertised widely in the community for people over 60 years old and people of any age who are living with dementia. Both volunteers and clients expressed positive feedback and several more volunteers have signed up to offer pro bono services through local volunteer lawyer programs in their communities as a result of the clinic.
- In July 2021, funding for this project transitioned from NJP to the new contractor, the Washington State Pro Bono Council.

Status: Ongoing

Next steps:

- NJP will continue mailing printed Dementia Legal Planning Toolkits upon request.
- Washington Pro Bono Council (PBC) will develop activities and coordinate with DAC staff and Public Awareness & Community Readiness subcommittee to plan for goals/activities, and implement next steps.
- The PBC will host additional trainings for volunteer lawyers and recruit volunteer attorneys throughout the state who will offer pro bono services to help people with dementia with their legal planning.

Greatest Challenge: Recruiting a pool of volunteer attorneys may be challenging over time. Getting the word out to individuals who can use this service is always challenging.

Project Team: Lisa Ellen Brodoff, Katie Denmark, Debbie Hunter, Myriam Marquez, Marie Eaton, Meredith Grigg, Lori Ichimura, Hilarie Hauptman, Lynne Korte, Bruce Smith, Michael Terasaki

☐ **Recommendation 2.D.4:** Promote and build upon National Alzheimer's Plan education and awareness campaigns as available.

Accomplishments 2018/2019/2020/2021:

- Included information on the Alzheimer's Disease Education and Referral Center (www.nia.nih.gov/health) to the Dementia Road Map: A Guide for Family and Care Partners.
- DOH included information on the Healthy Brain Initiative and Alzheimers.gov to their new public health facing page for Alzheimer's Disease and Dementia.
- DAC team includes national campaigns in Alzheimer's and Brain Awareness month activities in June each year. A "SmartHealth" employee wellness activity included on the state employees' wellness portal reaches out to state employees to participate in wellness activities, including state and/or national campaign materials. For example:
    - In 2020, the dementia and brain health activity included visiting the National Institute of Health's Mind Your Risks website to learn about the connection between high blood pressure and developing dementia later in life, then taking the interactive quiz to learn what you can do to minimize your risk.
    - In 2021, the activity incorporated the National Institute on Aging's Forgetfulness: Normal or Not? Campaign.

Status: Ongoing

Next steps:

- Continue to identify national campaigns and ways to use them to increase awareness.

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

☐ **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.**

Accomplishments 2019/2020/2021:

- Elected to utilize the global awareness program, Dementia Friends, for this purpose as it is intended to raise awareness and combat stigma.
- ALTSA paid for a statewide license to be managed by the University of Washington Memory and Brain Wellness Center (UW).
- 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).
- Created a Research Brief in March 2020 summarizing the evaluation of the Dementia Friends program in Washington state.
- With assist of a new MSW student in 2020, expanded the Dementia Friends public awareness program, now in three regions (defined as counties or tribes). Established partnerships with, and trained, regional lead organizations in Pierce County (Lutheran Community Services Northwest) and Spokane County (Aging & Long-Term Care of Eastern Washington) and have begun recruitment of Dementia Friends Champions in King County with special focus on the LGBTQ community through UW Memory and Brain Wellness Center and MSW practicum student, Jo Bechtold. Lutheran Services Northwest launched a virtual version of Dementia Friends in early/mid 2020, making content available to other regional lead organizations.

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.

- Created an outreach plan for Okanogan County with hope to work with the Colville Tribes Area Agency on Aging when the challenges of Covid-19 are behind us.
- Continuing that year, Jo Bechtold (MSW student) conducted tailored outreach to LGBTQ communities in King County and the rural area of Okanogan County. 75 new Dementia Friends were reached in these communities through outreach and partnerships with staff and clients associated with Methow at Home, Lifelong, AgePRIDE Center, GenPride, Gay City, Full Life Care and more. Created tip sheets for dementia-related outreach in LGBTQ+ communities and rural areas, and brought together the Master Champions from Pierce, Clark and Spokane Counties for a sharing/learning session.
- In fall 2021, the Greenwood Senior Center accepted the role as the lead organization for Dementia Friends in King County, and trained their Master Champion Alisa Tirado Strayer, who will be focusing on Latino community outreach.
- We now have a total of 4 counties with active Dementia Friends programs (Pierce, Spokane, Clark and King), and over 800 people have attended a Dementia Friends session.
- A proposal to expand the Dementia Friends program, by providing additional staff for this work at UW MBWC, was prioritized by the DAC Public Awareness & Community Readiness subcommittee and confirmed for legislative advocacy by the DAC in the 2022 session.

Status: Ongoing

Next Steps:

- The DAC Advocacy Subcommittee is moving a proposal for funding to provide staffing to expand the Dementia Friends program in the supplemental legislative session in January 2022.

Challenge: Due to lack of funding stream to administer this program, the project team is currently limited in its efforts to support ongoing implementation and sustainability.

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

☐ Recommendation 1.E.4: **Strengthen and leverage relationships and collaboration between the Alzheimer's Association, the Alzheimer Society, the Area Agencies on Aging (AAAs) and other partners in order to strengthen dementia-capable service information systems.**

Accomplishments 2016/2018/2020/2021:

- The Dementia Capable Systems federal grant helped strengthen and leverage relationships between the Alzheimer's Association and AAAs in participating areas. See 1.A.2.
- The DAC includes information for consumers and for professionals to access resources through the Alzheimer's Association, Alzheimer's Society (now Dementia Support Northwest) and AAAs in informational materials, such as the *Dementia Road Map: A Guide for Family and Care Partners,* the "Memorylossinfowa.org" website, the Memory Loss/Dementia Community Health Worker training, the Case Manager Program Training and more.

Status: Ongoing

Project Team: Kim Boon, Marci Getz, Lynne Korte, Carrie McBride, Ron, Vivion, Jamie Teuteberg, Cheryl Townsend Winter

☐ **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.

Accomplishments 2019/2020/2021:

- Updated DOH webpage on dementia.
- 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.
- Department of Health (DOH) offered a Brain Health Wellness Workshop Education with Kris Rhoads, PhD in June 2020 for their public health staff. This workshop focused on brain health and the connections to preventing and/or managing chronic diseases, and addressed work being done by the DOH Healthy Aging Workgroup.
- Coordinated digital campaigns, headed by DOH, HCA and ALTSA, integrating 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. The 2020 campaign during Alzheimer's and Brain Awareness Month in June included nearly 30 posts - on Facebook, Twitter and Linked In - about Alzheimer's, dementia and brain health through HCA alone. Many of these posts were shared by DSHS.
- Health Care Authority (HCA) sponsored a "SmartHealth" employee wellness activity on the state employees' wellness portal in honor of Alzheimer's and Brain Health Awareness Month in June. In this program state employees are incentivized to participate in wellness activities. The 2020 brain health activity included visiting the National Institute of Health's Mind Your Risks website to learn about the connection between high blood pressure and developing dementia later in life, then taking the interactive quiz to learn what you can do to minimize your risk. More than 1,200 employees joined in the activity with more than 1,100 completing it.
- For Alzheimer's and Brain Awareness Month in June 2021, the DAC staff team worked with HCA for another campaign. The 2021 awareness campaign – building off of national and state materials - offered information and activities (available June – November 2021) which included:
    - Forgetfulness, Normal or Not? 3,559 state employees joined this activity to view a video
    - 10 Ways to Love your brain: 2,152 joined this activity to read educational materials
    - View and share a "Let's Talk Dementia" video: 774 joined this activity to view and then share a video with someone in their lives
    - Become a Dementia Friend: 1,064 joined this activity
- In 2021, DOH produced the *Implementing the Healthy Brain Initiative Road Map: A Toolkit for Public Health Organizations* to encourage implementation of Healthy Brain Initiative actions

which include attention to brain health, health promotion and chronic disease management and interventions.

Status: Ongoing

Next steps:

- Work with DSHS-ALTSA and HCA to see where we can collaborate on HBI Road Map activities.
- Coordinate digital awareness campaigns as opportunities arise.
- Determine if there are opportunities to implement some of *the Healthy Brain Initiative Road Map* opportunities identified by the members of the DOH Healthy Aging Workgroup with the Trust for America's Health-*Age-Friendly Public Health Systems-State Expansion Opportunity* funding.

Project Team: Janna Bardi, Kim Boon, Marci Getz, Lynne Korte, Jamie Teuteberg, Pam Walker

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.**

Accomplishments 2018/2019/2020/2021:

- 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 (ALTSA/Older Americans Act funds).
- Applied for and achieved inclusion of Cognitive Decline Module in 2020 BRFSS Survey.
- Applied to have the BRFSS Optional Caregiver Module administered as part of the WA State 2021 BRFSS Survey. The DOH BRFSS survey creation team was over-extended with the number of questions and time to complete the survey. DOH offered the option to either pick a few of the BRFSS Caregiver Module questions for inclusion or wait until survey year 2022 and have the whole module administered. After consultation with partners and the national Alzheimer's Association, the group decided to wait for survey year 2022.
- Applied and achieved inclusion of the Optional Caregiver Module in the 2022 BRFSS Survey,

Status: In progress

Next Steps:

- Review and analyze 2020 Cognitive Module data

Project Team: Janna Bardi, Brad Forbes, Marci Getz, Nick Hart, 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.**

Accomplishments 2018/2019/2021:

- 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 explaining the state plan and desire to integrate dementia into others' strategic planning.
- DOH and partners recognized the heightened risk of falls for older adults and those with cognitive impairment/dementia in Finding Our Balance: 2018 Washington State Action Plan for Older Adult Falls Prevention. See 2.B.2.
- DOH is working to get healthy aging, Alzheimer's disease and other dementias into the State Health Improvement Plan (SHIP) when it moves forward in development.
- ALTSA included Alzheimer's and other dementias/Dementia Action Collaborative as a strategic focus area in its State Plan on Aging for 2018-2022.
- In 2021, a review of the Area Plans for our 13 Area Agencies on Aging (AAAs) show that all AAAs identify the issue of brain health and/or dementia and the varied approaches or services they are using to address the needs of people with memory loss or dementia and/or their family caregivers. Their activities and responses differ based on available funding and access to resources. More than half, though, identified challenges related to sustainable funding for addressing dementia-related needs.

Status: In progress

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

☐ **Recommendation 2.B.2: Ensure ongoing activities at Department of Health, such as injury/falls prevention and emergency preparedness, incorporate needs specific to persons with dementia.** See 2.B.1. for efforts related to falls prevention for people with dementia.

Accomplishments 2018/2020/2021:

- DOH and partners recognized the heightened risk of falls for older adults and those with cognitive impairment/dementia in Finding Our Balance: 2018 Washington State Action Plan for Older Adult Falls Prevention.
- DOH partnered with ALTSA and AAAs to educate family caregivers on falls prevention programs and interventions. Worked with ALTSA to develop a simple method for professionals to refer older adults to falls prevention programs, using the statewide GetCare information system.
- Strategies in this plan include working with AAAs and other partners around preventing falls, use of evidence-based interventions and including family caregivers.
- In 2021, activities included Marigrace Becker from the UW Memory and Brain Wellness Center offering a presentation on Dementia Friends and Dementia Friendly Communities at the WA

State Older Adult Falls Prevention Coalition meeting; and DOH contracting with Dr. Victoria Panzer, Brookside Research & Development to partner with Aging & Long Term Care of Eastern WA to provide FallsTalk ™ for Caregivers who care for older adults with dementia (i.e., once the caregiver has been trained, they will deliver FallsTalk ™ to the older adult).

Status: In progress

Project Team: Lori Clary, Carolyn Ham, Lynne Korte, Jamie Teuteberg

☑ 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.**

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 4.C.2/4.E.1.
- 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: Marigrace Becker, 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.

Accomplishments 2020/2021:

- 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.
- Under leadership of the UW Memory and Brain Wellness Center on behalf of the Dementia Action Collaborative (DAC) a statewide planning committee successfully planned and produced a virtual "Collaborating for a Dementia-Friendly Washington: Inspiring Change" conference in September 2020 – the first of its kind in Washington State. This conference aimed to inform, inspire and equip people throughout the state to take action to make their communities more dementia-friendly. Over 250 people from 23 counties registered for the conference. Speakers included a range of local and national champions including the project director for Dementia Friendly America.
- The 2020 conference provided the opportunity to showcase some DAC products including the Alzheimer's Café and Dementia-Friendly Walking Group How-To Guides. This event highlights the strength of working collaboratively, as this workgroup had to pivot rapidly to a virtual format due to the pandemic.
- A component of this conference was to incentivize dementia-friendly projects in different parts of the state by mobilizing sponsorship funds to offer three $500 "seed grants" to participants wanting to initiate new dementia-friendly programming.
- In 2021, the DAC a second "Collaborating for a Dementia-Friendly Washington" conference was held in September, reaching nearly 200 people in 18 Washington State counties, with 78 organizations represented and a virtual format.
- The 2021 conference focused on increasing the diverse representation among speakers. Feedback was overwhelmingly positive: "I enjoy the diversity of 'voices' and presenters from different parts of the country." "Every speaker was motivating; the Maude's Awards were mind blowing. So good to know there really ARE people out there doing things for dementia." Public videos can be viewed on the conference webpage.
- In June 2021, DAC partners launched the Dementia-Friendly Washington Learning Collaborative, a sister network to Project ECHO Dementia. The focus is on expanding dementia-friendly programs, with a goal that people with dementia in every Washington state county would have access to this kind of programming. Attendees include people who participate in, organize or facilitate dementia-friendly programs. In our first half year, this program held 5 meetings, with 50 individuals participating from around 25 organizations from across the state. These sessions receive very positive feedback, encouragement to meet more often and to create additional ways for people to interact with each other.

Status: In progress

Next Steps:

- Our budget will allow us to plan for an additional conference in 2022.
- Continue hosting the Dementia Friendly Washington Learning Collaborative

Project Team: Marigrace Becker, Allyson Schrier, Kris Rhoads, Kevin Kvarda, Joel Loiacono, Debbie Hunter, Marty Richards, Ka'imi Sinclair, Mikayla Springob, TJ Vu, Kim Boon, Ginger Opdyke, David Brown, Joann Clemo, Lynne Korte, Marie Holt, Karen Winston, Yolanda Vasquez

☐ Recommendation 2.D.1: **Request that all state and local public health organizations provide content specific to healthy aging, brain health, and Alzheimer's disease/dementia, including Internet links to national, state and local resources.**

Accomplishments 2020/2021:

- DOH applied for and received a competitive grant award from Trust for America's Health (TFAH) that is designed to foster an Age-Friendly Public Health Systems. Such Systems work towards:
    - Improving health equity among the older adult population
    - Building new partnerships
    - Enhancing data collection
    - Facilitating local health department and tribal health engagement in older adult health and well-being
- The TFAH *Age-Friendly Public Health Systems-State Expansion Opportunity* provides DOH, the DAC and our partners the opportunity to weave healthy aging, Alzheimer's disease and other dementias, and the needs of caregivers into our work.
- In 2021, an advisory group was formed to guide and advise the work of this project. Tribes and Local Health Jurisdictions across Washington were invited and encouraged to apply for a small mini-grant to support work towards age-friendly initiatives and be a part of the AFPHS Learning and Action Network. Part of their work will be to provide content specific to healthy aging, brain health and Alzheimer's disease/dementia on agency websites, including links to national, state, and local resources.
- The following five local health jurisdictions (LHJs) applied and will be joining this opportunity: Benton-Franklin Health District, Kitsap Public Health, Seattle and King County Public Health, Spokane Regional Health District and Walla Walla County Department of Health. Each LHJ had support from the Area Agency on Aging (AAA) that serve the same county.

Status: In progress

Next Steps:

- The AFPHS Learning and Action Network will begin in February 2022.

Project Team: Janna Bardi, Kim Boon, Susan Engels, Marci Getz, Lynne Korte, Jamie Teuteberg

☐ 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.

National Asian Pacific Center on Aging

Connecting with AAPIs About Dementia

AN ACTION GUIDE FOR SERVICE PROVIDERS

This action brief is for community-based organizations working to educate and empower Asian-American and Pacific Islander (AAPI) communities about dementia. The purpose of the brief is to share information on:

- Why dementia is such an important issue for the AAPI community;
- Barriers to dementia detection, treatment, and support for the AAPI community;
- Recent findings from a research study to test culturally appropriate messages to improve early identification of dementia by engaging adult children and their families;
- Recommendations and resources for better reaching the AAPI community.

Background

Asian Americans and Pacific Islanders (AAPI) are the fastest growing minority group in America.[1] Between 2010 and 2030, the AAPI older adult population is projected to increase by 145%! As this aging population rapidly increases, AAPI older adults face a public health crisis similar to older adults from other ethnic backgrounds, as age is the largest risk factor for Alzheimer's disease.[2]

The prevalence and incidence of Alzheimer's disease and related dementias within AAPI communities is not well understood. Researchers acknowledge that data on AAPI subpopulations is lacking.[3] Limited disaggregated research unveils that rates may vary by subpopulation, as Vietnamese older adults have a disproportionately high prevalence of cognitive problems (16.6%), more than double the rate for Koreans at 7.6%.[4] Native Hawaiians and Pacific Islanders have a higher risk of cognitive issues and activities of daily living impairments, which is two times the risk as compared to Chinese older adults.[4]

In 2011, 13.8% of older AAPIs reported an increase in confusion or memory loss, which was the second highest of all ethnic groups.[5] This finding is based on Behavioral Risk Factor Surveillance System (BRFSS) self-reports, and so whereas this data is limited by the lack of clinical measurement, it highlights the need to facilitate linkages to health care providers to ensure timely and accurate diagnosis of Alzheimer's disease and related dementias. Despite high rates of self-disclosure through BRFSS interviews, many AAPIs do not report symptoms of dementia to a medical professional, and consequently, AAPIs are unlikely to receive a diagnosis of Alzheimer's disease until the disease has progressed to the later stages.[6]

Accomplishments 2016/2018/2021:

- In 2016/2017, six focus groups were conducted with Chinese and Japanese adults with older relatives via the National Asian Pacific Center on Aging (NAPCA) and the UW Healthy Brain Research Network, to consider the acceptability of messages related to cognitive health in these communities.
- In 2018, NAPCA created Action Guides for Service Providers and Policy Makers. These were shared them with more than 800 area providers in more than 46 organizations.
- In 2018, Seattle area churches in partnership with the nonprofit Center for Multi-Cultural Health disseminated evidence-based messages about preserving brain health and other useful resources to African Americans during "Memory Sundays".
    - Memory Sundays (recognized by the Balm in Gilead organization as the second Sunday in June) is a program coordinated by Seattle Human Services' Aging and Disability Services division. Memory Sunday raises awareness of the disproportionate impact of Alzheimer's and other dementias among people of African descent within faith communities serving African Americans. Information about local resources for people living with memory loss, caregivers, and families is distributed.
    - As part of this effort, in 2018, culturally-tailored hand fans (with information on memory loss resources) were created and distributed through participating African American churches.
    - The number of congregations participating has increased each year since its beginning. Even during the pandemic, churches participated virtually. In 2021, 22 churches participated in Memory Sundays (representing an estimated 2,000 individuals).
- The two efforts above were recognized and featured in the new *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*.
- DOH dementia webpage was launched.

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: Basia Belza, Marci Getz, Lynne Korte, Myriam Marquez, Kathy Lofy, Janelle Okorogu, Ingrid Ulrey, K'aimi Sinclair, Karen Winston

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.**

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.**

Accomplishments 2017/2019/2021:

- 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
- Disseminated online and paper versions at conferences, trainings and meetings. May also be found on the memorylossinfowa.org webpage.
- Reviewed and updated content February 2019 and February 2021.

Status: Completed

Next Steps:

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

Project Team: Lynne Korte, Kim Boon, Dave Budd, Ron Vivion, Bob Wellington

☐ 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.**

Accomplishments 2019:

- 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.
- This work was suspended in 2020 due to competing demands with pandemic.

Next Steps:

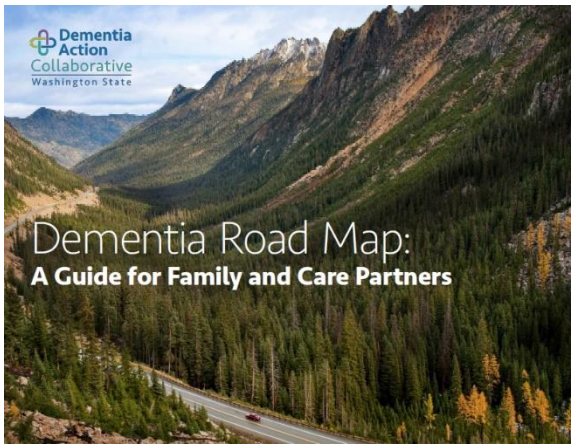
- Develop outline for an Informational Toolkit and create a draft.
- Finalize Info/Toolkit

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.



Accomplishments 2018/2019/2020:

- Collaboratively developed content for a unique educational document that brings together information, resources and action steps for family and care partners – the Dementia Road Map: A Guide for Family and Care Partners.
- Used Older Americans Act funds and Alzheimer's Association support to make print copies of this booklet. Published and disseminated this document widely through DAC network for placement on websites.
- Developed new system for managing distribution through the Department of Enterprise Systems. See box below for ordering instructions.
- In 2019, ALTSA provided funding to the Alzheimer's Association for translation into Spanish. This Spanish language translation is now also available in print through inquirywa@alz.org.
- Have disseminated more than 80,000 print copies to caregivers across Washington State.
- Granted permission for other locales and states, including Oregon and Idaho, to adapt the document for their use.

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

Status: Completed

Greatest Challenges: Keeping content of Dementia Roadmap up-to-date in printed and online versions, cost of translations/printing.

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

☐ **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.**

Accomplishments 2019/2020/2021:

- In 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.
- In 2020, the DAC advocacy subcommittee put forward a proposal to pilot "Dementia Resource Catalysts" that would foster dementia-capability in four AAA public service areas. While the legislature approved a budget proviso to support this pilot for two areas, the project was eventually vetoed in the budget due to the pandemic.
- In 2021, the DAC advocacy subcommittee again put forward a proposal to pilot "Dementia Resource Catalysts" along with funding to develop and expand dementia-capable services and foster dementia-capability in two AAA public service areas. The legislature approved $1.5 million via budget proviso to support the proposed pilot in two AAA areas for two years – one AAA in eastern Washington and one AAA in Western Washington to begin in July 2021.
- A request for proposal process selected Aging and Long Term Care of Eastern Washington (ALTCEW) and the Northwest Regional Council (NWRC) to implement this "Building Dementia Capable Communities" program. Projects are currently funded through June 2023.

Status: In progress

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 ongoing dementia awareness and training or the specialty supports and services to address the complex and heightened needs created by dementia. Funding of the pilot project is a beginning to demonstrate possible approaches.

Project team: Lynne Korte and participating AAAs – federal grant AAAs included 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. Current pilot project includes Aging and Long Term Care of Eastern Washington and Northwest Regional Council.

☐ **Recommendation 4.B.1: Increase availability of evidence-based programs for people with dementia and their family caregivers, e.g., STAR-C, Reducing Disability in Alzheimer's disease (RDAD), early-stage memory loss groups and Powerful Tools for Caregiving, and expand supportive services such as behavior consultation, counseling, flexible family supports, adult day services, etc.**

Accomplishments 2018/2020/2021:

- ALTSA leveraged a federal grant from the Administration for Community Living (ACL) to increase the availability of evidence-based/evidence-informed programs in five Area Agencies on Aging (AAAs). This included integration of an evidence-informed health promotion program targeting the early-stage population, called Staying Connected.
    - In the Staying Connected health promotion program, participants practice communication and strategies for coping with memory loss, discuss pleasant activities and how to maintain them, get started with a healthy living program that includes regular pleasant activities with family and friends; and are encouraged through friendships and networking among participants.
    - In this three-year grant, 59 facilitators were trained, 50 Staying connected class series were offered and more than 380 people (those with early-stage dementia and their care partners) participated. At grant's end in 2018, two of the AAAs committed to continuing the program/service in their areas using other fund sources.
- ALTSA subsequently contracted with the Alzheimer's Association to offer 11 additional trainings for additional facilitators for Staying Connected class series, although uptake of the classes by caregivers was slow and difficult due the emergence of the pandemic.
- ALTSA funded opportunities in 2017, 2019 and 2021 for AAA staff and/or their networks to become trained/certified as a coach for the evidence-based STAR-C dementia behavior consultation program. While 20+ people were trained over this time, competing and changing roles of staff require continuous effort to sustain this program.
- ALTSA coordinated with Sound Generations and other partners to help sustain the Powerful Tools for Caregiving program, an evidence-based class series for family caregivers. Nine trainings were offered over the last three years.

Status: Ongoing

Challenge: Evidence-based interventions are labor intensive due to the fidelity requirements and the need to continuously recruit and train 'leaders/trainers' in local communities. These programs require class leaders that are either experienced volunteers or staff that have competing demands, so keeping a roster of trained leaders is difficult and demands ongoing attention.

Next Steps:

- Seek opportunities to expand evidence-based/evidence-informed dementia-capable support services.
- Continue to expand fund sources to support such interventions.

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

☐ **Recommendation 4.B.2: Increase availability and delivery systems of education for family members about dementia communications skills, understanding and responding to non-verbal cues and behaviors, and home care activities such as assuring home safety, managing medications, using effective approaches for personal care and oral health needs, addressing hearing loss and other sensory deficits, and incorporating physical and meaningful activity into the day.**

☐ **Connected to Recommendation 4.I.1: Identify and promote opportunities to bring tele-health and web-based resources to more family caregivers, particularly in rural areas.**

Accomplishments 2020/2021:

- In 2020, ALTSA engaged with Trualta, an organization offering a personalized, skills-based training platform for family members caring for loved ones who are aging and living at home. In 2021, ALTSA established a contract that would make their web-based services available in Washington as a new delivery mechanism for educating and supporting family caregivers.
- Trualta offers a wide variety of learning materials that can be accessed remotely. Within their program are over 100 trainings that help caregivers to discover new ways to connect with their loved ones, learn about challenging behaviors, discover the importance of caregiver self-care, and learn lifting techniques and other ways to safely provide personal care. The system includes short and longer training videos specifically for dementia caregivers featuring Teepa Snow's Positive Approach to Care as well as interactive mechanisms to connect, share and learn with fellow caregivers.
- ALTSA purchased 1,000 licenses to be available for family caregivers statewide as a pilot project for the next year. These licenses are being approved for family caregivers within six Area Agencies on Aging (AAAs) – Aging & Long Term Care of Eastern Washington, Area Agency on Aging & Disabilities of Southwest Washington, Pierce County Aging & Disability Resources, Lewis-Mason-Thurston Area Agency on Aging, Aging & Adult Care of Central Washington and Southeast Washington Aging and Long Term Care. Family caregivers in these areas can contact their AAA if interested in Trualta. To find the appropriate AAA, go to the Community Living Connections site: waclc.org

Next Steps:

- Consider the possibility of the engaged AAAs taking on caregivers from areas of the state that are not in the pilot.
- Continue dissemination of licenses, track utilization and consider potential for continuance and expansion.

Status: In progress

Project Team: Dana Allard-Webb, Susan Engels, Aime Fink

☐ **Recommendation 4.C.1: Explore strategies to expand support groups, particularly in rural areas.**

Accomplishments 2020/2021:

- Necessitated by the pandemic in 2020, DAC partners worked to pivot their supports and services to remote means. Support groups, education and social engagement opportunities became available with the Alzheimer's Association, Dementia Support Northwest, and the UW Memory and Brain Wellness Center. Reports from partners have revealed that while some people are still not comfortable with the virtual modality, for others it has opened doors of engagement and support.
- ALTSA worked with DAC partners to promote these opportunities through a monthly e-edition of *Resources for Family Caregivers of People with Dementia During the Covid-19 Outbreak,* available on the DAC webpage and distributed by partners to their networks.
- ALTSA contracted with GetSetUp a company that helps older adults learn about technology and become more familiar with its use and ability to promote interactive learning, as a way to lessen isolation and allow the use of remote offerings such as online support groups and education.

Next Steps:

- As the risks of the pandemic lessen, consider the costs and benefits of online support groups, and how they might continue to be offered for those that can benefit.

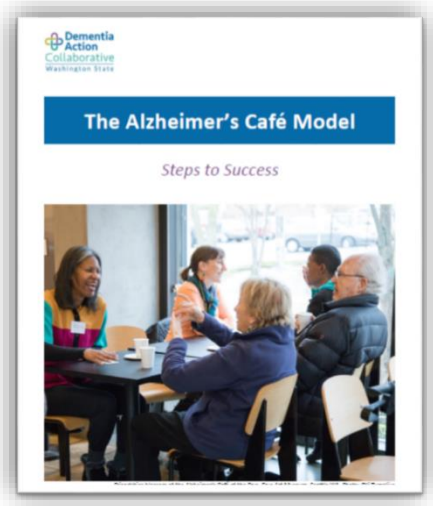
Status: In progress

Project Team: Dana Allard-Webb, Lexie Bartunek, Susan Engels, Lynne Korte

☐ **Recommendation 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.**

Accomplishments 2018/2020/2021:



- 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. Afterwards, ALTSA developed a contract with Alzheimer's Association to continue offering leader training for this program. From 2018-20, more than seven Staying Connected class series were offered along with one master trainer training. This contract was renewed in 2020 to train master trainers for Staying Connected.
- 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.

- In 2018, developed "how to" guidance documents for "Starting an Alzheimer's Café" and "Dementia Friendly Walking Groups", and offered four dementia-friendly program webinars (with follow-up networking opportunities attracting nearly 400 registrants from across the state). Find the "how to" guides on the DAC webpage, under Dementia Friendly resources. In monitoring uptake of Alzheimer's/Memory Cafes in Washington, there was a notable increase in the number of Café's listed, increasing from 15 to 35.
- In 2020, promoted models of early-stage engagement further at the first Dementia Friendly Washington conference. See Rec 2.C.2.
- In 2021, the DAC offered a second "Collaborating for a Dementia-Friendly Washington" conference in September. See Rec 2.C.2.
- Also in 2021, DAC partners launched the Dementia-Friendly Washington Learning Collaborative in June, a sister network to Project ECHO Dementia. The focus is on expanding dementia-friendly programs, with a goal that people with dementia in every Washington State county would have access to this kind of programming. Attendees include people who participate in, organize or facilitate dementia-friendly programs. In the first half year, this program held 5 meetings, with 50 individuals participating from around 25 organizations from across the state. These sessions receive very positive feedback, encouragement to meet more often and to create additional ways for people to interact with each other.

Status: In progress

Next Steps:

- Continue to monitor uptake of early stage and social engagement programs and promote interest during meetings, conferences, etc.
- Possibly work with LTSS joint team to develop new guidance materials to develop music-related engagement programs. This project was suspended due to the pandemic.

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.**

Accomplishments 2018/2019/2020/2021:

- 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 2019 DAC meeting, and on dementia disparities in LGBTQ community at September 2019 DAC meeting.

- In 2020, the Dementia Disparities workgroup collaborated to draft and audience-test an African American Action Brief focused on disparities in dementia which is targeted to community-based organizations, with the intent to increase awareness of and actions to address these disparities.
- In 2021, the workgroup finalized the document African Americans and Alzheimer's Disease: A Call to Action for Organizations, and developed a toolkit to use in disseminating the Action Brief, including social media posts and a magazine article. The dissemination toolkit was distributed to over 60 organizations statewide to promote circulation, with each receiving a follow-up survey requesting information on how the Action Brief has been used.
- In 2021, the Washington State Commission on African American Affairs published information about the DAC in their newsletter. The workgroup is currently seeking an endorsement from Mary Mahoney Professional Nurses Association.
- The Dementia Disparities workgroup is working in concert with the team effort on increasing awareness in communities with heightened risk of Alzheimer's. See Rec 1.C.1.

AFRICAN AMERICANS AND ALZHEIMER'S DISEASE:
A Call to Action for Organizations

The African American community is strong and resilient. Institutionalized racism drives the unequal distribution of power and resources, resulting in health, social, economic, environmental, and structural disparities for people of color. Among those disparities is the disproportionate occurrence of Alzheimer's disease and other dementias.

The number of older African Americans in Washington is growing. By 2040, this population is estimated to increase from about 43,000 to about 80,000 (83%).

African Americans are about 2 times more likely to have Alzheimer's disease than the non-Hispanic white population.

African Americans are more likely to be misdiagnosed or diagnosed with Alzheimer's in the later stages of the disease.

Institutional racism leads to multiple factors that put African Americans at risk for Alzheimer's and other dementias, including:

- Education and income inequalities
- Limited or no access to health care
- Increased stress and heart problems
- Untreated high blood pressure and diabetes

Certain factors may impact diagnosis and treatment of African Americans, such as:

- Perceptions about what is normal aging and what is not
- Mistrust of the health care system due to past mistreatment, which may delay access to care and assessment
- Cognitive screening tools that are not culturally appropriate

Dementia Action Collaborative Washington State

Established in 2016, the Dementia Action Collaborative is a group of public-private partners committed to preparing Washington state for the growth of the population living with dementia. For more information and to access resources on dementia, visit: **doh.wa.gov/ahca/dementia-action-collaborative**

Status: Ongoing

Next Steps:

- DAC Diversity/Disparities in Dementia workgroup to meet at least quarterly.
- Continue dissemination of and endorsements for African American Alzheimer's Action Brief
- Work with partners to find new ways to disseminate the Action Brief and promote awareness of disparities in dementia, which may include collaborating on podcasts and seminars for youth.
- Develop an Action Brief that targets the Hispanic/Latino community.

Challenge: Outreach and relationship building around disparities takes significant planning, linking and relationship building. This will be an ongoing process and involve all subcommittees.

Project Team: Basia Belza, Alison Boll, Marietta Bobba, Kim Boon, Marci Getz, Lynne Korte, Maureen Linehan, Ka'imi Sinclair, Jamie Teuteberg, Karen Winston, Tavares Terry, Maggie Ramirez**,** Mikaela Louie, Anuska Noori, Quyen Huynh

☑ 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.

Accomplishments 2018/2019/2020/2021:

- Engaged full DAC in September 2018 to discuss how to address diverse communities and health disparities within entirety of AD Plan implementation.
- 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 Americans.
- 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.
- ALTSA hosted Savvy Caregiver in Indian Country training – a native specific training on dementia – six times between 2017 and 2021: fifteen Washington tribes have representatives who have completed the training. See blue box.
- DAC partners provided speakers on dementia at the Money Follows the Person Tribal Summits in 2017, 2019 and 2021.
- The DAC also reached out to the Northwest Portland Area Indian Health Board to learn more about the BOLD grant and offer assistance. DAC partners spoke to the Indian Policy Advisory Subcommittee about Project ECHO Dementia and the Dementia Friendly Washington Learning Collaborative.

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.

Status: Ongoing

Next Steps:

- DAC Diversity/Disparities in Dementia workgroup to meet at least quarterly.
- Continue connections with tribal liaisons at DSHS, DOH and other DAC partner organizations.
- Continue to seek opportunities and partner with tribal organizations, for example through the Trust for America's Health (TFAH) DOH grant.
- Strengthen relationship with the Northwest Portland Area Indian Health Board.

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

Project Team: Basia Belza, Alison Boll, Marietta Bobba, Kim Boon, Marci Getz, Lynne Korte, Maureen Linehan, Ka'imi Sinclair, Jamie Teuteberg, Karen Winston, Tavares Terry, Maggie Ramirez**,** Mikaela Louie, Anuska Noori, Quyen Huynh, Bob LeRoy, Aziz Aladin, Emma Medicine White Crow, Shelly Zylstra

☐ **Recommendation 4.H.2: Inform caregivers and patients about the Family and Medical Leave Act, long-term care insurance, the benefits of advance legal and financial planning and existing support programs through agency websites, educational forums, service networks and the media.** See Rec 1.C.2.

☐ **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.**

Accomplishments 2018/2019/2020/2021:

- The Developmental Disabilities Council (DDC) 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 (IDD) 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 Service Employees International Union/Training Partnership (SEIU).
- Developed survey to gather information more directly from families in the parent-to-parent coalition.
- Created an IDD and Dementia Curriculum Development Workgroup with participation from ALTSA; DDC; DDA Training Unit; DDA EDI; Adult Family Home Council; Executive Director of Community Homes, a DDA provider.
- In 2020/2021, the curriculum workgroup developed and completed the IDD and Dementia training for direct support professionals (DSPs) including case managers, along with an instructor manual - three two-hour segments that includes Introduction to IDD and Dementia, How Providing Care Changes with Dementia Onset, and Self-Care for DSPs providing Dementia Care.

Status: In progress/ongoing

Next Steps:

- January – March 2022: practice teaching, incorporate updates as needed, seek instructors for and virtual/in-person locations for disseminating the training.
- March – June: Trainings begin being provided to DSPs throughout the state

Project Team: Aziz Aladin, Sarah Blanchette, Kim Boon, Karen Cordero, Emily Rogers, Justin Chan
Advisor: Linda Gil

☐ **Recommendation 4.I.1:** Identify and promote opportunities to bring tele-health and web-based resources to more family caregivers, particularly in rural areas. See Rec 4.B.2.

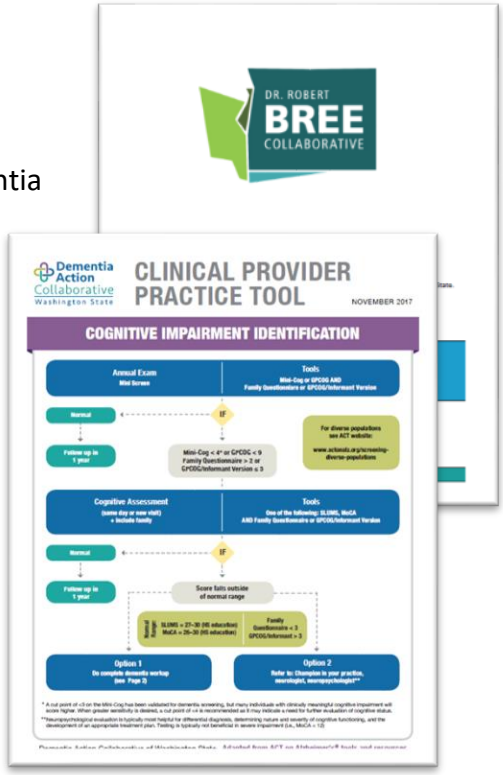
Goal 5: Identify dementia early and provide dementia-capable evidence-based health care

☑ **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.**

Accomplishments 2017/2020:

- 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 content experts for the Bree dementia workgroup 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 Dementia 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 on the DAC webpage under Resources for Providers.
- The Bree Collaborative invited a DAC team to present an update webinar in 2020; Kris Rhoads, PhD, Lynne Korte, and Jamie Teuteberg presented updates and offered action steps to attendees. The webinar was attended by 87 healthcare stakeholders including delivery sites, providers, clinical support staff, administrators, and state government agencies were in attendance.



Status: Completed

Project Team: Amanda Avalos, Nancy Isenberg, Lynne Korte, Kris Rhoads, Bruce Smith, Jamie Teuteberg

☐ 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.**

Accomplishments 2019/2020:

- The Bree Alzheimer's Disease and Other Dementia Report and Recommendations encourage discussing and screening of cognitive status.
- 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 were shared.
- 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.
- Cognitive screening is included as a foundational module in the Project ECHO Dementia curriculum.

Status: Ongoing

Next Steps:

- 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.**

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 is available on the DAC webpage.

Status: Completed

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

Project Team: Nancy Isenberg, Lynne Korte, Kris Rhoads

☐ 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.**

Accomplishments 2019/2020/2021:

- In 2019, DAC team (including Kris Rhoads and Nancy Isenberg) offered twenty-four (24) provider presentations disseminating the Bree recommendations, screening paper, and Clinical Provider Practice Tool. In 2020, this team offered twenty-five presentations on dementia best practices.
- Education around the importance of timely assessment and disclosure of cognitive impairment and/or diagnosis of dementia is incorporated into Project ECHO Dementia sessions.

Status: Ongoing

Next Steps:

- Work towards completing the Managing Across the Continuum Dementia tool.
- Update the Clinical Provider Practice Tool

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

Project Team: Kristen Childress, Tara Garland, Leslie Emerick, Bethany Fowler, Matthew Gower, Kathy Jacobi, Lynne Korte, Kris Rhoads, Carrie Rubenstein, Nancy Isenberg, Tatiana Sadak, Jamie Teuteberg

☐ Recommendation 5.C.4: **Partner with professional organizations and academic settings to develop or increase the availability of affordable continuing education/training programs.**

Accomplishments 2020/2021:

- In early 2020, the University of Washington (UW) Departments of Family Medicine, Epidemiology, and Global Health in collaboration with the UW Health Promotion Research Center – and with support of DAC partners - applied for and received a grant from the Centers for Disease Control and Prevention (CDC) for a project called "Enhancing Early Detection of Cognitive Impairment using the KAER Model in Primary Care".
- The Cognition in Primary Care Program (CPC) utilizes a model adapted from the Gerontological Society of America's GSA KAER Toolkit. The model is pragmatic and scalable, designed to increase the early detection of both mild cognitive impairment and dementia, and to improve PCPs' skills managing these conditions.
- The CPC Program consists of an education series for primary care providers (PCPs) which is paired with a process intervention for efficient in-clinic cognitive evaluations in the primary care setting. The in-clinic process-model provides PCPs with a structured approach for conducting cognitive evaluations, followed by a framework for office visits to review the results, and provide PCPs with clear next steps to improve dementia care and help their patients maintain brain health.

- In addition to efficient tools to use in the electronic health record, the program also features a website, Cognition-PrimaryCare.org, where PCPs can access practical information from the training as well as links to high yield community resources to provide to their patients.
- More than 100 PCPs in the UW Medicine Primary Care Network have registered for this training, and the in-clinic process model is currently being piloted in 2 primary care clinics in Shoreline and Kent-DesMoines.

For more information, visit Cognition-PrimaryCare.org or email either of the DAC members who are part of the CPC team: Barak Gaster (barakg@uw.edu) or Basia Belza (basiab@uw.edu.)

Status: Ongoing

Next Steps:

- In 2022, implement the model across the 16-clinic UW Primary Care Network and then offer it free to other health systems in Washington State.

Project Team: Barak Gaster, Basia Belza and more UW faculty, with support from a Technical Advisory Committee including DAC participants Kris Rhoads and Lynne Korte.

☑ 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.**

Accomplishments 2019/2020/2021:

- Achieved funding per budget proviso for the University of Washington Memory and Brain Wellness Center at Harborview, in the amount of $497,000 per biennium. Proviso funding is 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, and secured a dedicated location for the Zoom Room/technological hub, with ongoing collaboration with the UW regarding IT/tech needs and building renovations.
- Began ongoing recruitment of spoke provider sites in 2019 and early 2020, 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).
- UW Memory and Brain Wellness Center at Harborview, which hosts Project ECHO Dementia, using a 'hub and spoke' model, launched for provision in mid-2020. The UW 'hub' offers a multi-disciplinary, multi-organization panel of experts that join together with their interested 'spoke' community of primary care providers from across the state to learn together.

- Since its beginning in June 2020, the program has reached 32 clinics across the state, including 78 clinicians. This has included 441 hours of instruction.
- The program appears to be helping providers move towards using best-practices: 65 – 70% of participating providers (that respond to the post-session surveys) indicate that they will change their practice as a result of the program/session learnings.
- Recordings of sessions on topics such as Screening and Detection of Cognitive Impairment, Advance Care Planning for Dementia, Dementia and Care Resources for Patients and Families are available online. To access: http://depts.washington.edu/mbwc/resources/echo
- In 2021, the Project ECHO Dementia team identified the 'top ten' topics for participants. These are the sessions that will be encouraged for all new participants to so that they can attain an underpinning of learning that is common to all who attend. These topics include: ECHO Intro and Diseases Causing Dementia masquerading conditions and red flags; Prevention and addressing modifiable risks; Early and accurate diagnosis and evaluation/Delivering the diagnosis; Pharmaceuticals typically associated with dementia treatment, including approaches for behavioral management; Managing comorbid conditions/Coordinating Care/Delirium risk and prevention; Treatment (non-pharmacologic approaches, cognitive training, mindfulness, lifestyle, social engagement, creative aging, what matters); Dealing with difficult behaviors (Behavioral and psychological symptoms of dementia/sleep/incontinences/deprescribing); Advance care planning; Community resources (safety, driving, caregiver support); Palliative care/end-of-life issues/5M frame

Status: Completed, with ongoing work

Next Steps:

- Continue spoke site recruitment.
- Explore some kind of "certification" for Project ECHO Dementia participants.
- Explore a Dementia Champion in Primary Care program that would allow participants to receive recognition and possible other benefits for program attendance.
- Codify a core curriculum for incoming community members and connect this work to impact within the community.

Challenges: Reaching clinics, providers, and systems who really need the help (those who joined are already doing so much), systems-level engagement and coming up with ways to measure impact.

Project Team: Kris Rhoads, Nancy Isenberg, Barak Gaster, Carolyn Parsey, Mimi Pattison, Lynne Korte, Allyson Schrier, 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.** See Rec 5.E.2

Accomplishments 2019/2020/2021:

- 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.
- Education around the availability and use of the MAWV is incorporated into Project ECHO Dementia sessions.
- Complex care management codes for care coordination services presentations to the Health Care Authority clinical and policy leadership.

Status: Ongoing

Next Steps:

- Ongoing provider education and continual work to increase uptake and implementation of MAWV across systems.

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

☐ **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.**

Accomplishments 2018/2019/2020/2021:

- Dissemination of finalized billing code information in the Bree recommendations.
- Identification of best practices and information graphics from Alzheimer's Association and related organizations.
- Complex care management codes for care coordination services presentations to the Health Care Authority (HCA) clinical and policy leadership.
- HCA is working towards making Comprehensive Assessment and Care Planning Code (99483) service available to Medicaid clients effective January 2022.

Status: Ongoing

Next Steps:

- Provider outreach and education on new code
- Explore other possible billing codes to address needs

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

Project Team: Jamie Teuteberg, Kris Rhoads, Nancy Isenberg

☐ **Recommendation 5.F.1: Educate the clinical community on the impact and management of dementia and co-occurring chronic conditions. Once identified, cognitive impairment and dementia should become an organizing principle for all other care of the patient.**

☐ **Recommendation 5.F.2: Educate the clinical community, and include in guidelines, information on how sensory loss such as hearing, vision, and balance impacts the diagnosis and/or treatment of the cognitively impaired patient.**

☐ **Recommendation 5.F.3: Promote practices and initiatives that facilitate early enrollment into palliative and hospice care to support individuals with worsening dementia and their care partners.**

☐ **Recommendation 5.I.1 Increase awareness of the need to involve care partners/caregivers in every step of care planning and goal setting for the person with cognitive impairment and dementia.**

Accomplishments 2020/2021:

- Each of the above topics are addressed in the voluntary education provided by Project ECHO Dementia. See Rec 5.C.6.

Status: Ongoing

Project Team: Kris Rhoads, Nancy Isenberg, Barak Gaster, Carolyn Parsey, Mimi Pattison, Lynne Korte, Allyson Schrier, Jamie Teuteberg

☐ **Recommendation 5.G.1: Increase awareness among primary care clinicians and care partners of potentially avoidable causes for ED visits, hospital admissions, and readmissions for people with cognitive impairment and dementia. Emphasize the importance of partnership and communication between clinician and care partners.**

☐ **Connects with 6.A.3: Convene a workgroup to identify and seek funding to support best practice dementia capable models that minimize care transitions, including emergency room visits, hospital admissions and readmissions.**

Accomplishments 2020/2021:

- Established workgroup with members from both Health-Medical and Long Term Services and Supports Subcommittees. Subgroups are working to identify current practices, gaps, and best practices focusing on preventing/reducing potentially avoidable hospitalizations and ER visits and prevent/reduce potentially avoidable readmissions or subsequent ER visits.
- Completed research into programs, models and trainings that contribute to reduced readmissions to hospitals for people living with dementia.

- Recruited a doctoral nursing candidate intern from UW to recruit and schedule focus groups with hospital staff in order to better understand challenges, successes and opportunities in care transitions with persons living with dementia.
- Requested permission from the Alzheimer's Association to update the former Partnering with your Physician education program for family caregivers. A subgroup of stakeholders, including care partners and providers, then reviewed, updated and enhanced the content with an eye on promoting quality communications and care while providing information that can help reduce avoidable hospitalizations. This content will be developed into an online education program for family caregivers.
- Developed content/scripts for four videos about communication skills to use with health care providers that will be incorporated into the above online training.

Status: In progress

Next Steps:

- Create a toolkit that shares best practices for reducing hospital readmissions.
- Finalize the online education program, "Partnering with Your Healthcare Provider: A Resource for People with Memory Problems and their Care Partners".
- The Care Transitions Project Team will develop a plan for distribution/dissemination of the materials mentioned above, in the second quarter of 2022.

Project Team: Tatiana Sadak, Kim Boon, Kristin Childress, Leslie Emerick, Aime Fink, Jullie Gray, Nancy Isenberg, Lynne Korte, Todd Larson, Joel Loiacono, Phung Nguyen, Alyssa Odegaard, Mary Pat O'Leary, Cheri Perrazoli, Mary Lynn Pannen, Mary Pattison, Kris Rhoads, Marty Richards, Carrie Rubenstein, Allyson Schrier, Lori St. Ours, Jamie Teuteberg, Cathy Knight, Jess Welsch **Short-term participants** 2021: Holly Breyzinski (DNP intern); Dan Ryan, Emily A. Ishado, Jaime M. Hernandez, Sr., Kim Dirksen, Lita Wright, Lyndsy Vasquez, Melinda Schultz

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

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

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 to 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.**

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: Susan Engels, John Ficker, Julie Gray, Maureen Linehan, Leigh Beth Merrick, Mary Lynn Pannen, Mimi Pattison

☐ **Recommendation 6.A.3: Convene a workgroup to identify and seek funding to support best practice dementia capable models that minimize care transitions, including emergency room visits, hospital admissions and readmissions.**

☐ **Connects with 5.G.1: Increase awareness among primary care clinicians and care partners of potentially avoidable causes for ED visits, hospital admissions and readmissions for people with cognitive impairment and dementia. Emphasize the importance of partnership and communication between clinician and care partners.** See Rec 5.G.1 for this activity.

☐ **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.1: Support a robust array of community-based services to include adult day care and evidence-based practices such as Memory Care & Wellness, STAR-C, etc.** See 4.B.1. and 4.D.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.**

Accomplishments 2019/2020/2021:

- 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.
- ALTSA and external stakeholder teams consolidated all feedback in to four categories: Family and Resident Support, Provider Training and Support, Safety and Accessibility and Activities and Community.
- Feedback was used to separate the Meaningful Day Contracts between DDA and ALTSA, which will allow changes to make the contract more dementia focused.

Status: Completed

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, Alec Graham, Barb Hanneman, Natalie Lehl

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

Accomplishments 2017:

- After working with stakeholders to garner input, ALTSA finalized an enhanced Dementia Specialty Training in 2016.
- In 2016/2017, rolled out new training to residential long-term care settings.

Status: Completed

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

☑ Recommendation 6.C.2: **Ensure training and testing for all LTSS workers is more readily available throughout the state.**

Accomplishments 2017/2021:

- In 2016, ALTSA/SEIU Training Partnership increased the number of locations of classes available for LTSS workers.
- As of 2021, there are 66 training sites.

Status: Completed

Project Team (Staff): Kathy Lofy, Amy Persell/SEIU

☑ Recommendation 6.C.3: **Ensure certification of all LTSS workers is more achievable for limited English speakers.**

Accomplishments 2017/2021:

- New certification exam that minimizes role of literacy was launched in May 2016. New exam pass rates for non-English have increased about 30%.
- As of 2021, the certification exam is translated into 13 non-English languages and individual interpreters are available for those who speak a language not currently translated.
- The application form has also been translated into Russian, Spanish, and Vietnamese. The credentialing unit, which handles the processing of applications, works with applicants throughout the process, and issues the credential, has a telephone interpretation service they use to communicate with those who are not English proficient.

Status: Completed

Project Team (Staff/DOH): Stacey Saunders or James Chaney

☐ Recommendation 6.C.4: **Increase dementia-capability of HCS/AAA Case Management staff by enhancing Core training to include more information around the importance of early detection and diagnosis, responding to behaviors, and assessing and addressing hearing loss and other sensory limitations.**

Accomplishments 2020/2021:

- Attained an ongoing slot in ALTSA's Case Manager Program Training (CMPT) for HCS/AAA Case Management held regularly for newer staff, a component of the Core training for this staff.
- This CMPT module, "Dementia: How to Help", offers an introduction to best practices in assisting people with dementia including the importance of early diagnosis, how dementia impacts all other needs, support of family care partners/caregivers, medication management and balancing independence and safety. It provides access to a broad array of resource materials for sharing.
- Information geared towards enhancing other segments of the Core training related to dementia were also shared with ALTSA's training unit program manager.

Status: Ongoing

Next steps:

- Continue providing CMPT dementia module and encourage enhancement of the other Core training module containing dementia to include updated information on brain health and proactive support for people with memory loss and dementia.

Project Team: Kim Boon, Lynne Korte

☑ **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.

Accomplishments 2019/2021:

- 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.

Status: Completed/with ongoing related work

Next Steps:

The WA State Legislature will likely pause the timeline during the 2022 session to address concerns raised by constituents. Some of these policy reforms are:

- How it can serve disabled veterans, military spouses, non-residents and near retirees better;
- Address portability if a vested Washingtonian moves to a different state to retire; and
- Assuring that those who opted out of the program maintain their private insurance policies.

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.**

Accomplishments 2017/2021:

- Health Care Authority (HCA), Aging and Long Term Support Administration (ALTSA) and Area Agencies on Aging (AAAs) worked together, with approval needed from 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 two new programs – Medicaid Alternative Care (MAC) and Tailored Supports for Older Adults (TSOA) 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.
- Integrated the TCARE Caregiver Assessment tool into the primary GetCare system to improve efficiency and data management.
- Evaluated program for lessons learned to apply after the demonstration and seek ongoing funding strategy.
- Extension for a sixth year was requested and approved by CMS for CY 2022.

Status: In progress (5-year demonstration, with approved extension)

Ongoing Work:

- HCA will apply for a five-year renewal of the 1115 waiver that will include MAC and TSOA.
- Continue to promote awareness about these programs for long-term supports and services.
- Stabilize the caseload as we enter the sixth year and beyond.

Project Team: Bea Rector, Susan Engels, 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".

Accomplishments 2019/2020/2021:

- 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 professionals.
- Investigated other state's initiatives focusing on "memory care/specialized dementia care", current rules and regulations, and the work of other legislatively mandated workgroups concerning adult family homes and assisted living in Washington state. This included data from the Attorney General's office, Ombuds and Residential Care Services about dementia-related complaints as well as the Alzheimer's Association Dementia Care Practice Recommendations.
- Narrowed in on problem to address which is - there is not a commonly held definition of "memory care/Specialized Dementia Care (SDC)". No specific nomenclature or minimum requirements of providers that call themselves "memory care". These issues create challenges for consumers in terms of finding and knowing what to expect of such care.
- Developed a plan to further investigate specific issues of nomenclature/terminology, and examples of elements/components deemed important for facilities to identify themselves as "memory care/specialized dementia care".
- In 2021, the project team looked further into nomenclature by reviewing a sample of marketing materials/websites of these facilities in Washington. Findings were that the terms "memory care" and "dementia care" were most frequently used, yet no definition is provided to explain what the terms mean or require.
- In addition, in July 2021, the group developed and fielded a survey for providers of memory care to request their input around the meaning of "memory care" from their perspective. With a 20% return rate on the survey, the findings identified the following elements as important to the concept: training, behavior/behavior management, philosophy, person-centered care, and family connection.

- In November 2021, the group finalized a survey for family caregivers and other care partners that requests their input around their expectations and experiences in seeking and using memory care. The survey is being fielded through December 2021, disseminated through multiple organizations, including the Alzheimer's Association, AARP, AAAs and other DAC contacts.

Status: In progress

Next steps:

- January – March: Close, compile and analyze results of the family and care partner survey.
- April – May: Review and consider implications from results of both surveys.
- June – December: Based on implications, determine potential and recommended actions which might include a consumer guide, improvements to disclosure forms, possible endorsement or other regulatory action, etc.

Project Team: Maureen Linehan/Alyssa Odegaard, Kim Boon, Jeanette Childress, Vicki Elting, Erica Farrell, John Ficker, Amy Freeman, Candace Goehring, Kim Henderson, Laura Hoffman, Patricia Hunter, Lynne Korte, Joel Loiacono, Cathy McAvoy, Vicki McNealley, Lauri St. Ours, Mary Lynn Pannen, Mimi Pattison, Libby Wagner, Jess Welsch, Jamie Teuteberg

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.**

Accomplishments 2019/2020/2021:

- Continue compilation of state/local/regional research efforts.
- Launched a virtual quarterly Alzheimer's Research Network meeting to foster awareness and collaboration. Attendees participate from around the state to share dementia-related research with other researchers and professionals.
- In 2020, seven investigators shared their research with this learning network. Sixty-five interested persons were on the list to attend these quarterly presentations.
- In 2021, nine presenters shared research in five different meetings. Eighty-two different participants attended.

Status: Ongoing

Next Steps:

- Continue to offer a meeting place for the latest in Alzheimer's Research to be shared throughout Washington

- Follow through with current agency contacts, seeking investigators to present and keeping this interested parties list up-to-date.
- Connecting healthcare providers with research opportunity information.

Greatest Challenge: Time constraints due to Covid-19**.** 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 Teuteberg

☐ **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).**

Accomplishment 2019/2021:

- 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.
- In 2020, at request of a community stakeholder, interested community partners met to explore different models of dementia registries and the possibility of establishing a registry for Washington state. In 2021, the group reconvened with additional stakeholders around a dementia registry, considering models from other states. Views and goals around the purpose, scope and thus the funding required for a dementia registry differed widely among stakeholders. Given the ongoing challenges of the pandemic and the differing views, the topic was tabled for the present time.

Status: In progress

Next Steps:

- Consider this topic in the updating of the state Alzheimer's plan.

Project Team: Suman Jayadev, Lynne Korte, Carolyn Parsey, Kris Rhoads, Jamie Teuteberg

For more information

You can find more information on the DAC, the state plan, resources mentioned in this report, as well as a one-page compilation of DAC resources on our DAC webpage.

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