

CalHHS Alzheimer's Disease & Related Disorders Advisory Committee November 7, 2024 Meeting Minutes

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

Call to Order: Welcome and Introductions, August Minutes

• Catherine Blakemore, Committee Chair and Committee members

Members attending in person: Carlos Olivas III

Members attending remotely: Sally Bergman, Catherine Blakemore, Wynnelena Canlas Canio, Dolores Gallagher-Thompson, Myra Garcia, Barbra McLendon, William Mobley, Todd Shetter, Julie Souliere, Claire Day, Ken Graffeo

Members absent: Celine Regalia and Sarah Tomaszewski Farias (represented by Jason Gravano)

Sally Bergman moved to approve the August minutes and Todd Shetter seconded the motion. All members attending voted in favor of approving the minutes. No oppositions or abstentions.

Items shared in chat:

- CalHHS Alzheimer's Disease & Related Disorders Advisory Committee webpage
- Agenda, presenter bios and other meeting materials

Recognizing Californians Living with Dementia and Their Caregivers

The following presenter shared information on recognizing Californians with Dementia and their Caregivers.

- Kim McCoy Wade, Senior Advisor on Aging, Disability, and Alzheimer's at Office of California Governor Gavin Newsom
 - Ms. McCoy Wade announced that a proclamation will go out later this month for Alzheimer's Awareness month.
 - Confirmed that all 10 of the bold recommendations from the Alzheimer's Task
 Force are launched and underway and thanked everyone for their support.
 - Discussed the package of bills that got signed this year. Those bills include one that requires training for law enforcement in wandering and eloping often seen in people with dementia and one that requires geriatric and dementia training for certified medical professionals and licensed medical professionals who have a high percentage of older adults in their care.
 - This year, the implementation of wage replacement will help more working families and low-income families afford to take paid family leave.
 - We will be hearing from the Governor on both <u>Alzheimer's disease</u> and <u>family</u> caregiving this month.
 - She also stated there are opportunities to really think about the future of assisted living and that they're about to make historic investments in the behavioral health workforce that will begin July 1st.

Opportunities to Embed Dementia Care Navigation in California's No Wrong Door (NWD) System

The following presenters shared information on opportunities to embed dementia care navigation in California's No Wrong Door system. [Review presenter slides for additional details]

- Importance of dementia care navigation (DCN) Claire Day, Interim Executive Director and Chief Program Officer, Alzheimer's Association Northern California and Northern Nevada Chapter
 - Claire shared facts on the progression of Alzheimer's and their caregivers.
 - o Discussed their report on mapping a better future for dementia care navigation.
 - Two nationwide surveys were conducted: one for caregivers and one for health care workers who were most likely to provide navigation services that examined issues such as experience and exposure to DCN, services and supports needed/provided, perceived benefits of DCN, and barriers to DCN.
 - Caregiver key takeaways are that providing care is very stressful. Common stressors are the cost of care and coordinating it. Most caregivers think that a DCN would be helpful and would influence their choice of provider.
 - Healthcare workers key takeaways: deficiencies in the current healthcare system for dementia and a lack of dementia training for workers.
- A caregiver's experience Jezabel Galvan, Family Caregiver
 - Jezabel shared a personal story about her father who has younger-onset Alzheimer's and the difficulties in getting a proper diagnosis for him due to his younger age. She also talked about finding help for her father and how she was lucky to find help, but that often families are not supported by providers/systems.
- California state governance efforts related to No Wrong Door (NWD) Mark Beckley, Chief Deputy Director, California Department of Aging (CDA)
 - Mark explained the NWD system and how, once implemented, it will be able to help caregivers have better access to information and supports.
 - Key elements of the NWD system were shared as well as the development process.
- Piloting DCN in NWD through CAlz Connect Wynnelena Canlas Canio, CAlz Connect Steering Committee Member
 - Wynn gave an overview of the CAlz Connect program, which is funded by the Administration for Community Living and the US Dept of Health and Human Services, and how it provides evidence-based dementia care navigation for people living with Alzheimer's and other dementias, as well as their caregivers.

Items Shared in the Chat

- Alzheimer's Association 2024 Alzheimer's Disease Facts and Figures Report
- CMS Guiding an Improved Dementia Experience (GUIDE) Model Pilot
- Administration on Community Living No Wrong Door
- Master Plan for Aging
- CA 2030
- Aging and Disability Resource Connection program

- Aging Resource Guide
- Gap Analysis Home and Multi-Year Roadmap for non-Medi-Cal Home and Community-Based Services
- American Public Health Association Community Health Workers
- Medi-Cal Community Health Worker Benefit
- Medicare Community Health Worker Benefit
- CAlz Connect
- UCSF Care Ecosystem
- HomeMeds
- Materials from CA for ALL Ages & Abilities: 2024 MPA Day of Action
- To receive news and opportunities for engagement from the California Department of Aging and the Master Plan for Aging, subscribe to CDA's newsletter.

Committee Question & Answer (Q&A) for No Wrong Door

- Q: Barbra asked if there was a place in the state where the NWD system is more
 accessible by the community where they can really help people and it's working for
 people.
- A: Mark explained that one of the building blocks of NWD would be our Aging and
 Disability Resource Connections and that we have just started expanding those over
 the last five years. Some of those locations are where someone can go in and
 receive options counseling in person or over the phone. However, it may be several
 years until we can get the web portal component set up.
- Q: Catherine asked if there was any outreach planned for NWD, when it's launched.
- A: Mark stated that it will depend on budget. The current focus is more on development of the system, and will include naming and branding.
 - Catherine suggested using social media as it's cheaper. She would be willing to share what she has learned through another effort.
- Q: Dr. Mobley asked if there has been an attempt to see if this is cost effective for insurers and families.
 - A: Mark stated that he believes some research has been done. However, we have been working with a consulting vendor (Collaborative Consulting) and they have looked at no wrong door systems established elsewhere and that can be shared with everyone.
- Q: Dr. Gravano asked if the databases and interview assessments will be available to the people they are passing on the information to. He also suggested an opt-out referral system to reduce the burden on the caregivers to reach out to agencies.
- A: Mark answered, yes, that would be ideal, but that they would have to look at HIPAA, PHI, permissions, and eligible entities to pass information along to.
- Q: Catherine asked if there would be help completing applications as an expanded service.
- A: Mark said that it could be, but there would need to be an agreement with a partner agency and that might be difficult.

Public Comment #1

A caregiver whose daughter has Down syndrome expressed her concerns that it is
difficult for families to get assistance related to baseline cognitive testing, what to
look for and how to get a diagnosis if their loved one has dementia symptoms. She
would like the state to focus on making sure that Regional Centers and other
providers can advise people when asked for information about Alzheimer's and
other dementia services.

30 Minute Break

California Department of Aging (CDA) Update

- Sarah Steenhausen, Deputy Director, Division of Policy, Research and Equity, California Department of Aging [Review presenter slides for additional details]
 - o Sarah provided an update on some of the key initiatives related to the MPA.

California Department of Public Health (CDPH) Update

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

- Tina Fung, Chief, Alzheimer's Disease Section, California Department of Public Health [Review presenter slides for additional details]
 - Tina provided updates on the Alzheimer's Disease Program (ADP), activities related to prevention, clinical and caregiving support, and research and evaluation.

Items Shared in the Chat

- MPA Stakeholder Advisory Committee 2025-26 Recommendations
- Long-Term Services and Supports System Change in the MPA
- LTSS Financing
- Administration on Community Living grant award announcement
- National Strategy to Support Family Caregivers
- CDPH Alzheimer's Disease Program
- Media Campaign site
- California Healthy Brain Initiative
- Centers for Disease Control and Prevention Block Grant
- Brain Health Toolkit
- Our Path Forward Report
- California Legislative/Bill Information
- Alzheimer's Association
- Alzheimer's Disease and Related Dementia Voluntary Tax Contribution Fund reporting
- Governor Newsom's World Alzheimer's Day Release
- Alzheimer's Los Angeles
- CalHHS Alzheimer's Disease & Related Disorders Advisory Committee webpage

Alzheimer's Association State Legislative Update

- Eric Dowdy, Vice President of Public Policy and Advocacy, Alzheimer's Association
 - o Eric discussed the three bills they sponsored and were signed by the Governor.

Legislative Update

- Barbra McLendon, Public Policy Director, Alzheimer's Los Angeles
 - Barbara discussed legislation signed by the Governor that they sponsored or supported. [Review presenter slides for additional details]

Committee Question & Answer (Q&A)

No questions.

Public Comment #2

- There was no public comment.
- Additional public comments and questions can be sent via email to <u>EngAGE@aging.ca.gov</u>.
- CDA's Upcoming Events calendar can be found on CDA's homepage.
- To receive news and opportunities for engagement from the California Department of Aging and the Master Plan for Aging, subscribe to <u>CDA's newsletter</u>.

Finalize Recommendations and Items for CalHHS Secretary; Meeting Topic Ideas for 2025

- Wynnelena Canlas Canio, Committee Vice Chair and members Recommendations for CalHHS Secretary
 - Barbra noted that there were two other pieces of legislation that didn't make it out. They were related to family caregiver access to loved ones in a couple of different kinds of health and residential settings. She wanted to keep the issue alive by raising the issue to the Secretary even though the bills didn't pass.
 - o Catherine brought up, from previous discussion, the importance of outreach about the navigation services as a strategy.
 - Jason brought up the importance of a proper diagnosis, challenges in getting a timely diagnosis, and the lack of funding increases for the California Alzheimer's Disease Centers.
 - Dr. Mobley discussed the challenges of receiving high quality dementia care for persons living with Down syndrome as less than 5% of people with Down syndrome have access to a physician with expertise on the two conditions.

Potential Topics for 2025

- Getting a report on the state of older adult behavioral health services with a focus on families.
- Homeless population the average age is increasing and there is a growing percentage of the population that's living with a cognitive impairment.
- Brain health and dementia risk reduction.

Closing Comments

Wynnelena Canlas Canio, Committee Vice Chair

Upcoming Meeting Dates and Next Steps

Meetings for 2025 have been scheduled for February 6, May 1, August 7, and November 6.

Committee meetings will be held in-person in Sacramento with a Zoom option.

Meeting Adjourned

Public Comment: The time and order in which agenda items are considered may be subject to change. Public comment will be taken toward 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 in-person, 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 <u>CalHHS Alzheimer's Disease & Related Disorders Advisory Committee webpage</u>. If you have questions, please contact Michelle Johnston at <u>engage@aging.ca.gov</u>.