



Figure 1 California Health and Human Services Logo

CalHHS Alzheimer's Disease and Related Disorders Advisory Committee (Acronym ADRD)

February 1, 2024, Meeting Minutes

This meeting was held in-person at California Department of Aging Headquarters 2880 Gateway Oaks Drive, Sacramento, CA 95833, with a remote option.

Call to Order: Welcome and Introductions, Vice Chair appointment, November Minutes

- *Catherine Blakemore, Committee Chair and Committee members*

Members attending in person: Wynnelena Canlas Canio, MD; Barbra McLendon; Catherine Blakemore; and Myra Garcia

Members attending via Zoom: Ken Graffeo; Dolores Gallagher-Thompson, PhD; Sarah Tomaszewski Farias, Ph.D.; Dr. William Mobley; Sally G. Bergman; Julie Souliere; Celine Regalia; and Todd Shetter

Dr. Wynn Canio has been appointed the Vice Chair.

Todd Shetter moved to approve the November meeting minutes. Sally Bergman seconded the motion, and all voted in favor of approving the minutes. Two abstentions – Myra and Catherine abstained because they weren't at the November meeting.

Emergency Preparedness, Response and Recovery for Persons with Dementia and their Caregivers

The following presenters discussed the experiences of **older adults, including** people living with Alzheimer's **disease** and other dementias (**ADRD**) and their caregivers, related to emergency preparedness, response, and recovery. They also discussed what steps California has been taking to specifically address the needs of these populations, how they work with partner agencies, where the gaps still are and what is being planned.

- *Presenter 1: Celine Regalia, Director of Operations, Providence Community Health Napa Valley*
- *Presenter 2: Vance Taylor, Chief, Office of Access and Functional Needs, California Governor's Office of Emergency Services*
- *Presenter 3: Sydney Schellinger, Senior Emergency Services Coordinator, California Department of Aging*
- *Presenter 4: Michael Butier, Functional Assessment Service Team (FAST)*

The following links were shared in virtual chat:

Link 1:

[California Department of Aging – Emergency Preparedness and Response](#)

Link 2:

[Listos California](#)

Link 3:

[California Department of Social Services Disaster Volunteer Programs](#)

Committee Question and Answer (acronym Q and A) and Discussion

The committee expressed appreciation for this overview provided by the presenters.

They noted that there wasn't a specific mention of efforts focused on people living with Alzheimer's disease and related conditions. The members noted that they have heard in the past that there aren't a lot of materials out there that speak to the needs of people living with a cognitive impairment. It was exciting to learn about the assessment process – it would be great if it could result in best practice guidance for counties on what specifically needs to be in place to assist people living with a cognitive impairment. The California Office of Emergency Services (acronym Cal OES) could be a hub for this information.

For example, could there be a voluntary registry in each county that could be used for wandering **and** emergency preparedness? Then in an emergency they could send appropriately trained staff to their homes to help them evacuate safely and with less stress/anxiety.

What kind of training are first responders getting related to persons with dementia? A few years ago, legislation passed that required first responders to get some training on dementia. It proved to be difficult to implement the legislation due to the decentralized nature of the emergency response system. Under the California Emergency Medical Services Authority (acronym EMSA), could they set a floor to make sure staff in each county have the right kind of training to be able to address the needs of persons with dementia and engage their care partners?

Then support counties in ensuring that their plans include best practices for how staff communicate with persons living with dementia.

It's important that persons living with dementia don't get lost in the larger group of people living with disabilities when it comes to this topic.

Cal OES and the Department of Rehabilitation (acronym DOR) produced an [Emergency Preparedness Guide/Toolkit for Individuals with Disabilities](#). Is there or could there be a toolkit for people living with ADRD? Maybe this toolkit could serve as a base for that.

CDA doesn't have an emergency preparedness toolkit specific for people with dementia. The California Department of Aging (acronym CDA) is creating a personal emergency plan for older adults, and they will include information regarding ADRD.

A committee member had an aunt with dementia. The aunt didn't have anyone to help her, and she consequently lost her home. The committee member expressed appreciation for the work being done.

Providence Community Health Napa Valley includes information on emergency/disaster preparedness in their assessments and work with their clients. Emergency preparedness needs to be woven in care management through GUIDE and other models.

For people living with Alzheimer's, the risk of wandering and getting lost that is present during normal times may increase during a disaster. Are there teachings for caregivers and first responders that can be used so people know what they are dealing with?

Very few counties have any centralized prevention and response program related to wandering, especially those focused on preventing wandering. This hasn't been a focused effort at the state level. Sixty percent of people with Alzheimer's will wander and our systems need to support families.

San Diego has the [Take Me Home Program](#) through the Sheriff's Department. It's a model related to response for any wanderers (autism, acronym IDD, and acronym ADRD).

The Alzheimer's Association has a [free online course for first responders](#) that includes information on wandering. There is content for caregivers on wandering [on their website](#) for them. University of California Los Angeles Health has a short [caregiver training video on wandering](#).

It's important to have a specific plan for those with a cognitive impairment and identify the specific approaches that are helpful for that person. As part of the evacuation, it's important to make sure that the person with dementia and their caregiver can stay together.

Perspective from the field from an assisted living community: all licensed residential care facilities for the elderly (acronym RCFEs) need to have a disaster plan and update them annually. This is looked at during their survey. They also need to have an emergency exercise once a year where they simulate evacuation. Todd discussed having evacuated a 70-person facility to a sister facility – San Diego County has set up a network of sister facilities with protocols; they have also taken in residents from other facilities in Orange County.

There was a question about whether the Functional Assessment Staging Tool (acronym FAST) team assessment includes mental health. Persons with dementia

and caregivers may have their own mental health issues (depression and anxiety are common). The FAST program supports people into the recovery phase. In past deployments, mental health issues have come up frequently. The FAST volunteers will identify if there is something that is going on related to mental health; then at the shelter there should be a mental health representative who will assist in connecting the individual with resources.

Committee Meeting Break

California Department of Aging (acronym CDA) Update

The following presenter provided an update on activities related to CDA-led initiatives since the last meeting:

- *Presenter 1: Susan DeMarois, Director, California Department of Aging*

The following links were shared in the virtual chat:

- [Bridge to Recovery Grants](#):
- [Governor's Proposed 2024-25 State Budget](#)
- [LGBTQIA+ Older Adult Survey Launched](#)
- [Little Hoover Commission Reports on Master Plan for Aging](#)
- [CA 2030 recommendations](#)
- [CalHHS Agency Secretary Sets 2024 Program Priorities CalHHS 2024-25 Program Priorities](#)
- [MPA's 3rd Annual Report](#)
- [MPA 2023-2024 Initiatives for Implementation](#)
- [MPA Implementation Tracker](#)
- [CalGROWS](#)
- [IHSS Career Pathways](#)
- [Cal GROWS promotion toolkit](#)

Committee Questions or Comments

One of the members expressed appreciation for CDA's work related to long-term services and supports. There are many families who need support, can't afford to pay out of pocket and don't qualify for programs such as Medi-Cal.

Alzheimer's Public Awareness Campaign Update

The following presenter provided an update on the Alzheimer's public awareness campaign that the California Department of Public Health recently launched:

- *Lisa Gonzales, Communications & Prevention Lead, Alzheimer's Disease Program, California Department of Public Health*

The following links were shared in the chat:

- [Take on Alz campaign site](#)
- [Campaign video](#)
- [CDPH New Research Grants](#)

Committee Questions or Comments

Question: What happens with the ad campaign after it ends in June?

Answer: CDPH will own all the materials – paid ad placement after June will require additional funding. The website will still be up, CDPH will continue to post campaign materials on social media.

Question: How will they assess the outcome of the campaign?

Answer. They will be collecting quantitative data. They are implementing a tracking survey to see if behaviors change (baseline was conducted in January). They also had done a lot of formative research to develop campaign.

Question: How are you working to get it in the doctors' offices? Are you working with California Advancing and Innovating Medi-Cal (acronym CalAIM) or Dementia Care Aware (acronym DCA)?

Answer: Creating grab and go resources and posters; are leaning on existing partners. They don't have any specific CalAIM contacts yet but are working closely with DCA.

Question: As new therapies come online that are safe and effective, could there be updates in the future as part of the campaign?

Answer: Possibly, depending on resources

Question: Could County public health depts reach out to senior centers?

Answer: CDPH will be sharing campaign toolkits and resources with all local health jurisdictions. Those that are part of the Healthy Brain Initiative will use some of their resources to localize and get the campaign out.

Older Adult Behavioral Health (acronym OABH) Initiative

The following presenters provided an update on CDA's Older Adult Behavioral Health Initiative:

- *Sarah Steenhausen, Deputy Director, Division of Policy, Research and Equity, California Department of Aging*
- *Stephanie Blake, Behavioral Health Specialist, California Department of Aging*

Links shared in the chat:

[Older Adult Behavioral Health Roundtables Summary](#)

[Fact sheet on Older Adult Behavioral Health initiative](#)

Committee Questions or Comments

Question: Is there data available on how many people are accessing the Friendship Line?

Answer: The presenters did not have the data with them but will pull the data and share it with the Committee. The calls tend to be longer than other hotlines; there are also many repeat callers.

Question: There may be a need to raise awareness that the Friendship Line exists. Please share resources that committee members can use to promote and consider where paid ads could be used.

Answer: The Older Adult Behavior Initiative (acronym OABH) funding allows the Friendship Line to continue beyond the past short-term funding. Now that there is more secure funding, we can elevate it as a resource. It started in the Bay Area, so it's not as well known in other parts of the state.

Social isolation was identified by the Lancet Commission as a modifiable risk factor for Alzheimer's Disease and Related Disorders (acronym ADRD). Would there be a way to do research on explicitly linking older adults with each other in a community setting? It sounds like the Village Movement concept.

Legislative Update

The following presenters shared information on their organizations proposed legislative priorities and the status of the bills they are tracking.

- *Barbra McLendon, Public Policy Director, Alzheimer's Los Angeles*
- *Jason Gabhart, Government Affairs Director, Alzheimer's Association*

Members emphasized the importance of removing stigmatizing language in the current statute and term limits for the consumer members on the committee.

Suggested Topics for 2024 Meetings

The committee members recommended the following topics for the upcoming meetings:

Wandering – models from individual communities (San Diego and Los Angeles?) and examining what could be done more formally statewide.

- California Office of Emergency Services – What are they doing to set a floor across emergency response re: training and needs of those living with a cognitive impairment? How is authority delegated? Training for those who are wandering or expressing behaviors (including on kindness)?
- Barbra is also learning from Riverside County.
- Ripe for a public service campaign related to wandering (like prior campaign related to elder abuse).

Role of Antiphospholipid Syndrome (acronym APS) and ombudsman in dementia space; working with caregivers is sometimes missing – could also talk about abuse prevention.

Caregiver access to loved ones who go into the hospital – help us understand what role the Center for Health Care Quality (in the California Department of Public Health) licensing and certification program might be able to play re: hospital visitation rules to ensure that caregivers (acronym CG's) are allowed access to their loved one and help with care; similar to work of the [Long-Term Care Facility Access Policy Workgroup](#) that CDA had. Educate ourselves re: the

components. Also, what does ADA require in terms of accommodations (Disability Rights CA)? How do you ensure that people with dementia in the hospital have access to the supports they need?

Discussing modifiable risk factors for dementia in older adults (e.g., hearing loss) – Dementia Care Aware should help primary care physicians get ready to speak with families about risk factors. There are things that can be done even after people have been diagnosed. We should promote this to Secretary Ghaly as an important message to primary care providers.

Finalize Recommendations and Items for CalHHS Secretary

The committee members recommended putting the following items in the memo to Secretary Ghaly:

- Wandering – CalHHS should have a role.
- Dementia Care Aware should help primary care physicians get ready to speak with families about risk factors. There are things that can be done even after people have been diagnosed.
- Emergency preparation and response – materials, training, and approaches for people with dementia
- Importance of amending our statute re: removing stigmatizing language and term limits
- Public awareness campaign initial funding ends in June – importance of looking at the data and using it to inform subsequent steps, including potential need for additional funding to fully implement campaign effectively; don't want these resources to wither on the vine.
- DCA funding is also ending – these efforts also need to continue.
- In health care all providers take care of persons living with dementia but not all providers are sensitive to their needs and those of the caregivers. We need to help the rest of the health care workforce learn how to care for them effectively in the ER, hospital or wherever they enter the system. It took Myra many years to get a diagnosis – the primary care physician kept telling her she was fine.
- Peace officers – are they able to tell if someone has Alzheimer's or a related dementia? This is another area for training.

Public Comment

The emergency preparedness and response session were fabulous. Despite not hearing specific examples to ADRD, everything is translatable in guiding us in providing appropriate services for persons living with dementia. The commenter shared an experience she'd had in visiting a shelter. There are different kinds of shelters and in this one nobody could lie down. They didn't have anyone there who had ADRD expertise. The board and care home that evacuated didn't have a reciprocity agreement to move people to another facility.

The Office of Emergency Services is stripping money away from elder abuse, which predominantly impacts people living with dementia.

It is important to continue Cal-COMPASS funding. Alzheimer's Day Care Resource Centers is in the Master Plan for Aging. We must continue to elevate this work.

Geriatric medicine is an elective in med school. It's a problem that more physicians don't receive education related to dementia.

Alzheimer's Disease and Related Disorders Advisory Committee information and materials can be found here:

<https://www.chhs.ca.gov/home/committees/alzheimers-disease-and-related-disorders-advisory-committee>

Alzheimer's Task Force Report (*Our Path Forward: Alzheimer's Prevention and Preparedness*): http://caalztaskforce.org/wp-content/uploads/2021/01/2020-Alzheimers-Report_FinalDigital.pdf

CDA's Upcoming Events calendar can be found on CDA's homepage:

<https://aging.ca.gov/>

To subscribe to CDA's newsletter, please visit: [California Department of Aging \(list-manage.com\)](https://list-manage.com)

Recognition for Andrea Robert

The Committee acknowledged former committee member, Andrea Robert. She provided her thoughts as she stepped off the committee. She appreciated the chance to see what is going on in the background and passed the information about programs on to others. Andrea encouraged the committee to continue to look at workforce issues. Paid caregivers are working multiple jobs because they aren't paid enough. They need adequate training and a career ladder. She encouraged agencies and departments to hire more people of color who can make an impact for these communities.

Closing Comments, Upcoming Meeting Dates and Next Steps

- *Catherine Blakemore, Committee Chair*

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[CDA 50th Anniversary](#)

Meeting Adjourned

Public Comment: The time and order in which agenda items are considered may be subject to change. Public comment will be taken at the end of the meeting. Prior to making your comments, please state your name for the record and identify any group or organization you represent, if applicable. Depending on the number of individuals wishing to address the Advisory Committee, the Chair may establish specific time limits on comments.

Attendees joining by webinar (the virtual platform called Zoom) can use the Q&A function to ask a question or select the raise hand icon. When it is your turn to comment, the moderator will announce your name and will unmute your line.

Attendees joining by phone can press *9 on your dial pad to “raise your hand.” When it is your turn to comment, the moderator will announce the last four digits of your phone number and will unmute your line.

Accessibility: The public meeting will be accessible to the public in-person, via telephone or webinar. American Sign Language (ASL) interpretation and closed captioning will be provided via the ZOOM webinar.

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Meeting materials: Slide presentations, meeting transcripts, video recordings, and any other materials will be posted following the meeting on the [Advisory Committee website](#). If you have questions, please contact Michelle Johnston at engage@aging.ca.gov.