California Master Plan for Aging (MPA) Draft Committee Recommendations (2025-2026)

Committee Name: Alzheimer's Disease and Related Disorders Advisory Committee

Committee Recommendation #1

1. Describe your Committee's first recommendation:

Increase options to provide care to individuals with dementia through strategies such as:

- Developing and launching a Long-Term Services and Supports (LTSS) benefit,
- Establishing a voluntary savings account,
- Setting aside a percentage of ALW slots for people with a cognitive impairment, and/or
- Increasing slots in the Assisted Living Waiver (ALW).

2. Provide the background and problem statement that has led your Committee to prioritize this recommendation:

Currently it's estimated that there are over 720,000 Californians living with Alzheimer's disease or a related dementia and almost 1.4 million unpaid caregivers for persons living with dementia. The number of individuals living with Alzheimer's is predicted to increase by 22% between 2020 and 2025 alone. Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. There is a strong sense of urgency to implement these recommendations, improve care and support, and increase equity. The burden of caring for people living with dementia is higher than that of individuals with other health conditions. The total lifetime cost of care for a person living with dementia is estimated at almost \$400,000, with 70% of these costs being borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses. The Genworth Cost of Care Survey reported that the 2023 annual median costs of care in California varied from \$22,100 for adult day health care (5 days per week) to \$158,775 for a private room in a skilled nursing facility. Many middle-income families don't qualify for subsidized services but can't afford to pay out-of-pocket. Not all communities have adequate access to support resources.

3. If California implements this recommendation as part of the MPA, describe the expected outputs and outcomes: *include any proposed metrics to measure and track progress*.

- a. Outputs are the direct, tangible results of activities what we get.
 - i. More people with dementia who cannot safely live at home would be able to live in assisted living instead of skilled nursing.
 - ii. Californians would have access to a LTSS benefit, which is especially important for the forgotten middle, who don't qualify for Medi-Cal but can't afford the care with current resources.¹
 - iii. The LTSS benefit would help more people stay at home and reduce demand for placement in long-term care facilities.

¹ More data available in <u>Profile of Older Californians: Medicare Beneficiaries Near Income Eligibility for Medi-Cal</u> (2023). DHCS and ATI Advisory

- b. Outcomes are the desired results of the program what we achieve.
 - i. Reduced homelessness for older adults*2
 - ii. Reduced self-reported psychological distress among older adults and adults with disabilities*
 - iii. Reduced burdens faced by family and friend caregivers*
 - iv. More people will remain in their setting of choice for a longer time period
 - v. Cost savings to Medi-Cal program
 - vi. Reduced caregiver impoverishment
 - vii. Improvements in social determinants of health
- 4. Describe how this recommendation advances equity in aging and disability:

Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. Data from DHCS shows that near Medi-Cal income eligible beneficiaries had a higher representation of Black, Latino and Asian identities; more often had limited English proficiency; and more often had one or more disability than the beneficiary population with higher incomes. Strategies to financially support persons with dementia and their caregivers, especially if directed at those with the greatest need, will advance equity in aging and disability.

5. Describe how the recommendation aligns with one or more pillars of the long-term services and supports (LTSS) framework - Access, Navigation, Workforce, Financing:

By addressing a cost barrier and increasing access to LTSS, this recommendation most closely aligns with the financing and access pillars of the LTSS framework.

6. Which of MPA Goal Area(s) does your recommendation align with? Does the recommendation build on an existing MPA 2023-24 Initiative? If so, indicate below:

This recommendation aligns with multiple MPA goals:

- Goal 2 Health Reimagined (Strategies A: Bridging Health with Home and E: Dementia in Focus)
- Goal 3 Inclusion and Equity, Not Isolation (Strategy A: Inclusion and Equity in Aging)

This recommendation builds on two existing MPA initiatives:

- - 18 Continue to evaluate options for developing a Universal Long-Term Services and Supports (LTSS) benefit. Support research, data collection, and analysis of long-term services and supports financing for older adults and people with disabilities.
 - 24 Continue to expand access to the Medi-Cal Assisted Living Waiver, the Home and Community-Based Alternatives Waiver, the Program for All-Inclusive Care for the Elderly (PACE), Community-Based Adult Services (CBAS), and the Multipurpose Senior Services Program (MSSP).

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² Outcomes with an * are established MPA Key Outcome Measures

Committee Recommendation #2

1. Describe your Committee's second recommendation:

Secure funding to expand access to dementia capable, person-centered adult day services (ADS) provided by adult day health care centers and adult day programs with an enhanced rate for participants with mid to late-stage dementia.

2. Provide the background and problem statement that has led your Committee to prioritize this recommendation:

Currently it's estimated that there are over 720,000 Californians living with Alzheimer's disease or a related dementia and almost 1.4 million unpaid caregivers for persons living with dementia. The number of individuals living with Alzheimer's is predicted to increase by 22% between 2020 and 2025 alone. Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. There is a strong sense of urgency to implement these recommendations, improve care and support, and increase equity. The burden of caring for people living with dementia is higher than that of individuals with other health conditions. The total lifetime cost of care for a person living with dementia is estimated at almost \$400,000, with 70% of these costs being borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses. The Genworth Cost of Care Survey reported that the 2023 annual median costs of care in California varied from \$22,100 for adult day health care (5 days per week) to \$158,775 for a private room in a skilled nursing facility. Many middle-income families don't qualify for subsidized services but can't afford to pay out-of-pocket. Not all communities have adequate access to support resources.

A meta-review of review papers on the value of ADS conducted by the UC Davis Family Caregiving Institute identified a number of positive impacts of ADS on participants and their caregivers. The most common outcomes reported for the participants were improvements in well-being or quality of life; physical health or function; mental, emotional or psychological health (although three reviews reported mixed/no evidence); satisfaction or life satisfaction; and social relationships and engagement. Three reviews each also reported reductions in cognitive decline; mortality; social isolation; and emergency department (ED) use or hospitalization. The greatest improvements for caregivers of program participants included reductions in burden or strain; stress; and isolation. Several reviews also reported increases in caregiving confidence/self-efficacy and relationships in the dyad.

In 1984, the California legislature authorized a three-year pilot program (SB 1337, Chapter 1600, Statutes of 1984) for the Alzheimer's Day Care Resource Centers (ADCRC). Adult Day Programs and Adult Day Health Care centers both participated. Over the next decade, additional funding was allocated to increase the number of sites (from eight to 36), increase the annual funding; and extend and eventually eliminate the program's sunset. However, between 2001 and 2011, as part of cuts to the Community-Based Services Programs during lean fiscal years, funding for the ADCRC program was first cut, and then eliminated.

As part of the 2021 Home and Community-based Services (HCBS) spending plan, the 2021-22 state budget allocated \$5 million to CA Dept. of Aging (CDA) to re-establish and modernize the community-based Alzheimer's Day Care Resource Centers model of care. CDA conducted an RFP

process and selected seven adult day service providers to participate in California Community Program for Alzheimer's Services and Supports (Cal-COMPASS) pilot program. Program activities launched in November 2022 and are currently scheduled to end in September 2024. Besides providing adult day services, staff from CDA, project sites and the UCD Family Caregiver Institute (evaluation contractor) have participated in a learning community to develop a new framework based on the ADCRC model.

Adult day care is the most effective and affordable non-pharmacological option, allowing persons with dementia to age in place with the support and services needed to remain cognitively, socially, and physically active with a strong quality of life, while care partners receive the education, respite and support needed to alleviate stress, reduce isolation and care for their health needs.

3. If California implements this recommendation as part of the MPA, describe the expected outputs and outcomes: *include any proposed metrics to measure and track progress*.

- a. Outputs are the direct, tangible results of activities what we get.
 - i. ADS providers following the model developed through the Cal-COMPASS pilot will be recognized for providing cost-effective treatment for persons with dementia.
 - ii. Additional programs will adopt the standards of care developed in the Cal-COMPASS pilot and have the resources and expertise to serve individuals with dementia.
 - iii. Day programs that serve persons with I/DD & dementia will have expanded capacity.
 - iv. There will be increased support for persons with dementia in the mid to late stages.
 - v. ADS providers can be key partners to provide dementia care navigation/management through the Aging and Disability Resource Center/No Wrong Door model.
 - vi. Sustainability of organizations providing ADS will improve.
- b. Outcomes are the desired results of the program what we achieve.
 - Reduced self-reported psychological distress among older adults and adults with disabilities*
 - ii. Reduced burdens faced by family and friend caregivers*
 - iii. Increased caregiver well-being and quality of life (QOL)
 - iv. More people with dementia will remain in their setting of choice for a longer time period
 - v. Cost savings to Medi-Cal program
 - vi. Reduction in behavioral and psychological symptoms associated with dementia and improved QOL for person with dementia
 - vii. Reduced isolation for people with dementia and their caregivers

4. Describe how this recommendation advances equity in aging and disability:

Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. Data from DHCS shows that near Medi-Cal income eligible beneficiaries had a higher representation of Black, Latino and Asian identities; more often had limited English proficiency; and more often had one or more disability than the beneficiary population with higher incomes. Strategies to support persons with dementia and their caregivers, especially if directed at those with the greatest need, will advance equity in aging and disability.

5. Describe how the recommendation aligns with one or more pillars of the long-term services and supports (LTSS) framework - Access, Navigation, Workforce, Financing:

By increasing funding for these services and growing the number of programs able to provide these evidence-based services, the recommendation most closely aligns with the financing, navigation and access components of the LTSS framework. It also supports the workforce component.

6. Which of MPA Goal Area(s) does your recommendation align with? Does the recommendation build on an existing MPA 2023-24 Initiative? If so, indicate below:

This recommendation aligns with multiple MPA goals:

- Goal 2 Health Reimagined (Strategy E: Dementia in Focus)
- Goal 3 Inclusion and Equity, Not Isolation (Strategy A: Inclusion and Equity in Aging)
- Goal 4 Caregiving that Works (Strategy A: Family and Friends Caregiving)

This recommendation builds on three existing MPA initiatives:

- 43 Improve access to the Alzheimer's Day Care Resource Center (ADCRC) model for rural and disproportionately impacted communities by leveraging the Cal-COMPASS Learning Community.
- 81 Utilize data from the LTSS Dashboard, the DHCS Medi-Cal and CDA Non-Medi-Cal Home and Community-Based Services Gap Analyses and Multiyear Roadmaps, and the California Health Interview Survey to understand the unmet needs of family caregivers with a focus on addressing the emotional burden of care and the need for respite support.
- 82 Develop a Statewide Caregiver Equity Roadmap and Strategy to position California as a lead state partner in the federal Administration for Community Living's National Strategy to Support Family Caregivers, including strategies to address the financial burdens of caregiving and the risk to caregivers' financial security.

Committee Recommendation #3

1. Describe your Committee's third recommendation:

Secure continued funding to expand access to use of community health workers to provide dementia care management through the state's aging services network.

2. Provide the background and problem statement that has led your Committee to prioritize this recommendation:

Currently it's estimated that there are over 720,000 Californians living with Alzheimer's disease or a related dementia and almost 1.4 million unpaid caregivers for persons living with dementia. The number of individuals living with Alzheimer's is predicted to increase by 22% between 2020 and 2025 alone. Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. There is a strong sense of urgency to implement these recommendations, improve care and support, and increase equity. On average, unpaid caregivers of people with Alzheimer's disease spend nearly 31 hours per week of care per caregiver (1,612 hours per year). The burden of caring for people living with dementia is higher than that of individuals with other health conditions. The total lifetime cost of care for a person living with dementia is estimated at almost \$400,000, with 70% of these costs being borne by

family caregivers in the forms of unpaid caregiving and out-of-pocket expenses.

In a <u>recent survey</u> of current/recent caregivers of adults with cognitive issues commissioned by the Alzheimer's Association,

- Seventy percent of dementia caregivers reported that coordinating care was stressful and 53% said navigating health care is difficult.
- Two thirds of dementia caregivers reported difficulty finding support and resources for their needs.
- Ninety-seven percent of dementia caregivers surveyed said that navigation services would be helpful to them.

Many people living with dementia and their caregivers struggle to obtain information about the disease, what planning should be undertaken after a diagnosis, what supports are available, and how to access them. There are several evidence-based dementia care management programs, including UCSF's Care Ecosystem program, a telephone-based dementia care management program currently being piloted in three California counties as part of CDA's CAIz Connect program.

3. If California implements this recommendation as part of the MPA, describe the expected outputs and outcomes: *include any proposed metrics to measure and track progress*.

- a. Outputs are the direct, tangible results of activities what we get.
 - i. Increase in career ladder opportunities for non-licensed professionals.
 - ii. Increase in culturally appropriate services for people with dementia and their caregivers.
 - iii. Improved caregiver education, access to care and connections to existing resources.
 - iv. Increased ability of licensed staff to provide care at the highest level of their professional scope.
- b. Outcomes are the desired results of the program what we achieve.
 - Reduced self-reported psychological distress among older adults and adults with disabilities*
 - ii. Reduced burdens faced by family and friend caregivers*
 - iii. Improved quality of life for people with dementia and their caregivers.³
 - iv. Reduced crises and reduced emergency department use.
 - v. Reduced use of potentially inappropriate medications.
 - vi. Lower Medicare costs.
 - vii. Cost savings to Medi-Cal program
 - viii. More people with dementia will remain in their setting of choice for a longer time period.
 - ix. Reduction in behavioral and psychological symptoms associated with dementia
 - x. Reduced isolation for people with dementia and their caregivers
 - xi. Improvements in social determinants of health

4. Describe how this recommendation advances equity in aging and disability:

Alzheimer's disproportionately impacts women, people of color, the LGBTQIA+ community, and persons with intellectual/development disabilities. Data from DHCS shows that near Medi-Cal income eligible beneficiaries had a higher representation of Black, Latino and Asian identities; more

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³ Outputs 3biii. – vi. are based on published studies of Care Ecosystem.

often had limited English proficiency; and more often had one or more disability than the beneficiary population with higher incomes. Strategies to provide evidence-based dementia care management for persons with dementia and their caregivers, especially if directed at those with the greatest need, will advance equity in aging and disability. Hiring community health workers with lived experience caring for people with dementia and/or who are from the same cultures/communities as the persons being served will help to advance equity.

5. Describe how the recommendation aligns with one or more pillars of the long-term services and supports (LTSS) framework - Access, Navigation, Workforce, Financing:

By increasing the opportunities to fund dementia care management provided by CHWs, at least partially through Medi-Cal and Medicare reimbursement, this recommendation aligns with all four pillars of the LTSS framework:

- Increases utilization of existing financing vehicles
- Improves access to the service
- Includes improved navigation through the services provided
- Provides additional opportunities for non-licensed professionals to provide the service
- 6. Which of MPA Goal Area(s) does your recommendation align with? Does the recommendation build on an existing MPA 2023-24 Initiative? If so, indicate below:

This recommendation aligns with multiple MPA goals:

- Goal 2 Health Reimagined (Strategies A: Bridging Health with Home, B: Health Care as We Age and E: Dementia in Focus)
- Goal 4 Caregiving that Works (Strategies A: Family and Friends Caregiving, B: Good Caregiving Jobs Creation and Virtual Care Expansion)

This recommendation builds on multiple existing MPA initiatives:

- 83 Promote innovative models for Community Health Workers to serve older adults and people with disabilities in home and community-based settings, targeting underserved populations with a focus on equity, including through Medicare Fee-for-Service and Medicare Advantage delivery systems.
- 85 Diversify the pipeline for direct care workers in home and community settings by testing and scaling emerging models to meet the need, as funding allows.
- 22 Facilitate opportunities for community-based organizations to develop business acumen and organizational capacity to partner with managed care entities to ensure access to culturally responsive services for older adults and people with disabilities.

It also ties in to:

- 29 Advance the statewide goals of better integrating, coordinating, and aligning services across the Medicare and Medi-Cal programs for California's dual eligible beneficiaries.
- 30 Convene Medicare Advantage plans in partnership with the Centers for Medicare and Medicaid Services (CMS) to explore innovative strategies and common goals to improve quality, access, affordability, and equity for Medicare beneficiaries in California.