Alzheimer's Disease and Related Disorders Advisory Committee Meeting
Join by smart phone, tablet, or computer:
https://us06web.zoom.us/w/86009181582
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Tel: (888) 788-0099  |  Meeting ID: 860 0918 1582

- **Live captioning** accessible via webinar (Zoom)
- **American Sign Language Interpretation** via webinar (Zoom)
- **Recording, Slides, and Transcripts** will be posted to the CalHHS Alzheimer’s Disease & Related Disorders webpage post webinar
Time is reserved on the meeting agenda for public comment.

Attendees joining by webinar (Zoom), use the Q&A function to ask a question or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, press *9 on your dial pad to “raise your hand.” The moderator will announce the last 4 digits of your phone number and will unmute your line.
Welcome & Introductions

Catherine Blakemore
Committee Chair
Family Member Representative
I. Welcome & Introductions
II. Down Syndrome and Alzheimer’s Disease Presentations & Discussion
III. Public Comment
IV. Break – 30 min.
V. Alzheimer’s Plan Updates - California Department of Aging and California Department of Public Health
VI. 2023 Committee Meeting Schedule & Topic Ideas
VII. Finalization of Recommendations & Items for CalHHS Secretary
VIII. Public Comment
IX. Closing Comments & Next Steps
Committee Member Introductions

Committee Chairs
- Catherine Blakemore, Family Member Representative (Chair)
- Darrick Lam, ACC Senior Services, Family Member Rep (Vice Chair)

Stakeholder Committee Members
- Meg Barron, Alzheimer’s Association, Consumer Organization Rep
- Julie Souliere, CA Health & Human Services Agency
- Dr. Sarah Tomaszewski Farias, UC-Davis, Alzheimer’s Disease Diagnostic & Treatment Centers Rep
- Pam Montana, Consumer Rep
- Andrea Robert, Consumer Rep
Committee Member Introductions

Stakeholder Committee Members (Cont.)

- **Dr. Dolores Gallagher Thompson**, Stanford University, Social Research Rep
- **Dr. William Mobley**, UC San Diego, Academic Medical Research Rep
- **Todd Shetter**, ActivCare Living, Service Provider Rep
- **Celine Regalia**, Collabria Care, Alz. Day Care Resource Center Rep
- **Dr. Wynnelena Canlas Canio**, Kaiser Permanente, Mental Health Field Rep
- **Barbra McLendon**, Alzheimer's Los Angeles, Service Provider Rep

**Vacancy:**

- **Elder Law Representative**
Presentation on Down Syndrome and Alzheimer’s Disease

- **Data and research** – William C. Mobley, MD, PhD
- **California data and Department of Developmental Services initiatives** – Lucy Esralew, PhD
- **Community services** – Lisa Rund, RN
- **Residential care model** – Todd Shetter & Kimberly Keane
- **Family caregiver’s experience** – Marc Loupe
The Oncoming Era of Treating to Prevent Alzheimer Disease in People with Down Syndrome (Trisomy 21)

William Mobley
Department of Neurosciences
UC San Diego
Disclosures

- Co-inventor on patent applications for γ-secretase modulators held by UCSD and MGH.
- SAB Member for Alzheon Inc, and Promis Inc. with stock options.
- SAB Member for National Down Syndrome Society.
- Former consultant for Cortexyme and Annovis-Bio and received stock.
- Consultant for AC Immune.
Overview

- Adults with Down syndrome (DS) face many health challenges.
- The most significant is Alzheimer disease (DS-AD).
- An extra copy of the gene for APP is necessary for DS-AD.
- Recent advances enable future trials to prevent DS-AD.
- It is essential to enhance health care services for the care of adults with DS and to equip them to deliver treatments proven safe and effective for preventing DS-AD.
Caring for Adults with DS

- Adults with DS experience a number of clinical challenges.
- Changes in brain function are frequent.
- The most significant challenge is emergence of DS-AD.
- Clinicians with experience in the management of adults with DS are needed to address DS-AD and other conditions that impact learning, memory, and mood.
- Caregivers need to be able to engage physicians with expertise in DS to define problems and treatments.
- Clinicians must carefully consider the possible causes of neurologic dysfunction, including memory loss.
Adverse Impacts of DS on Health

- **Neurodevelopmental**
  - Intellectual disability
  - Developmental delay
  - Language disorders
  - Cerebellar hypoplasia

- **Psychiatric**
  - Anxiety and depression
  - Behavioural disturbance

- **Neurological**
  - Alzheimer disease
  - Epilepsy

- **Cardiovascular**
  - Congenital heart defects (especially AVSD)

- **Musculoskeletal**
  - Atlantoaxial instability
  - Small stature
  - Short fingers
  - Hypotonia

- **Other**
  - Haematological disorders
  - Immune dysfunction
  - Obesity
  - Bowel dysfunction
  - Gastrointestinal structural defects
  - Male infertility

- **Craniofacial**
  - Small, low-set ears
  - Epicanthic folds
  - Flat nasal bridge
  - Flat occiput
  - Small mouth
  - Upplasing palpebral fissures

- **Sensory**
  - Conductive and sensorineural hearing loss
  - Refractive errors, cataracts, keratoconus and amblyopia

- **Respiratory**
  - Obstructive sleep apnoea
  - Respiratory tract infections

- **Autoimmune**
  - Thyroid disease
  - Coeliac disease
  - Alopecia
  - Type 1 diabetes mellitus
  - Psoriasis
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Increasing Longevity and Size of DS Population in US

Life expectancy of individuals with DS in the USA:
- 1950: mean of 26 years; median of 4 years
- 2010: mean of 53 years; median of 58 years
Increasing Longevity and Size of DS Population in US

Life expectancy of individuals with DS in the USA:
- 1950: mean of 26 years; median of 4 years
- 2010: mean of 53 years; median of 58 years

Approx 100,000 at risk for DS-AD in 2022

Antonarakis et al, Nature Rev, 2020
Alzheimer Disease (AD) in DS (DS-AD)

- AD much more frequent and earlier in DS (incidence > 90% over age 65).
- Dementia: cognitive or behavioral symptoms in two domains that: 1) interfere with the ability to function normally; and 2) represent a decline from a previous level of functioning and performing. DS-AD typically includes memory loss and changes in mood.
- **Dementia occurs at a median age of ~55 years in DS.**
- Neuropathological changes very similar if not identical to typical AD, and found in essentially all by age 40.
DS Markedly Increases Risk of AD

Cumulative risk by age 65 is estimated to be 90%.


Sinai et al., JAD, 2018
DS-AD

• More frequent and earlier in adults with DS (incidence may exceed 90% beyond age 65).
• Dementia: cognitive or behavioral symptoms in two domains that: 1) interfere with the ability to function normally; and 2) represent a decline from a previous level of functioning and performing. AD typically includes memory loss.
• Dementia occurs at a median age of ~55 years.
• Neuropathological changes very similar if not identical to typical AD, and found in essentially all by age 40.
Neuropathology: AD-DS

Cortex

Amyloid plaque

Neurofibrillary tangle

Enlarged Endosome
(Cataldo et al., N’biol Aging, 2004)
DS-AD

• Genetics points to increased APP gene dose as necessary for DS-AD.
  – *Increased APP gene dose in DS-AD.*
    - Prasher et al., 1998
    - Korbel et al., 2009
    - Doran et al., 2016

• Relevant cell biological phenotypes are induced by increased expression of the APP gene.

• The APP gene has several products.
APP Gene Dose in DS: Doran et al., 2017

- Elderly man with DS and partial trisomy of chromosome 21 (pTs21); he had the normal two copies $APP$.
- Between 66–72 years: neuropsych testing, neuro exams, amyloid PET imaging, plasma amyloid-$\beta$ (A$\beta$) measurements.
- Intellectual disability was mild. Serial tests showed less than a 3% decline. No dementia.
- PiB-PET scans negative and plasma A$\beta_{42}$ lower than values for demented or non-demented adults with DS.
• Brain showed a single neuritic plaque; neurofibrillar degeneration consistent with normal aging.
• Findings support obligatory role of APP for DS-AD.
DS-AD

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  – Increased APP gene dose in DS-AD.
    - Prasher et al., 1998
    - Korbel et al., 2009
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• Relevant cell biological phenotypes are induced by increased expression of the APP gene.
Exploring Pathogenesis in Mouse Models of DS
Pathogenesis Studies in Mouse Models

• Increased APP gene dose results in increased levels of APP and its products.
• Dp16 mice show:
  • age-related degeneration of neurons affected in DS – BFCNs, LCNs, ECNs.
  • dysregulation of endosome structure and transport.
  • increased phosphorylation of tau.
• Increased APP dose is necessary for all changes.
APP and its Products

APP Gene → APP mRNA → F1-APP → APP-CTFs → Aβ

Diagram showing the APP pathway with AICD, C83, C99, and Aβ indicated in the extracellular space/ducts and in the cytoplasm.
APP and its Products in DS

APP Gene → APP mRNA → F1-APP → APP-CTFs → Aβ
Pathogenesis Studies in Mouse Models

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• Dp16 mice show:
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• Increased APP dose is necessary for all changes.
Targeting APP Gene Dose in DS: Several Approaches

Clinical trial networks now established to carry out studies in DS. Use measures to evaluate changes in cognition, function in adults with DS and employ biomarkers used in AD trials.
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- Clinicians must carefully consider the possible causes of neurologic dysfunction, including memory loss.
### Possible Causes of Memory Problems

<table>
<thead>
<tr>
<th>Condition</th>
<th>Presentation</th>
</tr>
</thead>
</table>
| Sensory deficits                 | Hearing loss  
Vision loss, low vision, depth perception changes                           |
| Metabolic disturbances           | Electrolyte abnormalities  
Hypoglycemia/hyperglycemia  
B<sub>12</sub> or folate deficiencies  
Undetected thyroid dysfunction  
Anemia  
Toxic levels of antiepileptic or psychoactive medications  
Toxic adverse effects of certain medications (eg, hyperammonemia in chronic valproic acid use) |
| Coexisting mood disorder         | Either newly detected or subacute worsening of baseline mood disorder  
Note: Depression can cause symptoms that seem similar to dementia |
## Possible Causes of Memory Problems

<table>
<thead>
<tr>
<th>Condition</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Sleep problems</td>
<td>Sleep apnea and other undetected sleep disorders</td>
</tr>
<tr>
<td>Seizures</td>
<td>Undetected or worsening seizure disorders</td>
</tr>
<tr>
<td>Pain</td>
<td>Undiagnosed pain or undertreated pain</td>
</tr>
<tr>
<td>Mobility problems</td>
<td>Mobility disorders and loss of functionality</td>
</tr>
<tr>
<td>Psychosocial or environmental stressors</td>
<td>Changes in routines, death or impairment of family members or close acquaintances, new regimen at home or in the workplace, reactions to threatening situations</td>
</tr>
<tr>
<td>Others</td>
<td>Conditions that may be associated with cognitive deficit (<em>stroke, chronic subdural hematoma</em>, brain tumors, multiple sclerosis, human immunodeficiency virus, and cryptococcal infection)</td>
</tr>
<tr>
<td>Additional considerations: prevalent conditions in adults with Down syndrome</td>
<td>Vision impairment: cataracts and keratoconus</td>
</tr>
</tbody>
</table>
Clinical Care for Adults with DS: Limited Availability

- Specialty centers improve care for patients with DS.
- While the number of adults with DS is increasing, there was unknown capacity for specialty centers.
- Conducted a national survey of staff of specialty clinics, reviewed online clinic listings, and calculated the number of adults with Down syndrome seen.
- Analysis identified the percent of adults with Down syndrome who could have their medical care needs met in a current specialty clinic.

Santoro et al., 2021. Am J Med Genet A
Clinical Care for Adults with DS: Limited Availability

- Fourteen specialty clinics provided care for 4038 DS adults.
- Reported gaps included: limitations of existing clinics, need for additional clinics, and health professionals with expertise in DS.
- Survey-respondent clinic capacity would meet needs of only 3% of adults with DS.
- Online data for twenty-five adult DS clinics indicated capacity to care for 6517 adults with DS, meeting the needs of only 5%.

Santoro et al., 2021. Am J Med Genet A
Clinical Care for Adults with DS: Conclusions

- Additional clinic capacity is needed to meet the needs of adults with DS.
- Survey of existing clinics provides guidance to create additional clinics, including: must-have team members, current sources of clinic financial support, and gaps in current clinical care.
- Creating a more robust clinical care network is essential for meeting the needs of adults with DS.
- This is especially urgent given the impact of Alzheimer disease in this population and the oncoming era of effective treatments.
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Alzheimer’s Disease and Related Disorders Advisory Committee

Dr. Lucy Esralew, Senior Psychologist Supervisor
Office of Statewide Clinical Services
December 8, 2022
People with intellectual and developmental disabilities experience **respect** for their culture and language preferences, their choices, beliefs, values, needs, and goals, from a **person-centered** service system made up of a network of community agencies that provide **high quality, outcome-based** and **equitable services**.
Eligibility for Lanterman Act Services

California law defines developmental disability as disability that originates prior to age 18, is expected to be lifelong, and constitutes “substantial disability” for that person.

Categories that qualify a person for Lanterman Act services include intellectual disability, autism, epilepsy, cerebral palsy, and/or other disability that closely resembles ID and/or individual requires similar services.

Lanterman Developmental Disabilities Services Act
Supporting Individuals Across the Lifespan

- Birth to age 3
- Ages 3-4
- Ages 5-21
- Age 22 and up

- Early Start
- Provisional Eligibility
- Lanterman
Consumer Population – 10 year view

Includes Early Start (0-2) and Lanterman (3+)

CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES
Consumer Population by Diagnoses – 10 year view

- Autism: 25% (2012), 45% (2022)
- Cerebral Palsy: 16% (2012), 11% (2022)
- Epilepsy: 17% (2012), 12% (2022)
- Intellectual Disability: 70% (2012), 53% (2022)
- Other: 11% (2012), 11% (2022)

Includes 20,000 individuals with Down syndrome.
Regional Center Consumers with Down Syndrome

**AGE**
- 18-64: 62%
- 3-17: 36%
- 0-2: 1%
- 65+: 1%

**ETHNICITY**
- Latinx/Hispanic: 50%
- White: 29%
- Asian: 9%
- Black: 4%
- Other: 9%

**RESIDENCE TYPE**
- Home of parent, guardian, or foster home: 88%
- ILS, SLS, OTHER: 1% each
- CCF: 7%
- ICF: 2%

ICF: Intermediate Care Facility
ILS: Independent Living Service
SLS: Supported Living Services
CCF: Community Care Facility
Down Syndrome

• The most frequently occurring chromosomal disorder and the leading cause of known genetic intellectual and developmental delay

• Most individuals with Down syndrome lead typical lives in their communities

• Individuals with Down syndrome are living longer, leading to increase in population over the next 20 years
  Average life expectancy in 1980s was only age 28 and in 2020 was age 60

• Longer life expectancy increases risk for certain conditions of older adults

• Approximately 50% of persons with Down syndrome have a congenital heart defect, increases risk for early onset dementia

• More likely than their non-Ds peers to exhibit “accelerated aging” during ages 40-50
Down Syndrome and Alzheimer’s Disease

• Chromosome 21 plays a key role

• Approximately 70-90% of older individuals with Down syndrome will eventually develop Alzheimer’s Disease and/or a related disordered

• Individuals with Down syndrome are at higher risk for Alzheimer's disease after age 50

• Individuals with Down syndrome may exhibit signs of Alzheimer’s disease in their late 40’s

• Signs of Alzheimer’s Disease are apparent approximately 20-25 years before the average age of onset in the population without I/DD

• Decrease in functioning progresses more quickly
Aging Inclusion Specialist

- Leadership and subject matter expertise
- Inform on and develop policies, resource materials, trainings and supports consistent with the Lanterman Act, Governor Newsom’s Master Plan for Aging, and other federal and state statutes and regulations

Coordinated Family Supports

- New service model to provide supports to adults living in their family homes
- Improve service equity and meet evolving needs of adults and their families without having to move from the family home (supports aging in place)
- Pilot beginning in 2023
Aging and Down Syndrome: A Health & Well-Being Guidebook

National Down Syndrome Society (NDSS)
Resources & Links

- Lanterman Act and Related Laws - CA Department of Developmental Services
- Laws & Regulations - CA Department of Developmental Services
- Regional Center Map
- Regional Center Lookup Tool
- Regional Center Eligibility & Services
- Regional Center Services & Descriptions (available in multiple languages)
- Resources for Families, Parents & Caregivers
- Family Resources Centers Network of California
- Stakeholder Events
- Developmental Services Task Force
Dementia in Intellectual/Developmental Disabilities (I/DD) at San Andreas Regional Center: A Snapshot

Health Services Unit
Lisa Rund, RN Health Services Associate Coordinator
lrund@sarc.org 408-341-3885
The Lanterman Act

The Lanterman Developmental Disabilities Services Act of 1969 established eligibility requirements and outlines how regional centers work.

It says people with I/DD have a right to services and supports to help them live the most independent and productive lives possible in the least restrictive environment.
Regional Centers are private, non-profit community agencies

For individuals, the RCs:

- Diagnostic assessment
- Determine eligibility for services
- Facilitate Individualized Family Service Plan (IFSP)
  *Birth through 2*
- Facilitate Individual Program Plan (IPP) *3 years & older*
- Service coordination
- Authorize funding of services, when generic resources are unavailable

For their communities, the RCs:

- Develop resources with vendored service providers
- Provide monitoring and oversight of services
- Provide community education and outreach
What services are provided and how it works

• Regional Centers (RC) provides service coordination and develops an individual program plan (IPP) with the individual and their planning team

• After generic resources have been explored and exhausted, service providers who are "vendored" with the RC may be identified to meet the needs of the individual

• The RC authorizes services for the individual and payment to vendored service providers

• Services may include family respite, adult day programs, employment supports, residential services, and transportation, among others
• Serves about 18,000 people with I/DD of all ages
• Covers 4 counties: Santa Clara, Santa Cruz, Monterey, San Benito
• Works with community partners to support individuals to access generic resources and other specialists for dementia care
• Working to build internal resources through education and information
• Looking to broaden and elevate the education outside the RC for the benefit of the people served by SARC

www.sanandreasregional.org
Importance of education, information, building partnerships

• Internally to SARC Service Coordinators
• Vended service providers in all settings, including families
• Health care providers- individual cases as well as outreach from SARC to Social Work and Case Management departments in hospitals, SNFs, subacutes, and FHCs (federally qualified health clinics)
• Other agencies such as Medi-Cal managed care plans, social services, local law enforcement
• Parents Helping Parents, a local organization that provides support and education for families of people with I/DD
What we teach

• Importance of knowing the individual’s baseline state of being so that changes are observed, reported, and documented

• Early identification of observed changes allows for correct diagnosis to be made by the professional

• Define key terms: dementia, DD, ID, MCI, normal aging

• Different types, stages of dementia

• Signs of dementia, diagnosis, treatment

• Providing care through the stages
We now have a tool to look at decline in people with ID/DD

**Early Detection Screen for Dementia**

https://www.the-ntg.org/ntg-edsd
Person-Centered Planning

• Must tailor care to meet the needs of the individual, to enter THEIR reality
• These needs and abilities change as time goes on, sometimes unpredictably
• This requires us to be educated, trained, flexible, and creative in our approach
For More Information

• Alzheimer’s Association e-learning

• UCLA resources and video series for caregivers
  https://www.uclahealth.org/medical-services/geriatrics/dementia/patient-resources

• National Institute on Aging
  https://www.nia.nih.gov/alzheimers/topics/alzheimers-basics

• National Task Group on Intellectual Disabilities and Dementia Practices
  Caring for a Family Member with ID and Dementia (the-ntg.org)
Thank you for this opportunity to advocate for an often-overlooked segment of the population in California. Your time and attention is appreciated, as well as your efforts for inclusion at all levels.
Noah Homes and
ActivCare Living:
A Special Memory Care Partnership
Establishing a Collaborative Partnership

- In November 2021, ActivCare Living set out on a mission to address the shortage of Memory Care options for adults with intellectual and developmental disabilities.
- This will offer a pathway to those with Down syndrome and dementia to live in one of two ActivCare communities in San Diego County.
Noah Homes and ActivCare Living:  
A Collaborative Partnership  
The below text was pulled from both organizations’ websites.

"We cherish our residents and strive to bring fulfillment to their lives daily. To provide meaning and purpose each day, we build a routine and provide an environment where they can be successful.

The ActivCare program of structured activities is designed to maintain the highest possible functioning level of each resident while enhancing their self-esteem."

"Our goal is to maximize each individual’s independence in a community environment that fosters dignity and respect, as well as personal and spiritual growth.

Noah Homes is an oasis of peace as well as a hub of activity, offering residents continued opportunities for personal growth and fulfillment."
ActivCare Living: A History

- Recognizing the need for a specialized memory care community, the first ActivCare was opened in 1988 in California with assistance from Alzheimer's disease specialists and family caregivers.
- For more than 30 years, ActivCare has led the industry in providing personalized memory care and enhancing the quality of life for its residents and their families.
ActivCare Living: A Future

• Now, ActivCare is once again expanding its mission to enhance the quality of life for those with memory loss and embrace an underserved population affected by dementia – individuals with intellectual and developmental disabilities, particularly Down syndrome.

• This is an opportunity to further strengthen our innovative care practices, expand our connections with other leaders in our field, and provide even more ways for those living in their communities to feel useful and have a greater sense of belonging.
Visiting ActivCare Rolling Hills Ranch

- Noah Homes toured an ActivCare Living location for the first time over three years ago, and we were truly impressed with what we observed.
- It is a beautiful inclusive community with **dedicated caregivers** who encourage residents to engage in activities and programs that help stimulate cognitive functioning and increase self-confidence, much like Noah Homes!
ActivCare in Action: Virtual Tour of ActivCare Rolling Hills Ranch

ActivCare Living specializes in providing the highest level of care to residents with memory loss.
The Folks Meet New Friends
So, what's going on now?

(Continued)

- Our first residents moved into ActivCare 4S Ranch on August 1 and ActivCare Rolling Hills Ranch on September 1.
- Currently, 3 residents in total are living in ActivCare communities.
- A total of 40 accommodations are available in San Diego County.
So, what's going on now?

Teri is enjoying her new home!
Population We Serve

Individuals with intellectual and developmental disabilities who can still benefit from our social programs and:

- Have a diagnosis of dementia and/or cognitive decline, or
- Are inappropriately placed in skilled nursing facilities, or
- Are living at home with family who can no longer provide appropriate care and support, or
- Exceed Level 3 care who may require additional safety features and nursing support
THANK YOU!

ActivCare 4S Ranch
10603 Rancho Bernardo Road
San Diego, CA 92127
(858) 485-8001

ActivCare Rolling Hills Ranch
850 Duncan Ranch Rd
Chula Vista, CA 91914
(619) 482-8000
Down Syndrome and Alzheimer’s Disease – Discussion & Public Comment

Facilitated by Catherine Blakemore
Committee Chair
Family Caregiver Representative
Attendees joining by webinar (Zoom), use the Q&A function to ask a questions or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, press *9 on your dial pad to “raise your hand.” The moderator will announce the last 4 digits of your phone number and will unmute your line.
Break

The meeting will resume at 12:20pm
Alzheimer’s Plan Updates

Susan DeMaroïs
Director
California Department of Aging
Our Path Forward: Final Report Issued November 2020

BIG BOLD IDEAS

1. Appoint a Senior Advisor on Alzheimer’s
2. Keep California at the forefront of cutting-edge global research
3. Create an Alzheimer’s disease public awareness campaign
4. Build a California Cares (digital portal)
5. Establish California voluntary savings accounts for long-term care
6. Invest in career incentives for Alzheimer’s health care workforce
7. Introduce a new caregiver training and certification program
8. Launch a California Blue Zone City Challenge
9. Launch a Californians for all care core program
10. Model a state-wide standard of care to the nation

10 Recommendations for Alzheimer’s Prevention, Preparedness and the Path Forward
Recent Activities

- Recognition of National Alzheimer’s Disease Awareness and Family Caregivers Months
- ACL grants received – CAIz Connect and No Wrong Door
- Cal-COMPASS awards
- CalGrows Innovation Fund applications
- MHSOAC Older Adult Behavioral Health
- ADRC Advisory Committee
- American Society on Aging
Alzheimer’s Plan Update:
California Community Program for Alzheimer’s Services and Support (Cal-COMPASS)

Michelle Johnston
Program Director, Dementia Initiatives
California Department of Aging
Cal-COMPASS Pilot Project Overview

- **Purpose**: Support existing licensed Adult Day Programs and Adult Day Health Care centers in providing dementia-capable services to prevent institutionalization and advance health equity.

- **Total budget**: $4.5 million + $300,000 for evaluator

- **Award amounts**: $350,000 - $750,000 per awardee

- **Timeline**: Nov. 2022 – Dec. 2023
Cal-COMPASS Goals

Provide dementia capable, person-centered support for persons living with Alzheimer’s or other dementias and their caregivers

• Leverage state and local partnerships/initiatives
• Create a statewide learning community
• Implement best practices and test strategies
• Build Alzheimer’s and dementia-capable care providers
• Create uniform measures and evaluate outcomes
• Ensure that services meet the needs of communities disproportionately impacted by dementia
Goals Identified by Proposers

- Increase persons served
- Enhance programs
- Staffing, training and workforce development
- Assessment, evaluation and documentation
- Caregiver education and support
## Cal-COMPASS Awardees

<table>
<thead>
<tr>
<th>Organization</th>
<th>License Type(s)</th>
<th>County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Family Center</td>
<td>ADHC</td>
<td>Orange</td>
</tr>
<tr>
<td>Choice In Aging</td>
<td>ADHC/ADCRC</td>
<td>Contra Costa</td>
</tr>
<tr>
<td>City of Sacramento, Triple R Adult Day Centers</td>
<td>ADP/ADCRC</td>
<td>Sacramento</td>
</tr>
<tr>
<td>Collabria Care</td>
<td>ADHC/ADP/ADCRC</td>
<td>Napa</td>
</tr>
<tr>
<td>Hearts and Minds Activity Center</td>
<td>ADP/ADCRC</td>
<td>Santa Clara</td>
</tr>
<tr>
<td>Innovative Health Care Services (Peg Taylor Center for ADHC)</td>
<td>ADHC/ADCRC</td>
<td>Butte</td>
</tr>
<tr>
<td>OPICA ADP &amp; Counseling Center</td>
<td>ADP</td>
<td>Los Angeles</td>
</tr>
</tbody>
</table>

ADHC – Adult Day Health Care; ADP – Adult Day Program; ADCRC – Adult Day Care Resource Center
Cal-COMPASS Next Steps

• Learning Community has begun to meet
• Reviewing ADCRC materials
• Contracting with outside evaluator
• Finalizing set of deliverables for new model
• Dividing into workgroups
Alzheimer’s Plan: CAIz Connect Update

Tanya Bautista
Bureau Chief, Supportive Services
California Department of Aging
Funding
Administration for Community Living (ACL), Alzheimer’s Disease Program Initiative (ADPI) grant for state entities

Objectives
• Create and sustain a dementia-capable home and community-based services system for people living with Alzheimer’s disease and related disorders and their caregivers, using a no wrong door (NWD) approach.
• Ensure access to a comprehensive, sustainable set of quality services/interventions that are dementia-capable and provide innovative services to people with dementia and their caregivers.
Pilot counties

- Ventura (Area Agency on Aging)
- Marin (Center for Independent Living)
- Imperial (Area Agency on Aging)

Additional partners

- Clinical supervision (nursing, social work and medication management)
- Evaluator
Offer UC San Francisco’s evidence-based Care Ecosystem program outside of a healthcare setting

- Staffed by bilingual Community Health Workers trained as Care Team Navigators (CTNs)
- CTNs provide specialized dementia education, work with the family to develop a plan of care, connect families with community services/supports, and aid in care transitions
- Contract for clinical supervision
UCSF's Care Ecosystem Model

Source: UCSF Care Ecosystem, https://memory.ucsf.edu/research-trials/professional/care-ecosystem
Pilot a dementia-capable Consumer Navigation Contact Center

- Promote to health care system (community clinics, hospitals, doctors, health plans), especially Medi-Cal providers
- Help bridge the divide between medical and social services – more person-centered
- Increase accessibility and equity amongst the communities hardest hit by dementia

**Project status**: planning stage
Desired Outcomes

• **Person-level**: improve the quality of life for individuals living with dementia and decrease caregiver burden.

• **System level**: development of dementia capacity in California's project sites, and eventually throughout California’s NWD system.

• **Sustainability goals**:
  
  • Adopt the piloted Contact Center as an established, sustainable community resource throughout California.

  • Ensure best practice resources that will inform related statewide dementia-capable No Wrong Door systems and programs.
Alzheimer’s Plan: California Department of Public Health Updates

Lauren Groves
Chief, Chronic Disease Control Branch Center for Healthy Communities
California Department of Public Health
Report to the California Health and Human Services Agency
Alzheimer’s Disease and Related Disorders Advisory Committee

Lauren Groves, MPH, Chief
California Department of Public Health
Chronic Disease Control Branch
Alzheimer’s Disease Program
California Alzheimer’s Disease Centers

- Improve dementia health care delivery - provide specialized training and education to health care professionals
- Advance the diagnosis and treatment of ADRDs
- $281,000/Year/Center
California Healthy Brain Initiative

- Advance cognitive health as an integral component of public health

- Implement the CDC Healthy Brain Initiative 2018-2023 Road Map

- $10 Million over 3 years – Two Cohorts
California Research Projects

- Scientists engaged in the study of Alzheimer's disease and related disorders

- Encompasses areas of basic science, diagnosis, treatment, epidemiology, health disparities, behavioral management, drug therapies and caregiving

- $8.7 Million – 7 2022 Projects
Public Awareness Campaign

- Vendor Proposals in Review
- Campaign:
  - Focused on public education
  - Addressing Signs and Symptoms
  - Target At Risk Populations
  - Multilingual, multicultural, and intergenerational
- $8.5 million expected to be funded
Dementia Friendly Communities

- Focus on prevention of dementia
- Long-term, place-based interventions to support healthy behaviors
- Blue Zone County Pilot
- $1.7 Million dollars
Caregiver Training Program

- Focusing on unpaid family caregivers
- No cost, online, multi-lingual
- Includes partnership with local community organizations
- $3.4 million between northern and southern CA
Standards of Dementia Care

- Standard of Dementia Care Model
  - Public Health Risk Reduction
  - Post Diagnosis Resources for Providers

- Risk Calculator

- $3.825 Million
State Dementia Services Coordinator Summit

• Hosted by Alzheimer’s Association
• October 25-26, 2022
• Washington DC

• Importance of establishing a State government response to Alzheimer’s
• The future of Alzheimer’s treatments
• The Public Health approach to Dementia
• Supporting Caregivers
Questions?

Alzheimer’s Disease Program, CDCB, CDPH
AlzheimersD@cdph.ca.gov
2023 Meeting Schedule & Topic Ideas

Catherine Blakemore
Committee Chair
Family Member Representative
2023 Meeting Schedule

February 2, 2023
May 4, 2023
August 3, 2023
November 2, 2023

10 am – 2 pm
Finalization of Recommendations & Items for CalHSS Secretary

Catherine Blakemore
Committee Chair
Family Member Representative
Attendees joining by webinar (Zoom), use the Q&A function to ask a questions or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, press *9 on your dial pad to “raise your hand.” The moderator will announce the last 4 digits of your phone number and will unmute your line.
Closing Comments & Next Steps

Catherine Blakemore
Committee Chair
Family Member Representative
Visit the [CalHHS Alzheimer’s Disease & Related Disorders Advisory Committee webpage](#) for:

- More information about the Committee
- Upcoming meeting dates
- Presentations, recordings, and transcripts of past meetings

Thank you!