



Successful Public Health Approaches in Dementia Caregiving: *Colorado*

A Virtual Roundtable Series

October 10th, 2024



Welcome from...



Elma Johnson, MPH, *Coordinator*

BOLD Public Health Center of Excellence on

Dementia Caregiving (PHCOE-DC)

Center for Healthy Aging and Innovation (CHAI)

University of Minnesota



Land acknowledgement




The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.



The BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

Visit our
website!

-  Improving access to evidence-based programs and best practices.
-  Facilitating connections and collaboration among public health agencies and a wide range of service organizations.
-  Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies.



 **HEALTHYBRAIN
INITIATIVE**
Collaborative



hbicollaborative.org



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

American Indian/
Alaska Native Peoples



NATIONAL COORDINATORS

POPULATION EXPERTS

SUBJECT MATTER EXPERTS



UNIVERSITY OF
ILLINOIS CHICAGO

Individuals living with
Intellectual/Developmental
Disabilities



US AGAINST ALZHEIMER'S CENTER for
BRAIN HEALTH EQUITY

Black/African American and
Hispanic/Latino Communities



PUBLIC HEALTH
CENTER OF EXCELLENCE
IN DEMENTIA CAREGIVING



BOLD PUBLIC HEALTH
CENTER OF EXCELLENCE
EARLY DETECTION OF DEMENTIA

Successful Public Health Approaches in Dementia Caregiving: *A Virtual Roundtable Series*

- ✓ **Bi-monthly**, roundtable series for **public health**.
- ✓ We will highlight **the story of one state**.
- ✓ Opportunity for **networking, peer-learning and idea generation**.
- ✓ A **community of practice**, where agencies can share their successes and learnings, and get ideas for action.



Reminders for the Presentation Session

- Please, **MUTE yourself** and **turn your VIDEO ON** while the panelists are presenting.
- Display **your name and organization in Zoom**.
- **Submit your questions for the speakers into the Q&A feature.**
- During the Q&A time, please raise your hand if you wish to speak and **only unmute if you are prompted.**
- Use the **CHAT to share comments, resources, links, and ideas.**
- Feel free to use your reaction buttons!
- The recording, slides and resources will be shared after the event.
- **Please complete the survey at the end of this event** (linked in chat). We greatly appreciate your feedback!



We value your feedback!

Please give us your feedback before you leave today's meeting!

Scan the QR code

OR visit

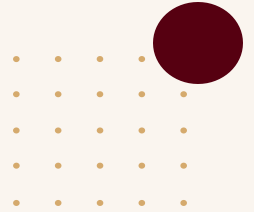
https://bit.ly/COroundtable_eval



Poll Question

In what capacity are you attending this event?

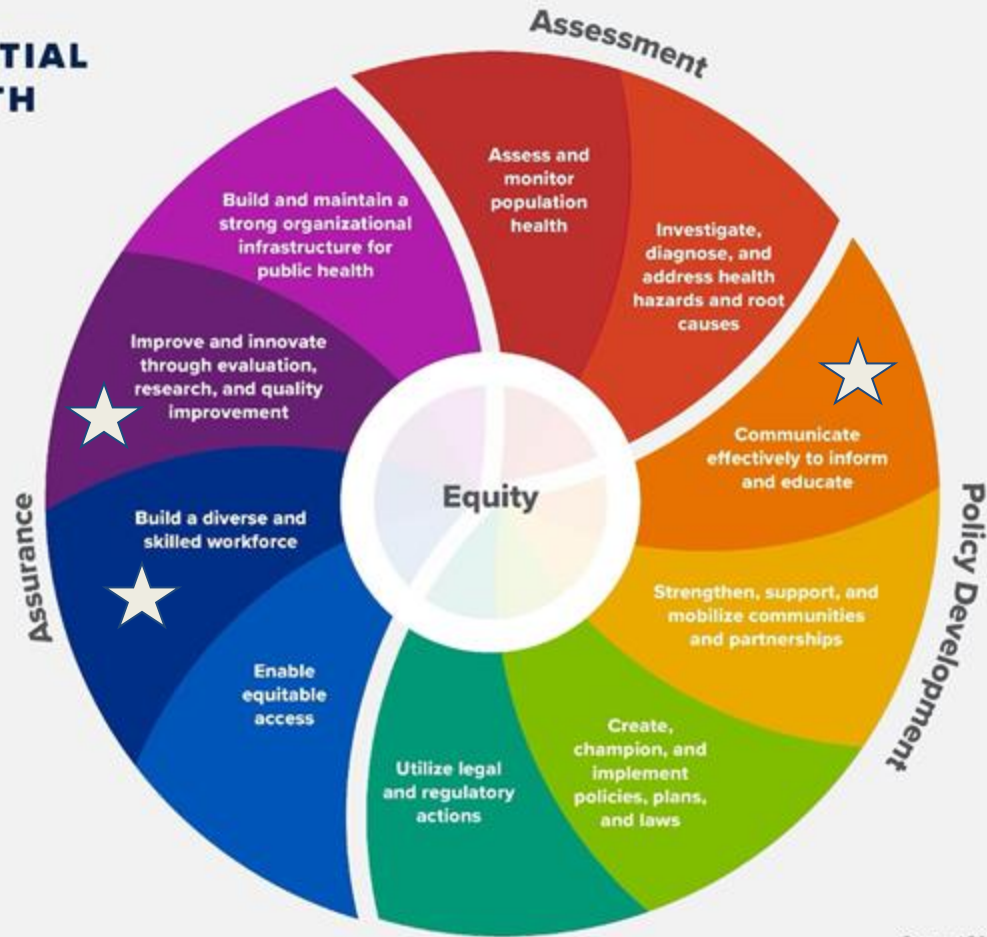
- BOLD Public Health Agency
- Non-BOLD Public Health Agency
- Community organization/service provider
- Person living with dementia
- Interested caregiver and/or community member
- Care/clinical professional
- Other



THE 10 ESSENTIAL PUBLIC HEALTH SERVICES

To protect and promote the health of all people in all communities

The 10 Essential Public Health Services provide a framework for public health to protect and promote the health of all people in all communities. To achieve optimal health for all, the Essential Public Health Services actively promote policies, systems, and services that enable good health and seek to remove obstacles and systemic and structural barriers, such as poverty, racism, gender discrimination, and other forms of oppression, that have resulted in health inequities. Everyone should have a fair and just opportunity to achieve good health and well-being.



Created 2020



Connect with us!

Visit us online at <https://bolddementiacaregiving.org>
to...

- ✓
- ✓ Find today's slides and recording.
Request Technical Assistance to support your
- ✓ public health work in dementia caregiving.
- ✓ Access resources and materials.

Stay up to date with PHCOE-DC activities.

Follow us on X @PHCOE_DC



Welcome to our speakers!



Monica Maly, MPH

Alzheimer's Disease and Related Dementias Program Coordinator,
Colorado Department of Public Health & Environment (CDPHE)



Joanna Espinoza Robbins, MPH

Alzheimer's Disease and Related Dementias Program Manager,
Colorado Department of Public Health & Environment (CDPHE)





PHCOE-DC Roundtable
Colorado BOLD
October 10, 2024



ADRD ACTION COALITION

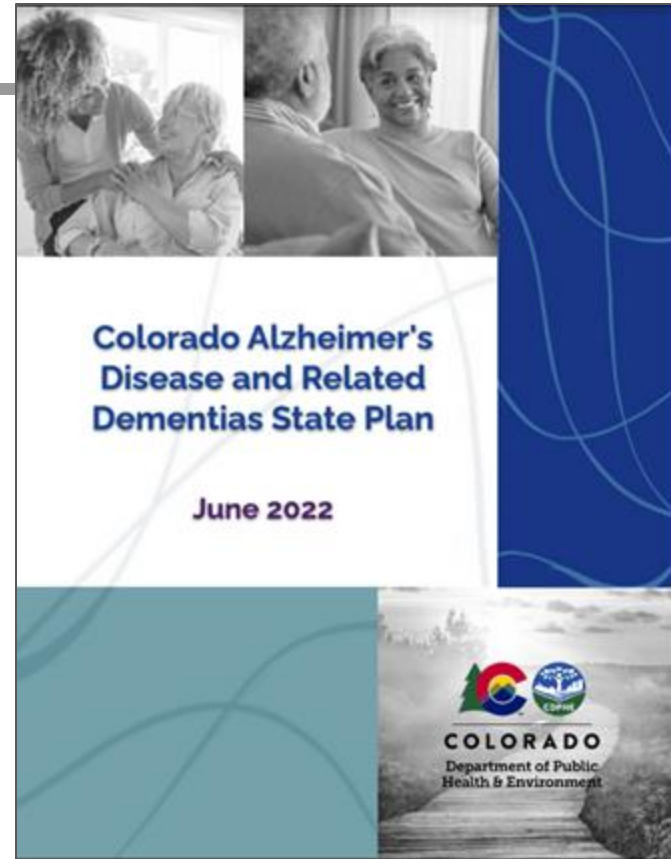
Alzheimer's Disease and Related Dementias Action Coalition

Overview *Presentation Objectives*

- Overview of ADRD in Colorado
 - Colorado ADRD and Care Partner Statistics
 - Action Coalition and Workgroups
 - Integrating Care Partners and Caregiving in Activities
- ADRD Data Source Matrix
- How Data is Used by the Action Coalition
- Success and Challenges
 - Data
 - Implementation of the ADRD State Plan

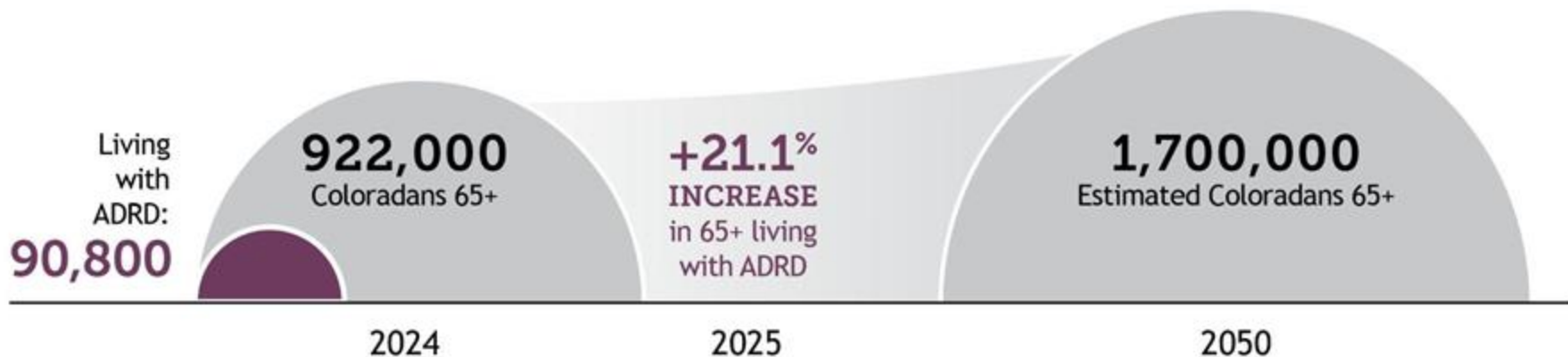


Colorado ADRD Statistics



Colorado Alzheimer's Statistics

AGE is the #1 risk factor for ADRD



7th leading cause of death in adults in Colorado

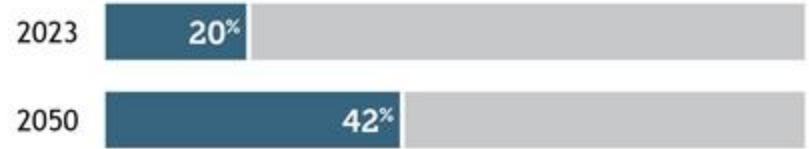


Racial Disparities *in Dementia*

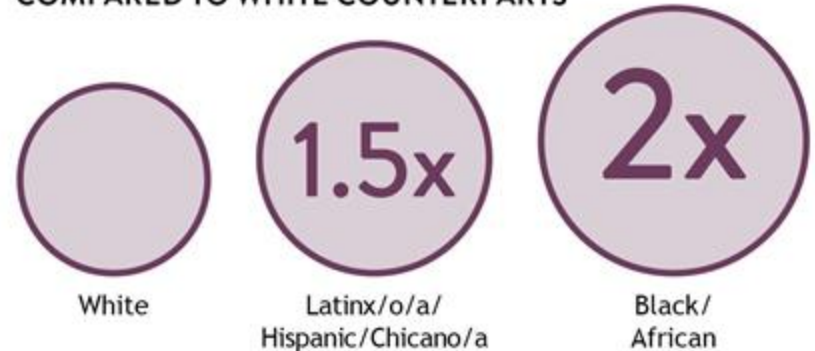
Colorado's Priority Populations

- 1 Black/African American
- 2 American Indian/Alaska Native
- 3 Latinx/o/a/Hispanic/Chicano/a

PEOPLE OF COLOR AGE 65 AND OVER IN THE U.S.



LIKELIHOOD OF HAVING ADRD BY RACE AS COMPARED TO WHITE COUNTERPARTS



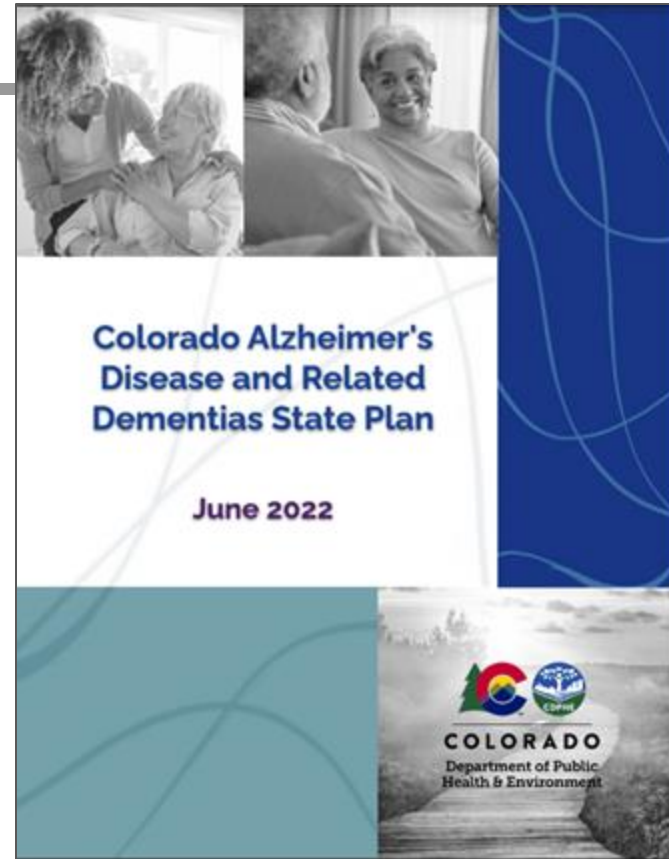
↑5x The number of American Indian/Alaska Natives 65+ living with dementia is projected to grow over five times by 2060.

Colorado Dementia Financial Implications/Impact

There are proven strategies that can reduce these costs.

- In 2020, it cost Colorado Medicaid \$635 million to care for people with Alzheimer's
 - This is projected to increase by 24.1% by 2025.³
 - Average per-person Medicare spending for those with ADRD is more than 3xs the Medicare average.⁴
- Impaired financial decision-making is often a precursor to ADRD
 - In Colorado, adults over 60 lost more than \$33 million to internet fraud in 2021, representing over 3,500 victims (8th highest in the nation)*

Colorado Alzheimer's Disease and Related Dementias (ADRD) State Plan



The Path to Colorado's ADRD State Plan



**BOLD
funding
awarded**



Convened a diverse and multi-sectoral advisory committee (ADRDAC)



Conducted a partner assessment to determine resources and data available



Conducted key informant interviews to further inform Colorado priorities



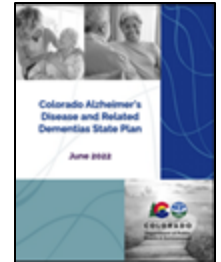
Gathered community input through Community Engagement Sessions that engaged and empowered community members including those representing each priority population



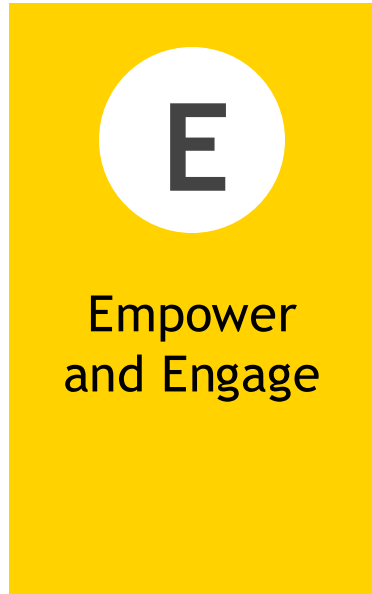
Narrowed and prioritized Road Map actions and activities of the Colorado ADRD State Plan with input from ADRDAC



**CO ADRD
State Plan
published**



ADRD State Plan Domains of Public Health



E

Empower
and Engage



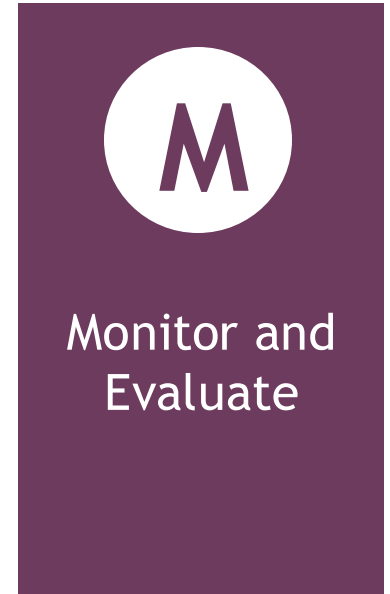
P

Develop
Policies and
Mobilize
Partnership
S



W

Assure a
Competent
Workforce



M

Monitor and
Evaluate

Empower and Engage

E

Empower
and Engage

- Public awareness campaign to reduce stigma and understand early warning signs
- Promote education to prepare people for living with ADRD/caring for someone with ADRD
- Deliver messaging to prepare care partners
- Integrate brain health and cognitive aging into existing health communications
- Facilitate access to services and supports

Develop Policies and Mobilize Partnerships



Develop
Policies and
Mobilize
Partnerships

- Promote best practices and evidence based interventions
- Educate policy-makers on ADRD and the impact on care partners
- Ensure access to care planning services for those recently diagnosed
- Engage health systems and community-based organizations to identify opportunities for communication and collaboration that can enhance support for people with ADRD and their care partners
- Provide technical assistance to health systems interested in achieving IHI's Age Friendly Health system recognition for mobilizing their local communities, and to understand priorities, including the mentation component



Assure a Competent Workforce



Assure a
Competent
Workforce

- Train public health professionals about ADRD
- Educate primary care providers about the importance of cognitive assessments
- Integrate education for healthcare professionals about care partners, ADRD counseling, and care planning
- Offer ADRD training to professionals who offer services to people living with ADRD, including first responders



Monitor and Evaluate

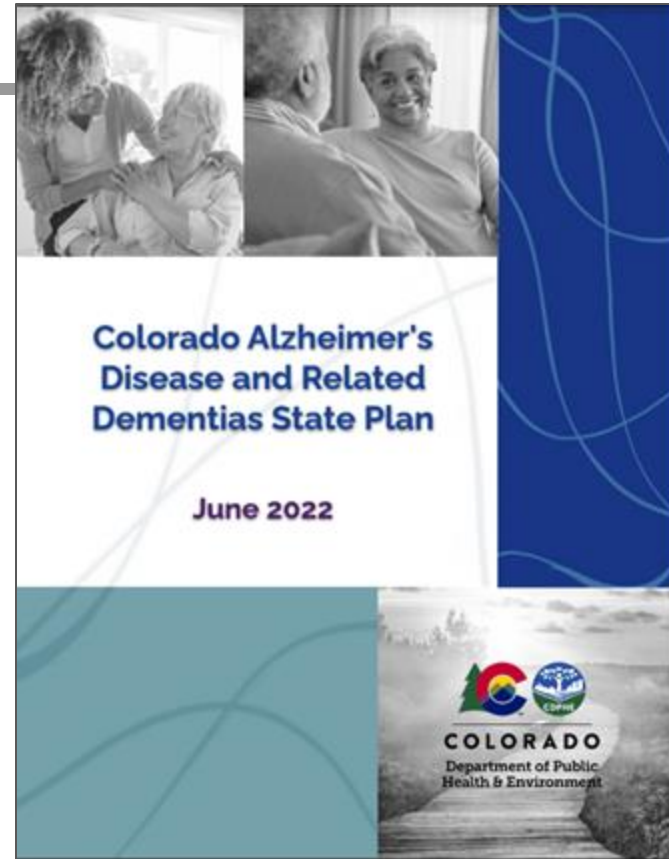


Monitor and Evaluate

- Maintain a list of surveillance systems and data sources for ADRD indicators
- Convene a data sub-committee
- Review available qualitative and quantitative data to inform implementation and evaluation of the State Plan



Integrating Care Partners and Caregiving into the Colorado ADRD State Plan



Colorado Statistics - Care Partners

Informal, unpaid caregivers, usually friends or family members that partner with the person living with ADRD to provide support, resources, and care.

- On average, a person with Alzheimer's lives 4 to 8 years after diagnosis
 - Can live as long as 20 years depending on many factors.⁵
- Older adults with dementia are more likely to need help with daily activities than older adults without dementia.
- In Colorado 177,000 care partners provided 307,000,000 hours of unpaid care.⁵
 - 58.0% of care partners have a chronic health condition.⁵
 - 36.7% report depression.⁵
 - 1 in 3 care partners for people with ADRD report their health has gotten worse
 - Compared to 1 in 5 care partners of older adults without dementia.⁶
- The total value of unpaid care was estimated at over \$7 billion dollars in Colorado.⁵



Care partners can receive support through the Alzheimer's Association's education courses, respite care programs, and AAAs, but one of the main barriers is the lack of awareness about available of services and supports.

Incorporating Care Partners & Caregiving

E

E.1.1
E.1.2
E.1.5
E.7.1

P

P.1.1
P.1.4
P.1.5
P.3.1
P.5.2
P.5.3

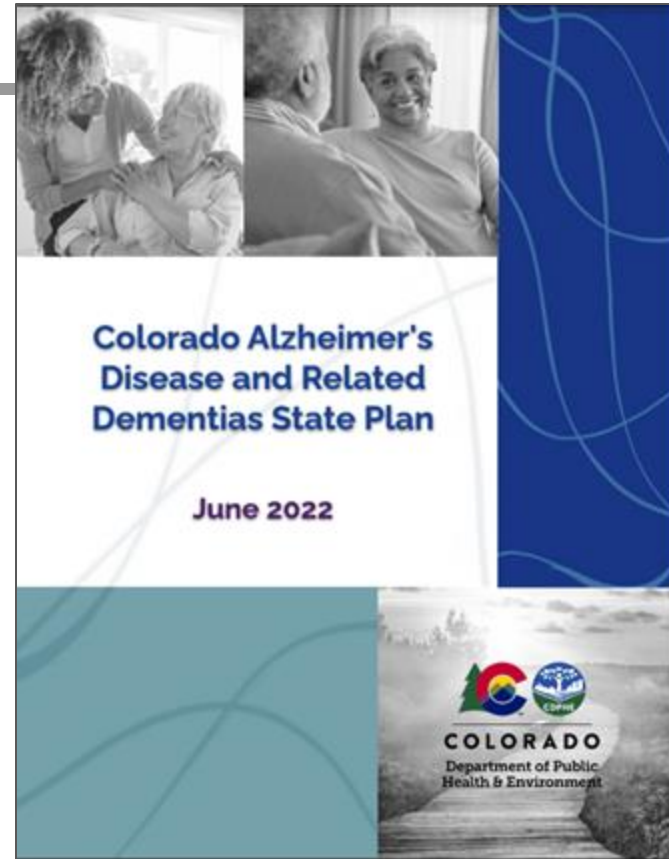
W

W.2.2
W.3.2
W.4.3

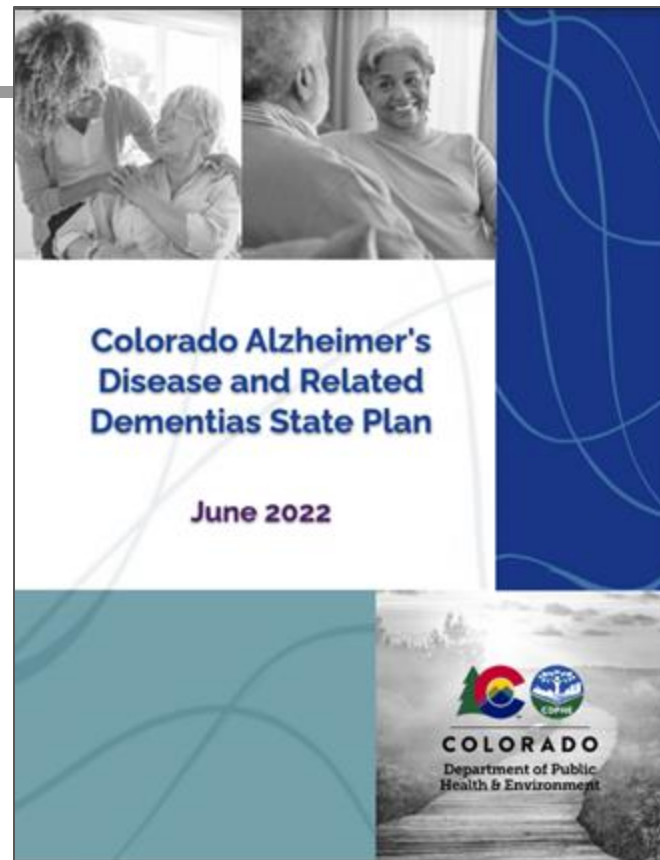
M

M.3.1
M.3.2
M.3.3
M.3.4

What have you and your organization done to engage care partners in the work you are doing?



Data



Data Source Matrix



- Primary and Secondary Data Sources
 - Older adult, ADRD, and care partner data
- Development
 - Email Outreach
 - Key Informant Interviews
 - Question Types
 - Internal Coalition Requests
- Implementation
 - Disseminated to the Coalition
 - Reference for data availability and resources
- Replication
 - Posted on AMP for BOLD Grantees to utilize

Data Source Matrix - Items to Include



Monitor and
Evaluate

- Source Type
- Data Source
- Population Represented
- Owner
- Primary Contact
- Role At Organization
- Secondary Contact
- Accessibility - Data Collection/Cost
- Topics Covered by Data Source
- Specific Question(s) Answered by Source
- Notes
- Resource Location - i.e., website

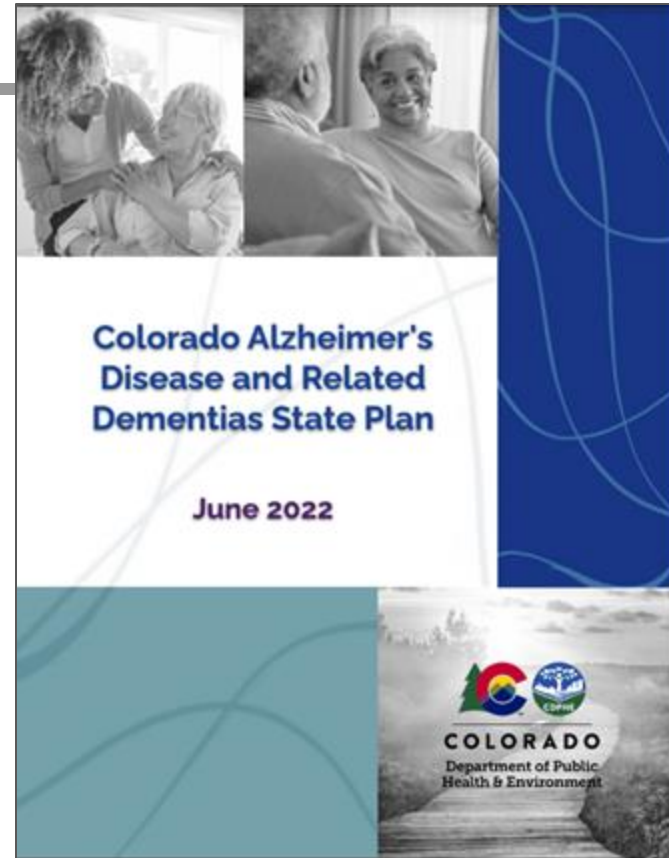


Data Sources used by the ADRDAC



- Colorado State Level Data - ADRD and Care Partners
 - Colorado County and Local Data
 - Facts and Figures from the Alzheimer's Association
- Behavioral Risk Factor Surveillance System (BRFSS) Data
 - Cognitive Decline and Care Partner
- *Analysis in Process:* Center for Improved Value in Healthcare (CIVHC)
 - All Payers Claims Data
 - CPT Codes
- *Coming Soon:* The Bell Policy and Colorado Respite Coalition Caregiver Mental Health Survey
- *Future Outreach:* Colorado Community Managed Care Network
 - Rural hospitalization data and FQHCs

Does your organization, coalition, or committee have access to data sources that collect data on the different types of dementia? What are those sources?



Empower and Engage - Use of Data

E

Empower
and Engage

- **County Level and Local Data - prioritization**
 - E.1.1: Public Awareness Campaign
 - E.1.2: Community Education Partners
 - E.1.4: ADRD Rural Survey - ADRDAC data collection method
 - Community Health Assessments
- **BRFSS Data**
 - E.1.2 & E.1.5: Promote education to prepare people for living with ADRD/caring for someone with ADRD
 - E.2.2 & E.2.3: Integrate brain health and cognitive aging into existing health communications
 - Impact of multiple chronic conditions, risk behaviors from BRFSS

Develop Policies and Mobilize Partnerships - Use of Data



Develop
Policies and
Mobilize
Partnership
S

External Data Sources

- **The Bell Policy and Colorado Respite Coalition - Caregiver Mental Health Survey**
 - P.1.5: Identification of barriers and needs for care partners
- **Colorado State Level ADRD and Care Partner Data**
 - P.3.1: Educating policymakers and legislators

ADRDAC Data Collection Method

- **Health Occupations Students of America (HOSA) Questionnaire**
 - P.1.3: Results informed implementation steps to engage students at the high school and college level

Assure a Competent Workforce - Use of Data



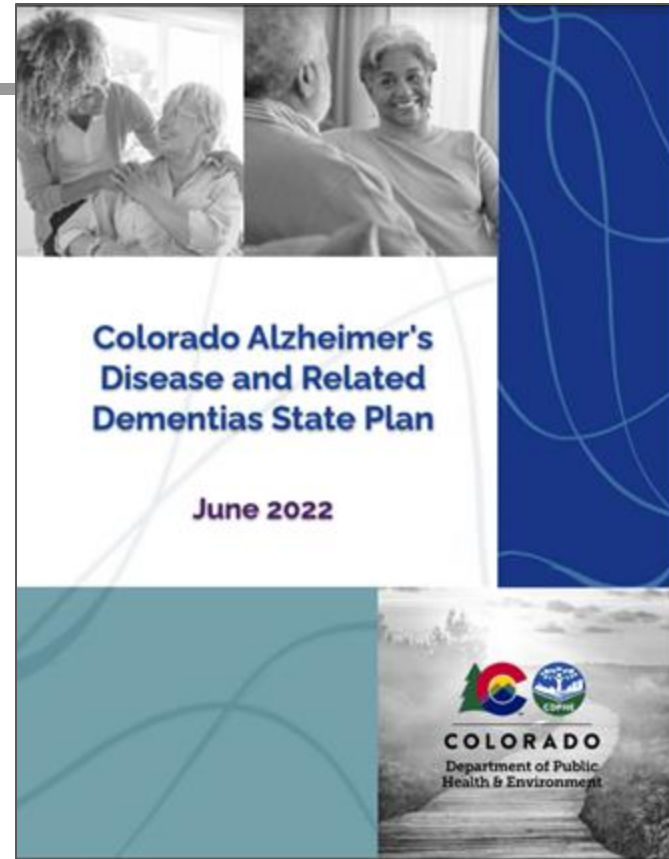
- **Center for Improving Value in Health Care (CIVHC)**
 - **All Payers Claims Data**
 - **CPT Codes**
 - 99497 - Advance Care Planning - first 30 minutes
 - 99498 - Advance Care Planning - addtl 30 minutes
 - 99483 - Cognitive Assessment and Care Planning
 - **Activities**
 - W.4.1 & W.4.2: Provider education
 - E.1.5: Care planning and care partners
- **Hospitalization and Emergency Room Visit Data**
 - Looking at types of dementia vs. collective ADRD
 - Proper use of codes

Monitor and Evaluate



- Data Request Form
- Data Walks
- Data Analysis
 - ADRD Rural Survey
 - Health Occupations Students of America (HOSA) Questionnaire
 - Care Partner Stories Questionnaire
 - CIVHC All Payers Claims Data
- Priority Population Champions (Air Traffic Controllers)
 - Aid in outreach
- SMARTIE Goals Tracker

How has your organization used data?



Successes & Challenges - Data

Successes

1. This is one of the first repositories of quantitative AND qualitative data on older adults and aging.
2. Collaboration across the ADRDAC and crowdsource nature ensured that we had a comprehensive list
3. List has been helpful in identifying where data gaps may exist.

Challenges

1. Finding information for each data source provided by the ADRDAC
2. Data Use Agreements and privacy requirements
 - a. Personal Health Information (PHI)
3. Identifying a contact for each data source
4. Limited data around experiences of older adults
5. Limited data sources for non-white populations, including priority populations
6. Lack of data sources for other types of dementias
7. Time it takes to analyze the data



Successes & Challenges - ADRD State Plan

Successes

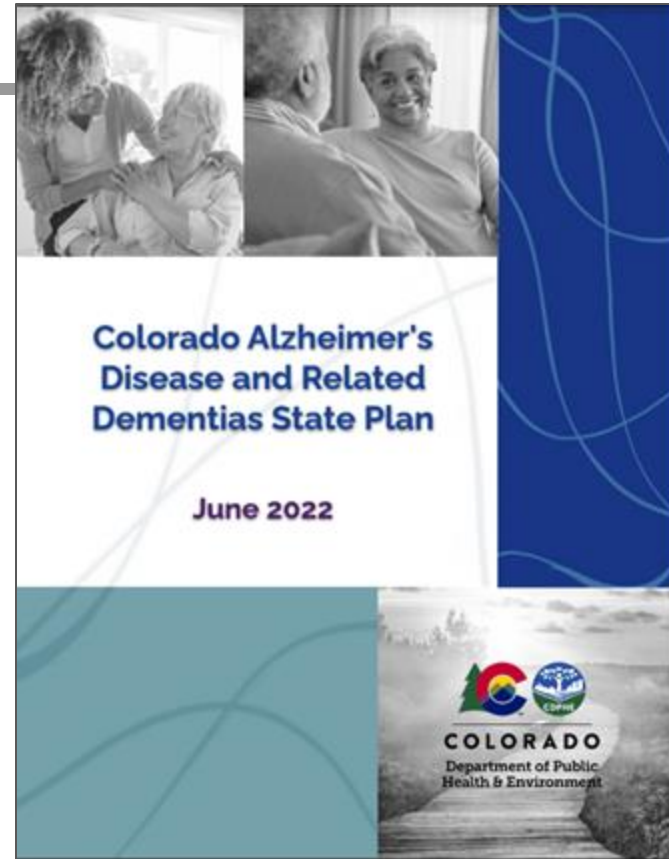
1. Retention of ADRDAC members
 - a. Passionate group of Coalition members who are dedicated to implementing the State Plan
2. Recruitment of new members
3. Engagement of care partners in ADRD Action Coalition
4. Presentations, education, and training opportunities - conferences
5. We are making progress!

Challenges

1. Capacity of priority population representatives/organizations
 - a. Lack of people resources even though there is a desire/want to participate
 - b. Particularly challenging to engage the AI/AN community
2. Capacity of care partners
 - a. The reality of dementia disease progression



What definition do you use to define an equity lens when thinking about it from a data perspective?



ADRD Quarterly Newsletter



Scan the QR Code to stay up to date with the latest work being accomplished by the Alzheimer's Disease and Related Dementias Action Coalition (ADRDAC)!

Newsletters are sent via email on a quarterly basis. Next newsletter will be sent in October!

Thank you to Colorado's M-workgroup!

- Danelle Hubbard - Alzheimer's Association and Care Partner
- Hannah Peterson - Colorado Department of Public Health and Environment
- Rachel Jardim - Center for Improving Value in Health Care (CIVHC)
- Amy Meyering - Colorado Department of Public Health and Environment
- Meredith Koob - Telligen
- Lisa - Data Surveillance Subject Matter Expert and Care Partner

Big thank you to the Colorado Alzheimer's Disease and Related Dementias Action Coalition (ADRDAC)!



Questions?

Please put questions in Q&A

**Joanna Espinoza
Robbins, MPH**

Alzheimer's Disease and
Related Dementias (ADRD)
Program Manager

Email:
joanna.espinozarobbins@
state.co.us



Monica Maly, MPH

Alzheimer's Disease and
Related Dementias (ADRD)
Program Coordinator

Email:
monica.maly@state.co.us