

Proposal #3 Caregiving That Works: Family and Friend Caregiving Support

POLICY ISSUE: Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8%). Well over half (57%) of family caregivers of people with Alzheimer’s or other dementias living in the community had provided care for four or more years.ⁱ The amount of time required for caregiving increases as dementia progresses; one study showed that people with dementia required 151 hours of caregiving per month at the outset of dementia and increased to 283 hours per month eight years later.ⁱⁱ Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.ⁱⁱⁱ Hispanic, Black, and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use, and greater depression when compared with White caregivers.

BACKGROUND

The Master Plan for Aging indicates that by 2025, the number of Californians living with Alzheimer's disease will increase 25% from 690,000 today to 840,000 in 2025. Most persons with Alzheimer’s or related dementia (ADRD) live at home, in the community, relying on a network of family/friend caregivers and home care providers. There are almost 1.2 million Californians providing care for someone with ADRD, valued at over \$18 billion in unpaid care. Dementia caregivers are primarily women, and many are from the Black, Indigenous, Latino, or Asian American communities. Most family caregivers do not receive any formal training but are expected to help with activities of daily living such as bathing, cooking meals, and providing transportation. They are also expected to administer medications, give wound care, and provide emotional support.^{iv}

Providing care for someone with ADRD often exacts a toll on the emotional and physical health of the caregiver. It also places a large economic burden on families as many caregivers of people with Alzheimer’s disease and other dementias have to quit work, reduce their work hours, or take time off because of caregiving responsibilities.^v If these individuals are to continue to play such a critically important role in caring for people living with ADRD, it is essential that California do a better job providing them with the supportive services that will enable them to keep their loved ones at home for as long as possible and buffer them from adverse consequences of caregiving, such as depression, anxiety and impoverishment.^{vi}

RECENT EFFORTS BY THE NEWSOM ADMINISTRATION AND LEGISLATURE

The Master Plan for Aging, the Home and Community Based Services spending plan and the recently adopted state budget all include recommendations that provide indirect benefits to caregivers in the form of improved services and supports to the person living with dementia. While these recommendations and budget items represent a historic

investment in older adults and their caregivers, the number of recommendations across these documents designed specifically to meet the needs of informal, family/friend caregivers are relatively few as compared to the significant role these individuals play in helping our health care system meet the needs of those living with dementia. As California confronts acute workforce shortages across all health and human services sectors, it is critical to acknowledge the foundational role that family/friend caregivers serve in our state's long-term services and supports system. Caregivers need financial relief, skills training, and emotional support to continue to meet the demands of their informal job.

Master Plan for Aging Recommendations:

Caregiving that Works- Initiatives:

- 107. Promote current state paid family leave benefits to older Californians, people with disabilities, and family caregivers.
- 108. Assess participation in state paid family leave, including recent legislation to expand equity, including LGBTQ, race, income, gender.
- 109. Develop options to include family caregivers in home and community assessments.
- 110. Consistent with CalAIM, expand respite care for family caregivers.
- 121. Advocate for new federal Administration to assess Social Security gaps for California's diverse workforce, including caregivers, farmworkers, and more. State Budget
- Caregiver Training and Certification - \$4 million to the California Department of Public Health to provide access to evidence-based dementia related education and training for both paid and unpaid caregivers, as well as those providing In-Home Supportive Services.
- Caregiver Resource Centers: -\$10 million in on-going funding
- Long-Term Care Career Pathways Program: \$200 million in one-time funding to incentivize, support, and fund career pathways for IHSS providers, many of whom are paid family members.

HCBS Federal Spending Plan

- Family Caregivers
 - Family Caregiver Support Program - \$2.8 M to the CA Department of Aging. This funding is in addition to the on-going federal funding CDA receives for this program. Funds are distributed to the Area Agencies on Aging to provide access assistance, respite care, supplemental services like home adaptation and assistive devices, and supportive services like counseling.
- Paid Caregivers
 - HCBS IHSS and Non-IHSS Care Economy Payments of \$500 to all IHSS and non-IHSS HCBS providers who worked at least two months between March 2020 and March 2021.
 - IHSS Career Pathways Funding: \$295.1M to expand upon existing training and support the specialized training of IHSS providers in care of

people with complex care needs, in part through pilot projects designed to build capacity for IHSS providers to serve recipients with Alzheimer's or related dementia.

OPPORTUNITIES

California Department of Aging- The CDA has long been the lead agency managing the Older American Act's Family Caregiver Support Act funds. It is also the lead department in development of the Master Plan for Aging and the State budget includes funding for additional staff to support the plan's implementation. CDA also has the most expertise in caregiving issues having been the home for the Family Caregiver Support program for many years.

Cal-AIM- California is redesigning the State's system for delivering health care to Medi-Cal recipients. Given the size of the Medi-Cal population and the fact that most health plans participate in the Medi-Cal program, these changes are likely to impact the larger health care delivery system as well. Embedding best practices for identifying and assessing caregiver needs into the Cal-AIM program and in the State's related health care contracts has the potential to result in significant improvements in care for people with dementia and for their family caregivers. Moreover, CalAIM's in lieu of services provision includes respite care for family caregivers.

Aging and Disability Resource Connections – The state budget and the HCBS spending plan both include funding to support the expansion of ADRCs statewide and promote a "No Wrong Door" philosophy to connect people to services. Successfully connecting people to services is much less likely to happen if the needs of the caregivers who facilitate those connections are not also addressed.

ADVISORY COMMITTEE RECOMMENDATIONS

The growing number of caregivers and the relatively small funding for caregiver-focused programs requires the State to be very efficient with caregiver expenditures. CDA should be the lead agency coordinating policy development and program implementation and oversight to ensure resources are used strategically and to leverage opportunities to increase services and supports. The Advisory Committee recommends that the Secretary:

- 1) In light of historic investments in the direct care workforce (more than \$800 million), consider dedicating all \$4 million in the CDPH budget for caregiver training and certification to work exclusively benefiting family/friend caregivers. We further suggest that this work be done in tandem with CDA's caregiver initiative funded at \$2 million to maximize the state's impact on this constituency.
- 2) Make CDA the lead agency on family/informal caregivers and request that it:
 - a. Develop a webpage for caregivers and agencies that serve them including a repository of caregiver information, services, programs, etc.

- b. Link to the Family Caregiver Alliance’s Best Practice Caregiving website for accessing evidenced-based dementia caregiver trainings and interventions.
 - c. Proactively support expansion statewide of evidenced-based family caregiver training programs and interventions.
- 3) Advise DHCS of the importance of formally incorporating family/friend caregivers into CalAIM documents to ensure, where appropriate and as available, caregivers are identified and documented in the medical records of those diagnosed with dementia.
 - 4) Advise CDA, the lead agency for implementing the State’s “No Wrong Door” expansion of the ADRC network, that the model should include protocols for assessing caregiver needs and connecting those individuals to local caregiver support programs. Encourage dementia training for ADRC staff.
 - 5) Encourage CDA’s Master Plan for Aging Equity Workgroup, in partnership with trusted community-based organizations, to highlight linguistically and culturally competent caregiver training to extend reach to underserved communities.

ⁱ Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff* 2015;34(10):1642-49

ⁱⁱ Jutkowitz E, Gaugler JE, Trivedi AN, Mitchell LL, Gozalo P. Family caregiving in the community up to 8-years after onset of dementia. *BMC Geriatr* 2020;20(1):216.

ⁱⁱⁱ Sanjeev G, Weuve J, Jackson JW, VanderWeele TJ, Bennett DA, Grodstein F, et al. Late-life cognitive activity and dementia. *Epidemiology* 2016;27(5):732-42.

^{iv} Alzheimer’s Association. 2021 Alzheimer’s Disease Facts and Figures. *Alzheimer’s Dement* 2021; 17(3): 36.

^v Alzheimer’s Association. 2021 Alzheimer’s Disease Facts and Figures. *Alzheimer’s Dement* 2021;17(3): 45-46.

^{vi} Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet* 2020;396(10248):413-46.