Alzheimer's Disease & Related Dementias Strategic Plan for Idaho

2023-2028





We, in Idaho, recognize the importance of brain health and wellness for all ages, and unite to provide an unrivaled level of coordinated support and care for individuals and families facing the challenges of Alzheimer's and related dementias.

We take this journey together.

Acknowledgments

This Alzheimer's Disease and Related Dementias (ADRD) Five Year Strategic Plan for Idaho, 2023-2028 (known throughout as the 2023-2028 ADRD Plan for Idaho), is possible thanks to the champions and advocates throughout Idaho who made this plan a reality; including family caregivers and persons with dementia.

Special thanks to Governor Little and the Idaho Legislature for their foresight in recognizing the significance of the growing challenges of ADRD in Idaho and the wisdom to identify ADRD as a priority by funding the Idaho ADRD Program. Many devoted Idahoans serve on the ADRD Alliance, Marketing Workgroup, and Steering Committee, including individuals representing private, non-profit, public entities, and expertise in various fields. The Alliance and the process to create this plan are managed by the Idaho Department of Health and Welfare's ADRD Program and facilitated by Interaction International, Inc.

And finally, thank you to the ADRD Strategic Planning Subcommittee who worked tirelessly on sifting through information, word-wrangling, and making sure the hard work got done. This work aided the ADRD Alliance members in building a successful strategic plan Idahoans can be proud of.

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Table of Contents

Acknowledgments	. 2
Stakeholders and Community Members Letter	. 4
Strategic Planning Subcommittee Members	. 5
Acronyms	. 6
Definitions	. 6
Introduction	. 8
Background	. 9
Critical Success Factors, Strategies, and Goals	.12
Critical Success Factor #1: Awareness of Brain Health and Wellness and Benefits of Early Detection	13
Critical Success Factor #2: Proactive Actions to Improve Quality of Life	14
Critical Success Factor #3: Training for Healthcare Professionals	. 15
Critical Success Factor #4: Training for Others in the Community	. 16
Critical Success Factor #5: Caregiver Supports	17
Critical Success Factor #6: Access and Equity-Enabling Factors: Systems, Funding, Etc.	. 18
Critical Success Factor #7: Strengthening Workforce	. 19
Next Steps	20
References	21

Dear Alzheimer's Disease and Related Dementias (ADRD) Stakeholders and Community Members,

It is with great enthusiasm and pride that we present to you the 2023-2028 ADRD Plan for Idaho! Many of you were kind enough to support its development and we want to express our sincere gratitude for all your collaboration, participation, and support during this process. This plan has been in development for 13 months and its goal is not just to provide a strategic roadmap to help all of us increase awareness of ADRD and improve brain health in our communities, but to help hold us all accountable to the goals set forth.

The ADRD Program developed a website healthandwelfare.idaho.gov/
ADRDstrategicplan specifically for this strategic plan to make it easily accessible and convenient to read. We invite you to read it and take part in helping Idaho address ADRD and brain health. If you would like more information and education on ADRD in Idaho, we encourage you to also review a companion document to the plan, Alzheimer's Disease and Related Dementias (ADRD) in Idaho: Developing the 2023-2028 Strategic Plan.

For now, read on and know we are very grateful for your continued support and participation in this very important work.

Sincerely,

Tiffany Robb, MHS (She/her)

Chair, Alzheimer's Disease and Related Dementias (ADRD) Alliance,

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Acronyms

ADRD - Alzheimer's disease and related dementias

CDC - Centers for Disease Control and Prevention

DPH - Division of Public Health

OPE - Office of Performance Evaluation

PWD - Person or people with dementia

PCP - Primary care provider

SMART - Specific, Measurable, Achievable, Relevant, Time-Based

Definitions

Alzheimer's disease: a disease that slowly damages the neurons within the brain, identified by the buildup of plaques and proteins within the brain that over time cause damage and may attribute to shrinkage of white matter.

Alzheimer's dementia: the progression of Alzheimer's disease to the stage a person's cognitive ability is impaired.

Brain health: is enhancing the health and function of a person's brain beyond avoiding disease.

Cognition: the function of language, memory, thinking, and behavior.

Cognitive decline: the function of language, memory, thinking, and behavior interfering with daily living tasks.

Critical success factors: elements set forth that must be accomplished to achieve the overall vision.

Dementia: an umbrella term for cognitive symptoms characterized by noticeable memory, language, thinking, or behavioral symptoms that impair a person's ability to perform activities of daily living.

Family caregiver: an extension of the healthcare system, family or friends who provide services or support to an individual, assisting them with activities of daily living and serve as care coordinators and advocates.



Mild cognitive impairment: changes in memory, language, and thinking but not the person's ability to perform daily tasks.

Other dementias: could be, but are not limited to, vascular dementia, Lewy Bodies dementia, Parkinson's dementia, Frontotemporal dementia, Huntington's disease, and dementia associated with Down syndrome, intellectual and developmental disabilities, post-traumatic stress disorder, traumatic brain injury/concussions, and alcoholism.

Public health approach: involves defining and measuring the problem, determining the cause or risk factors for the problem, determining how to prevent or delay the problem, and implementing effective strategies on a larger scale and evaluating the impact.

Level of Prevention Model: a theoretical way of understanding the continuum of disease and the idea of promoting health and arresting the disease process at three different points along the continuum; primary, secondary, and tertiary levels of prevention.

Risk factors: characteristics at the biological, community, cultural, family, and psychological level that lead to, and are associated with, a higher probability of negative outcomes.



Introduction

This plan identifies gaps between the needs of individuals and the services available, strategic short- and long-term goals, and provides a starting point as we prepare for the next five years and beyond.

This 2023-2028 ADRD Plan for Idaho recognizes opportunities to make positive changes, offering hope for living better with dementia by promoting early detection and better management of the disease, protecting persons with dementia (PWD) from abuse, neglect, and exploitation, expanding cost-effective services for PWD and their family caregivers, preparing communities for a better response to dementia, and improving the dementia-capability of long-term supports and services.

Background

Idaho is home to 1,900,923 individuals, including tribal members from the Coeur d'Alene, Kootenai Tribe of Idaho, Nez Perce, Northwest Band of the Shoshone Nation, Shoshone Bannock Tribes, and the Shoshone-Paiute Tribes: spanning over 82,643 square miles of mountainous high desert land (United States Census Bureau, 2021).

Every corner of Idaho is touched by Alzheimer's and other dementias. The impact in Idaho is greatest on individuals and families who bear the emotional and financial responsibility, on businesses through lost productivity of family caregivers, and on local communities and the State that incur significant costs for care and services. As of 2020, Idaho had an estimated 27,000 individuals with a diagnosis of Alzheimer's disease (Alzheimer's Association, 2023). Unfortunately, there are no estimates of the total number of Idahoans with a related dementia diagnosis as it tends to be underdiagnosed and underreported on death certificates. It is estimated that if all types of dementia were grouped together, dementia would be the 3rd leading cause of death in Idaho (Bureau Vital Records and Health Statistics, 2016). Even so, in Idaho alone, \$149 million was paid by Medicaid (2020) and an estimated \$638.8 million was paid by Medicare (2022) for services and supports for persons with Alzheimer's and related dementias. The combination of a steadily increasing older population and the intensified likelihood of dementia with advanced age, will lead to a significant increase of Idahoans, estimated at 33,000 by 2025, diagnosed with Alzheimer's (Alzheimer's Association, 2023).

A person with an ADRD diagnosis (identified throughout this plan as person with dementia or PWD) may require assistance with daily living activities. Currently in Idaho, 65,000 family or informal caregivers of those with dementia provide unpaid care totaling \$1,848,000,000 (Alzheimer's Association, 2023). Many of these caregivers work a full or part-time job in addition to providing care. The steady increase in care required by a PWD forces many family caregivers into early retirement and leaving the workforce, especially as the number of memory units and beds in Idaho are limited and unaffordable for the average Idahoan.

In response to an assessment and report conducted in 2021 by the Office of Performance Evaluation (OPE), the Idaho legislature with the support of Governor Brad Little, recognized the need to invest in Idaho's ADRD response and established the ADRD Program housed within the

To learn more, please refer to the Alzheimer's Disease and Related Dementias (ADRD) in Idaho: Developing the 2023-2028 Strategic Plan. The document will provide history, planning process, detail on data, and justifications of determining the critical success factors outlined in this 2023-2028 strategic plan.

Idaho Department of Health and Welfare, Division of Public Health (DPH). The intention of placing the ADRD Program within DPH was not just to address the 27,000 Idahoans with Alzheimer's or their 65,000 family caregivers, but to recognize that:



Informing Idahoans that they can take action to improve brain health and wellness and reduce the risk of future dementia in 40% of dementia cases.



Informing Idahoans of the signs of dementia and the benefits of receiving an early diagnosis increases their ability to self-determine future care, identify supports earlier, and save costs (Alzheimer's Association, 2018).

In 2021, a statewide ADRD Alliance was formed, and a revision of the 2013 State Plan for Alzheimer's Disease and Related Dementias began.

To ensure the ADRD Alliance was prepared, the ADRD Program provided the most current Behavioral Risk Factor Surveillance System data, information on Idaho's most at-risk populations, and other guiding documents. Those documents were the

- 2013 ADRD Strategic Plan for Idaho
- 2020 State Response to Alzheimer's and Related Dementias: OPE Report
- 2022 ADRD Landscape Analysis and Needs-Based Assessment
- Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative Road Map
- CDC Healthy Brain Initiative Road Map for Indian Country
- Association of State and Territorial Health Officials State Plan Guidance
- 2030 Social Determinants of Health Framework

It was essential the ADRD Alliance look to address ADRD and brain health through a public health approach. Visualizing the disease process through the Public Health Prevention Framework helped the Alliance determine the critical success factors Idaho should focus on while addressing ADRD and brain health (Figure 1).

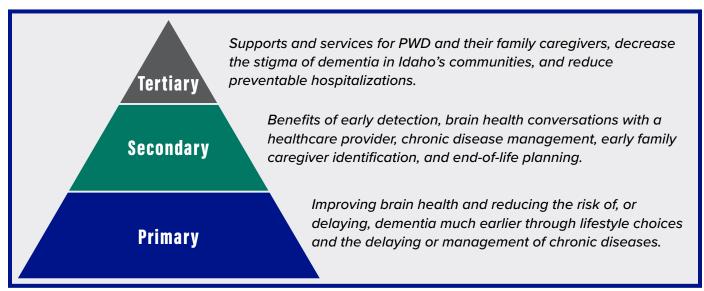


Figure 1.

To ensure Idaho addresses brain health and ADRD with the most up-to-date research and information, the ADRD Alliance aligned Idaho's critical success factors with five (5) of CDCs Healthy Brain Initiative Road Map and Road Map for Indian Country activities. These activities are:

- **Educate & Empower: E-1** Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis,
- Educate & Empower: E-2 Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span,
- Develop Policies & Mobilize Partnerships: P-1 Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia,
- Monitor & Evaluate: M-3 Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving, and
 - Assure a Competent Workforce: W-4 Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management (Alzheimer's Association and Centers for Disease Control and Prevention, 2018).

Throughout the process of developing the state plan, it was recognized that key system level factors must be addressed. These include the need to:

- Improve healthcare (including preventive healthcare), hospital care, long-term services
 and supports, and behavioral health systems' capacities for early detection, diagnosis,
 referral, and treatment for PWD and their caregivers.
- Increase community supports and communication that enable PWD and caregivers to feel included, access needed resources, and reach their goals.
- Create an innovative system to affordably cover the costs of services required by PWD and their caregivers.
- Advance caregivers' ability to provide necessary care while balancing their own needs.

Within this context, critical success factors and strategies that focused on collaboration across systems were identified. The critical success factors embedded in the plan include:

- 1. Awareness of brain health and benefits of early detection.
- 2. Proactive actions to improve quality of life.
- 3. Training for healthcare professionals.
- 4. Training for others in the community.
- 5. Caregiver supports.
- 6. Access and equity-enabling factors: systems, funding, etc.
- 7. Strengthening workforce.

Critical Success Factors, Strategies, and Goals

The vision put forth in this plan will improve care for individuals and help reduce growing costs and burdens related to dementia. Below are the seven critical success factors and their corresponding strategies the ADRD Alliance will be tracking over the next five years. The ADRD Alliance went further to push Idaho to be accountable by creating an ambitious corresponding Specific, Measurable, Achievable Upon, Relevant, Time-Based (SMART) goal for each critical success factor.

Critical Success Factor #1: Awareness of Brain Health and Wellness and Benefits of Early Detection

<u>Rationale:</u> Evidence-based public health information and education about brain health and wellness provides Idahoans the knowledge and awareness to make lifestyle choices to support their brain health and wellness across the lifespan. Benefits of early detection can span from potential clinical trial participation, gaining benefits from existing treatments, being actively involved in personal decisions, healthcare, end of life planning, reducing stigma, and empowering family caregivers with information and understanding of disease progress to better support the PWD.

Healthy Brain Initiative Road Map Activities: E-1, E-2, P-1, M-3

Strategies

- Create and implement a public service awareness campaign.
- Implement a brain trauma train-the-trainer model for youth sports coaches that also educates students and parents.
- Explore the integration of brain health education into K-12 curriculum.
- Incorporate brain health information into required sports physicals.
- Work with local school districts on foodservice and nutrition and leverage existing programs in schools (Smarter Lunchroom Movement, etc.). Collaborate with other programs, like the Idaho Physical Activity and Nutrition Program, as appropriate.
- Promote early detection education and classes, which includes the use of screening tools for people 45 years and above, in various settings.
- Identify and create (or partner with existing) databases to host all the already existing resources, programs, support groups, etc.

SMART Goal #1: By December 2028, 25% of Idahoans 18 years and older have an increased understanding of the importance of brain health and early detection of ADRD.

Critical Success Factor #2: Proactive Actions to Improve Quality of Life

<u>Rationale:</u> Easy-to-access and culturally sensitive resources will help PWD and their caregivers navigate the diagnosis and the system, relieving some of the burden Idahoans experience when going through such a diagnosis. Ensuring these resources are provided early on will increase potential options that may not be available if a diagnosis is given in the later stages of the disease.

Healthy Brain Initiative Road Map Activities: E-1, P-1, M-3, W-4

Strategies

- Develop and disseminate culturally appropriate brain health and ADRD information and resources to local organizations. Recommendations of resources may included such organizations as the Family Support Network, Catholic Charities of Idaho, Head Start, Children's Defense Fund members, etc.
- Develop a statewide road map similar to the Washington Dementia Road Map: A Guide for Family and Care Partners that will provide updated resources and services available in Idaho. To do this, gaps in resources especially in rural or under-resourced areas need to be identified and strategies to fill the gaps need to be developed. Include a 'Smart-Start Checklist' that can reside in a statewide road map.
- Utilize the National Alzheimer's Disease Resource Center and local Aging and Disability Resource Center to target varying populations especially populations at higher risk of ADRD.

SMART Goal #2: By December 2025, Idahoans are substantially better equipped with the information they need to be proactive when they or a loved one is experiencing cognitive decline.



Critical Success Factor #3: Training for Healthcare Professionals

<u>Rationale:</u> Enhancing healthcare professionals' knowledge of the benefits of early detection of cognitive decline and dementia care is essential to improving quality of life for a PWD, reducing public misconceptions and stigma, and empowers families to seek assistance and resources.

Healthy Brain Initiative Road Map Activities: E-1, E-2, P-1, M-3, W-4

Strategies

- Perform an assessment of primary care provider (PCP) dementia trainings to uncover currently available evidence-based or research driven dementia trainings, create a grid with variables such as targeted audience, learning methodology, evidence-based or research informed, cost to participate, and modality delivery.
- Conduct post-analysis, evaluate trainings for suitability in Idaho as necessary, determine most valuable and appropriate, and connect healthcare workforce with identified opportunities.
- Subsidize cost of resources and training for facilities and or individuals to encourage participation.
- Partner with colleges and universities to create/provide trainings.
- Expand these strategies to additional workforce populations.

SMART Goal #3: By December 2028, 45% of Idaho's PCPs will have engaged in continuing education or training that increases their knowledge, skills, or attitudes in relation to brain health and ADRD.

Critical Success Factor #4: Training for Others in the Community

<u>Rationale:</u> Easy-to-find and understand dementia training for various community members as well as dementia-friendly and dementia-inclusive communities, helps to ensure PWD and their families have access to informed dementia care, are supported, engaged, and experience the highest possible quality of life.

Healthy Brain Initiative Road Map Activities: E-1, E-2, P-1, M-3

Strategies

- Identify and partner with existing community initiatives (Age-friendly, Brain Injury Alliance) to assess opportunities for synergies.
- Conduct a review of the literature to assess impact of dementia-friendly initiatives (change of attitudes, behaviors, systems, policies, etc.).
- Define the parameters and process of becoming a dementia-friendly community if value and impact are established.
- Develop a network of trainers to provide a dementia-friendly information session to community members, agencies, and organizations.
- Conduct a pilot of the Dementia Friends initiative.

SMART Goal #4: By December 2028, we will have ten dementia-friendly communities across Idaho, including rural areas.

Critical Success Factor #5: Caregiver Supports

<u>Rationale:</u> As the first point of contact for a person with cognitive decline and dementia, a caregivers' capacity to respond to challenges and seek referrals needs to be robust. This capacity development will ensure caregivers are better able to care for the PWD and navigate available services.

Healthy Brain Initiative Road Map Activities: E-1, P-1, M-3, W-4

Strategies

- Increase the number of family caregivers that recognize they are a critical part of the care team with resources available to them.
- Identify, provide, and map options for caregiver supports such as respite care (e.g. Certified Family Homes, consumer-directed resources through Area Agencies on Aging and Independent Living Centers, Senior Companions Program, etc.) and other supports.
- Educate and inform caregivers about supports and services available and how to access them.
- Recommend policies to policymakers that would offset the cost of respite care and/or support services for families in need.
- Educate caregivers about services available to help loved ones live safe with dignity and respect in their home or preferred living environment.
- Establish (or promote) a coordinated, searchable database with up-to-date resources, and promote awareness of support groups.

SMART Goal #5: By December 2028, caregivers across Idaho will have a "no wrong door" approach to access the information and resources they need to support their well-being and success.

Critical Success Factor #6: Access and Equity-Enabling Factors: Systems, Funding, Etc.

<u>Rationale:</u> Ensuring resources and services are available to Idaho's most vulnerable populations at risk of ADRD, building and maintaining strategic partnerships, sharing information and resources, and pursuing new resource opportunities are vital to the ability of Idaho to address the growing needs of ADRD and to address systemic gaps in services to PWD and their caregivers.

Healthy Brain Initiative Road Map Activities: E-1, P-1, M-3

Strategies

- Find ways to eliminate the stigma associated with ADRD.
- Identify pathways for people with ADRD to access healthcare and support via insurance (Medicaid, Medicare, and private payors) and other health systems and technical assistance, including telehealth.
- Identify alternatives to the internet and assure resources are readily available to PWD and their caregivers through other mediums such as mobile apps and 211-CareLine.
- Identify opportunities to ensure that detection and screening materials are culturally competent and widely available to all populations including rural, and persons with an intellectual, developmental, and mental disability, refugee, Spanish-speaking, Native American, Black, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and More, and other marginalized populations in Idaho.
- Identify resources for behavior support and management strategies of PWD having severe dementia related psychosis and other behavioral disturbances and how we will care for them humanely and with dignity.
- Improve financial and other support (e.g. employer supported working from home option) to family caregivers so they can continue to care for their loved one at home, delaying expensive institutionalization, and increasing community-based services and supports available to Idahoans.

SMART Goal #6: By December 2028, remove significant systemic barriers to ADRD and brain health and wellness-related healthcare access, education, and other key factors to ensure equitable support for all in Idaho.

Critical Success Factor #7: Strengthening Workforce

<u>Rationale:</u> Optimal support for individuals living with cognitive decline and dementia includes efforts to support the volunteers, formal and informal caregivers, and healthcare professionals, specifically around person-centered care. A workforce that is designed to proactively work with people living with cognitive impairment and dementia, including Alzheimer's disease, is better positioned to serve PWD and their caregivers.

Healthy Brain Initiative Road Map Activities: M-3, W-4

Strategies

- a. Strengthen the healthcare workforce by minimizing shortages and creating incentives and career pathways to recruit and retain professionals who specialize in all levels of dementia care.
- b. Establish or strengthen programs that provide support to informal caregivers of individuals living with dementia.
- c. Secure financial incentives to encourage communities to become dementia friendly.
- d. Establish a registry of individuals in the state of Idaho that are dementia specialists.
- e. Secure funding for education on dementia specific training for certified family homes, certified nursing assistants, etc., that are in rural areas within the state.
- f. Make information accessible through Alzheimer's support groups and resources for all who provide care.
- g. Increase culturally competent dementia-specific training for PCPs to deliver personcentered care for their patients.

SMART Goal #7: By December 2028, all caregivers (formal and informal) belong to a system that supports, educates, and connects them to their community and healthcare systems, and are accessible to all Idahoans who need them.

It is acknowledged that the above goals and strategies may be geared toward a single dimension of the critical success factor and that additional goals and strategies may be identified as work is implemented and evaluated annually.



Next Steps

Although this is a five-year plan, the ADRD Alliance will be working actively to ensure the 2023-2028 ADRD Plan for Idaho stays active by developing "live" action plans and performance measures. To keep up to date on the progress of these actions plans and performance measures, or to get involved, please follow the link (ADRD Strategic Plan - healthandwelfare.idaho.gov/ADRDstrategicplan).

It is through these action plans and performance measures the ADRD Alliance will work to track progress towards achieving the seven goals defined and the five-year vision.

The needs and gaps identified throughout Idaho will continue to evolve and change. The 2023-2028 ADRD Plan for Idaho is organic and requires input from Idaho's communities. Over the next five years, we need to hear from stakeholders and community members in all areas of our state. Please reach out to us at adrd@dhw.idaho.gov and let us know what is transpiring in your community.

References

Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures: Special report on the financial and personal benefits of early detection. https://alz.org/media/homeoffice/facts%20 and%20figures/facts-and-figures.pdf.

Alzheimer's Association. (2023). Idaho Alzheimer's statistics. https://www.alz.org/media/ Documents/idaho-alzheimers-facts-figures-2023.pdf.

Alzheimer's Association and Center for Disease Control and Prevention. (2018). Healthy brain initiative state and local public health partnerships to address dementia: The 2018-2023 road map. https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf.

Bureau of Vital Records and Health Statistics. (2016). Dementia, Idaho resident mortality 2014. Idaho Department of Health and Welfare.

United States Census Bureau. (2021). Idaho was the second-fastest growing state last decade. https://www.census.gov/library/stories/state-by-state/idaho-population-change-between-census-decade.html.

