

November 18, 2020

Mark Ghaly, M.D., M.P.H., Secretary
California Health and Human Services Agency
1600 9th Street, Suite 460
Sacramento, CA 95814

Dear Secretary Ghaly:

Thank you for your leadership over the past eight months as our state has responded to the global COVID-19 pandemic, abrupt budget deficits, power shut-offs and unprecedented wildfires. Against these external threats, we appreciate all the more your continued focus on the Governor's Alzheimer's Prevention and Preparedness Task Force (ATF) and the Master Plan for Aging (MPA) processes. As your official Advisory Committee on these issues, we are proud to weigh in with the most urgent priorities for the millions of Californians – especially women – living with Alzheimer's disease or caring for a loved one with dementia.

This pandemic has laid bare the acute needs of individuals and families impacted by Alzheimer's exacerbated by systemic health care disparities and racial inequities. When California recovers, and we will, we imagine individuals with dementia being engaged, caregivers getting reinforcements, families finding relief, underserved populations achieving equity, communities gaining strength, health workers accessing resources, congregate settings adopting reforms and systems oriented toward person-centered care. Fortunately, because of Governor Newsom's vision and leadership, California has the potential to achieve all this and more over the next decade.

The California Health and Human Services Agency Secretary's Alzheimer's Disease and Related Disorders Advisory Committee has reviewed the preliminary recommendations advanced by the Task Force and the MPA Stakeholder Advisory Committee. Among the nearly 800 combined recommendations, we call your immediate attention to three key themes:

- 1. Identification**
- 2. Integration**
- 3. Investment**

Identification:

Data indicates that nearly half of all persons with Alzheimer's have not been formally assessed with a medical diagnosis documented in the health record. Moreover, many patients are not informed of their cognitive condition by their health care provider. Beyond this, family caregivers are often

overlooked and seldom identified as an essential member of the care team. To address this, we call out five recommendations:

1. Model a statewide standard of Alzheimer's care to the nation drawing on evidence-based models, e.g. CADCs, Cal MediConnect/ACL grants, UCLA, UCSF and OSG
2. Identify, assess and support family caregivers with respite and education leveraging the existing strength of the Caregiver Resource Centers and community-based organizations
3. Address the imperatives of social isolation and its connection to depression, dementias and suicides through active community engagement, (e.g. Blue Zones, Dementia Friendly, WHO Age Friendly and AARP Livable Communities) as well as work underway on the CDC Healthy Brain Initiative in six counties
4. Improve access to IHSS protective supervision hours for persons with dementia with revised screening and identification protocols tailored to the needs of beneficiaries with cognitive impairments to prevent, delay or avoid costly placements in Medi-Cal Long-Term Care nursing facilities
5. Develop a multilingual, culturally competent statewide public awareness campaign to identify and reach disproportionately impacted populations at higher risk of developing Alzheimer's including those with Down Syndrome

Integration:

An estimated 97 percent of Californians with Alzheimer's and related dementias are Medicare beneficiaries and approximately 1.1 million are dually eligible for Medi-Cal. This is a significant population that warrants targeted care coordination and focused case management to halt the detrimental – and costly – cycle of emergency room visits, hospital admissions, nursing home placements, hospital readmissions and frequent transfers between levels of care. In addition, co-occurring mental health conditions and behavioral health challenges associated with Alzheimer's and related dementias are often the driver of high-cost institutional care. Better integration across health care systems, including mental health care, would facilitate the kind of in-depth coordination needed to truly meet the full range of person-centered care needs. The following recommendations would help California move in this direction:

1. Ensure Californians with Alzheimer's and related dementias receive care coordination and care plans through both managed care and fee-for-service providers
2. Conduct an inter-departmental examination of admission, retention and transfer policies within and between levels of care – including acute care, to prevent residents with dementia who have behavioral issues from being improperly displaced from residential settings
3. Establish an office of Medicare/Medi-Cal integration and innovation to formally link medical care, health care, long-term care and mental/behavioral health care

Investment:

Alzheimer's is the most expensive disease in America, estimated to cost our nation \$305 billion in 2020 alone. The lifetime cost of the disease, per person, exceeds \$350,000. This economic burden is shared

by individuals, families and government, and it's unsustainable for all. We need immediate and long-term solutions to address the affordability crisis, starting with these recommendations:

1. Expand home and community-based options as alternatives to nursing home placement and avoidable hospitalizations, including respite care, adult day care, Alzheimer's Day Care Resource Centers (ADCRC), Community Based Adult Services (CBAS)/Adult Day Health Care (ADHC), Multi-Purpose Seniors Services Program (MSSP), Program for All-inclusive Care for the Elderly (PACE), In-Home Supportive Services (IHSS), Caregiver Resource Centers (CRCs) and the Medi-Cal Assisted Living Waiver (ALW)
2. Build geriatric knowledge, cultural proficiency and dementia competency through education and training of the health care workforce to extend reach and maximize capacity of all practitioners to combat extreme workforce shortages
3. Pursue new financing models to generate future revenue to directly support families who today are forced into impoverishment in order to access services that are available only upon qualification for Medi-Cal. [Note, the Advisory Committee would like to commend this Administration for its exploration of a universal LTSS benefit as demonstrated by commissioning the recent Milliman study.] For Californians living with Alzheimer's and related dementias and their caregivers at all income levels, this is the end goal.

Individuals with dementia and their family caregivers cannot wait any longer. California's diverse population has been asked to carry an enormous burden of care with inadequate support for far too long. California must act now and make the systemic changes needed to create a health system better equipped to meet the full range of health and social care needs of these families. Fortunately, the recommendations from the Master Plan for Aging and the Governor's Alzheimer's Prevention and Preparedness Task Force highlighted here offer sensible first steps toward building just such a health care system.

The Advisory Committee looks forward to meeting with you on December 10th and to working with you and the Governor's Senior Advisor to support and implement these recommendations.

Sincerely,

Howard Rosen, MD

Chair, CHHS Agency Secretary's Alzheimer's Disease and Related Disorders Advisory Committee

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