

Follow-up report
October 2023

State Response to Alzheimer's Disease and Related Dementias

Office of Performance Evaluations
Idaho Legislature





**Rakesh Mohan
directs the Office
of Performance
Evaluations.**

**Senator Melissa
Wintrow (D) and
Representative
David M. Cannon
(R) cochair the
committee.**

Office of Performance Evaluations

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Joint Legislative Oversight Committee 2023-2024

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Senators



Melissa Wintrow

C. Scott Grow

Dave Lent

James D. Ruchti

Representatives



David M. Cannon

Douglas T. Pickett

Ilana Rubel

Steve Berch

Follow-up report



In our 2020 report, *State Response to Alzheimer's Disease and Related Dementias*, we found that services were fragmented for people with dementia in Idaho. Although many organizations played a role in responding to dementia, their efforts were not coordinated. Idaho also did not have a system to oversee, evaluate progress on, or update its state plan to address dementia. We found that a network of supported and engaged stakeholders was needed to address service gaps and fragmentation.



What is dementia?

Dementia refers to a group of symptoms caused by damage to nerve cells in the brain. According to the Centers for Disease Control, Alzheimer's disease is the most common type of dementia and accounts for an estimated 60 to 80 percent of cases.

We recommended that the state create a dedicated coordinator position and a system-wide oversight entity. We also identified 21 policy considerations covering four policy areas for the coordinator, oversight entity, and other dementia stakeholders to consider (see exhibit 1).

Exhibit 1

Our policy considerations for the coordinator and oversight entity covered four policy areas.



Source: Office of Performance Evaluations' 2020 report.

The Joint Legislative Oversight Committee requested that we follow-up on our 2020 evaluation during the 2024 legislative session. This follow-up assessed the implementation of our two recommendations and provided a status update on each of our 21 policy considerations.

For this follow-up report, we requested information from the Department of Health and Welfare's new Alzheimer's Disease and Related Dementias program. We conducted over 25 interviews with dementia stakeholders across the state. We also reviewed Idaho Code, Idaho Administrative Code, documents from various Department of Health and Welfare programs and the Commission on Aging, and publications from state and national organizations.

Mackenzie Moss and Sasha O'Connell conducted this follow-up with assistance from Casey Petti and Lauren Bailey.

Leslie Baker copyedited the follow-up.

The state's new dementia program increased public education on prevention and early detection.

In our 2020 report, we found that despite increasing national emphasis on prevention, Idaho lacked a public health response to dementia like it had for other chronic diseases. We recommended that the Department of Health and Welfare create a coordinator position in the Division of Public Health to develop prevention efforts, help guide a dementia oversight entity, and coordinate efforts among stakeholders. Following the release of our report, the Legislature appropriated \$275,000 for an Alzheimer's Disease and Related Dementias program within Public Health.¹ In this follow-up, we found that the new dementia program and coordinator made progress on each of our recommended priorities, including developing statewide public education on prevention and early detection (see pages 9–12 for more on prevention and early detection).

In addition to the state appropriation, the dementia program was awarded a \$275,000 annual federal grant in 2021 and 2022 to develop a strategy to address dementia.² The program was awarded an additional \$450,000 in 2023 for implementation. Based on its progress, the program may receive this funding annually through 2028 (see appendix A for more on dementia related grants in Idaho). Stakeholders reported that the dementia program has taken the initiative to identify gaps and develop collaboration across the state. Many attributed the progress made on our 21 policy considerations to the existence of a statewide program.

Recommendation
1: Complete

Stakeholders attributed the progress made on our policy considerations to the existence of a statewide program.

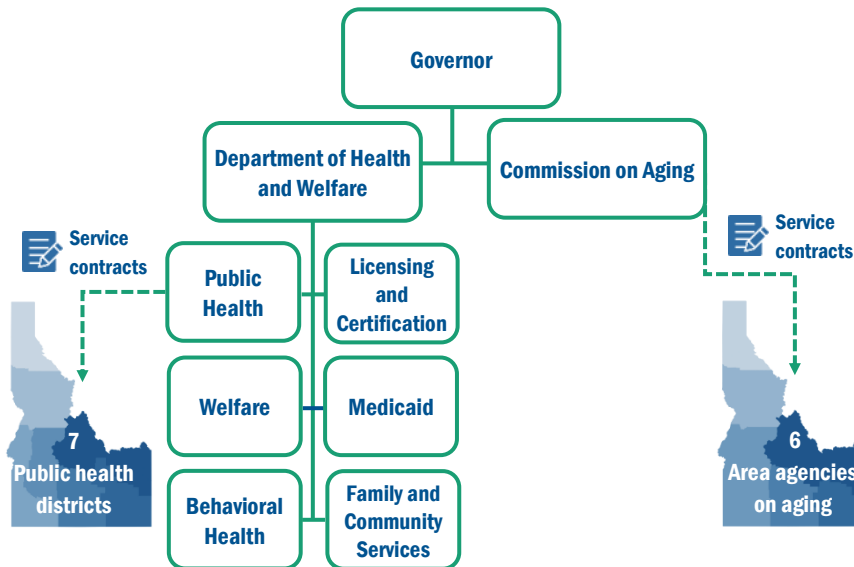
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1. IDAHO LEGIS. SERVICES OFF., 2021 LEGISLATIVE FISCAL REPORT, (2021), <https://legislature.idaho.gov/wp-content/uploads/budget/publications/Legislative-Fiscal-Report/2021/Legislative%20Fiscal%20Report.pdf>.
 2. The Centers for Disease Control awarded Idaho the Building Our Largest Dementia Infrastructure grant. Idaho was initially denied the grant before state appropriation for the dementia program.

Why public health?

We recommended that the statewide coordinator position be located in the Department of Health and Welfare’s Division of Public Health because dementia is a public health issue. About 27,000 Idahoans over the age of 65 had Alzheimer’s disease in 2020, with an expected growth of 22 percent by 2025. Alzheimer’s disease was also the 6th leading cause of death in Idaho in 2021. If all types of dementia were ranked as a group, they would have been the state’s fourth leading cause of death, behind cancer, heart disease, and COVID-19. By being located in Public Health, the dementia program also has connections to other brain health stakeholders and initiatives. Although some stakeholders reported concerns about the time needed for review processes in Public Health, we found value in the dementia program’s ability to connect internally with other divisions and programs in the department that serve people with dementia (see exhibit 2).

Exhibit 2

The state has several entities that provide services to Idahoans with dementia.



Note: Public health districts and area agencies on aging are independent organizations that can pursue their own service contracts and grants. This exhibit depicts the primary state agency relationships as they relate to services used by Idahoans with dementia. The dementia program does not contract with the public health districts .

Source: Office of Performance Evaluations' simplification of stakeholder interviews and agency organizational charts.

The new statewide alliance built on dementia program efforts and improved collaboration among dementia partners.

In 2020, we recommended the establishment of a system-wide oversight entity to support the dementia program’s efforts, improve collaboration among dementia partners, and ensure ongoing accountability for outcomes. In 2021, the dementia program created a statewide Alzheimer’s Disease and Related Dementias alliance, chaired by the program coordinator, to oversee and coordinate dementia efforts.

We found that the dementia alliance provided a forum for the program coordinator to work with dementia stakeholders across the state. Stakeholders reported that the alliance improved collaboration among dementia partners. The alliance had 186 members in June 2023. Members represented entities, such as community organizations, hospitals, and Department of Health and Welfare employees, that serve people with dementia and their caregivers at various stages of the disease.

Recommendation
2: Complete

How effective is the alliance?

We asked many alliance members how effective they thought the dementia alliance was. Stakeholders overwhelmingly reported that the range of member experiences created opportunities for collaboration that did not exist before the alliance. The alliance also recently transitioned to more specialized workgroups focused on enacting the state plan, which may address concerns from some alliance members’ about the alliance’s large size.

The Legislature ensured accountability through regular updates and annual state plan revisions.

In 2023, the dementia alliance published a strategic plan outlining alliance priorities through 2028 (see exhibit 3). Stakeholders reported that having a current and collaborative state plan was a significant achievement toward improving dementia efforts in Idaho.

Exhibit 3

The dementia alliance’s strategic plan has seven priority areas.

Alliance’s critical success factors for 2023 through 2028

- 1** Awareness of brain health and wellness 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 like funding
- 7** Strengthening workforce

Source: Alzheimer’s Disease and Related Dementias Alliance strategic plan for 2023 through 2028.

The Legislature ensured ongoing accountability for alliance and state plan outcomes through regular updates and annual revisions to the plan. In 2023, legislators directed the dementia program to convene the dementia alliance to report annually on service coordination, public safety issues, public education, and recommendations for state policy.

The dementia program made significant progress in developing prevention and early detection efforts.

Although most forms of dementia are not yet curable, early detection can support quality of life for people with dementia through medical and psychological interventions. Early detection can give people time to address safety issues in their homes, prepare advanced care directives, and make legal plans. Some dementia is also preventable through addressing modifiable risk factors such as high blood pressure, air pollution, smoking, traumatic brain injury, alcohol misuse, and obesity.³ In 2020, six of our 21 policy considerations were for prevention and early detection.

Prevention and early detection



Photo of example resources shared with community organizations by the dementia program

3. 40 percent of dementia cases could be delayed by addressing modifiable risk factors. Gill Livingston et al., *Dementia prevention, intervention, and care*, THE LANCET COMMISSION, (2020), <https://www.thelancet.com/action/showPdf?pii=S0140-6736%2820%2930367-6>

Consideration 1: Increase outreach to decrease stigma, improve awareness of modifiable risk factors, and emphasize importance of early detection

We found that the dementia program developed and led several statewide public education efforts about dementia prevention and early detection (see exhibit 4). Stakeholders reported that the program’s public education efforts were helpful in sharing information on the importance of brain health with service providers and the public.

Exhibit 4

The dementia program led public education on prevention and early detection.

Examples of the dementia program’s public education efforts.

Launched dementia program and dementia alliance webpages with information on brain health and resources

Ran several media campaigns on brain health, early detection, and caregivers

Hosted six project ECHO sessions that covered topics such as screening, brain health, diagnosis, and risk reduction strategies

Hosted 24 Dementia Friends sessions that covered the basics of dementia and how to interact with someone with dementia

Produced and distributed informational materials to community organizations such as Area Agencies on Aging and libraries

Hosted or participated in several other presentations and events with community partners like the department’s Fit and Fall Proof program and KTVB Idaho

Source: Office of Performance Evaluations’ synthesis of Alzheimer’s Disease and Related Dementias program reporting.

What is Dementia Friends?

Dementia Friends is a national curriculum to increase awareness of dementia and education on how to interact with people with dementia. The dementia program partnered with the University of Idaho to provide 24 informational sessions in 2023. At the time this follow-up was released, over 300 people across the state participated. Stakeholders reported that Dementia Friends is a valuable new resource for educating their clients, providers, and the public about dementia.

Consideration 2: Promote existing programs that train providers who can diagnose and treat dementia

We found in 2020 that nationally, people with dementia often did not get an early diagnosis and most were first diagnosed by a provider who was not a dementia specialist. Idaho also did not have enough qualified professionals such as adequately trained primary care providers or geriatricians to care for people with dementia. Stakeholders reported during this follow-up that the lack of qualified professionals was still a challenge, especially in rural areas. The dementia program took steps to connect providers with available training and develop relationships with medical organizations.⁴ The program was also working on a healthcare professional webpage to host provider resources.

Consideration 3: Work with healthcare groups to set standards for workforce training specific to dementia and expand existing programs to include ongoing modules that reach rural communities

In our 2020 report, we found that Project ECHO, a telehealth program that connects specialists with healthcare teams in rural areas, had continuing education modules that may be a good fit to train physicians about dementia. We suggested an expansion of the project to include dementia specific modules. The dementia program hosted six project ECHO sessions in 2023 that covered topics such as screening, diagnosis, brain health, and risk reduction strategies. Officials reported that they will expand the sessions if there are additional funding opportunities. They were also exploring other modules that may be more cost effective.

Consideration 4: Increase collaboration with physicians to connect patients with resources after diagnosis

Since our 2020 report, Saint Alphonsus Regional Medical Center developed a memory care clinic that the dementia program collaborates with to discuss dementia education and services. Dementia program officials reported that collaborating with physicians is a program and alliance priority in the coming years.

4. The program reported relationships with medical organizations including the Idaho College of Osteopathic Medicine, the North Idaho Resident Program, St. Luke's Health System, Saint Alphonsus Regional Medical Center, Kootenai Health, and Full Circle Health (formally Family Medicine Residency of Idaho).

Stakeholders reported that the lack of qualified professionals was still a challenge.

Consideration 5: Expand primary care provider knowledge of Medicare reimbursement

Medicare primarily serves older adults and has a cognitive evaluation as part of its annual wellness visit. According to a 2021 survey by the Alzheimer’s Association, only 16 percent of adults over 65 reported having their memory and thinking checked. Program officials reported sharing information about Medicare screening with alliance members and the public as available, and encouraging some medical organizations to participate in a federal model for additional Medicare reimbursement for dementia care.⁵

Consideration 6: Develop a plan to encourage partnerships between area agencies on aging, public health districts, and other local service providers to connect older adults with information about support services

The Department of Health and Welfare and the Commission on Aging provide and help direct many services for Idahoans with dementia and their families. For example, the department manages health care plans for Idahoans with dementia on Medicaid, oversees standards for residential care facilities, and has contracts with seven regional public health districts that offer programs for older adults. The commission helps older adults who live at home with support services such as respite, meal delivery, and homemaking through contracts with six area agencies on aging. In 2020, we found a lack of coordination between the area agencies on aging, public health districts, and other local service providers. Some stakeholders reported that the dementia alliance improved service coordination among these agencies by increasing information and resource sharing (see pages 15–16 for more on information and resource sharing).

5. U.S. CTRS. FOR MEDICARE & MEDICAID SERVICES., *Guiding an Improved Dementia Experience Model*, (2023), <https://www.cms.gov/priorities/innovation/innovation-models/guide#:~:text=Through%20the%20GUIDE%20Model%2C%20CMS,access%20to%20a%20support%20line>.

State agencies and local service providers are struggling to keep up with the growing need for caregivers.

Direct care workers and unpaid caregivers assist with housework, transportation, and finances. Many eventually provide support for daily living activities including getting dressed, bathing, and feeding. According to the Alzheimer’s Association, 65,000 unpaid caregivers provided 103 million hours of care in Idaho in 2022. Support for unpaid caregivers is one way to improve quality of life for people with dementia and reduce the costs of premature entry into a residential care facility. We found in this follow-up that the Commission on Aging, Idaho Caregiver Alliance, and dementia program took significant steps to address our seven policy considerations for unpaid caregivers.

Consideration 7: Increase public awareness of caregiver support services

Unpaid caregivers often need resources such as respite, support groups, and training. In 2020, we found that caregivers often did not access services because they were unaware of what resources were available and where to access them. Since then, several state agencies developed programs to provide resources and educate unpaid caregivers about available support (see exhibit 5).

Consideration 8: Examine ways to expand the caregiver workforce

In 2020 we found that respite services were sometimes unavailable to caregivers, especially in rural areas, because of a shortage of providers due to low wages. In our 2023 report, *Sustainability of Idaho’s Direct Care Workforce*, we found that Idaho had a shortage of direct care workers that was worse than the national average.



Idaho had a shortage of direct care workers that was worse than the national average.

Exhibit 5

State agencies worked to serve and educate unpaid caregivers.

Commission on Aging

The Legislature appropriated \$720,000 to the commission for dementia caregiver support in fiscal year 2023. The commission developed the community care program* which employs case managers at the area agencies on aging who work statewide to connect caregivers with resources like consumer-directed respite. The commission also hosts online dementia training modules* for caregivers.

Boise State University

The Center for the Study of Aging at Boise State University operates the Idaho Caregiver Alliance. The alliance has a caregiver navigator program* that develops case plans to connect caregivers with resources.

Department of Health and Welfare

The dementia program led statewide public education on caregiver support services. For example, it hosted training for service providers and produced and shared information on available resources with community organizations and the public. In 2023, the Administration for Community Living awarded the dementia program a lifespan respite grant* for caregiver support services.

Note: See appendix A for more on these programs and grants.

Source: Office of Performance Evaluations' synopsis of publications from and interviews with state agencies.

The dementia program met with officials from neighboring states and facilitated meetings between Idaho service providers and the Centers for Disease Control to learn about best practices for supporting the caregiver workforce. The commission's consumer-directed respite services are one potential way to expand the caregiver support work force. Increasing state investment in services to raise provider pay may also address workforce challenges.

What is consumer-directed respite?

Consumer-directed, self-directed, and family-directed models of support allow the person receiving services or their family to hire their own workers within an approved budget and other guidelines. These models allow caregivers to hire people they know in the community for a few hours of respite rather than trying to find a direct care worker through a company. They can expand the caregiver workforce to include friends or neighbors who would like to support someone they know but might not otherwise pursue direct care work.

Consideration 9: Develop a dementia roadmap for Idahoans to learn about what should be done at various stages of their disease and where to go for support

We found in 2020 that Idaho did not have a roadmap for dementia services like many of our neighboring states. The dementia program, in partnership with the dementia alliance, developed a roadmap for unpaid caregivers of people with dementia. At the time of this follow-up, the program planned to release the roadmap in 2023 and to develop another roadmap for Idahoans with mild cognitive impairment or dementia.

Considerations 10–12: Improve information and resource sharing

In our 2020 report, we found several issues with information and resource sharing among dementia stakeholders. For example, there was no certainty that someone with signs of dementia who called various service providers, such as the Department of Health and Welfare's 2-1-1 Careline, the Alzheimer's Association, and the area agencies on aging, would be referred to the same resources. There was also no statewide plan to ensure that area agencies on aging staff received training on how to help people apply for services through the department. We had three policy considerations for information and resource sharing:

- Improve consistency in cross referrals among information portals by developing a statewide plan for collaboration

- Improve sharing and vetting of information portal resource lists for community referrals

- Leverage existing resources by training area agencies on aging staff on how to help older adults apply for eligible services through the department

Although the dementia program encourages collaboration at alliance meetings, some stakeholders reported in 2023 that they continued to see issues with information and resource sharing. The dementia program took some steps such as contracting the caregiver alliance to increase the number of dementia specific resources in its resource database. Program officials also reported training some commission staff on resources available through the department.

Many cases of maltreatment could be avoided with more caregiver support and education.

The dementia alliance’s strategic plan includes establishing a coordinated, searchable database for caregivers of people with dementia. Program officials reported that they were considering hosting a resource database specific to dementia through FindHelpIdaho.org, an online platform to connect residents with services. Many stakeholders reported that FindHelp is a useful tool for their clients. However, some shared concerns that their clients would not access an online resource.

Consideration 13: Expand prevention efforts of adult protective services

In our 2020 report, we found that the Commission on Aging’s adult protective services play a critical role when caregivers do not get the support they need early enough. Stakeholders reported that many cases of maltreatment could be avoided with more caregiver support and education. Since our 2020 report, the commission developed a dementia toolkit for their staff (see appendix A for more on the toolkit). The dementia program also provided training on dementia to some adult protective staff.



Photo of information available to the public at the Area 3 Agency on Aging

Does the state have a caregiver misconduct registry?

In our 2019 report, *Southwest Idaho Treatment Center*, we found that Idaho did not have a process to investigate perpetrators of misconduct involving vulnerable adults outside of nursing facilities. People who care for vulnerable adults cannot be investigated for misconduct and placed on a registry if they work in someone’s home, an intermediate care facility, or a community-based setting, including assisted living facilities. We recommended that the Legislature consider establishing a registry of perpetrators of maltreatment so that they could be excluded from working as caregivers of vulnerable adults.⁶

Shortly after our report was released in 2019, the Department of Health and Welfare, the Commission on Aging, and other stakeholders produced a whitepaper outlining several paths the state could take to create a registry. The workgroup concluded that the Legislature must determine which agency is responsible to develop and implement a registry. We referenced this recommendation and reiterated its importance for the safety of older adults and people with disabilities in several of our past reports:

State Response to Alzheimer’s Disease and Related Dementias (2020)

Sustainability of Idaho’s Direct Care Workforce (2023)

Follow-up Report: Southwest Idaho Treatment Center (2023)

Idaho still did not have a caregiver misconduct registry at the release of this follow-up.

Idaho still does not have a caregiver misconduct registry.

6. Maltreatment includes financial exploitation, trafficking, neglect, and abuse. Idaho Code § 39-5302(ee) (2023).

An official with the Commission on Aging reported that the commission’s work in revising the Abuse, Neglect, and Exploitation Act during the 2023 legislative session was an important step towards supporting a caregiver misconduct registry.



Crisis
management

The state still struggles to meet the needs of Idahoans with behavioral symptoms of dementia.

Some people experience behavioral symptoms of dementia that can be disruptive and distressing. While caregivers can often manage or avoid these symptoms through appropriate responses, handling these behaviors can be difficult and sometimes dangerous. In 2020, we found that people with dementia may not receive appropriate crisis intervention and had four policy considerations for crisis management. We found in this follow-up that the state still did not have the training or infrastructure to meet the needs of Idahoans with behavioral symptoms of dementia.

Consideration 14: Work with the Bureau of Emergency Medical Services and Preparedness to develop protocols for caring for dementia patients in crisis and distribute the protocols to first responders statewide

In 2020, we found that some emergency medical service providers may have received dementia training, but it was limited and not standardized. During this follow-up, we found the same of law enforcement personnel such as police officers and county sheriffs. Adequate training could result in fewer hospitalizations and better outcomes for people with dementia.

We found during this follow-up that little progress was made to address the lack of training. The dementia program met with the Department of Health and Welfare's Bureau of Emergency Medical Services and Preparedness and a few emergency medical service and law enforcement agencies to discuss training. The program planned to address this issue more in the future using federal grant funding for implementing dementia infrastructure (see appendix A for more on the grant).

Considerations 15–16: Develop protocols for families who call for emergency assistance to receive information about available support services and increase public awareness of the Mobile Crisis Unit

We found in 2020 that people calling for emergency assistance to handle a behavioral crisis of someone with dementia were often unaware of the resources available to them like the Department of Health and Welfare’s mobile crisis units. The units treat people at the scene, when possible, to avoid unnecessary admissions to jails or hospitals. In situations without immediate danger, the units are better equipped than other first responders to support people in behavioral crisis because of specialized training. Since our 2020 report, the department expanded the mobile crisis units to operate in all seven regions.

We found during this follow-up that although dispatchers in Ada County often work with the mobile crisis units, there is not a statewide protocol to use the units as part of dispatch. The dementia program hosted an informational session in which unit responders presented to alliance members about their crisis response. The program could consider working with dispatch agencies to develop protocols for people calling for assistance with dementia specific emergencies.

Consideration 17: Evaluate infrastructure needed to expand state psychiatric hospitals and barriers to the development of geriatric psychiatry units in community hospitals

In 2020 we found that Idaho lacked the legal and supportive infrastructures to appropriately care for people with dementia in behavioral crisis. The treatment needs of someone with dementia in behavioral crisis can vary widely, from on the scene intervention to inpatient hospitalization. We found that the state faced two challenges in providing for Idahoans with dementia with the highest needs for behavioral care:

Idaho Code did not allow involuntary holds for people with dementia

Infrastructure did not exist to help with stabilization after a behavioral crisis

The department expanded the mobile crisis units to operate in all seven regions.

The dementia program could consider working with dispatch agencies to develop protocols.

Idaho still lacked the needed infrastructures to support Idahoans with behavioral symptoms of dementia.

Idaho Code permits temporary involuntary holds to stabilize people with mental health diagnoses. Because dementia is considered a group of neurocognitive disorders and not a mental health condition, code does not allow involuntary holds for people with a primary diagnosis of dementia. We found in 2020 that without an involuntary hold, people with dementia in behavioral crisis could refuse treatment or be transported to jail.⁷ The state also lacked the needed infrastructure to assist with stabilization after a behavioral crisis. We identified the expansion of state psychiatric hospitals or the development of geriatric psychiatric units in community hospitals as options to accommodate people with dementia with severe behavioral symptoms.

We found in this follow-up that Idaho still lacked the needed legal and supportive infrastructures. Stakeholders reported concerns over the lack of options for someone with dementia in behavioral crisis, both for stabilization and long-term support services. The dementia program was working with stakeholders, including lawmakers, other divisions within the Department of Health and Welfare, and service providers, to consider legislation to create an involuntary hold process for people with dementia. The workgroup was also discussing crisis intervention options for the families and caregivers of people who may be placed on a hold.

Has any other progress been made to support people with dementia in crisis?

The Legislature passed a bill in 2022 to create a voluntary alert system for endangered missing persons in Idaho, including people with dementia.

⁷ When a person with dementia is in behavioral crisis, they may not have the wherewithal to determine the best healthcare treatment necessary.

The state still struggles to measure access to residential care for people with dementia.

People with dementia often rely on residential care. We found in 2020 that Idahoans with dementia had trouble finding residential care placement. Because the high cost of dementia care makes people more likely to need Medicaid, barriers for Medicaid participants disproportionately affect people with dementia. The Social Security Administration requires the state to ensure access and quality of care when it designs Medicaid payment methods, but we found in our 2022 report, *Medicaid Rate Setting*, that the state does not collect sufficient information to determine whether it is meeting these goals. We found during this follow-up that the state still did not collect sufficient data to determine the scale of residential care placement issues for Idahoans with dementia. The dementia program should consider working with the Department of Health and Welfare's Divisions of Medicaid and Licensing and Certification to develop mechanisms to address our two policy considerations for measuring access.

Consideration 18: Work with the Division of Medicaid and nursing facilities to develop a mechanism to track bed capacity at behavioral care units

Some skilled nursing facilities operate behavioral care units that support people with diagnoses that can cause cognitive impairment and behavioral issues, like dementia. The units often receive higher reimbursement from the Division of Medicaid.⁸ Stakeholders reported that there were not enough behavioral care unit beds for people with dementia, but we could not determine access to the units in 2020 because the Department of Health and Welfare did not track capacity. The department's Divisions of Medicaid and Licensing and Certification reported no change in the ability to track bed capacity.⁹

8. Facilities that operate behavioral care units often receive higher reimbursement from the Division of Medicaid based on an acknowledgement that specialized care for some participants may require additional workers and work hours.

9. Officials with Licensing and Certification reported that the division does track which skilled nursing facilities have a behavioral care designation, but not bed capacity.



Residential
care

The dementia program should consider working with Medicaid and Licensing and Certification to measure access to residential care.

Consideration 19: Develop a mechanism to track bed use by payor type at secure memory care units

The department's Division of Licensing and Certification has a licensing designation for assisted living facilities that have secure memory care units. The units ensure that residents with cognitive or memory impairments have a safe and supervised living environment. Though Medicaid does not reimburse more for secure memory care units, the private market sets a higher price for them.¹⁰ Stakeholders reported in 2020 that there were not enough secure memory care unit beds for Idahoans on Medicaid. We could not determine access to secure memory care units in 2020 because data was not available on the number of beds that go to people who rely on Medicaid or other payment sources. Licensing and Certification reported during this follow-up that there was still not a mechanism to determine how many residents in secure memory care units were on Medicaid.

Both the Divisions of Medicaid and Licensing and Certification reported willingness to work with the dementia program to develop tracking mechanisms, but current data collection and storage systems were not equipped to measure access to residential care placements for Idahoans with dementia.

Are there any other ways to measure access?

At the time of this follow-up, the dementia program was exploring another way to measure access to skilled nursing facilities for people with dementia. The program began discussions with the Division of Medicaid about using data from a screening tool to determine how many admissions to institutional settings are requested for Idahoans with dementia. Data from the screening tool is currently stored in paper forms that are scanned and not easily queried. A Medicaid official reported that updating and automating this system could help the division answer other questions about access and placement in skilled nursing facilities.

10. Medicaid reimburses assisted living facilities on a per participant basis. The rate is higher for residents with behavioral health needs based on their assessment and care plan. Some residents in memory care units may be authorized for a higher reimbursement rate, but participation in a memory care unit does not guarantee higher reimbursement.

Idaho's dementia training standards are still lower than other states.

Similar to unpaid caregivers, direct care workers and other staff in residential care facilities need adequate training to ensure quality of care. Most people with dementia in residential care facilities have behavioral symptoms. Research shows that behavioral symptoms can be decreased with provider training on topics including environmental triggers and de-escalation. We found in this follow-up that no progress had been made on our policy consideration for examining training requirements at residential care facilities.

Consideration 20: Examine feasibility and barriers to having a minimum number of hours for dementia training for residential care staff

In 2020, we found that Idaho had lower dementia training standards for residential care staff than many neighboring states. Nursing facility staff in Idaho were not required to undergo dementia training annually nor did they need to have a certain number of hours of dementia training. Idaho also did not require that staff at assisted living facilities undergo a certain number of hours of dementia training or follow a specific training module. Idaho Administrative Code stated that the “means and methods of training are at the facility’s discretion.”¹¹

We found in this follow-up that no changes were made to dementia training requirements for staff at residential care facilities. The dementia program pursued discussions with Project ECHO and Saint Alphonsus Regional Medical Center to determine whether healthcare providers may be able to offer additional training to residential care staff. Dementia program officials also reported that the program may focus on dementia training for staff at residential care facilities in the future.

No changes were made to requirements for dementia training for residential care staff.

11. Idaho Admin. Code 16.03.22.625.01 (2022).

What happens when residential care staff can't manage behavioral symptoms of dementia?

Stakeholders reported concerns about how often assisted living facilities evict residents with behavioral issues. Idaho Administrative Code states that assisted living facilities shall not have residents who are a danger to themselves or others.¹² As a result, Idahoans with behavioral symptoms of dementia may not be able to reside in an assisted living facility if that facility lacks well-trained staff and effective plans to manage their symptoms. Evidence also suggests that overmedication and maltreatment can result from insufficient training.^{13, 14}



12. Idaho Admin Code. 16.03.22.152.03 (2022).

13. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-15-211, *Antipsychotic Drug Use*, 28 (2015), <https://www.gao.gov/assets/gao-15-211.pdf>.

14. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-19-433, *Nursing Homes*, 28 (2019), <https://www.gao.gov/assets/gao-19-433.pdf>.

Medicaid rates better account for symptoms of dementia, but systemic challenges remain in the state's rate setting process.

Medicaid pays providers differently depending on the needs of the patients and the setting in which they receive services. We found in 2020 that Medicaid likely did not accurately reimburse assisted living facilities for the time needed to care for residents with dementia. We had one policy consideration for the adjustment of the Medicaid rate formula for assisted living facilities.

Consideration 21: Formally assess and adjust the Medicaid rate formula for assisted living facilities to appropriately account for cognitive decline

After the release of our 2020 report, the Department of Health and Welfare's Division of Medicaid sought an external review by the Idaho Health Care Association of the formula it uses to determine the amount of time needed to care for resident's with varying needs. Medicaid then adjusted its formula to better account for the time it takes to care for people exhibiting behavioral symptoms of dementia and other conditions. The Legislature approved a rate adjustment to account for behavioral symptoms in 2022.

We found in this follow-up that although Medicaid took steps to address the time it takes to care for someone with behavioral symptoms, it still struggled to ensure that the rates keep up with market wages. We found in our 2022 report, *Medicaid Rate Setting*, that Medicaid lacked the management capacity to effectively keep rates updated. In our 2023 report, *Sustainability of Idaho's Direct Care Workforce*, we found that the ineffective rate review process affected the ability of Idahoans to access residential care and other services. We made several recommendations in those reports to sustainably address access issues, including more frequent rate reviews, incorporating information about wages offered by competitive industries, and improving management capacity at Medicaid.

The Legislature approved a rate adjustment to account for behavioral symptoms in 2022.

A

Programs and Grants

In our 2020 evaluation, we reported on the main competitive grants affecting Idahoans with dementia. At the time of this follow-up, those same grants, as well as others, still played a role in the services Idahoans with dementia receive.

Adult Protective Services

The Commission on Aging received two new federal grants for adult protective services since our 2020 report. Using grant funding, the commission developed a dementia toolkit for adult protective services staff and was identifying high-risk clients with unmet needs to purchase necessary goods or services such as groceries, rent, home cleaning, and personal care items.

Building Our Largest Dementia Infrastructure

The Centers for Disease Control awarded the dementia program \$275,000 in 2021 and 2022, and \$450,000 in 2023 to develop Idaho's dementia infrastructure. Grant activities included overseeing the dementia alliance and state plan, and funding programs including Project ECHO and Dementia Friends.

Community Care

The Legislature appropriated \$720,000 to the Commission on Aging for dementia caregiver support in fiscal year 2023. Using the state dollars and some additional grant funding, the commission developed the community care program which connects caregivers to resources and subsidizes caregivers to hire their own respite providers. An official with the commission reported that priority is given to caregivers who are caring for a loved one with dementia. The dementia program reported working with the governor's office to recommend funding for the community care program.

Dementia Capable

At the time of our 2020 report, the Commission on Aging was receiving federal grant dollars to build dementia capability. An official with the commission reported that the funding helped build dementia capability such as the commission's ongoing online dementia training modules for caregivers.

Family Caregiver Navigator

We found in 2020 that Boise State University's Center for the Study of Aging and the Department of Health and Welfare's Division of Medicaid were partnered in the Idaho Caregiver Alliance's Family Caregiver Navigator program. The program assessed caregivers and provided them with case management services to connect with resources. At the time of this follow-up, the program had assessed over 800 caregivers and developed case plans for over 350 caregivers. The top diagnosis of the care recipients of caregivers served by the program was dementia.

Lifespan Respite

At the time of our 2020 report, the Commission on Aging was receiving grant funding from the Administration for Community Living to expand respite services to family caregivers through increasing coordination, service efforts, training, and information access points. The commission administered the grant and contracted the Idaho Caregiver Alliance to provide some services, including consumer-directed respite. In 2023, the Administration for Community Living awarded the dementia program the \$400,000 lifespan respite grant. The program reported that funding may be used for a consumer-directed respite service model.



Responses to the follow-up



**Dave Jeppesen, Director
Idaho Department of
Health and Welfare**

“ I will borrow the slogan from the ADRD alliance that says, “We take this journey together;” I firmly believe this is how we need to continue to work to address Idaho’s dementia response and improve Idahoans’ outcomes.



**Judy Taylor, Director
Idaho Commission on Aging**

“ As the strategic leader for the Commission on Aging I pledge to you that our agency will focus on dementia capability throughout the state, supporting family caregivers, and providing community services to keep people living with dementia in their own homes for as long as possible, as a highest priority.



IDAHO DEPARTMENT OF
HEALTH & WELFARE

BRAD LITTLE – GOVERNOR
DAVE JEPPESEN – DIRECTOR

OFFICE OF THE DIRECTOR
450 West State Street, 10th Floor
P.O. Box 83720
Boise, Idaho 83720-0036
PHONE 208-334-5500
FAX 208-334-6558

October 11, 2023

Rakesh Mohan, Director
Office of Performance Evaluations
Idaho Legislature

Dear Director Mohan,

Please accept this letter as my formal response to your final follow-up report on “Idaho’s Response to Alzheimer’s Disease and Related Dementias (ADRD),” dated October 2023. I want to commend you and your team’s efforts on providing a fair and comprehensive evaluation of the progress Idaho has made over the last two years. There are a few points I would like to make.

First, I would like to address the stated concern about the size of the ADRD Alliance being too large. The Department’s position is that it is appropriately sized. Transparency and inclusivity are essential to develop and maintain a relatively new statewide program. Every Idahoan is at risk of being impacted by ADRD, so a broad array of stakeholders involved in the ADRD Alliance is important.

I agree with the mention of early detection benefits on page 9, but feel it is important to note that the ADRD Program, local healthcare professionals, and national partners all believe that early detection also provides an opportunity to treat reversible causes of memory loss. Another benefit is preparing family caregivers, so they know they can reach out for help anytime, not only during times of crisis.

I would like to highlight a few additional accomplishments of the ADRD Program not mentioned in the report demonstrating the appropriateness of placing the ADRD Program in the Division of Public Health. The Program, being able to coordinate and integrate with other programs to magnify health education messaging, has launched a public health media campaign on brain health in partnership with Project Filter. This was a back-to-school campaign to get kids thinking about the lifestyle choices they are starting to adopt and how those choices may impact their brain health. The Program has also partnered with the Diabetes, Heart Disease, and Stroke Program and the Idaho Physical Activity and Nutrition Program to produce public health messaging on healthy aging and healthy brain. As we

know from research, these lifestyles choices can decrease dementia cases by upwards of 40%.

The report states that Idaho “still struggles to meet the needs of Idahoans with behavioral symptoms of dementia.” I wholeheartedly agree with this statement. It pains me when we hear stories from Idahoans about the availability of housing and dementia care, especially in a residential care facility, or when a family is forced to provide care that is unsafe for themselves and the person with dementia because they cannot afford in-home direct care staff. To assist with this, the ADRD Program is investigating how to offer de-escalation training most cost-effectively for care providers, emergency responders, and healthcare professionals. The Program is also supporting internal Department cross-division work with the divisions of Public Health, Behavioral Health, Medicaid, Licensing and Certification, and Self Reliance to determine how to better serve people with a dementia diagnosis and their family caregivers. This partnership and work are also defined in our Department Strategic Plan.

In an effort to assist family caregiver, the ADRD Program applied for the federal Administration for Community Living (ACL) grant that the Idaho Commission on Aging had previously held for several years. This grant allows state agencies the opportunity to increase respite access and education for Idahoans across the lifespan. If the ADRD Program receives legislative approval to spend the ACL funds, the ADRD Program will work to expand consumer-directed respite across Idaho with the disability community and increase community-led respite programming. Currently in Idaho, respite funding for dementia care comes from the Older Americans Act awarded to the Idaho Commission on Aging.

The OPE report states the development of a mechanism to track bed use by payor type for secure memory care units. While this seems like a feasible option, tracking bed capacity will always be a snapshot in time as facilities must assess the individual needs of each resident relative to the care staff available when admitting. The cost of providing this, must be determined.

In this report it states, “no changes were made to requirements for dementia training for residential care staff.” As previously mentioned in response to OPE’s 2020 report on ADRD, additional training would help direct care staff provide more effective care for Idahoans with dementia. That said, just putting additional training requirements in place will not be sufficient. Imposing additional training requirements will necessitate added operational costs for residential care operators. Over the last year and a half, the ADRD Program has been working alongside the Idaho Alzheimer’s Association’s Policy Director to investigate costs and requirements needed to bring the Alzheimer’s Association’s education platform to Idaho. This platform provides online evidence-based training not just to direct care staff and healthcare professionals, but also to law enforcement, Adult Protection and other community workers, guardians and conservators, and the general layperson. The platform will also allow the Program to access data on the number of trainings completed in Idaho. We are aware that this platform is one option and the ADRD Program staff as well as other stakeholders are willing to get out into the community to offer in-person trainings.

Last, long-term, sustainable funding and staffing support is imperative to move the needle forward to address ADRD in Idaho. The problem is large, and the solutions are complex. I will borrow the slogan from the ADRD Alliance that says, "We take this journey together;" I firmly believe this is how we need to continue to work to address Idaho's dementia response and improve Idahoans' outcomes, not just for Idahoans who have ADRD today, but for those who will have it ten -twenty years from today.

Sincerely,

A handwritten signature in black ink, appearing to read "D. Jeppesen".

DAVE JEPPESEN
Director



Brad Little, Governor

Judy B. Taylor, Director

To: Joint Legislative Oversight Committee
From: Idaho Commission on Aging
RE: Official response to OPE Alzheimer's Disease and Related Dementias follow-up report

Thank you for the opportunity to respond to the OPE Dementia follow up report. The Commission on Aging appreciates the thoroughness, breadth and accuracy of the content. We believe that Idaho has made great strides in addressing dementia for our citizens in the years since the initial report and are proud of our strategic leadership in many areas of progress.

We are just hitting our stride on many important issues and goals, and I expect great gains in the near future and beyond. As the strategic leader for the Commission on Aging I pledge to you that our agency will focus on dementia capability throughout the state, supporting family caregivers, and providing community services to keep people living with dementia in their own homes for as long as possible, as a highest priority.

In service to Idaho,

A handwritten signature in black ink that reads "Judy B Taylor".

Judy B Taylor MSN, RN

