



CalHHS Alzheimer's Disease & Related Disorders Advisory Committee

Meeting Minutes

August 3, 2023, 10:00 am – 2:00 pm

This meeting was held in-person (CA Department of Aging
2880 Gateway Oaks Drive, Sacramento, CA 95833) with a remote participation
option.

Call to Order: Welcome and Introductions, May Minutes

- *Catherine Blakemore, Committee Chair and Committee members*

Members attending in-person: Julie Souliere, Barbra McLendon, Celine Regalia,
Wynnelena Canlas Canio, Todd Shetter, Andrea Robert, Darrick Lam

Members attending via Zoom: Catherine Blakemore, Sarah Tomaszewski Farias, Pam
Montana, Sally Bergman, William Mobley, Meg Barron

Not in attendance: Dolores Gallagher-Thompson

Dr. Mobley moved to approve the May meeting minutes. Darrick Lam seconded the motion
and all voted in favor approving the minutes.

California's Leadership in Implementing Federal Alzheimer's & Caregiver Plan Recommendations

The following presenters gave a presentation on the federal [Alzheimer's Plan Update](#) and
the [National Strategy to Support Family Caregivers](#) recommendations, what California is
doing related to the recommendations and their ideas related to additional opportunities for
California to implement these recommendations

- *Wynnelena Canlas Canio, MD, Chief of Geriatric Medicine, Kaiser Permanente San
Rafael, Committee Member*
- *Barbra McLendon, Public Policy Director, Alzheimer's Los Angeles, Committee
Member*
- *Jared Giarrusso-Khlok, Government Affairs Director, Alzheimer's Association*
- *Darrick Lam, Committee Co-chair, Family Representative, Vice President, Self-Help
for the Elderly*

Committee Question and Answer (Q&A) and Discussion

- The committee appreciated the thoroughness of the presentation.
- It is important to raise awareness about Alzheimer's and other dementias, to
help people understand the risk. The Healthy Brain Initiative and the

California Department of Public Health (CDPH) public awareness campaign are good first steps and more needs to be done. Raising awareness around brain health is a less threatening opener for some who shy away from discussing Alzheimer's.

- It could be helpful to break out Alzheimer's and other dementias and their caregivers as a special population of focus in CalAIM (not just included within those at risk of institutionalization).
- The Alzheimer's Day Care Resource Centers (ADCRCs) have been a resource for community – beyond just the care they provide. They also provide community supports, offer care planning, are a one stop shop, work with caregivers, and provide respite. It would be great to work with the Aging and Disability Resource Connections (ADRCs) to have an Alzheimer's specialty component that could involve the ADCRCs.
- Celine read a statement from the [Cal-COMPASS](#) project providers: "With the growing need in the state and increased community awareness, it's urgent that care and services be available for individuals and families living with dementia. This can be accomplished by increasing the dementia capability of adult day services, both ADHC/CBAS and ADPs. We've been working on ways to do this through the Cal-COMPASS project, but Cal-COMPASS is not about creating a new model of care; it's about enhancing the capability of our statewide Adult Day Services network. We want to ensure that the Advisory Committee understands the importance of our work and what we're accomplishing through this project so that this is recognized and elevated because the grant funding will be going away, but these efforts need to continue."
- There are additional ways the Alzheimer's Disease Centers (ADCs) could contribute to these initiatives (would require more funding). They are currently primarily funded to see patients and diagnose, along with a little on caregiver support and community education. They are poised to be able to do more related to brain health and public awareness. They do a lot of caregiver support already but with their knowledge base and experience they could do more community education if they secured additional sustainable funding. SB 639 is current legislation but didn't include additional funding. The Alzheimer's Association is interested in budget opportunities for next year for ADCs.
- With the new, potentially disease-modifying treatments coming on the market for those in the early stage, this may change physician practice. The ADCs have toolkits and other resources that can help them.
- A member with a cognitive impairment mentioned that the direct care workforce initiative going well. Her IHSS provider is taking the trainings and she also shares it with others. The classes are going so well that they are filling up. She also wants them to continue to bridge training programs to LVN, RN programs, etc. for the providers' career growth so that they can have career pathways.
- People with dementia who may be on both Medi-Cal and Medicare don't know how to access services or recertify and they lose their benefits. HICAP is helpful but they lost some of the funding so they couldn't have their

consultant for long-term care benefits – this is a gap in being able to assist people who have questions about their long-term care insurance.

- Support activities around awareness and education. Sometimes we miss the issue of addressing stigma. It's similar to the mental health space where they have made great strides in reducing stigma. We should do that related to Alzheimer's disease as well – showing people living with Alzheimer's.
- Interest in [CMS GUIDE Model](#) for dementia care management. It's important for California to adopt the use of person-centered planning tools.
- Related to homelessness – it would be helpful to collect data and pilot programs for those living with dementia who are also unhoused.
- It would be great to connect RAISE outcome measures to our work. It's a powerful tool to create synergy and connectedness – think about how California's work connects to national outcomes.

Public Comment

- Wanda Smith with the CA Senior Legislature asked if the slide deck would be shared (yes it will). She also mentioned that families are often telling her about “diagnosis and adios” – it's important to approve diagnoses and shoring up accurate diagnoses for related dementias.

Alzheimer's Plan Implementation Update

The following presenters gave an update on implementation of tasks related to implementation activities of *Our Path Forward: Alzheimer's Prevention and Preparedness* report, including initial concepts for a media campaign:

- *Susan DeMarois, Director, California Department of Aging*
- *Lauren Groves, Chief, Chronic Disease Control Branch, California Department of Public Health*
- Q&A: Thanks CDPH for sharing the creative media concepts. In terms of "audience" I wonder how people with developmental disabilities (e.g., Down syndrome) will be included in assets and visuals. They will consider engaging with this audience for focus group testing to get their feedback on the proposed campaign.
- They were encouraged to make sure there is enough representation from all the subgroups under AANHPI as sometimes we just focus on Asian Americans.

30 Minute Break

Legislative Update

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

- *Barbra McLendon, Public Policy Director, Alzheimer's Los Angeles*

- *Jared Giarrusso-Khlok, Government Affairs Director, Alzheimer's Association*

Committee Q&A and Discussion

- Suggestion to have the Committee address the issue of wandering in a future meeting; ties into emergency preparedness as well – opportunities to make recommendations to the Secretary.
- Discussion around strategies to get AB 387 out of committee – if SB 544 passed, it would reduce travel costs; or remove additional members or change it so that the Agency Secretary could add all additional members at their discretion as budget allows. It's important to look at options to reduce cost so we can figure out how to address the language and term issues.
- A current consumer member stated that it takes a year to really understand and get familiar with the committee so it would be helpful to remove the term limit length. She is willing to advocate for members who are living with a cognitive impairment to have longer terms.
- There was a question regarding how it will work to put Dementia Care Aware (DCA) under ADCs. DCS would be brought under CDPH but the Department of Health Care Services (DHCS) would continue to manage the Medi-Cal billing piece. There's an opportunity in combining the two since they have been working collaboratively for the past two years. It's a different and useful role for the ADCs – maybe each ADC could become a local hub responsible for training people in their region. This would require additional funding to keep DCA going. ADCs already feel that they need more funding. This bill can help position them to make those decisions about how it will work in each site.

Update on the CDA Long-Term Care Facility Access Policy Workgroup

The following presenters presented a session on the progress of the Long-Term Care Facility Access Policy Workgroup.

- *Brandie Devall, Attorney, California Department of Aging*
- *Mark Beckley, Chief Deputy Director, California Department of Aging*

Committee Q&A and Discussion

- There was appreciation expressed to CDA and the committee for taking on this issue. Agencies were dealing with different regulatory agencies and residents' rights were often ignored. There were important lessons learned that can be applied in the future.
- It's important to specify protocols and resident/caregiver rights.
- There was a question regarding what will happen to the recommendations and acknowledgement that these issues are also applicable in hospital setting. One member mentioned that she couldn't see her hospitalized sister last year when she was dying until they changed her status. Another member mentioned that he had a very positive experience in a hospital when a family member was dying, but that the rules were dependent on the hospital. It's

important to have standards for all facilities.

- This work was structured by the legislature to get all of the voices at the table and negotiate a solution that is acceptable to all. The recommendations will go to the legislature so that they have an opportunity to pursue legislation. Some of the lessons learned from this work could also be applied to hospital settings.

Finalize Recommendations and Items for CalHHS Secretary

- *Darrick Lam, Committee Vice Chair*

The committee members discussed items that they wanted to bring to Secretary Ghaly's attention:

- It's important to bring more awareness and education related to Alzheimer's and related dementias and reduce stigma. Members referenced the needs of particular communities and the success that the mental health field has had in recent years in reducing stigma around mental health.
- Encourage California to promote participation in CMS' GUIDE Model to improve Alzheimer's care for persons with the disease and their caregivers. This is an exciting opportunity.
- We need more data on how many unhoused Californians have dementia so that we can seek opportunities to provide services to them.
- Suggestion to incorporate RAISE national indicators into California's MPA efforts.
- AB 387 – Importance of increasing membership, removing stigmatizing language and discriminatory term limits for consumer members. Could a middle ground option be making the increase in membership up to the Secretary so that it could be rolled out as the fiscal situation improves and/or SB 544 increased flexibility regarding remote attendance?
- Make sure Secretary is aware of the wandering safety issue and discuss how the state might address issue and helping counties respond. If there isn't a good system for finding a missing person with dementia in the first 24 hours, the outcomes are often bad. It has not been addressed throughout the state. We need an awareness campaign and more coordination among agencies. There are also equity issues – often law enforcement responds first. Issues related to race relations with law enforcement and community members surface in wandering situations as well.

Public Comment

- Priscilla Nichols expressed her appreciation to the Committee for their hard work.

Closing Comments and Next Steps

- *Darrick Lam, Committee Vice Chair*

- Opportunities presented in morning presentation – there should be a chance for the committee to prioritize the list prior to sending out to the

Secretary. We will send out the list for the committee to review and provide recommendations regarding priorities.

- The topic for the November meeting is caregiver health. Barbra, Celine and Dr. Mobley volunteered to help develop the session outline and recommend speakers.
- If AB 387 passes, we will need to update the bylaws. Jared and Sally volunteered to help. The group will also see if Catherine is available. Barbra said that she could help, if needed.
- There is a current committee vacancy for a person living with Alzheimer's or a related condition. The [application](#) is available online. Please help get the word out about this vacancy.

Adjourn – the meeting adjourned at 1:53pm.

Public Comment: The time and order in which agenda items are considered may be subject to change. Public comment will be taken at various points during the meeting and/or 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 (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 via telephone or webinar. American Sign Language (ASL) interpretation and closed captioning will be provided via the ZOOM webinar.

Pursuant to the Americans with Disabilities Act, individuals with disabilities may request a reasonable accommodation or modification to access and participate in the meeting. Please contact us at least five (5) business days prior to the meeting, using the contact information below. CalHHS will ensure that it makes every effort to fulfill the request. To submit a request or if you have any questions or comments, you may contact us at engage@aging.ca.gov or (916) 419-7500.

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.