



CalHHS Alzheimer's Disease & Related Disorders Advisory Committee

MINUTES

December 8, 2022

This meeting was held virtually.

Call to Order: Welcome and Introductions, September Minutes

- *Catherine Blakemore, Committee Chair and Committee members*

Advisory Committee members in attendance: Catherine Blakemore, Julie Souliere, Dr. Sarah Tomaszewski Farias, Andrea Robert, Dr. William Mobley, Todd Shetter, Celine Regalia, Dr. Wynnelena Canlas Canio, Barbra McLendon, Meg Barron, Dolores Gallagher Thompson, PhD

Absent: Pam Montana & Darrick Lam

Approved minutes – Barbra McLendon moved to approve the September meeting minutes and Todd Shetter seconded the motion. The minutes were approved (all ayes, zero no's or abstentions).

Down Syndrome and Alzheimer's Disease Presentation

The following speakers gave a presentation and held a discussion about the intersection of dementia and Down syndrome.

- *Data and research – William C. Mobley, MD, PhD, Distinguished Professor, Department of Neurosciences, UC San Diego School of Medicine (15 min.)*
- *California data and Department of Developmental Services (DDS) initiatives related to aging and dementia – Dr. Lucy Esralew, Senior Supervising Psychologist, Department of Developmental Services (15 min.)*
- *Community services – Lisa Rund, RN, Health Services Associate Coordinator, San Andreas Regional Center (10 min.)*
- *Residential care model – Todd Shetter, Chief Operating Officer, ActivCare Living – Residential Memory Care & Kimberly Keane, Director of Program Development, Noah Homes (10 min.)*
- *A family caregiver's experience – Marc Loupe (10 min.)*

Down Syndrome and Alzheimer's - Discussion and Public Comment

The panelists and committee discussed the presentations and issues faced by individuals living with both an intellectual or developmental disability and Alzheimer's or other form of dementia. Some of the issues raised included:

- Importance of brain health messaging for persons with IDD – e.g., physical activity, nutrition, sleep, testing hearing and vision, social engagement, mental health (e.g., depression), cardiovascular health. There is an opportunity for the Alzheimer's Association, DDS and CDA to disseminate the information through the regional centers.

- Vision for Coordinated Family Support Systems - it is meant to help aging families and individuals with Down syndrome and dementia. The workers will have exposure to relevant resources and can help families navigate accessing them.
- Need to create a more robust community care and community services network – importance of interagency collaboration; takes funding
- Partnerships between regional centers and community-based organizations (e.g., adult day health centers) are important; would be helpful for them to use the same screening tools
- Need for more healthcare providers with skill in diagnosing cognitive impairments in those with IDD; how can California's network of Alzheimer's Disease Centers play a role? Also, how do we make families of an adult with IDD aware and primary care providers of the ADCs? Maybe the regional centers can play a role – how to connect regional centers and ADCs? Can training be added to medical school education?
- Sometimes a proper diagnostic work up isn't done because Down syndrome is assumed to be the cause of many health issues/symptoms
- Importance of education for caregivers of people with IDD on dementia
- As parents of adults with IDD and AD are aging, there are challenges and concerns related to who can care for the persons with IDD; sometimes a sibling steps in
- Lack of care homes, especially in northern California, for people with IDD and AD
- Need for all adults with Down syndrome have a baseline assessment at 35 and all adults with IDD have a baseline assessment at 50. This could really help identify those who are developing dementia and will need additional support

30 Minute Break

Alzheimer's Plan Update

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

Director DeMarois provided an update on CDA activities related to California's Alzheimer's plan.

She also mentioned that the Master Plan for Aging (MPA) is on track – the annual report to legislature will be submitted in January. It will include a summary of 2021-2022 work; also will include draft initiatives for 2023-24 (around 100 initiatives). The information can be shared with the Advisory Committee in the February meeting.

Alzheimer's Plan: Cal-COMPASS Update

- *Michelle Johnston, Program Director, Dementia Initiatives, California Department of Aging*

Michelle Johnston gave an update on Cal-COMPASS, a pilot program to build a model of dementia-capable adult day services.

Alzheimer's Plan: CAIz Connect Update

- *Tanya Bautista, Bureau Chief, Supportive Services Bureau, California Department of Aging*

Tanya Bautista gave an update on CAIz Connect, a project funded by the Administration on Community Living to implement the Care Ecosystem model in three counties, in collaboration with the Aging and Disability Resource Connection sites and to implement a no wrong door system for families impacted by dementia.

Alzheimer's Plan: California Department of Public Health Update

- *Lauren Groves, Chief, Chronic Disease Control Branch, Center for Healthy Communities, California Department of Public Health*

Lauren Groves gave an update on CDPH's progress related to contracts for the Healthy Brain Initiative, dementia research, a public awareness campaign, Blue Zone pilot, caregiver training programs and standards of dementia care. She also introduced Lynnely Stern, the new Chief of the Alzheimer's Disease Program at CDPH.

2023 Meeting schedule and topic ideas

- *Catherine Blakemore, Committee Chair*

Committee members suggested topic ideas for the 2023 Advisory Committee meetings.

Finalize Recommendations and Items for CalHHS Secretary

- *Catherine Blakemore, Committee Chair*

Committee members offered their recommendations to be shared with Secretary Ghaly. Topics included:

- Intersection of Alzheimer's and IDD – strategies to better collaborate and reduce silos among departments within HHS
- Upcoming legislative session – so much incredible work is happening – don't want it to be cut/eliminated – want continued commitment to building on great work on MPA, even in difficult fiscal times
- Pilot projects are very valuable – change to test out on a small scale; identify savings to state as a result of innovations; research so solid to point to financial benefits – enhance quality of diagnosis and care
- Residential care home model for individuals with IDD and dementia that was highlighted today is not distributed equitably throughout CA – need more work to ensure those with IDD and dementia have access
- RFPs – is there a percentage requirement to make sure that people with disparities and underserved communities are a part of those services? Do RFPs require for them to serve a certain percentage of underserved communities- how do we make sure it's being allocated to those communities – HHS has a set of equity principles that guides all of the work

Public Comment

Jared Giarrusso-Khlok of the Alzheimer's Association gave a brief update on their legislative activities. They are working on:

- AB 21 (Gibson) – continuation of peace officer training bill that did not pass last year

- They will be taking a portion of AB 1618 related to the Advisory Committee and reintroducing it with Assemblymember Aguiar-Curry as the bill author. They will have more information at our February Advisory Committee Meeting.

Barbra McLendon from Alzheimer's Los Angeles mentioned that they will be reintroducing a bill around wandering; there is currently no coordinated way for law enforcement in different counties to cooperate when someone is missing.

Closing Comments and Next Steps

- *Catherine Blakemore, Committee Chair*

Catherine expressed her appreciation for the speakers and all who participated in the meeting and adjourned the meeting.

Adjourn