



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

AGENDA

November 2, 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, August Minutes

- *Darrick Lam, Committee Vice Chair and Committee members*

Members attending via Zoom: Darrick Lam, Dolores Gallagher-Thompson, Wynnelena Canlas Canio, MD, Sarah Tomaszewski Farias, Ph.D., Barbra McLendon, Dr. William Mobley, Andrea Robert, Meg Barron, Sally G. Bergman, Julie Souliere, and Celine Regalia
Not in attendance: Catherine Blakemore, Todd Shetter

Sally Bergman moved to approve the August meeting minutes. Dolores Gallagher-Thompson seconded the motion, and all voted in favor of approving the minutes.

Recognizing Californians Living with Dementia and Their Caregivers

- *Mark Ghaly, MD, MPH, Secretary, California Health and Human Services Agency (CalHHS)*
- *Darci Delgado, Assistant Secretary, California Health and Human Services Agency (CalHHS)*

Dr. Ghaly had a schedule change and spoke later in the meeting.

Ms. Delgado spoke about the numbers of persons in California living with dementia and helping to care for them, and recognized that November is National Alzheimer's Disease Awareness Month (NADAM) and National Family Caregivers Month (NFCM). This is the longest standing advisory committee within CalHHS. She shared her family's caregiving story.

She talked about being proud of efforts such as Dementia Care Aware and the direct care worker training and stipend programs as policy and program work that comes out of this committee's recommendations. The fiscal situation is different from three years ago, but last year the California Department of Aging (CDA) received \$50M for an older adult behavioral health initiative. It emphasizes this administration's focus on behavioral health issues, including those among older adults.

Supporting Unpaid Caregivers of People Living with Dementia

The following presenters presented data on California caregivers:

- California's Behavioral Risk Factor Surveillance System (BRFSS) caregiver data – *Angalar Chi, DHSc, MPH, Research Scientist II, California Department of Public Health*
- Profile of Caregivers in California Caregiver Resource Centers: Analysis of Data from CareNav™ – *Janice Bell, MN, MPH, PhD, FAAN, Professor/Associate Dean, Betty Irene Moore School of Nursing, UC Davis*

The following presenter share her experience caring for her mother, who is living with Alzheimer's:

- *Hilda Gutierrez, Caregiver*

The following presenters spoke about programs and services to support California caregivers, as well as some of the gaps and barriers to accessing the services:

- California's Support for Caregivers – *Denise Likar, Deputy Director, California Department of Aging*
- California Community Program for Alzheimer's Services and Supports and Its Future (Cal-COMPASS) – *Celine Regalia, Director of Operations, Providence Community Health Napa Valley, Committee Member*
- California Caregiver Resource Centers – *Kathy Kelly, Executive Director, Family Caregiver Alliance*

The following presenter spoke about the behavioral health needs of caregivers and some of the evidence-based programs related to caregiver behavioral health:

- *Dolores Gallagher-Thompson, Professor Emerita, Stanford University, Committee Member*

The following presenter provided a summary of the gaps in services for California caregivers:

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

Committee Question and Answer (Q&A) and Discussion

- The committee expressed appreciation for this comprehensive overview provided by the presenters.
- There's a lot out there but how do people find it and connect to it? The No Wrong Door initiative will be essential so people can enter the system and connect to services, with an eye on people living with dementia and their caregivers.
- With there currently being over 1.1M caregivers of people living with dementia in California, we will need a lot of services. More funding is needed for this area of service delivery.
- Regarding the data shared on sandwich generation caregivers – can there be a role for employers and maybe a matching role for the state? One option would be to package something to make it easy for employers to connect with employees around caregiving (work to help people recognize that they are caregivers and bring them into the system and connect them to resources).
- This committee has been looking at mental health (MH) issues. There is a double layer of stigma with MH and dementia. There is also some cultural reluctance to access services. It would be helpful for the committee to receive more details on the

new Older Adult Behavioral Health initiative.

- One member has been watching the work of the Mental Health Services Oversight and Advisory Committee (MHSOAC). The group has had a strong focus on youth and families. It's important not to forget about older adults and their significant MH needs.
- Question: Does the committee see a way to work on the continuity of the Cal-COMPASS model? This committee has made recommendations and could make a statement related to the value of the programs. The services they offer cover the whole journey from the beginning through bereavement, which is so important related to ADRD since it is a progressive disease. The caregiver needs shift along the progression too. The committee can encourage a service delivery system that moves with the person living with dementia and their caregivers, which the Alzheimer's Day Care Resource Centers do, it's so important.

Recognizing Californians Living with Dementia and Their Caregivers

- *Mark Ghaly, MD, MPH, Secretary, California Health and Human Services Agency (CalHHS)*
- Dr. Ghaly thanked the committee members for their ongoing service and recognized National Alzheimer's Disease Awareness Month (NADAM) and National Family Caregivers Month (NFCM). He has been spending time talking about the care economy on both ends of the lifespan. His biggest privilege was providing care for his father at the end of his life. There is a growing need in California with a shrinking set of workforce resources. How do we serve those with real needs effectively and with dignity while also building up the workforce? Caregivers are making sacrifices and losing career opportunities – how do we balance this? He encouraged the committee to keep working at this and share their new and fresh ideas, along with recycling the old ones that didn't stick.
- He also took a few questions/comments from the committee:
 - Andrea Robert thanked Dr. Ghaly for sharing his personal story and mentioned that it's so important to have the stories from consumers. Given that AB 387 didn't pass, she encouraged CalHHS to work to remove term limit restriction on the committee for persons living with ADRD. That way they can get more time to share their stories with the committee.
 - Andrea also expressed her appreciation for work that's being done to support caregivers, especially related to pay and training for the direct care workforce.
 - Barbra McLendon talked about the large group in the missing middle (people who make too much to qualify for Medi-Cal but not enough to pay out-of-pocket for services). There is more for people who have Medi-Cal than those who are just over the line. She discussed the challenge of creating a long-term care benefit and asked what committee members can do to support/advocate.
- Dr. Ghaly shared that we have a lot of places to look in supporting the missing middle. There are a number of strategies are being considered,

including where the eligibility line is drawn. California is looking at options to create a long-term care benefit but want to make sure it's a worthwhile benefit. All these ideas are moving slowly – he encouraged the committee to continue to give feedback.

- Dr. Ghaly also mentioned that they are looking at how to push Medicare to do more (most of the missing middle are covered by Medicare).

Public Comment

The following comments were shared in the Q&A:

- Thank you all for the wonderful information. I'd like to note that many individuals with dementia from a variety of causes are living alone without family caregivers, striving to maintain independence and continue living in the community. The ability to reach these people with Cal-COMPASS support will help with many related concerns, including the maintenance of housing and reduction of hospitalizations, etc.
- To put my comment in the context of caregiving, this also helps to ensure that families are not faced with sudden crises and the need to begin caregiving on an emergency basis.

30 Minute Break

Older Americans Act/Older Californians Act Modernization

The following presenter discussed the CDA-led caregiving initiatives and CDA's approach to moving away from isolated programs and initiatives to a more focused strategy approach.

- *Susan DeMarois, Director, California Department of Aging*

BOLD Public Health Programs Grant

The following presenter shared information on a recent grant CDPH received, the BOLD Public Health State Grant and talked about how they will work with 13 county public health departments and this committee to implement the Healthy Brain Initiative Road Map.

- *Lynnley Stern, DrPH, MPH, RD, Interim Chief, Chronic Disease Control Branch, California Department of Public Health (CDPH)*

Priorities from August presentation

The following presenters provided a recap of the opportunities that were presented at the August meeting during the presentation on California's Leadership in Implementing Federal Alzheimer's & Caregiver Plan Recommendations. The group reviewed the list, made some suggestions, and then voted to share the updated list in the next letter to Secretary Ghaly.

- *Darrick Lam and Wynnelena Canlas Canio, MD, Chief of Geriatric Medicine, Kaiser Permanente San Rafael, Committee Member*

Barbra McLendon moved to adopt the revised list of priorities. Sally Bergman seconded the motion and all voted in favor.

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*
- *Eric Dowdy, Vice President, Public Policy (CA & NV), Alzheimer's Association*

There was a recommendation to continue to seek to remove the limitation on the terms of members who are living with a cognitive impairment.

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:

- Barbra will share a list of the gaps she compiled from the morning caregiver presentations.
- Removing the term limit (in statute: maximum of two, one-year terms) for those living with a cognitive impairment would be very helpful. It takes a year to get familiar with the committee process, activities, etc. Members would be able to contribute more if they were able to stay on the committee longer, like the other members.
- In the recommendations from the August presentation, it's important to be sure to highlight the challenges of the missing/forgotten middle.

Public Comment

Two comments were received in the Q&A:

- This event has been impressive!! As a Social Work Major/Geron Minor - I am finding my way to work in the trenches with teams like yours. I look forward to the recording. Thank you.
- Comment not question - concerned that persons like Barbra McLendon and Eric Dowdy are not approaching the California Alliance for Retired Americans (CARA) for legislative boost via letters of support, phone calls, emails on legislative issues they presented. CARA has nearly 1 million members throughout the State of California. The Alzheimer's Association is notably absent from CARA's legislative calendar.

Closing Comments, 2024 Meeting Dates and Next Steps

- *Darrick Lam, Committee Vice Chair*

The group reviewed the dates for the 2024 meetings. With the increased flexibility related to attending in-person or via Zoom, the members discussed selecting a meeting or two to encourage in-person attendance. They chose February for people to attend in person if they can.

Darrick announced that he recently accepted a job offer to become the CMS Region 9

Administrator. He will be starting his position in December. He will let the committee know whether he is able to continue to participate once he has started his new position.

Adjourn – the meeting adjourned at 1:58.

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.