

Washington State Dementia Action Collaborative

- Formerly the Alzheimer’s Disease Working Group
- Charter, Update 2018-2020

Mission and Vision

Alzheimer’s disease is the 3rd leading age-adjusted cause of death in Washington State. While death rates of cancer, stroke and heart disease have declined, the death rate for Alzheimer’s is on the rise. In 2016, about 107,000 people in Washington have Alzheimer’s or other dementias. By 2040, that number is expected to grow to over 270,000. This increasing prevalence is an urgent call for action.

In 2014, advocates led legislation that established an Alzheimer’s Disease Working Group (ADWG) to create a state plan to address Alzheimer’s disease. This plan, released in January 2016 identifies goals, strategies and recommendations as a starting point for action.

The ADWG developed the first Washington State’s Plan to Address Alzheimer’s Disease and Other Dementias as a public-private partnership. Its implementation – including action planning, next steps, and policy changes – depends upon the participation and contributions of a broad group of committed partners. This next generation workgroup is action oriented - a voluntary statewide collaboration committed to preparing our state for the future. To reflect this, the group will transition to a new name - the **Dementia Action Collaborative**.

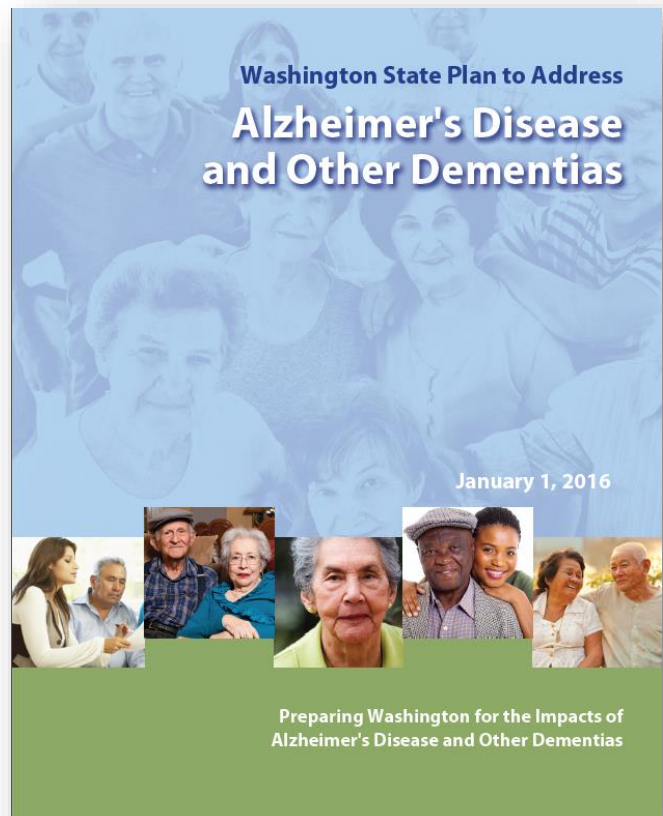
See [State Plan](#).

This group **envisions** a future that fosters hope and empowerment for Washingtonians with Alzheimer’s disease, one in which they and their families will receive the support and care they need through early detection and diagnosis, dementia-capable health and long term supports and services and communities that are prepared to meet their needs.

A Call to Action

The plan assumes that changes can be made within or built upon the existing systems of care and services, yet also acknowledges the need for new actions and accountability. The original ADWG group recognizes that the strategies and recommendations in this plan cannot be accomplished by any single organization. They cannot be accomplished by state government alone.

Update 2018



The original ADWG issued a Call to Action:

- To establish a next generation Alzheimer’s Disease/Dementia Action Advisory Group to provide guidance and oversight to state plan implementation.
- To collectively pursue the proposed goals, strategies and recommendations
- To engage and sustain commitment from a network of public and private partners
- To integrate activities into broader initiatives that are addressing improved health and quality of life such as Healthier Washington, Medicaid Transformation Waiver and the Bree Collaborative End of Life Care Recommendations.
- To identify opportunities to improve our state’s response to dementia.

Organizational Structure and Roles

Organizational structure and roles are outlined below:

- **Dementia Action Collaborative (formerly the Alzheimer’s Disease Working Group/ADWG).** This group is responsible for providing leadership and direction for implementation of the overall state plan, providing a coordinating point for implementation activities, identifying strategies to address issues that overlap topic areas, developing action steps for recommendations that do not require legislative action, establishing and advising subcommittees to guide/support successful implementation, preparing a periodic progress report, and informing partners as new opportunities and knowledge emerge. The group will meet 2-3 times a year. Terms of service will be two to three years, to be determined by individual willingness to participate, with the intention of balancing the group so that not all terms expire at the same time.
- **Chair, Dementia Action Collaborative (DAC).** Will convene meetings of the full Advisory Group and will serve on the AD Plan Steering/Planning Team, guiding and providing direction for the overall efforts of the Dementia Action Collaborative. Will also serve as external spokesperson for the DAC as needed. **[Chair is currently Bill Moss, Aging and Long Term Support Administration, DSHS.]**
- **Dementia Action Collaborative Steering (Planning) Team.** The Chair will be supported by a Steering Team to include administrative representation from DSHS, DOH, HCA, Alzheimer’s Association and the Governor’s Office. This Steering Team will include a link with the Joint Executive Committee on Aging & Disability, and with the Chairpersons of any subcommittees developed within the Dementia Action Collaborative.

At the outset, this team will provide in-kind resources to maintain basic infrastructure for plan implementation. The role of this team includes monitoring overall work process, preparing agendas for DAC meetings, making decisions on cross-cutting issues across goals and subcommittees, and identifying issues for the DAC as needed.

- **Subcommittees.**
- Three topic-focused subcommittees are established. The subcommittees are :
 - Public Awareness and Community Readiness (includes community outreach/education and safety); focused on Goals 1, 2 and 3 of the plan
 - Health and Medical Care; focused on Goals 5 and 7 of the plan

- Long-Term Supports and Services; focused on goals 4 and 6 of the plan

The DAC has also formed an Advocacy subcommittee/team.

Subcommittees will be made up of DAC members and may include additional people who are part of an organization or coalition working to address one or more of the goals in the state AD Plan. The role of the subcommittees is to implement or support the implementation of specific recommendations identified in the plan that are assigned to their committee by the Steering Team. This includes developing an implementation plan, to include sequencing/prioritizing work, determining leaders and teams for each recommendation, identifying action steps and success measures; and, executing the implementation plan. The subcommittees will meet as determined by the subcommittee chair, most likely every one to two months.

- **Subcommittee Chairs.** Subcommittee chairs will be project leaders focused on implementing the short-term recommendations identified in the plan. They will advise, direct and track the work of the subcommittee members. They will report periodically to the Plan Coordinator and seek advice and guidance from the Plan Coordinator as necessary.

Subcommittee Chairs will be appointed by the Steering Team. They:

- Initiate subcommittee meetings,
- Follow up with individuals to monitor progress, and
- Organize the work of their subcommittee.

Subcommittee Chairs will figure out efficient, effective ways to advance the plan recommendations.

Subcommittee Chairs will attend Steering Team meetings. Above all, they are collaborators who share the vision of the plan and are committed to advancing the plan's goals, strategies and recommendations.

- **Organizational Support.** Organizational support is critical to successful collaborative action. Currently no funding is allotted toward implementation steps. DSHS has agreed, for the initial years, to provide staff support toward convening the ongoing advisory group (see below, Plan Coordinator), with assistance from private partner, the Alzheimer's Association. Moving forward, the goal is to implement recommendations possible with existing resources through heightened collaborative work. The group recognizes that implementing some of the other recommendations will require increased staff resources and funding to be fully executed.
- **Plan Coordinator and Support Staff.** The plan coordinator (PC) is responsible for working with the Dementia Action Collaborative, Steering Team, Subcommittee Chairs and DAC staff. The PC provides operations support to facilitate the effective operation of the DAC. This includes working with the Chair, Steering Team and DAC staff to prepare meeting agendas and facilitate internal communications; conveying guidance from the Steering Team to the subcommittees, and offering advice, support, and guidance to subcommittee Chairs in their active leadership role. The PC will provide status reports to the Steering Team about implementation progress, and draft periodic progress reports to be submitted to the full DAC organizational executives and the legislature, as directed by the Steering Team. **[Lynne Korte is current Plan Coordinator]**

The Alzheimer's Association will provide administrative and technical support for subcommittee meetings, and is responsible for production and dissemination of meeting notes/minutes.

Funding was provided, beginning July 1, 2018, for part-time staff at each of the following agencies to support the implementation of the state plan: Department of Health (DOH), Department of Social and Health Services (Aging and Long-Term Support Administration and Developmental Disabilities Administration), and the Health Care Authority (HCA). These positions are intended to work with the Plan Coordinator, one another, 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.

Participating Member Expectations

The group is made up of members from various disciplines, perspectives and sectors who agree to serve on the Dementia Action Collaborative and/or its subcommittees. Expectations include the following:

- **Term of appointment/service.** Members commit to a two to three year term of participation, beginning in April 2016.
- **Subcommittee participation.** Members of the Dementia Action Collaborative will serve on a minimum of one of the subcommittees.
- **Meeting attendance.** Each member will attend each meeting, either in person or via electronic means, to the best of their ability. If a member cannot attend a meeting by either means, s/he may send a representative to observe (but who may not vote on issues).
- **Resourcefulness/travel expenses.** With no identified funding available for implementation:
 - Members representing agencies or organizations are requested to consider their travel expenses as in-kind contributions to the effort. Consumer representatives are offered reimbursement for travel expenses to/from related meetings.
 - Organizers will use complimentary meeting spaces for meetings of the DAC and subcommittees, and web- or tele-conference options as needed.
 - Members will help to identify resources, either within their organization or potential resources available within their networks, to foster successful implementation of the state plan recommendations.
- **Addition of new membership.** Members of the DAC are appointed by the Chair (Assistant Secretary of Aging and Long Term Support Administration), in line with original membership set forth in the legislation creating the Alzheimer's Disease Working Group (SSB 6124), with additional representation needs identified by the ADWG/DAC and Steering Team.

New representative membership for the full DAC may be recommended to the Steering Team for consideration. New subcommittee participants may be added based upon the needs of the subcommittees and with approval of the subcommittee Chair.

As of August 2018, individuals that have been recruited or who express interest in participating on a subcommittee or project team will complete the DAC Information & Application Form – which should be forwarded to the Plan Coordinator.

- **Decision Making.** Decisions will, whenever possible, be reached through consensus. Consensus based decision making means group members agree to support a decision, even if not one's first choice. Part of a strong consensus tradition is to allow members to abstain or stand aside as a decision is being reached. In cases where the group cannot reach consensus it will be important to record opinions of dissenters. If, after due discussion consensus cannot be reached, a vote will be taken. Simple majority rules will apply.

Project Objectives and Timeline – 2018 - 2020

- 1) The state plan indicates that short-term recommendations will be initiated within two years, and mid-term recommendations within 3-4 years. Subcommittees will develop detailed plans and initiate implementation of the short- and mid-term recommendations to address Alzheimer's disease in Washington State. The original ADWG identified short-term recommendations that had potential to be initiated within existing funding – these were identified as “Start Now” recommendations.
 - a) The Steering Team will review the short- and mid-term recommendations and identify those appropriate for subcommittees to implement, along with suggested priorities.
 - b) Subcommittees will each determine their priorities for the next year and develop detailed implementation plans for identified recommendations.
 - c) Work collaboratively as a public-private partnership to ensure the recommendations are implemented as intended, in the most user-friendly and cost-effective manner.
 - d) Initiate action on the detailed implementation plans.
- 2) Track and report on progress made.
 - a) Periodically report progress on the plan recommendations to the PC.
 - b) Develop periodic reports to show progress made on the plan.
 - c) Distribute progress reports to the legislature, organizational executives, other stakeholder groups and the public.
 - d) Identify and pursue human and financial resources necessary to achieve plan goals, strategies, and recommendations.

Project Constraints

- Subcommittee Chairs are volunteers, as are subcommittee members.