

State Plan for Alzheimer's Disease and Related Dementias in Oregon



Update - May 2015

Goal 1: Enhance Public Awareness & Engagement

Recommendation 1A:

Increase public awareness about Alzheimer's disease and how to access resources that help those impacted by the disease.

Strategies:

1. Identify a marketing firm to develop a public-awareness campaign, coordinated with national efforts to focus on Alzheimer's, to raise awareness of Alzheimer's and where to turn for help.
2. Engage local and statewide organizations to disseminate information to their clients and constituents to raise awareness, with particular focus on reaching multi-cultural, low-income, and rural populations.
3. Ensure that Oregon's Aging and Disability Resource Connection (ADRC) and other statewide organizations serving older adults and their families receive training about dementia and develop clear policies and practices to effectively assist and refer people with the disease and their families to appropriate services.

Achievements:

1. The State Unit on Aging (SUA) received a three-year grant (September 30, 2013–September 29, 2016) from the Administration for Community Living's Alzheimer's Disease Supportive Services Program that is helping to address this goal through funding for outreach and marketing, increased training for ADRC staff, and development of an Alzheimer's website. As of March 31, 2015, 335 staff statewide completed core modules of the training.
2. The 2013 Legislature passed an increase in state funding that increased the number of ADRC options counselors; providing more information resources for Oregonians affected by Alzheimer's.
3. In FY2015 (to-date)¹, the Alzheimer's Association provided 143 education programs addressing the general public, diagnosed individuals and their families, as well as health care and social service professionals, reaching over 1812 participants.
4. The Oregon Care Partners (OCP)², LLC is a consortium of lead organizations working closely with older adults. They received a contract pursuant to the Department of Human Services (DHS) Aging and People with Disabilities (APD) Caregiver Training Initiative, commencing on August 14, 2014 through June 30, 2015. To-date³ 4,000 classes have been completed.
5. Completed a comprehensive catalog of caregiver trainings and a report analyzing current caregiver trainings. The report also provided recommendations including better promotion of existing trainings, expanding respite and adult day service availability, and greater use of technology to provide.

¹ Fiscal Year 2015: July 2014-March 2015

² Funding for several projects and programs in the State Plan were part of a package to spend savings generated by changes to the senior medical deduction (Special Purpose Appropriation "SPA"). SPA funding allocated to provide caregiver training and increase access to training (\$3.3 million)

³ As of April 2015.

Goal 1: *Enhance Public Awareness & Engagement*

Next Steps:

1. Under the ACL grant, close to 100% of ADRC staff will be trained to identify consumers with potential dementia and provide dementia-capable information & assistance, options counseling, care transitions and streamlined access to public services using Oregon's dementia training curriculum and standards by the fall of 2016.
2. Once SUA/APD receives the results from the annual ADRC Consumer Satisfaction phone survey for individuals with dementia and their family caregivers, they will review and analyze them to ensure follow-up is being provided and to identify gaps.
3. OCP and the Alzheimer's Association will continue conducting educational programs addressing the general public, diagnosed individuals and their families, as well as health care, social service professionals, first responders and law enforcement.

Goal 1: Enhance Public Awareness & Engagement

✓ Recommendation 1B: **ACHIEVED**

Create a website that provides a single entry point to link to existing information and resources on Alzheimer's disease and related dementias.

Strategies:

1. Establish a workgroup to develop and maintain a new ADRC information website that provides a single entry point linking the public and professionals to existing local, state, and national information relating to resources and education opportunities.
2. Website should include up-to-date and culturally appropriate information on the various dementias, as well as local resources and services to support people with dementia throughout the disease process (including newly diagnosed individuals and those with young-onset dementia)
3. The workgroup should explore the possibility of including a wiki section of the website as well as a forum section to allow for the development of an online community.

Achievements:

The website launched in May of 2014 as a subsection of the revamped ADRC website. This site has a unique URL to make it easier for people to find the site. The website can be accessed at helpforalz.org.

Goal 2: Optimize Care Quality & Efficiency

Recommendation 2A:

Develop and implement quality standards and measurable outcomes for dementia care in Oregon's long-term care and hospital settings and measure success of existing standards for memory care.

Strategies:

1. Convene a workgroup composed of providers of various settings, advocates, and state-agency staff by December 2012 that would:
 - a. Review examples from Oregon and other states of standards and programs that support people with dementia, such as the recently adopted DHS rules for memory care communities in Oregon,
 - b. Analyze the level of success of DHS rules for memory care communities adopted in 2011.
 - c. Draw upon examples of best practices to develop and adopt quality standards for all long-term care and hospital settings that incorporate person-directed standards and address the common characteristics of people with dementia. Standards and quality measures should address person-directed care and quality of life, as well as other key health and safety areas identified by the committee.
2. Educate providers, advocates, and state agency staff on the new quality standards and methods for implementation.

Achievements:

1. The Standards have been developed. Standards have been reviewed with OLRO and other stakeholders such as providers, advocates, etc.
2. Scenarios have been developed.
3. A comparison tool has been developed for all long term care settings to determine what current rules meet the standards and which rules need to be enhanced. This tool has been shared with OLRO.

Next Steps

1. Revised audit tools are being developed and sent to core workgroup. Core workgroup has met and will continue to meet to review and analyze the revised audit and comparison tools
2. We are considering next steps specific to rule making.

Goal 2: Optimize Care Quality & Efficiency

Recommendation 2B:

Ensure that Oregon has a dementia-capable licensed health care workforce.

Strategies:

1. Establish a workgroup to create a strategy to grow the provider workforce and improve its skill levels. This work group will:
 - a. Recommend ways to integrate basic dementia education into the curricula in all schools teaching healthcare-related subjects in Oregon, from trade schools through undergraduate and graduate schools.
 - b. Work with professional healthcare licensing boards and organizations whose licensees and members provide services to people with dementia-specific training in continuing education opportunities for their licensees and members. The work group will explore establishing ongoing requirements and incentives for continuing education about dementia at a determined interval for professionals in long-term care settings and those working with the elderly in hospitals.
 - c. Recommend ways to increase the size of the workforce that provides services to people with dementia and their families, at all levels of care and service provision.
2. Promote statewide educational conferences and events about dementia to educate Oregonians. Encourage healthcare organizations to promote the availability of information about dementia by expanding the number and kind of places that organizations attend and distribute information and talk with Oregonians about dementia.

The Recommendation 2.B workgroup met for some time as a larger group before splitting into three workgroups to develop suggested protocols for health care professionals to follow when dementia is (or may be an issue). These subgroups focused on:

- Responsibilities of medical/health care professionals in terms of screening, diagnosis, and/or referral (if needed)
- Challenges family members frequently experience and their right to an accurate and timely diagnosis
- Ensuring that the personhood of each individual with dementia is honored during clinical experiences and beyond. Eventually the family and personhood workgroups joined to work together.

Achievements:

1. As of April 2015, the 2.B team has developed three draft algorithms: one for health care providers and two for families and other health care representatives. These algorithms are nearing completion.
 - The algorithm for medical professionals is based on the Alzheimer's Association's Medicare Annual Wellness Visit Algorithm for Cognitive Assessment. It also includes resources to help physicians to better understand how to code and bill for services related to dementia. (http://www.alz.org/documents_custom/awv_algorithm_web.pdf)

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- The algorithms for families and other health care representatives is designed to give families and people with dementia a sense of what to expect both pre- and post-diagnosis, as well as to help them understand their right to an accurate and timely diagnosis. This also contains links to resources geared toward issues families may face.

Next Steps:

At this point, the workgroup has completed the algorithms and has developed a two-tier plan to vet the algorithms with physicians who are willing to train on them and recruit other practitioners to use these tools. Following is the timeframe for this plan:

Tier 1: (May through July 2015)

- 5-6 presentations given by Drs. Pat Gillette, Sarah Goodlin & Marian Hodges
- Provide audiences with 3 – 4 general questions regarding usefulness of algorithm and screening tools.
- At those sessions request for volunteer practitioners to utilize the algorithm and tools and provide feedback. Ask for office contacts.
- Develop the “Packet” (algorithm & tools) that will be sent to practitioners or their office contacts.

Tier 2: (August – September)

- The “Packet” to Practitioners/office contacts;
- Practitioners will pilot the tool (hoping for 50 to 75 patients)
- A survey via Survey Monkey will be sent to the practitioner or their designated office contact to complete the survey.
- Analyze information to determine what changes need to be made to the algorithm and to the training.

Goal 3: *Protect Individuals with Dementia*

Recommendation 3A:

Require that all Oregon guardians, both family and professional, receive training on dementia, as well as on the responsibilities and ethics of representing a person with dementia.⁴

Strategies:

1. Collaborate with a broad set of stakeholders to develop a comprehensive training package that includes dementia as one element of mandatory training for existing guardians and all new guardians appointed in Oregon
2. Develop a pilot training on dementia and guardianship and provide it online as a voluntary training for guardians until a mandatory training package is established

Achievements:

1. The 2014 legislature established a statewide public guardian program, the guardian stakeholder collaborative, Working Interdisciplinary Network of Guardian Stakeholders (WINGS), continues to meet and comprehensively address broad fiduciary issues.
WINGS work groups developed the following:
 - a. A brochure, “Guardianship Issues Explained in Brief for Medical and Other Care Professionals”
 - b. A mini-booklet, “Options in Oregon to Help Another Person Make Decisions,”
 - c. A tool for first year guardians to conduct person-centered planning for protected persons
2. The Multnomah County based nonprofit, Special Advocates for Vulnerable Oregonians (SAVO), recently hired its first Program Manager while also officially expanding its mission to encompass mandatory training for non-professional guardians.
3. In coordination with a Multnomah County Circuit Court mandate, all non-professional guardians must now complete, as of July 15, 2014, a SAVO provided training course within 60 days of court appointment as guardian. (see: savooregon.org/Oregon-fiduciary-101/)
4. The SAVO training has been piloted and delivered once a month beginning August 2014. Twenty-eight of the students were non-professional guardians.
5. Professional fiduciaries in Oregon are now required to be certified as of January 2014 following legislation passed in 2013.

Next Steps:

1. Collaboration between Alzheimer’s Association and SAVO to ensure once guardians are trained they are provided with resources and connection to trainings on dementia offered by the Alzheimer’s Association
2. Oregon’s WINGS collaborative expects to support SAVO or SAVO-like approaches, including the mandatory training, for expansion into other jurisdictions across the state.

⁴ SPA funding allocated toward Public Guardianship Program (approx. \$1 million)

Goal 3: *Protect Individuals with Dementia*

Recommendation 3B:

Expand capacity to protect the safety and well-being of individuals with dementia.

Strategies:

1. Increase transportation options for individuals with dementia by ensuring that the needs of individuals with dementia and their families are considered in planning decisions by state and local transportation agencies, and by expanding volunteer and state/federal options available to support their transportation needs.
2. Establish a stakeholder work group to determine how to protect residents of assisted-living facilities and residential-care Facilities that terminate their Medicaid contracts from being negatively impacted by the contract termination.
3. Secure state and/or federal funding to expand the Gatekeeper Program statewide through existing Area Agencies on Aging or other aging-services partners in each community. Gatekeeper programs train identified community members, such as letter carriers, meter readers, bank tellers, and trash haulers, about ways to identify potential harm to at-risk older adults and how to alert existing services.

Achievements:

1. Funding appropriated toward expanding rural transportation needs for seniors and people with disabilities.⁵
2. Gatekeeper Program expanded statewide.⁶ Funding was provided to the nine ADRC's in 2014. Seven Gatekeeper programs started in July 2014. Most ADRC's have designated regional coordinators and they have begun to train potential gatekeepers and taking calls from referral sources. As of April 2015, referrals were made by 208 community partners and more than 2,200 individuals have been trained. By the end of the biennium, the program will be available in all 36 counties. The ADRCs are operating the programs in each region.
3. The State Unit on Aging has also set up a central webpage to provide resources to Gatekeeper programs <http://www.oregon.gov/dhs/spwpd/Pages/SUA-Gatekeeper.aspx>.

Next Steps:

1. Meet with transportation stakeholders to understand how the additional funding directly impacted rural transportation needs for seniors and people with disabilities
2. Continue evaluating the growth of transportation options
3. Coordinate a meeting with stakeholders to establish stakeholder work group and identify group leader, to determine how to protect residents of assisted-living facilities and residential-care facilities that terminate their Medicaid contracts from being negatively impacted by the contract termination.

⁵ \$9 million was allocated for transportation needs for seniors from SPA

⁶ \$1.7 million allocated for Gatekeeper Program

Goal 4: Improve Access to Quality Care

Recommendation 4A:

Develop appropriate care settings and services for persons with dementia who require a higher level of expertise and staff in helping manage their significant behavioral needs.

Strategies:

1. Establish a workgroup to:
 - a. Evaluate existing settings and services that have traditionally supported individuals with ADRD who have serious behavior needs and identify the issues that prevent finding appropriate support or placement for them.
 - b. Review current models either within Oregon or from other states that have proven to be best practices and cost effective.
 - c. Develop proposals for model(s) to serve this population, including an economic analysis of the proposed models and suggestions on how to fund them.
 - d. Determine if there is a need for legislation, additional administrative rules or changes to current rules.

Achievements:

1. DHS/APD has been very active in developing settings and services for people with dementia who exhibit significant behaviors. This is partly due to not only prevent move-outs related to behaviors, but also because the Oregon State Hospital conducts a very extensive screening for individuals who have a diagnosis with dementia other settings needed to be developed that can appropriately support this population.
2. DHS/APD has developed special needs contracts with APD Medicaid providers of residential care facilities and adult foster homes that ensure there are a certain number of beds and person centered support services for persons with dementia who have significant behavioral needs.
3. DHS provides Behavior Support Services (BSS) as part of the Medicaid funded Community First Choice State Plan option to provide support within a person's environment and improve interactions between the person with dementia and their caregivers. This service can be provided in home and community based settings through a referral with the person's case manager. It is also a required service in some of the settings that have special needs contracts.

Next Steps:

1. Ongoing evaluation of the effectiveness of the care settings and services

Goal 4: *Improve Access to Quality Care*

Recommendation 4B:

Increase access to medical care providers who serve those with Alzheimer's and related dementia.

Strategies:

1. Develop and maintain a statewide list on the central Alzheimer's website of health care providers who serve those with dementia, including providers in primary care, geriatrics, psychiatry, and neurology.
2. Create a work group to identify ways to expand utilization of telemedicine and other technology to keep healthcare providers updated on current treatment developments, and increase access to rural areas to expertise in other areas.

Achievements:

The Oregon Health & Science University (OHSU) C. Rex and Ruth H. Layton Center was found in 1989 by a group of individuals committed to high-quality dementia care and research. It is now one of 29 National Institutes of Health funded Alzheimer's Disease Centers in the US, and the only one in Oregon. An important mission of the Layton Center is to increase access to specialty care for patients with dementia. Two ways that the Layton Center members have been working towards this goal is by use of telemedicine technologies to increase access to specialty care for patients with dementia and by efforts to training future dementia specialists to meet the ever-growing national need.

1. Telemedicine:

Alzheimer's disease and related dementias directly affect one in three Oregonians, and innovative programs including use of telemedicine technologies are clearly needed to address this public health issue. Members of the Layton Center developed telemedicine programs to address this need.

The Layton Center recently developed a telemedicine program: the Alzheimer's Care via Telemedicine for Oregon (ACT-ON). This project, funded through the Oregon Health Authority's federal State Innovation Model (SIM) grant, is designed to assess the feasibility of providing direct-to-home dementia care. ACT-ON will improve care for persons with dementia by facilitating access to specialists and improving medical and mental health management for patients and caregivers. ACT-ON will reduce costs due to travel or lost workdays for caregivers, and prevent avoidable crisis care through more timely management of the disease. Unlike previous attempts at telemedicine, ACT-ON's in-home care will not require travel to a regional facility in order to connect with specialists.

Goal 4: *Improve Access to Quality Care*

2. Training:

Every year, neurologists, nurses, neuropsychologists, and researchers at the Layton Center train new professionals in dementia care. Since its inception, the Layton Center has trained over 50 neurology residents, 20 fellows, and numerous medical students. The training program involves careful instruction in dementia diagnosis, cognitive evaluation, and management of chronic dementia concerns (e.g., behavioral symptom management, caregiver burden). Trainees are provided with examples of hands-on care and experience first-hand how dementia affects patients and families, which they can incorporate in their future careers as health care providers.

Along with training new professionals, the Layton team also provides lectures in the community to primary care providers, social workers, nurses and other professionals caring for individuals with dementia to refine providers' knowledge about dementia diagnosis and management. Layton neurologists, researchers and nurses have provided over 100 lectures in the past decade, addressing dementia diagnosis, care, and prevention.

In collaboration with the Alzheimer's Association, the Layton Center runs a monthly Memory Workshop, free of charge, where any member of the community can attend and have direct access to experts, including a social worker, a nurse and a dementia expert clinician to learn more about medical, legal and social aspects of dementia.

3. Outreach:

Recognizing the value of cross-culture access, the Layton Center supports the work of PreSERVE, a coalition of academicians and community members who work to promote the health of African Americans in Oregon. Since 2011, the Layton Center has contributed to the success of two community conferences, which focused on brain health for African Americans. Among attendees were health care professionals who learned about dementia-prevention, the role of depression in dementia, and strategies which encourage African Americans to participate in research.

Next Steps:

1. Fund Telemedicine Access:

The ACT-ON pilot is limited in scope. Along with establishing feasibility, the goals include identifying sources of funding for visits once the pilot is complete. Currently, families who will want this service will need to pay out of pocket because direct-to-home telemedicine care is not covered by Medicare. In accordance with our payor agreements, OHSU is required to bill for all patient care. OHSU does offer charity care to patients that meet certain criteria. We offer this charity care on a sliding scale after patient's ability to pay is evaluated. Nonetheless, the average cost of one telemedicine visit is over \$300.00. This further exacerbates the access problem in that, while rural access may be improved, financial access will be limited. A short-term solution would be for SPADO to provide coupons to families with dementia to supplement the out-of-pocket costs. Long term strategies would include working with the Federal government to remove restrictions on telemedicine care for Medicare recipients.

Goal 4: *Improve Access to Quality Care*

2. Increase Access to Specialty Care:

The Layton Center has played an important role in training future professionals. However, more specialists are needed to care for the 60,000-plus Oregonians with dementia. Strategies should focus on training clinicians outside of the metro areas. This could be accomplished using telemedicine technology. For example, Layton specialists could “attend” patient visits via a remote connection, then provide feedback to the remote clinician on diagnostic strategies, cognitive evaluation, and long-term management issues. Another approach includes quarterly meetings where rural clinicians can attend telemedicine consultation meetings where a dementia expert is present to answer patient management issues and discuss specific cases.

Access to specialty care could be improved by continuing our efforts to reach, and teach, community providers. The educational scope could be widened to include rural institutions such as the Western University of Health Sciences College of Osteopathic Medicine in Lebanon, Oregon, or the OHSU School of Nursing in La Grande. However, educational missions should not depend solely on volunteer efforts and should include reimbursement for professional effort.

Summary:

The OHSU Layton Center has improved access to specialty dementia-care in Oregon. However, the Center’s work is constrained by limited funding and regulations for patient care. Specialty care needs to be affordable and accessible across the entire state.

Goal 5: *Comprehend, Prevent, & Effectively Treat Dementia & Its Impact*

Recommendation 5A:

Establish a coordinated data system to improve Oregon's ability to plan for and provide effective resources regarding Alzheimer's disease and related dementias.⁷

Strategies:

1. Create a work group of stakeholders to identify existing data, identify gaps, and design and implement a system that ensures data can be collected, analyzed, and reported to guide policy and funding decisions related to dementia care in Oregon.
2. Increase public-health surveillance and analysis of impacts of ADRD and caregiving in Oregon using the Behavioral Risk Factor Surveillance System (BRFSS) cognitive impairment and caregiver modules. Explore use of other existing data sources available that are related to state-funded medical and long-term care services.
3. Assess current capacity (including Medicaid-eligible) in licensed long-term care settings that serve people with dementia in Oregon to determine availability and potential gaps in this service statewide.

Achievements:

1. Alzheimer's and Dementia Data Source materials developed due to working group and intern. Data available at: <https://adrcforegon.org/consite/explore-alzheimers-disease-and-related-dementias-research.php>.
2. Cognitive Impairment and Caregiving modules of the Behavioral Risk Factor Surveillance System (BRFSS) have been collected in 2012 and 2013. Data has been analyzed for 2012 and shared with lawmakers and other stakeholders through a range of mechanism.
3. In 2013-2014, state legislators funded BRFSS at 50,599 per year on an ongoing basis through OHA.

Next Steps:

1. Cognitive Impairment and Caregiving modules will be conducted in 2015. Including panel groups to bring in more data for diverse communities.
2. On-going data analysis, determination of usage mechanisms and information distribution.

⁷ SPA funding allocation toward BRFSS (ongoing) in the amount of \$50,599.

Goal 5: *Comprehend, Prevent, & Effectively Treat Dementia & Its Impact*

Recommendation 5B:

Expand existing dementia research and participation in Oregon research.

Strategies:

1. Create an online list of all current state and national dementia-related research in order to increase the number of Oregonians participating in Alzheimer's research trials.
2. Promote increased use of the state income tax check off through a publicity campaign.

✓ Achievements (5.B.1): **ACHIEVED**

1. A spreadsheet of more than 200 research projects was created that includes the name of the project, funding sources, whether the project is recruiting clinical trial participants, and other details.

Achievements (5.B.2):

1. Raised \$18,000 in donations for 2014 tax year.
2. Postcards and posters distributed to OHSU, OPAR and SPADO networks, policy makers, ADRC's and Alzheimer's Association newsletters/events. Social media was also utilized to promote check off donations.
3. A review of the history of the Alzheimer's Research Fund in 2013 revealed that revenues received by Oregon researchers who launched their career projects using tax check-off pilot funds have exceeded 30 times the investment by Oregon Taxpayers over the history of the program.

Challenges:

1. 2014 tax year resulted in the lowest revenue of any year for Alzheimer's Research. Over the years, many more well-known charities have been added to the Charitable Check off program, creating increased competition for tax refund donor attention and dollars. Additionally, because the program now includes so many charities, a third of the charities are omitted from the list on the form on a two year rotation. Despite the fact that people may still donate to any tax check-off charity, the decreased visibility results in drastic decreases in revenue.
2. The Fund for Alzheimer's Research was one of the founding funds of the Charitable Check-off program over 20 years ago. The Fund was established solely for this opportunity, recognized as a good investment for our State by the legislature that initiated the program. All funds generated through tax check-off donations go directly to research; none are used for administration. The Fund and its governing Partnership do not have an infrastructure for raising other revenues, or for supporting publicity campaigns. A very small separate account holds monies donated to the Fund apart from the tax-check off mechanism; this account provides the occasional support for printing or other publicity efforts, and augments the research grants on the leanest years.

Goal 5: *Comprehend, Prevent, & Effectively Treat Dementia & Its Impact*

Next Steps:

1. Identify an intern/student to conduct outreach to CPAs (via Associations and other networks), possibly do presentations to community groups
2. Continue public awareness/outreach through volunteer networks.
3. SPADO-IT to brainstorm other publicity methods or structures to support this fund, as competition from other charities with greater resources for promotion on the now long tax check off list has eroded support over the years, particularly during years that Alzheimer's research is not on the form.
4. Discuss options regarding increased research funding with lawmakers.