Comment Letters from Stakeholders

The following comment letters were received from stakeholders since the previous Commission meeting on October 2, 2018:

1. Alzheimer’s Association, dated October 24, 2018
   - Enclosure 1: Alzheimer’s Statistics: California
   - Enclosure 2: Making Alzheimer’s Our Next Public Health Success Story
   - Enclosure 3: Mental Health Services for Californians with Alzheimer’s Disease

2. Clinica de Salud del Valle de Salinas, dated October 31, 2018. Note that identical letters were submitted individually to Commission Co-chairs.

3. California Nurses Association/National Nurses United, dated December 14, 2018
Re: Additional Resources and Final Comments

Dear Co-Chair Napolitano and Co-Chair Dean:

On behalf of the 650,000 Californians living with Alzheimer’s disease and the 1.6 million family caregivers who support them, I am writing in support of the Commission’s work to-date. First, we want to acknowledge how much we appreciate the inclusion of the Subcommittee on Healthy Aging & Care for Older Adults from the outset. This is important acknowledgement of a significant and growing population in our state.

As the Commission concludes its important work, the Alzheimer’s Association wanted to reinforce your priorities in several key areas with the addition of several new resources.

**Primary Care and Prevention** – Currently, just 45 percent of all Californians affected by Alzheimer’s have been formally diagnosed by a doctor. Primary care physicians, nurse practitioners, physician assistants, nurses and social workers are key to early detection and timely diagnosis, yet very few have training in geriatrics or gerontology. While Alzheimer’s disease can’t be prevented today, effective primary care has proven to reduce emergency room use and avoid hospital readmissions. This is noteworthy because data indicates for every 1,000 Californians with dementia there are 1,428 emergency room visits – a factor of 1.5. What’s more, patients with dementia are readmitted to the hospital 22 percent of the time – or more than one in five patients. [see California Fact Sheet]

**Behavioral Health** – Nearly all individuals with Alzheimer’s disease experience psychological and behavioral symptoms, with prevalence, frequency and severity increasing as dementia progresses. Apathy, depression, irritability, and anxiety are particularly common during Mild Cognitive Impairment (MCI). In addition to these, other symptoms that may emerge as cognitive impairment advances include agitation, verbal and/or physical aggressiveness, delusions, hallucinations, disinhibition, hyperactivity (e.g., wandering, pacing, rummaging), and sleep disturbances. It is well documented that worsening behavior – that becomes intolerable or
unmanageable for family caregivers, is a primary precipitant of costly long-term care placement. To effectively address this constellation of behaviors requires health professionals with either behavioral health or geriatric training, preferably both. Equally important, direct care staff working in the home or residential settings need specialized training on dementia and the behavioral manifestations of Alzheimer’s disease. [See Mental Health Paper]

Healthy Aging & Care for Older Adults - According to the California Department of Finance, by 2025 California’s 60+ population will be roughly the same size as its 0-19 population (approximately 10 million each). This is unprecedented in our state’s history, and the imbalance will create workforce challenges as we’ve never seen before. One solution is to draw on the expertise of public health to leverage clinical and community resources. Historically, public health hasn’t played a major role in healthy aging and care for older adults but the burden to the state is large, there are ways to intervene and the impact is major – three key indicators that warrant a public health response. Other states, including Florida and Oregon, have adopted a population health approach to optimize aging and there are several examples of “age-friendly” or “dementia-friendly” communities in California. Central to these models are public health nurses, community health workers and promotores. Just last week, the Centers for Disease Control issued the Healthy Brain Initiative: A Road Map for State and Local Public Health Partnerships. Local public health departments have experience with assessing community needs, developing implementation strategies, measuring results and evaluating outcomes. With a burgeoning aging population, public health is a vital, local partner. [See Executive Summary]

Finally, Alzheimer’s disease – and family caregiving – disproportionately impact Blacks/African Americans and Hispanics/Latinos, as well as women, calling for continued emphasis on cultural competency in education and training programs spanning the health workforce.

Thank you for the opportunity to provide additional resources and final comments as you conclude your work. Should you have questions, please feel free to contact me at 916-447-2731 or via email at sdemarois@alz.org.

Sincerely,

Susan DeMarois
California Government Affairs Director

Enclosures (3)
ALZHEIMER'S STATISTICS

CALIFORNIA

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER’S BY AGE*

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
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<tr>
<td>2018</td>
<td>98,000</td>
<td>270,000</td>
<td>280,000</td>
<td>650,000</td>
</tr>
<tr>
<td>2020</td>
<td>110,000</td>
<td>290,000</td>
<td>290,000</td>
<td>690,000</td>
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<tr>
<td>2025</td>
<td>120,000</td>
<td>380,000</td>
<td>330,000</td>
<td>840,000</td>
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* Totals may not add due to rounding

Estimated percentage change: 29.2%

MEDICAID

$3.776 BILLION
Medicaid costs of caring for people with Alzheimer’s (2018)

36.4% change in costs from 2018 to 2025

MEDICARE

$30,072 per capita Medicare spending on people with dementia (2017)

HOSPICE (2015)

# of people in hospice with a primary diagnosis of dementia: 27,013

HOSPITALS (2015)

# of emergency department visits per 1,000 people with dementia: 1,428

21% of people in hospice have a primary diagnosis of dementia

21.7% dementia patient hospital readmission rate

US STATISTICS

Over 5 million Americans are living with Alzheimer’s, and as many as 16 million will have the disease in 2050. The cost of caring for those with Alzheimer’s and other dementias is estimated to total $277 billion in 2018, increasing to $1.1 trillion (in today’s dollars) by mid-century. Nearly one in every three seniors who dies each year has Alzheimer’s or another dementia.

CAREGIVING (2017)

1,616,000 Number of Caregivers

1,841,000,000 Total Hours of Unpaid Care

$23,250,000,000 Total Value of Unpaid Care

$1,073,000,000 Higher Health Costs of Caregivers

For more information, view the 2018 Alzheimer’s Disease Facts and Figures report at alz.org/facts.
Are communities ready to respond to a large population of older people with dementia? Current projections indicate the number of people living with Alzheimer’s and other dementias is ballooning as the Baby Boom generation gets older. Those with dementia will require more and more support as cognitive, behavioral, and physical functioning worsens over time. This means Medicare and Medicaid costs are rising dramatically, and the additional burden on family caregivers is endangering their own health.

With a strong response, public health can mitigate the future impacts of Alzheimer’s and other dementias, especially among vulnerable populations. The Alzheimer’s disease continuum spans decades, providing many opportunities to change outcomes across communities. Just as with other chronic and degenerative conditions, public health can reduce risk in populations, further early detection and diagnosis, improve safety and quality of care for people living with cognitive impairment, and attend to caregivers’ health and wellbeing.

The Healthy Brain Initiative’s (HBI) State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map will chart a course for state and local public health agencies and their partners to act quickly and strategically to prepare their communities by stimulating needed changes in policies, systems, and environments. To focus the public health response, experts developed an agenda of 25 actions for public health leaders to promote brain health, better care for people with cognitive impairment, and increase attention to caregivers. Other Road Map actions build public health capacity.

Alignment of HBI Road Map actions with Essential Services of Public Health ensures that initiatives to address Alzheimer’s can be easily and efficiently incorporated into existing public health initiatives. Cross-sector partnerships, data, and pursuit of health equity are critical to achieving major gains against Alzheimer’s—just as they underlie public health successes in HIV/AIDS, cardiovascular disease, and cancer.

Accelerated progress against dementia requires state and local public health leaders to chart a course for better outcomes. The HBI Road Map outlines the most needed and practical steps that state and local health departments can accomplish. Implementation of the HBI Road Map enables public health to lead with urgency and act for impact.

> Sign up to receive the full HBI Road Map and learn about opportunities for leadership action at alz.org/publichealth.

In October 2018, CDC and the Alzheimer’s Association will release this HBI Road Map for State and Local Public Health Partnerships as well as a companion HBI Road Map for Indian Country.
The HBI Road Map has an agenda of 25 actions for state and local public health agencies and their partners to accomplish. Actions highlighted with a >> are primed for implementation.

**EDUCATE & EMPOWER**

- **E-1** Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.
- **E-2** Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span.
- **E-3** Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers’ health and well-being.
- **E-4** Promote prevention of abuse, neglect, and exploitation of people with dementia.
- **E-5** Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.
- **E-6** Strengthen knowledge about, and greater use of, care planning and related tools for people with all stages of dementia.
- **E-7** Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.

**DEVELOP POLICIES AND MOBILIZE PARTNERSHIPS**

- **P-1** Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.
- **P-2** Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces.
- **P-3** Support better informed decisions by educating policy makers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem.
- **P-4** Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.
- **P-5** Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.
- **P-6** Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.

**ASSURE A COMPETENT WORKFORCE**

- **W-1** Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve.
- **W-2** Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.
- **W-3** Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.
- **W-4** Foster continuing education to improve healthcare professionals’ ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.
- **W-5** Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies.
- **W-6** Educate healthcare professionals about the importance of treating co-morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia.
- **W-7** Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers’ use of available information and tools, and make referrals to supportive programs and services.

**MONITOR & EVALUATE**

- **M-1** Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.
- **M-2** Support national data collection on dementia and caregiving.
- **M-3** Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.
- **M-4** Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.
- **M-5** Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

cdc.gov/aging
alz.org/publichealth
Mental Health Services for Californians with Alzheimer’s Disease

Prepared for the Alzheimer’s Association by Cordula Dick-Muehlke, Ph.D. Cordula Cares
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EXECUTIVE SUMMARY

“We come across this every day.” So echoed county mental health workers in Northern and Southern California who were asked about the extent to which people with dementia experiencing complicated behavioral and psychological symptoms seek services. As revealed in the heartbreaking and costly real-life stories shared in this paper, individuals with Alzheimer’s disease in crisis seek county mental health services daily only to be denied access, simply due to the presence of dementia. Families – and even skilled nursing facilities – unable to cope with difficult-to-manage symptoms, abandon individuals with dementia at the doors of county hospitals regularly, forcing the mental health system to respond in limited and inadequate ways, including placement in a higher-than-needed level of care.

Today, 610,000 Californians have Alzheimer’s disease with that number expected to grow 37.7% to 840,000 by 2025. Throughout the progression of Alzheimer’s disease, affected individuals experience a variety of behavioral and psychological symptoms that can be alleviated through effective treatment, including mental health interventions. Yet, when asked about treating behavioral and psychological symptoms, one county licensed mental health professional commented, “Well, what can you do anyway? You can’t take the dementia away.”

Such lack of knowledge about the opportunities to treat behavioral and psychological symptoms in Alzheimer’s disease effectively is deeply rooted in societal stigma surrounding aging, dementia, and mental health disorders.

In essence, this results in persons with dementia who have mild-to-moderate behavioral and psychological symptoms being able to access – while imperfectly and likely insufficiently – mental health services through a Medi-Cal plan. When symptoms become severe, however, individuals with dementia are referred to the county, where they are denied services at worst and provided limited and inadequate services at best.

As this paper proposes, California has a number of timely opportunities to improve access to mental health services for people with dementia, beginning at the point of diagnosis. An urgent need exists to pursue such opportunities immediately to prevent the types of crises presented here, enable families to stay together, improve quality of life, and reduce the cost of care.
POPULATION PROFILE

PREVALENCE
Today, an estimated 5.4 million Americans, including 610,000 Californians, are living with Alzheimer’s disease. By 2025, the number of Californians with Alzheimer’s disease is projected to escalate 37.7% to 840,000, with 7.2 million people across the country affected (Alzheimer’s Association, 2016).

Alzheimer’s disease is the most common cause of dementia, a condition that impairs memory and other thinking abilities, alters behavior, and ultimately leads to total dependence and death. Accounting for 60-80% of all cases of dementia, Alzheimer’s disease disproportionately affects older adults and women. Of the 5.4 million Americans with Alzheimer’s disease, 5.2 million are over age 65. Advancing age is the greatest risk factor for Alzheimer’s disease, with the percentage of older adults affected doubling every five years after age 65, from 5% in persons 65-70 to 40% or more in those 80 or older. Across all older adults, 1 in 9 (11%) are affected. Additionally, women are at particular risk. Nearly two-thirds of older adults with Alzheimer’s disease are women, due to biological, genetic, and/or socioeconomic differences that are still poorly understood (Alzheimer’s Association, 2016).

Given California’s well-documented diversity, it is particularly important to understand the differential impact of Alzheimer’s disease on California’s three largest communities of color. Latinos – now California’s largest diverse population, numbering nearly 14.1 million in 2010 – are expected to total 23.6 million by 2050, a growth of 59%. Simultaneously, the number of Asian-Pacific Islanders in the state, at just over 4.8 million in 2010, is estimated to grow 37% to nearly 7.6 million. African-Americans, numbered at nearly 2.2 million in 2010, will, however, see only 5% growth in the coming decades (California Department of Finance, 2014). Compared to Caucasians, Hispanics are approximately 1.5 times more likely and African-Americans twice as likely to develop Alzheimer’s disease or another dementia. Currently, insufficient research exists to estimate the prevalence of Alzheimer’s disease and other dementias in Asian-Pacific Islanders. Available knowledge does, however, suggest that health, lifestyle and socioeconomic risks rather than genetic factors account for known racial differences in the prevalence of Alzheimer’s disease and other dementias (Alzheimer’s Association, 2016).

PROGRESSION OF ALZHEIMER’S DISEASE
From the first biological changes until death, Alzheimer’s disease progresses through three major phases: (1) preclinical, (2) mild cognitive impairment, and (3) dementia (Sperling, et al., 2011). In the pre-clinical or silent phase, the individual begins to undergo biological changes associated with Alzheimer’s disease yet stays free of symptoms. Brain cells or neurons are damaged and destroyed over time as the toxic beta-amyloid protein accumulates into “senile plaques” outside cells and an abnormal form of tau, another protein, disintegrates intra-cellular structures into “neurofibrillary tangles.” Eventually the accumulation of plaques and tangles surpass the brain’s ability to withstand the assault. With the emergence of noticeable symptoms, Alzheimer’s disease progresses to mild cognitive impairment (MCI), a transitional state between normal cognitive aging and dementia. In MCI, the individual develops mild but measurable changes in memory and/or other thinking abilities that are noticeable to the individual and/or close family members and friends, but do not yet impair everyday living abilities (Albert, et al. 2011). MCI can stem from a variety of causes, including Alzheimer’s disease, other dementias, and medical or psychiatric conditions. While some individuals diagnosed with MCI revert to normal, the majority will progress to dementia over time. (Galvin & Kelleher, 2015). Research suggests that 46% of people with MCI, as compared to 3% of
cognitively normal individuals, will develop a full-blown dementia due to Alzheimer’s disease within three years (Tschanz et al., 2006).

Gradually, the neuropathological changes of Alzheimer’s disease spread throughout the brain, impacting all areas of cognitive functioning, affecting behavior, and impairing the individual’s everyday living abilities. Whereas, in MCI the individual often develops some functional limitations — such as difficulties managing financial affairs, driving, continuing to work, or preparing complex meals — in dementia, the person needs increasing assistance with everyday living skills. From preparing simple meals to dressing and grooming, and eventually personal hygiene and self-feeding, the person with dementia becomes totally dependent on others (McKhann, et al., 2011).

As the dementia phase of Alzheimer’s disease progresses through mild, moderate, and severe stages, cognitive decline progresses from difficulties in remembering recent experiences to loss of even the most treasured long-term memories; from forgetting names to not knowing who others — even the closest loved ones — are; from problems with organizing and expressing thoughts to speaking only a handful of words, if any; from getting lost in familiar places to not having any idea where one is in space and time; and from making poor decisions (e.g., financial) to being unable to keep oneself safe. From diagnosis until death, the course of Alzheimer’s disease lasts an average of 4–8 years, although some individuals survive longer (Alzheimer’s Association, 2013).

Despite the extensive losses which threaten the personhood of individuals with Alzheimer’s disease, we recognize that they remain whole human beings who have a right to the treatment and services which enable them to live life fully.

**DIAGNOSIS**

Today, Alzheimer’s is the most feared disease among Americans 60 and older, more feared than cancer, stroke, and diabetes (Alzheimer’s Association, 2014). While media attention to Alzheimer’s disease has grown exponentially, studies show that it is still poorly understood among the general public (Cahill, Pierce, Werner, Darley, & Bobersky, 2015) and, most importantly, among physicians and other health care professionals. With the earliest symptoms of Alzheimer’s disease still often misattributed to “normal aging,” physicians overlook or ignore up to 9 out of 10 cases of individuals with mild dementia and 7 out of 10 of those with moderate-to-severe dementia (van den Dungen, et al., 2012).

When recognized, physicians diagnose mild cognitive impairment and dementia using the *International Classification of Diseases-Tenth Revision* (ICD-10), the coding system required by public and private health care reimbursement systems as of October 1, 2015. Both Alzheimer’s disease and mild cognitive impairment fall under the major ICD-10 category of “diseases of the nervous system” (G30-32). Subcategory G30 is dedicated to Alzheimer’s disease with separate codes for early and late onset, other Alzheimer’s disease, and Alzheimer’s disease not specified. Along with Alzheimer’s disease, an additional code is assigned for delirium, dementia with behavioral disturbance, or dementia without behavioral disturbance (ICD-10 List, 2013). Mild cognitive impairment is classified under the separate subcategory of “other degenerative diseases of the nervous system” (G31.84) (ICD-10 List, 2016).
Alzheimer’s disease and its precursor, mild cognitive impairment, are classified not just as medical disorders in ICD-10, but also as psychiatric disorders in the Diagnostic and Statistical Manual of Mental Disorders—Fifth Edition (DSM-V). In this latest 2013 version of the American Psychiatric Association’s diagnostic manual, the term “neurocognitive disorders” replaces dementia. Mild and major neurocognitive disorder align with mild cognitive impairment and dementia, respectively, in this classification system and the underlying cause (e.g., Alzheimer’s disease, frontotemporal lobar degeneration, traumatic brain injury) for the symptoms is included in the diagnosis.

DSM-V also requires the clinician to specify the level of diagnostic certainty by differentiating probable from possible Alzheimer’s disease. Probable Alzheimer’s disease is diagnosed when evidence of a causative Alzheimer’s disease genetic mutation from either genetic testing or family history is present, while possible Alzheimer’s disease is diagnosed absent such evidence when a clear decline in memory and learning, and steadily progressive, gradual worsening of cognition, without plateaus are present, and there is no evidence of mixed etiology. Consequently, mild cognitive impairment and dementia stemming from Alzheimer’s disease would be diagnosed as mild and major neurocognitive disorder, respectively, due to probable or possible Alzheimer’s disease based on the level of diagnostic certainty. In DSM-V, the primary diagnostic code for probable major neurocognitive disorder due to Alzheimer’s disease is 331.0, followed by specifiers for with or without behavioral disturbance, and must be accompanied by the ICD-10 medical code, G30.9 for Alzheimer’s disease not specified. DSM-V has separate codes for possible major cognitive disorder as well as mild cognitive disorder due to Alzheimer’s disease, with neither requiring the inclusion of the ICD-10 code.

Clearly, these dual medical and psychiatric diagnostic classification systems for Alzheimer’s disease reflect the complexity of the condition, which impacts the person physically, emotionally, socially, and spiritually. With its widespread effects, Alzheimer’s disease does not readily fit fully into either system and requires a holistic approach that integrates medical and psychiatric treatment approaches for the greatest benefit. Hence, diagnostic systems, such as DSM-V (American Psychiatric Association, 2013) and the earlier DSM-IV (American Psychiatric Association, 2004), which require clinicians to demonstrate that a psychiatric illness (e.g., depression) is unrelated to the dementia are problematic (Yang, 2016).

**POPULATION EXPERIENCE**

Scientific and biomedical descriptions of Alzheimer’s, which focus on intricate disease processes, too often lose sight of the person who is experiencing the illness. In its efforts to find more effective treatments, prevention strategies and ultimately a cure for Alzheimer’s, researchers intentionally attempt to separate out and target the unique biological processes underlying the development and progression of the disease. Alzheimer’s disease, in real life, is inextricably intertwined with a host of medical, emotional, social, and spiritual factors.

In other words, Alzheimer’s is not experienced in isolation from the multiple medical comorbidities affected individuals typically have, the variety of behavioral and psychological changes that may occur across the course of the disease, socioeconomic influences (e.g., ethnicity, financial status), and one’s
spiritual understanding of life. Ultimately, it is the confluence of all these factors and their interaction that support or detract from the well-being of any given person with Alzheimer’s disease.

**MEDICAL COMORBIDITIES**

Of particular concern are the complex and interrelated medical and mental health needs that people with Alzheimer’s disease experience. Of all Medicaid and Medicare beneficiaries with dementia, 90% and 85%, respectively, have three or more chronic health conditions (Kaiser Commission on Medicaid and the Uninsured, 2015), such as hypertension, diabetes, chronic pulmonary disorder, and congestive heart disease (Fox et al., 2014; Poblador-Plou, et al. 2014). Poorly managed chronic and acute (e.g., pneumonia, urinary tract infections) medical comorbidities are a source of preventable emergency room visits and hospital admissions, escalating health care costs for individuals with dementia. On average, Medicare spending is three times higher for persons with Alzheimer’s disease than for beneficiaries without, while Medicaid spending is 19 times higher (Alzheimer’s Association, 2016). In fact, the Lewin Group has estimated that California will spend $3.3 billion in 2016 alone on Medi-Cal beneficiaries with Alzheimer’s disease (Alzheimer’s Association, 2015a).

**BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS**

As Alzheimer’s disease progresses from MCI to advanced dementia, affected individuals may experience a variety of behavioral and psychological symptoms. Apathy, depression, irritability, and anxiety are particularly common during MCI (Apostolova & Cummings, 2008). In addition to these, other symptoms that may emerge as cognitive impairment advances include agitation, verbal and/or physical aggressiveness, delusions, hallucinations, disinhibition, hyperactivity (e.g., wandering, pacing, rummaging), and sleep disturbances. Nearly all individuals with Alzheimer’s disease (i.e., 97%) experience behavioral and psychological symptoms (Steinberg, et al., 2008), with prevalence, frequency, and severity increasing as dementia progresses (Steinberg, et al., 2008; Trivedi, Subramanyam, Pinto, & Gambhire, 2013). Importantly, behavioral and psychological symptoms vary greatly from person to person (Gauthier, et al., 2010; Landes, Sperry, & Strauss, 2005), suggesting that multiple, including treatable, factors contribute to their occurrence.

Of the behavioral and psychological symptoms that people with dementia may experience, depression deserves special attention. Overall, studies suggest that depressive symptoms occur in an estimated 34% of individuals with MCI (Panza et al., 2010) and up to 55% of those with dementia (Lyketsos & Lee, 2004). In the large longitudinal Cache County Study of Memory Health and Aging, the cumulative prevalence of depression in dementia over five years was 77% (Steinberg, et al., 2008). Notably, comments from individuals with Alzheimer’s disease reveal the impact of receiving the diagnosis on
their mental health. For example, Joan, an attorney diagnosed with MCI, shared, “[I] cried my eyes out, thought about suicide . . . . I am a stubborn person. I wasn’t ready to lose my mind at this time in my life.” While researchers debate about the extent to which depression is a risk factor for Alzheimer’s, a co-occurring condition, and/or a consequence of the disease process itself (Enache, Winblad, & Aarsland, 2011), it is essential that depression, such as that experienced by Joan, be recognized and treated in a timely manner. Notably, as depression has been shown to increase risk for “conversion” from MCI to dementia (Mourao, Mansur, Malloy-Diniz, Castro, & Diniz, 2015), treatment has the potential to prevent or at least delay this progression.

Behavioral and psychological symptoms often are more difficult for individuals with Alzheimer’s disease, caregivers, and providers to cope with than the progressive decline in memory and thinking abilities. For all involved, but especially those with Alzheimer’s disease, behavioral and psychological symptoms have numerous negative consequences. Early institutionalization, increased risk for hospitalization, faster disease progression, greater disability in activities of daily living, increased risk of falls, injury and mortality, and lower quality of life are repeatedly linked to behavioral and psychological symptoms in the research literature (Kales, Gitlin, & Lyketsos, 2014; Lyketsos & Lee, 2004). Not surprisingly, behavioral and psychological symptoms of dementia contribute to the escalating cost of health care for individuals with dementia. In one study, 30% of the cost of caring for community-dwelling individuals with dementia was attributable to management of behavioral and psychological symptoms (Beeri, Werner, Davidson, & Noy, 2002).

As importantly, managing complex behavioral and psychological symptoms can threaten the health and well-being of the family caregivers on whom our society relies to provide the majority of care for people with dementia. Notably, caregivers are more likely to experience both burden and depression when a loved one’s dementia is complicated by behavioral and psychological symptoms (Covinsky et al., 2003; Wolfs et al., 2012).

**BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS ARE POORLY ADDRESSED**

Effective treatments for behavioral and psychological symptoms in Alzheimer’s disease have the potential to enhance independence, facilitate coping, improve overall quality of life, reduce health care utilization and costs, and enable family caregivers to continue care at home. Yet mental health interventions, despite their potential to alleviate behavioral and psychological symptoms of dementia, remain largely inaccessible to those most in need.

In MCI and early dementia, medications such as antidepressants are commonly used to treat anxiety and depression, and are generally accessible. Psychotherapy for such symptoms, while covered by Medicare and Medi-Cal to the extent that the individual can participate and benefit (CMS, 2016), is less available despite documented effectiveness. In a pilot randomized control trial, Aimee Spector and her colleagues (2015) demonstrated that cognitive behavioral therapy can reduce both depression and anxiety in individuals with mild-to-moderate dementia. In a panel presentation involving individuals with MCI and early dementia, Paul, who
was struggling with the impact of MCI on his sense of self at the time, explained, “Seeing a psychologist is helpful; it helps me cope with my depression. I don’t feel so good about myself most of the time” (Dick-Muehlke, 2014). Steve, who documented life with MCI in a recent book chapter (Heins, Heins, & Dick-Muehlke, 2015), noted, “Every morning it feels like the depression will get me. I’ve got to get up every morning and fight to keep going. . . . Seeing a therapist helps me because it’s another input. . . . My psychologist holds my feet to the fire when I tell her I want to do something. You said you’d do this and you didn’t.”

In moderate-to-severe dementia, the types of mental health interventions the individual needs change and expand. As verbal abilities are lost, traditional psychotherapeutic approaches yield to person-centered care that emphasizes compassionate, caring relationships. Earlier behavioral and psychological symptoms, such as anxiety and depression worsen while new more challenging ones (e.g., delusions, hallucinations, wandering) emerge. Within a person-centered framework for dementia care, it is recognized that multiple factors – medical, cognitive, psychological, and environmental – may contribute to the presence and severity of behavioral and psychological symptoms. Given the increasingly limited ability of individuals with dementia to express themselves and cope with everyday life, simple difficulties can evolve into mental health crises that require urgent professional intervention.

Crises occur in the multiple settings where people with dementia live and receive care. Worsening behavior – that becomes intolerable and unmanageable for family caregivers – is a primary precipitant of placement (Gaugler, Yu, Krichbaum, & Wyman, 2009). All too often, the mental health needs of persons with dementia have been poorly if at all addressed prior to placement. Disorienting and often disconcerting for the individual, placement, like other care transitions, can exacerbate behavioral and psychological symptoms and/or contribute to development of delirium (Burke, et al., 2016; Ray, Ingram, & Cohen Mansfield, 2015). Hence, mental health crises are a common occurrence among residents with dementia in residential and skilled nursing facilities. In combination, the complexity of mental health needs combined with limitations in knowledge, skills, and resources to care adequately for people with dementia, particularly in facilities that accept Medi-Cal, leave these residents vulnerable to repeated crises.

While focused on older adults with Alzheimer’s disease whose behavioral and psychological symptoms are poorly addressed, we recognize the impact of dementia on the mental health needs of two other vulnerable populations – the seriously and persistently mentally ill and individuals with an intellectual disability. To date, research has demonstrated that certain longstanding mental health conditions – namely, depression (Geerlings, den Heijer, Koudstall, Hofman, & Gretler, 2008) and schizophrenia (Ribe et al., 2015) – and intellectual disabilities, (Carey, et al., 2016) particularly Down syndrome (Sabbagh & Edgin, 2016), increase risk for dementia. As will be discussed later, advancing dementia in people with serious mental illness can, in some counties, result in the termination of mental health services. And, in Down syndrome, dementia may be characterized by a worsening of behavioral symptoms that make it increasingly difficult for affected individuals to function in traditional service settings (e.g., workshops). For these individuals, few alternatives beyond care from family and/or in a residential setting exist once significant behavioral and psychological symptoms of dementia emerge.
POPULATION ACCESS

In the nearly 60 years since the Short-Doyle Act established California’s community-based mental health system, it has evolved into a financially and programmatically complex service delivery structure. Federal, state, and county dollars are interwoven to offer a continuum of services that it will become evident here fail to adequately address the mental health needs of people with dementia.

For purposes of this discussion, we highlight several key elements of California’s public mental health system, with a comprehensive description of the history, funding streams, structure and governance, and delivery available in the California HealthCare Foundation report, A Complex Case: Public Mental Health Delivery and Financing in California (Armquist & Harbage, 2013).

MENTAL HEALTH “CARVE-OUT”

From 1995 to 1998, California consolidated its then separate fee-for-service and Short-Doyle/Medi-Cal into a single “carved out” specialty mental health managed care delivery system operated by the counties under a 1915(b) Medicaid “freedom of choice” waiver. Essentially, this process separated (i.e., “carved out”) specialty mental health services, as defined in Title 9 (see below) from other Medi-Cal benefits. In June 2015, the Centers for Medicare and Medicaid Services (CMS) renewed California’s 1915(b) Specialty Mental Health Services (SMHS) waiver, preserving California’s county-based mental health system until at least 2020. Currently, each of California’s 58 counties provides specialty mental health services through a publicly or privately operated mental health managed care plan, under contract with the Department of Health Care Services, and shares in the financial risk.

MEDICAL NECESSITY CRITERIA

To qualify for specialty mental health services, Medi-Cal beneficiaries must meet the medical necessity criteria outlined in Title 9, California Code of Regulations, 1830.205 (Medical Necessity Criteria for MHP Reimbursement of Specialty Mental Health Services, 1997) or 1820.205 (Medical Necessity Criteria for Reimbursement Psychiatric Inpatient Hospital Services, 1997). In summary, outpatient criteria require that the adult needing services (1) carries one or more of 18 diagnoses in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV, 1994), (2) is significantly impaired or likely to deteriorate in an important area of life functioning, and, (3) will improve as a result of treating the condition, which would not be responsive to physical health care. When these requirements are met, Section 1830.205 asserts that, beneficiaries shall receive specialty mental health services for an included diagnosis even if an excluded diagnosis is also present.

In January 2003, as directed by SB 639 (Chapter 692, Statutes of 2001), the California Health and Human Services Agency (2003) issued a strategic plan to improve access to mental health services for persons with Alzheimer’s disease and related disorders. This plan asserts, “To the extent that resources are available, all Californians who require mental health services are eligible to obtain services through the county mental health departments based on medical necessity... An individual with dementia would not be excluded from receiving mental health services as long as he or she also meets medical necessity criteria for medically necessary mental health services” (p. 26-27) as articulated in the Medical Necessity Criteria for MHP Reimbursement of Specialty Mental Health Services (1997). Clearly, multiple factors — including a lack of financial resources, variability in the interpretation and application of mental necessity criteria, lack of professionals knowledgeable and skilled in geriatric mental health, and a faulty belief that people with Alzheimer’s disease cannot benefit from psychological interventions such as psychotherapy (Yang, 2016) — contribute to behavioral and psychological symptoms being under-addressed and evolving into the crisis situations documented through multiple case examples later in this paper.
MEDI-CAL EXPANSION

One of the first states to take advantage of the opportunity to expand Medicaid under the Patient Protection and Affordable Care Act (PPACA), California has enlarged its public health care delivery system to serve 13.3 million beneficiaries – or 1 out of 3 Californians. Today, nearly all beneficiaries in California’s 58 counties receive health care services, including components of specialty mental health care, via Medi-Cal managed care. Medi-Cal managed care varies operationally across California. Medi-Cal benefits are managed via a single county organized health system (COHS) in 22 counties. In the Two-Plan model, the Department of Health Care Services contracts with a county-organized and commercial plan (14 counties), in both the Regional and Imperial models with two commercial plans (19 counties), in the Geographic Managed Care model with multiple commercial plans (2 counties), and in the San Benito model with one commercial plan, allowing beneficiaries the option to choose fee-for-service Medi-Cal (1 county) (California Department of Health Care Services, 2014).

In July 2012, California adopted the Coordinated Care Initiative (CCI), to integrate the delivery of medical, behavioral, and long-term care for individuals with complex care needs, including “dual eligibles” who qualify for both Medicare and Medi-Cal. CCI includes (1) mandatory enrollment of all Medi-Cal beneficiaries, including dual eligibles, into managed care for all Medi-Cal benefits, including long-term services and supports (LTSS), and (2) optional enrollment into Cal MediConnect, an integrated managed care plan that combines Medicare and Medi-Cal benefits. Eight counties – Alameda, San Mateo, Santa Clara, Los Angeles, Orange, San Diego, Riverside, and San Bernardino – are implementing CCI, with all but Alameda incorporating Cal MediConnect. As of April 1, 2016, 122,087 beneficiaries were enrolled in Cal MediConnect in seven counties (California Department of Health Care Services, 2016). While benefits across plans are governed by federal Medicare and Medicaid law, and overseen by the California Department of Health Care Services, the multiplicity of models and plans within California’s Medi-Cal managed care system lends itself to variability and inconsistency in how services are delivered. Furthermore, for low income, disabled, and the many multi-lingual beneficiaries served, the complexity can be daunting and impede access to services.

RESPONSIBILITY FOR THE DELIVERY OF MENTAL HEALTH SERVICES

In all counties, including those with CCI, responsibility for the delivery of specialty mental health services is split between the Medi-Cal and mental health managed care plans, referred to hereafter as Medi-Cal plans and mental health plans, respectively. Since January 1, 2014, Medi-Cal plans have been required to provide certain specialty mental health services, as described in All Plan Letter 13-021 (California Department of Health Care Services, 2013). In addition to those mental health services that primary care physicians can provide within their scope of practice, Medi-Cal plans must offer outpatient mental health services for beneficiaries with “mild-to-moderate” impairment in mental, emotional, or behavioral functioning as assessed by a licensed mental health professional. When services are “medically necessary,” physicians or licensed mental professionals in the Medi-Cal plans must provide the following “within the scope of their practice:

1. Individual and group mental health evaluation and treatment (psychotherapy);
2. Psychological testing, when clinically indicated to evaluate a mental health condition;
3. Outpatient services for the purposes of monitoring drug therapy;
4. Outpatient laboratory, drugs, supplies, and supplements [excluding specified medications]; and
5. Psychiatric consultation” (p. 4).
As the All Plan Letter makes clear, medical necessity for mental health services provided by the Medi-Cal plans is different from that established by Title 9, as described earlier. Within the Medi-Cal plans, “medically necessary” mental health services “are defined as reasonable and necessary services to protect life, prevent significant illness or significant disability, or to alleviate severe pain through the diagnosis and treatment of disease, illness or injury. These include services to:

1. Diagnose a mental health condition and determine a treatment plan;
2. Provide medically necessary treatment for mental health conditions (excluding couples and family counseling for relational problems) that result in mild or moderate impairment; and,
3. Refer adults to the county mental health plan for specialty mental health services when a mental health diagnosis covered by the mental health plan results in significant impairment…." (p. 4).

Consequently, individuals with MCI or early dementia who experience depression, anxiety, or other behavioral health symptoms should be able to access not just medications but also psychotherapy, if able to meaningfully participate and benefit (Centers for Medicare and Medicaid Services, 2016). Of course, access depends on primary care physicians first having the knowledge to identify Alzheimer’s disease and willingness to disclose the diagnosis. Sadly, less than half (i.e., 45%) of people with Alzheimer’s disease and their caregivers have even been told the diagnosis (Alzheimer’s Association, 2015b). While physicians hesitate to share the diagnosis for multiple reasons – ranging from fear of causing emotional distress to time constraints – families struggle to cope with multiple challenges. Certainly, one of the most common challenges involves the early emergence of behavioral and psychological symptoms, which absent a diagnosis can appear inexplicable and absent treatment can escalate into a crisis.

Should the individual and family receive a diagnosis, the next hurdle is physician recognition of early behavioral and psychological symptoms (e.g., depression, anxiety) and awareness that affected individuals can benefit from mental health services.

When a mental health condition, as defined in Title 9, causes significant impairment in functioning, the mental health plan assumes responsibility for providing outpatient, emergency, and/or inpatient services as medically necessary per Title 9, Chapter 11, Sections 1830.205 (Medical Necessity Criteria for MHP Reimbursement of Specialty Mental Health Services, 1997) and 1820.205 (Medical Necessity Criteria for Reimbursement Psychiatric Inpatient Hospital Services, 1997) briefly summarized above. As outlined by the California Mental Health Directors Association (2013), mental health plans are responsible for serving individuals who have a “serious and disabling mental disorder.” In other words, the condition must be severe and persistent, and impair everyday living skills, hinder social relationships, or interfere with the ability to work and sustain an income and housing. Severe and persistent mental health conditions are further defined as chronic with complex symptoms that require management over the lifespan and tend to worsen if left untreated.

Within the above mental health plan framework, individuals with dementia can be readily denied emergency services if the particular mental health condition or symptoms cannot be shown to predate the cognitive impairment. As detailed in the coverage responsibility matrix for behavioral health benefits in the duals demonstration (“Behavioral health benefits,” 2013), access to mental health services for people with dementia clearly breaks down when crisis intervention is required. With Medi-Cal as the only payor, these services are governed by Title 9 criteria, which as interpreted by the California Mental Health Directors Association (2013), clearly exclude cognitively impaired older
adults with recent behavioral and psychological symptoms. While access to mental health services (e.g., medications, psychotherapy) for older adults with dementia exhibiting mild-to-moderate behavioral and psychological symptoms is imperfect and likely insufficient within Medi-Cal plans, lack of accessibility is greatest for individuals in crisis.

**WHEN THE SYSTEM FAILS**

**FROM THE PERSPECTIVE OF THE MENTAL HEALTH PLANS**

For purposes of this paper, clinical and director-level mental health plan staff in two large California counties – one in Southern and one in Northern California – were contacted to assess the extent to which mental health needs of people with dementia are unaddressed. In both cases, those interviewed reported people with dementia and their families are seeking crisis mental health services from the county on a daily basis. In Southern California, staff were largely hesitant to discuss the issue apart from reporting that (1) an individual with dementia who presents with behavioral and psychological symptoms is not eligible for services, and (2) an existing client with a serious mental illness who develops dementia can continue to receive mental health treatment until it is determined that he/she is no longer benefiting because “the dementia has become primary.” When this occurs, the individual is at risk for homelessness if placement cannot be found. While not the focus of this paper, the lack of continued support for people with serious mental illness who develop dementia represents another significant gap in services within California’s mental health system.

When asked for case examples involving people with dementia referred for county mental health services, the licensed professional being interviewed deferred sharing stories until after seeking authorization from a supervisor. Interestingly, she did not respond to follow up, suggesting an overall discomfort, at least in this Southern California County, about discussing the lack of mental health services for people with dementia. Such hesitance suggests that the extent of the problem may remain largely hidden in a system that currently doesn’t encompass much-needed crisis mental health services for people with dementia.

In comparison, staff from a large well-resourced Northern California county – who had managed two cases involving individuals with dementia and urgent mental health needs the very day they were interviewed – spoke openly about their daily challenges. Four typical patterns were described.

1. A resident with dementia living in a skilled nursing facility is placed on an involuntary hold due to unmanageable behavioral and psychological symptoms by a consulting psychiatrist. Upon arrival at the county hospital, which has both emergency medical and psychiatry services, the individual sees, in either order, a physician for a medical clearance, and a psychiatrist. Typically, the person is deemed ineligible for services due to the dementia. If, however, the psychiatrist gives a mental health diagnosis, e.g., psychosis, the individual receives whatever treatment is deemed appropriate during the 3-day hold, but no additional mental health services thereafter. After the individual is medically and psychiatrically cleared, the hospital attempts discharge to the referring skilled nursing facility, which, in some instances refuses readmission due to “risk to others.” This results in a report to the California Department of Public Health, Licensing and Certification, and a prolonged effort to locate an alternative placement.

2. A family caregiver brings a loved one with dementia who has difficult-to-manage behavioral and psychological symptoms to the hospital. After a same-day clearance by both a physician and a psychiatrist, as described
above, the caregiver may be referred to the county mental health call center. If the caregiver follows through with the referral, call center staff screen for dementia, which, if present, results in further referral to alternative resources (e.g., community-based agencies, skilled nursing, other medical centers). In the meantime, as the caregiver pursues this circular process, urgent mental health needs remain unmet and may further escalate, requiring more intensive intervention than if addressed immediately.

3. A family caregiver contacts the call center directly about a loved one with dementia who is exhibiting difficult-to-manage behavioral and psychological symptoms. As described immediately above, call center staff refuse mental health services and refer the caregiver to alternative resources.

4. A family caregiver who is at wits end in managing complex behavioral and psychological symptoms of a loved one with dementia abandons that individual at the county hospital. In the absence of a safe discharge plan, the individual is hospitalized after being medically and psychiatrically cleared, as described above, until a bed in a skilled nursing facility is available. At any given time, this county hospital is caring for 3-5 non-acute patients with dementia who have been abandoned and are waiting for placement. On average, these individuals are hospitalized for 30-45 days – at a cost of $6,500 per day – before placement. In this Northern California county, an estimated 1,250-1,350 individuals who are eligible for but cannot afford residential care (e.g., in a board and care home) and would otherwise be homeless are living in skilled nursing facilities, leading to a placement bottleneck. Additionally, this Band-Aid solution ties up acute care beds needed for seriously medically ill patients.

Finally, in this particular Northern California county, individuals with serious mental illness who develop dementia continue to receive services until the end of life.

As is illustrated in the following real-life case examples, the absence of mental health services for people with dementia has tragic and costly consequences.

AHMAD
Jabbar first brought his father, Ahmad, 81, who is deaf and has Alzheimer’s disease, benign prostatic hyperplasia, and hypertension, to emergency services after he started hallucinating. At the time, he received a psychiatric consult and was hospitalized voluntarily overnight for altered mental status. Less than two weeks later, Ahmad returned to the hospital on an involuntary hold. While the psychiatrist who saw Ahmad cleared him, the medical doctor hospitalized him again, this time for delirium. After a two-day stay, Ahmad was released to his son. As they were leaving the hospital, Ahmad started hallucinating, acting frightened of his son, and walking around the hallways. Eventually, Jabbar was able to redirect his father and get him into the car. As they were driving, Ahmad opened the car door twice. Then, when they stopped at a gas station, Ahmad left the car, walked around frantically, repeatedly referred to the attendant as “magical,” got into a stranger’s vehicle, and tried to cross the street in traffic. For a second time, Jabbar was able to calm his father, but as soon as they were driving, Ahmad opened the car door again. A day later, Jabbar brought Ahmad – who was getting lost, hallucinating, and aggressive – back to the hospital. As Jabbar was unable to provide round-the-clock care and did not feel safe taking his father
home, Ahmad was admitted to the hospital and is awaiting placement.

**FRANK**

Frank, 78, who has dementia, was brought to the mental health urgent care by his daughter, Sarah, for evaluation. After Frank lost his apartment a year ago, he moved in with friends, but for the last six months he’s been homeless, living out of his car. Recently, Frank drove to Oregon for unknown reasons. After being pulled over by police there for erratic driving, Frank was sent to the emergency room and subsequently hospitalized for uncontrolled hypertension. As Frank was clearly confused and unable to take care of himself, hospital discharge planners located Sarah, who flew to Oregon and drove her father back to California. Upon evaluation, Frank reported paranoid thoughts but denied any suicidal ideation. He was placed on an involuntary hold for grave disability and sent to emergency psychiatric services at the county hospital where he was cleared for release. When the social worker contacted Sarah to pick up her father, she claimed that she was unable to take care of him and asked the hospital to apply for Medi-Cal on his behalf and find placement. Sarah revealed that both an attorney and a nurse had advised her to drop off her father at urgent care, as once he was transferred to emergency psychiatric services, staff there would find a placement for him if she refused to pick him up. Sadly, Sarah refused to respond to any subsequent follow-up calls by the social worker. Frank awaits placement in the hospital.

**EMMA**

Emma, 86, was brought into emergency psychiatric services at the county hospital on an involuntary hold for danger to self by a sheriff’s deputy. Up until a week ago, Emma had been living in her own home of 54 years. Due to increasing memory loss, Emma has had a part-time in-home caregiver for the past three years. Emma’s daughter, Mary, and sister, Isabella, recently discovered that the in-home caregiver had been taking advantage of their mother financially. When they tried to move Emma into an assisted living facility, she was declined admission due to a risk for wandering. Last week Emma moved in temporarily with Isabella, but since then she has been irritable and unhappy, repeatedly pushing the door and trying to leave the house and making statements such as “You’ll find me in a pool of blood” and “I will find a knife and kill myself.” Officers were called after Emma ran into the street, tried to flag down a neighbor as she was screaming for help, and threatened to kill herself. As Mary and Isabella did not feel safe taking Emma home after the incident, the psychiatrist transferred Emma to emergency medical services, where she would await placement the next day. Fortunately, in this case, the social worker was able to quickly find a suitable living environment for Emma.

**HENRY**

Henry, 71, who has dementia, was brought to emergency psychiatric services on an involuntary hold from a skilled nursing facility for “outbursts.” As Henry was calm and cooperative while at emergency psychiatric services, staff attempted to release him back to the skilled nursing facility. Staff there reported “having issues” with Henry, who had entered other residents’ rooms repeatedly, walked away from the facility twice, and “harassed and attempted to assault” staff several times. Facility staff noted, “We’re not shutting our doors to him, but we want to know he cannot be violent because we have older people who need to feel safe here.” After several conversations with the facility’s director of nursing, she declined to readmit him. When the health plan care manager suggested moving Henry to another facility, the medical social worker provided education, explaining that relocation would not solve the problem, but might even exacerbate Henry’s behaviors. Upon the social worker’s request and direction, the health plan arranged for a psychiatric consult to develop a behavioral care plan and adjust medications as needed.
FROM THE PERSPECTIVE OF THE PERSON WITH ALZHEIMER’S DISEASE AND CARE PARTNER

Steve, 68, and Kay, his wife and care partner, have been living with Alzheimer’s disease for the past five years. Steve, who is still able to clearly articulate his experience, and Kay agreed to be interviewed about a recent incident in which police placed him on an involuntary hold and sent him to the county hospital. Although Steve is covered by Medicare and a supplemental health insurance plan, he was sent to the county’s emergency psychiatric services based on police protocol. Steve brings not only his perspective as a person with Alzheimer’s disease to this particular experience, but also his background in process/quality improvement, strategic planning, and emergency medical care (i.e., as a former EMT). As well, as a registered nurse, Kay brings unique insights, viewing this experience through the lenses of a health care professional as well as a care partner.

On the particular day the incident occurred, Steve went out for a run in the hills around his home as he does regularly. Feeling more disoriented than usual, Steve identified the flag on the home to the left of his own as a landmark for his return. On Steve’s run, he came to another home with a flag and thought the house next to it was his own. Steve identified himself as having Alzheimer’s disease to the teen living there and now reflects, “Once I said I had Alzheimer’s disease, he automatically thought I was in worse condition than I was” and called the police. Although Steve repeatedly asked the police to call Kay, he recalls becoming more panicked and eventually feeling almost suicidal because, “Nobody would get my wife. It seemed so fricking simple, just listen to the patient.” Reflecting on the “futility” of asking to see his wife, Steve noted, “They took away part of who I was” by not respecting his request.

In the meantime, Kay, who monitors Steve’s whereabouts with the Life 360 family locator app, received a phone call from the teen about Steve’s location. By the time Kay arrived, Steve was very upset, saying he wanted to “end this,” and at one point, putting his hands up to his neck as if to choke himself. It became apparent to Kay that the police had not looked at Steve’s MedicAlert bracelet. Despite Kay’s request that she be allowed to take Steve home, police insisted that he be evaluated by emergency psychiatric services and sent him via ambulance to the county hospital. Rather than calling the number on the MedicAlert bracelet, which was never done, the medics restrained Steve while transporting him to the hospital even as he tried to connect with them, noting that he had been an EMT. Steve recalls, “I’m in the patty wagon; I can’t see where I’m going or connect; it’s snowballing.”

While Steve was enroute to the hospital, Kay called emergency psychiatric services and was told that he won’t be brought there because “we don’t serve people with Alzheimer’s disease.” To her, this response seemed ironic given Steve’s suicidal ideation and the officers’ decision to place him on an involuntary hold. At the county hospital, Kay found Steve in emergency medical services, strapped down in a gurney, crying, and pleading, “Someone wake me up from this nightmare. Where am I? Please call my wife.” Multiple nurses, none of whom seemed particularly busy, just walked by and failed to respond to Steve’s distress. As the couple waited together for the next 90 minutes, Kay used techniques she’s been fortunate enough to learn to start calming Steve and eventually got permission to untie his restraints. When the medical doctor arrived, she completed a standard physical exam and showed no concern for the reason Steve had been brought to the hospital. Instead, she made small talk, noting that Steve has “great legs,” as Kay recalls. Once Steve was medically cleared, they waited another 30 minutes to be seen by a psychiatrist, who asked no questions related to Steve’s earlier suicidal ideation or the reason for his being at...
the emergency room. As a nurse, Kay asked the psychiatrist about giving Steve an appropriate medication to help reduce his anxiety, but the doctor refused, explaining that he couldn’t do so because he’s not a neurologist. Finally, after being cleared psychiatrically as well as medically, Steve was released. After the incident, Steve and Kay contacted his neurologist to obtain a prescription for any future crisis moments, but not because they were ever advised to do so at the hospital.

As a result of this incident, Steve and Kay have become advocates to improve the care of people with Alzheimer’s disease within the health care system. In Steve’s words, “I want a standard protocol for treating Alzheimer’s disease patients as real people. People have an atypical view of what Alzheimer’s is – treat you totally differently and it diminishes who you are as a person.”

**WHAT REAL-LIFE STORIES REVEAL**
The real-life stories recounted here clearly reveal the inadequacy of California’s health care and social service system to address the complex and intertwining medical, mental health, social service, and long-term care needs of people with Alzheimer’s disease and other dementias. Key takeaways from the stories include:

- In each case, multiple factors – including socioeconomic status, family dynamics, lack of knowledge and skills needed to support and treat people with dementia among both emergency responders and health care professionals, insufficient long-term care facilities, and, of particular concern here, eligibility for mental health services – converge and contribute to negative outcomes.
- Significant human and financial resources are spent on NOT treating behavioral and psychological symptoms of dementia, escalating costs. For example, in the majority of cases shared for this report, individuals with dementia were placed in a higher-than-needed-level of care, such as in the hospital rather than a skilled nursing facility, or in a skilled nursing facility rather than a residential care facility, simply based on what is available and reimbursable.
- Abandonment by caregivers is forcing the system to provide limited mental health interventions to allow transition from emergency psychiatric services to either the acute care hospital or a skilled nursing facility.
- Identification of people with Alzheimer’s disease or another dementia early by primary care physicians with the knowledge and skills to treat them medically and facilitate referral to home- and community-based services that could prevent crises and enable families to continue care is critical.
- Emergency responders and professionals across the health care continuum need education about responding to and treating the behavioral and psychological symptoms of dementia. Most importantly, education should address the inappropriate nihilism expressed by a marriage and family therapist within a Southern California mental health plan, who asked, “Well, what can you do anyway? You can’t take dementia away.”
OPPORTUNITIES FOR IMPROVED ACCESS
AREAS FOR EXPLORATION BY THE CHHS ALZHEIMER’S DISEASE AND RELATED DISORDERS ADVISORY COMMITTEE

1. Articulate overarching statewide Medi-Cal policy irrespective of delivery model and communicate this to the health plans, counties and beneficiaries, thereby clarifying eligibility criteria, especially for crisis mental health services.

2. Access data from the Coordinated Care Initiative (CCI) to identify utilization trends based on diagnostic codes and advise CCI contracted plans; include strategies – such as use of screening tools for early identification and training to facilitate referrals to available resources – to remove barriers to access. The California Department of Aging’s federal Alzheimer’s Disease Supportive Services Program grant is a best practice in this regard.

3. Seize opportunities within the current RFAs for the Medi-Cal Health Homes program and Whole Person Care regional pilots. Both waiver programs offer additional resources to better integrate and serve the population described in this paper.

4. Revisit the Universal Home- and Community-Based Services (HCBS) Assessment Tool process still underway to determine if it adequately addresses the mental health needs of older adults, particularly those with Alzheimer’s disease or another dementia.

5. Engage leadership on the Mental Health Services Act to access Proposition 63 dollars to pilot new models of care for older adults with dementia in need of mental health services.

6. Foster joint planning and an active partnership between the Department of Health Care Services and the Department of Public Health to educate health care professionals and increase public awareness of the mental health needs of older adults, as outlined in the Mental Health and Wellbeing section of California’s Wellness Plan (California Department of Public Health, 2014, pp. 44-45).

7. Reinvest in the California Department of Aging’s successful Alzheimer’s Day Care Resource Center (ADCRC) model of care as an effective preventive service to manage challenging behavioral and psychological symptoms, and reduce escalation to crises.

8. Expand Community Based Adult Services (CBAS) sites and ensure adequate Medi-Cal rates to provide interdisciplinary, supervised care to this population.

9. Open dialogue with the Office of Statewide Health Planning and Development (OSHPD) about workforce opportunities to expand capacity and competency in geriatrics and mental health, two persistently underserved areas.

10. Collaborate with the California Medical Board to promote statutorily mandated Continuing Medical Education (CME) on geriatrics for physicians whose practices include a high percentage of older adults.
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October 31, 2018

Mr. Lloyd Dean, MA
President and Chief Executive Officer
Dignity Health
California Future Health Workforce Commission
185 Berry Street, Suite 300
San Francisco, CA 94107

Dear Mr. Dean:

Over the last twenty years we have heard, read and experienced the shortages of the physician workforce in California and the nation. Factors related to an aging physician workforce have exacerbated these shortages as our physicians get older, or retire earlier than expected. Also contributing to the shortage is "burn-out" and its impact on the longevity of the physician's career, productivity, and quality of care. Despite the fact that we have been dealing with doctor shortages in this state and country for decades, the ever-worsening shortage comes at a time when expectations for higher health care coverage and services are more significant than ever before, coverage has expanded, and access to health care has a higher priority in the lives of a significant majority of Americans.

A significant reality that has been ignored, over the many decades of shortages, are the linguistic and culturally diverse demographics that add to the complexity of providing the necessary access to health care services. Of particular concern has been the ever-constant challenge and structural problem of the doctor shortage in rural areas throughout the nation, especially in California.

These factors and trends were present decades before the debate on the Affordable Care Act (ACA) began. The ACA has now brought even more light on these problems which have only gotten worse. While some in our news media and academic institutions have reported on the severe barriers to health access, these realities have taken secondary importance during the ACA's operation. They have not been part of any substantive policy discussions in the California legislature nor in the one-sided deliberations in both houses of the US Congress throughout the high drama on the repeal and replace of the ACA. In essence, the debate around the ACA has not effectively included how the doctor shortage undermines the priority of creating greater access to medical care!

The lack of primary care providers and medical specialists, especially in rural and agricultural producing regions in California and the nation have been more a "talking point" than a policy priority. In California, there are currently 607 federally designated Health Professional Shortage Areas (HPSA). The preferred ratio of primary care physicians to population is 1,041 to 1. The only counties in California that meet this ratio is Orange, Sacramento and the Greater Bay Area region! When we examine this ratio in counties in California's central and coastal valleys and the
north, the ratios often are twice the preferred ratio. Access to medical specialists is significantly higher in these regions. While there is no doubt having more individuals covered under Medi-Cal and the ACA is a vast improvement, we cannot ignore the reality that many of these new patients with insurance continue to go without a primary care doctor and appropriate access to specialists.

Not only has the challenge of access to preventive primary health care services become worse, but we must also confront that policymakers and medical schools' response to this severe structural problem have been ineffective and misguided. We have seen the creation of programs in medically underserved regions of the state with the intent of having resident physicians train and then practice in these communities. The success of these programs has been minimal in effectively addressing the shortage of doctors in rural communities. A glaring weakness by policymakers and medical schools has been the failure to alter their curriculums to prepare the future physician workforce to handle the cultural and linguistic realities of a significant percentage of the California patients that has been growing since the mid-1990's. These realities have placed enormous pressures on physicians to be able to communicate effectively in the language and with knowledge of the cultural beliefs of the diversity of patients that were not present in California while the current physician workforce was in medical school. This diversity is not a challenge relegated only to patients from outside of the U.S. with different language and culture. We must recognize that advocates for gay, disabled and transgender communities have underscored this concern of poor communication and a disconnect with many in the medical profession.

**Studies Underscoring Physician "Burn-Out," Doctor Shortages, and Lack of Diversity**

These severe structural problems have existed for several decades, and they have had a profound impact on the health delivery system of California and the nation.

The Journal of American Medical Association (JAMA) issued the results of an original investigation *Association of Clinical Specialty with Symptoms of Burnout and Career Choice Regret Among US Resident Physicians*. September 2018 concluded "Among US resident physicians, symptoms of burnout and career choice regret were prevalent, but varied substantially by clinical specialty. Further research is needed to better understand these differences and to address these issues."

The Doctors Company, a primary malpractice insurance entity in California conducted a national survey of physicians *The Future of Healthcare: A National Survey of Physicians*, September 2018, that among many other key findings, 54% of physicians conveyed their plan to retire within the next five years. Specifically, "Doctors are considering retirement as they feel the pressure of declining reimbursement, increased administrative burden, and industry consolidation."

The Commonwealth Fund just issued the consequences of these problems *From Last to First --- Could the U.S. Health Care System Become the Best in the World?*, published in the New England Journal of Medicine July 17. It compared the health care delivery systems in eleven nations. The key finding was that "... The US
ranked last on performance overall, and ranked last or near last on the Access, Administrative Efficiency, Equity, and Health Care Outcomes domains."

Those of us located and practicing in a rural/agricultural producing community have known of these barriers and problems for a very long time. While we cannot argue against the newly created access to health care brought about by the Affordable Care Act (ACA) and Medicaid expansion, many of our patients and others are still afflicted by the lack of primary care doctors and specialists in these communities. As I stated above, California only has three counties in the state that have the preferred population to primary care provider ratio of 1,041 to 1.

Reinforcing the poor access is the study, "A National Longitudinal Survey of Medical Students’ Intentions to Practice Among the Underserved", published in American Medicine July 2017 found that "...lack of formative education experiences may dissuade students from considering underserved practice." The study found that "...among fourth-year medical students, an estimated 34.3% had an intention to practice among the underserved." The reality is we have not seen over the last 20 years anything close to 34.3% of fourth-year medical students deciding to practice in medically underserved communities, especially in rural areas.

Speaking to the lack of diversity in culture and language in our physician workforce, was a research paper published in Academic Medicine Vol. 90, No. 7/July 2015 entitled "Latino Physicians in the United States, 1980-2010: A Thirty-Year Overview from the Census". This paper found that non-Hispanic white physician rate per 100,000 of the non-Hispanic white population increased from 211 in 1980 to 315 in 2010. In the case of the Latino population to Latino physicians, the rate dropped significantly from 135 to 105 per 100,000 Hispanics. It concluded that "The Latino physician shortage has worsened over the past 30 years. The authors recommend immediate action on the national and local level to increase the supply of Latino physicians". This lack of cultural and linguistic connection appears to manifest itself in the data that tells us that Latino patients who are limited English proficient make fewer office visits, while having a language connection has found that patients are less confused, frustrated, and "...language related poor-quality rating."

Furthermore, this research paper pointed out a growing trend that has been ignored over the last 30 years and what the Association of American Medical Colleges discussed in their Recent Studies and Reports on the Physician Shortage in the US that "...nearly every state is facing a physician shortage. Absent from these published concerns regarding the overall physician workforce has been any discussion of the Latino physician supply.

The growth of the healthcare industry has been a constant over the last seven years due to the ACA and the expansion of persons securing private and public health insurance. In March 2017 Goldman Sachs reported that because of the ACA 500,000 jobs were added to the health-care sector since 2012. Many of those jobs, unfortunately, did not include the appropriate increase in medical school admissions or creating the necessary residency slots in hospitals. Also not included was the development of new criteria for ensuring that federally designated Health Professional Shortage Areas (HPSA) would be targeted for placement of more
doctors or connecting the need for specific medical specialties to admission and training programs. Medical schools nationwide have not altered their curriculums to integrate cultural and linguistic competency (because of the growing diversity in the patient population) and creating initiatives to have medical schools be more inclusive of students from these communities that are recruited for admission to their institutions.

Certain aspects of these issues receive some public attention through discussion of workforce development in the health sector. Many articles appear in various medical publications and health policy arenas, but they do not and have not resulted in meaningful results that improved access to primary and specialty care in rural and agriculturally producing regions in California and throughout the nation.

**Public Policy Focus and Foundation**

Based on the personal experiences I had in deciding to become a doctor, in selecting obstetrics and gynecology as my specialty, in working in a community health center, serving as the CEO of the most extensive primary health care system in the County of Monterey, and constant never-ending challenge of confronting the severe doctor shortage in the service areas our clinics target and having to recruit doctors to practice in our system, I believe it is time that we concretely create public policy that directs comprehensive initiatives to bring about short and long-term solutions to reducing the doctor shortage in California (with particular emphasis on rural/agriculture communities) and developing a more culturally and linguistically competent healthcare workforce.

I am part of an effort that is drafting legislation that will focus on the policy foundation below:

1.) Have an ethnically and racially diverse physician community.
2.) Require that all medical schools ensure that physician candidates be culturally and linguistically competent, as defined in California law, and that this competency be directly linked to the diverse demographics of California.
3.) There shall be sufficient medical residencies in California targeted to California residents as candidates that shall practice in California and provide a sufficient number of physicians in all specialties necessary to provide effective access to health care.
4.) California shall ensure that the sufficient number of physicians educated at California universities, both public and private, be placed in communities federally designated as being medically underserved.

**Initiatives Designed to Implement and Accomplish Policy Objectives**

1.) Increase the number of students admitted to medical school and base that increase on the specific number of the medical specialties necessary to meet the current population to provider ratios in urban and rural communities in the state.

2.) Identify the cultural and linguistic profile of the patient populations that need having appropriate levels of access to primary and specialty care.
3.) Require medical schools to add to their curriculums requirements for language acquisition and knowledge of cultural beliefs and practices that would enhance the communication between doctors and their patients. These changes should not be limited to cultures of patients whose country of origin is outside the U.S only, but deals with sub-cultures of patients who are California and the U.S. born such as disabled, gay, and transgender patients.

4.) Identify the specific number of primary care and specialty doctors to eliminate/reduce the medically underserved areas in rural and urban communities in the state of California that are designated as shortage and medically underserved census tracts by the federal government.

5.) Create a track for medical school admissions of candidates who will be accepted based on their commitment and legal agreement to work in these specific medically underserved communities for no less than twelve years. Those candidates, agreeing to admission to medical school under this “track”, will have a portion (to be determined) of their medical school education costs covered by outside sources including private and public funds.

6.) Students choosing this track will all be required to have one of their school years designated "social service" where they will be assigned to work in private practice, hospital or community health center that is in a federally designated Medically Underserved Community, Medically Underserved Population, or Health Professional Shortage Area.

7.) California recognizes the physician shortage and the need for additional medical residencies. It is essential that more residencies are created to address the ever-increasing need for accessing medical care in the state. A new program would be developed to expand current residency programs or develop new residency programs to create another 750 residency positions by 2028. 200 new residency positions shall be in place by 2024 another 300 by 2026 and the final 200 new positions by 2028. This residency program would meet federal standards, and all other required professional and national standards for this residency program to be officially recognized.

8.) Extending the life of the Licensed Physicians and Dentists from Mexico Pilot Program (AB 1045/Chapter 1157) passed by the state legislature in August 2002 and signed by then-Governor Gray Davis September 2002. This pilot program allows board certified doctors from Mexico who meet other criteria and have various levels of oversight, to receive a three-year, non-renewable California medical license to practice in community health centers located in medically underserved and health professional shortage areas in rural/agricultural producing counties in California. This pilot program is for three years and the findings of the evaluation required under its enabling legislation shall determine whether it should be extended and whether any conditions or changes associated with its continuation. should be included. It will be extended until the other initiatives have taken hold and are increasing
the number of physicians working in federally designated medically underserved communities.

**Physicians from Mexico Pilot Program**

In the year 2000, the California Hispanic Health Care Association (CCHCA), Inc. a network of community health centers serving primarily rural/agricultural communities, drafted legislation AB 1045 (Firebaugh) to create a pilot program to allow 30 physicians from Mexico to practice in California under a three-year medical license. This legislation was supported by the Director of Health Care Services, Ms. Diane Bonta under the-Governor Gray Davis who signed the bill (Chapter 1157) in September 2002. From 2000 to 2002, representatives from each of the UC medical schools and the Deputy Chancellor for the University of California (UC) medical schools opposed this legislation. All argued that this legislation was not necessary since the UC system made many commitments, statements, and posturing about its commitment to recruiting more US-born minorities for medical school but did not propose any changes to its curriculum for acquiring cultural and linguistic competency.

This bill took 15 years to get to the point where we are 5 months away from submitting the visa applications to the US Citizenship and Immigration Service (USCIS). The reason for the delay was due to the continued opposition to this legislation and the reluctance of all UC medical schools including Loma Linda and USC to undertake the orientation curriculum that the Mexican doctors had to undertake before having a California medical license issued. We were finally able to secure the assistance of a medical facility with an approved residency program to agree to undertake the orientation program.

Throughout the debate on this legislation, the UC representatives consistently represented that not only was the pilot program unnecessary it was dangerous to allow non-US trained foreign doctors treat patients. The UC advocated that they were in the process of increasing their recruitment efforts of Latinos and other minorities and that AB 1045 would not be required. The study we have referenced above on Latino physicians confirms that in the year 2010, there were less US-born Latino physicians than there was in 1980. This was seven years after this legislation passed and the numbers have not improved from 2010 to 2017.

At least one member of the commission recently expressed the very same arguments about Mexican doctors that were made in 2000 at a hearing before a Senate Committee on AB 1045. This commissioner implied that doctors from Mexico required residency training in the US and should not be allowed to treat patients in California without additional training and education. However, this member, who is a physician in California has not introduced any public policy initiative that concretely has moved the needle to increase the number of physicians in the state who would have the necessary cultural and linguistic competency to work in the many medically underserved rural, urban and agricultural communities in the state.

AB 1045 requires all Mexican doctors to be board certified with a passing score equivalent to the scores posted by US-trained doctors passing board certification exams in the US. They must be enrolled in English Language classes before coming to California and during their three years in this program. The community health
centers that will employ them must be Joint Commission or NCQA accredited. They will go through the same process of being credentialed as US trained/licensed doctors in California. There will be an evaluation of how these doctors are performing their duties in these health centers. The physicians will participate in an externship program and have a third-party monitoring of their performance and outcomes. Lastly, they will be enrolled in continuing medical education (CME) and will obtain the required CME units annually as all physicians in California are required to meet.

In other words, the working environment, conditions, requirements, standards, and expectations are absolutely no different than a US-trained doctor, in fact, they will be monitored much more than any private practice physician has ever encountered.

Perhaps the most upsetting statements and tone we heard against AB 1045 from 2000 to 2002 and during the recent hearing in the Senate Committee, is the impression cast by the Commission member and the UC that they are more concerned than the community health center CEO’s, health center Board of Directors, Medical Directors, doctors, nurses and MA’s for the healthcare of the patients we serve and do not want to place their well-being in jeopardy.

Those of us who work in these health centers and communities have made a lifetime commitment to improving access, and healthcare outcomes of every patient served in our health centers. We are on the front line and have been so for decades. We have proposed policy initiatives to address the problems we did not create but have had to deal with while increasing access and ensuring that the best possible outcomes and measures are applied to working poor communities.

We are proposing that the current pilot program be extended another five cycles (each for three years) and that the number of Mexican doctors increases up to 200. This would serve as a temporary initiative until the structural improvements and expansion efforts are undertaken. This proposed expansion of this program will only take place if the program evaluation justifies its extension.

**CONCLUSION**

Based on more than 50 years of analysis, research and policy discussions on doctor shortages in rural areas, I am convinced that we have largely failed to develop concrete policy and programmatic paths to reduce and correct this shortage institutionally. In the process, the medical profession and academia are now confronted by challenges that have made the doctor shortage even more complicated to address. We now must confront and overcome the barriers to health care access that have been created by the lack of cultural and linguistic competency to effectively deal with the patient population diversity that has developed over these years. We must integrate the medical profession in a responsible manner that does not compromise the required standards for providing the highest level of care, and recognizes that our patients and their expectations and needs have changed on many levels. The expansion of the private insurance market by the ACA and Medicaid (Medi-Cal) has brought into systems of care populations that have not had a doctor or on-going access in communities that have long been underserved and unserved.
profession, and healthcare policymakers. We have no choice but to be bold, creative and disciplined in having a short and long-term approach for resolving these severe and life-threatening barriers. Being a doctor requires us to lead on these issues, and that is the role we must take.

Respectfully submitted,

Dr. Maximiliano Cuevas
Chief Executive Officer

Aurelio Gonzales
Board President
December 14, 2018

California Future Health Workforce Commission
c/o Public Health Institute
555 12th Street, 10th Floor
Oakland, CA 94607
Attn: Kevin Barnett, DrPH, MCP; Jeffrey Oxendine, MBA, MPH
VIA ELECTRONIC MAIL to: kevinph@pacbell.net; oxendine@berkeley.edu

RE: “Meeting the Demand for Health” – Final Report of the California Future Health Workforce Commission

Dear Commissioners;

The California Nurses Association/National Nurses United (CNA) representing more than 100,000 registered nurses appreciates the opportunity to comment on the draft “Meeting the Demand for Health,” the final report of the California Future Health Workforce Commission (“Commission”).

- **CNA Requests Important Information to be Included in Appendices**

As an initial matter, CNA respectfully requests that the Commission include in Appendices to the final report the following: (1) copies of all written comments received on the draft final report; and (2) complete copies of the Impact Assessments performed on each recommendation. While there is discussion in the final report and Appendix A of each recommendation, it would be helpful for policymakers, the public, and other stakeholders to understand the full panoply of issues that may surround each recommendation. Similarly, Appendix A contains only excerpts from each Impact Assessment, but not the complete Assessment. It would likewise be helpful if the complete analysis were made available so that policymakers, the public, and other stakeholders best understand the impacts of each recommendation.

- **CNA Supportive of the Use of Public Funds for Scholarships and Loan Repayment Where Funds Are Used for Direct Support of Students**

CNA supports the use of public funds to create scholarships and forgivable student loans for primary care and behavioral health professional providers who agree to work in medically underserved areas of California. However, many of the proposals focus on study process expansion, problem assessment, and oversight costs rather than direct support of students in the health professions. A direct connection between scholarship/loan support for a racially and
ethically diverse group of students and service to medically underserved areas of California is a critical element in meeting the needs of underserved populations. We believe recruiting and supporting students from underserved areas of medical needs could increase the number of healthcare providers who remain in these areas to serve community needs, as suggested in several proposals.

- **Recommendation 3.1 – Establish and Scale a Universal Home Care Worker Family of Jobs with Career Ladders and Associated Training**

CNA has a number of concerns about this draft proposal which would create a new universal home care worker (UHCW) job with a legislative strategy to “modernize the Nurse Practice Act.” First, CNA is concerned that this proposal will lower the standards of care for the minority of clients/patients actually requiring registered nurse (RN) oversight in the home setting and increase costs for those who do not require the professional services of an RN. The proposal fails to acknowledge that services provided in the home setting are provided under different funding streams, different regulatory standards, and for different purposes.

Under the premise of standardizing the existing care available to the elderly through licensed Home Health Agencies, Licensed Home Care Organizations (HCOs), Independent Home Care Aides (HCAs), and county-provided In-Home Supportive Services (IHSS), CNA worries this proposal will simply lead to greater profits within the home care industry at the expense of clients/patients and the UHCWs themselves.

According to a 2013 UCLA report, *Home Care Quality and Safety: A Profile of Home Care Providers in California*, 88% of home care agencies were for-profit (investor owned). The report stated:

> Individual providers in California are frequently low-income individuals, with personal care aides and home health aides earning about 10 dollars per hour and nursing aides earning wages of about 13 dollars per hour in 2011. The wages for these workers declined slightly from 11 dollars for personal care aides since 2001, but increased since 2001 to 12 dollars for nursing aides. Approximately half of these workers rely on means-tested public assistance, including Medi-Cal and food and nutrition programs.

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6. Id. at 34.
According to the Paraprofessional Health Institute, California unlicensed care givers have only seen an average 2% wage increase over the past decade from 2006 to 2016 (Table 1.).

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</thead>
<tbody>
<tr>
<td>Personal Care Aides</td>
<td>$11.18</td>
<td>$11.17</td>
<td>$11.12</td>
<td>$10.77</td>
<td>$10.64</td>
<td>$10.43</td>
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<td>$10.56</td>
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<td>Home Health Aides</td>
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<td>$11.01</td>
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<td>$10.86</td>
<td>$11.30</td>
<td>$11.00</td>
<td>$11.52</td>
<td>$11.72</td>
<td>$0.73</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$12.29</td>
<td>$12.35</td>
<td>$12.46</td>
<td>$12.42</td>
<td>$12.20</td>
<td>$12.08</td>
<td>$11.83</td>
<td>$12.06</td>
<td>$12.49</td>
<td>$0.20</td>
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Because the Commission has no control over wages and benefits for these home care workers, it is not likely that this proposal will actually result in better wages and benefits. Past experiences with the for-profit healthcare industry should clearly demonstrate that investors are more interested in profits than in paying a living wage and benefits to their employees. Increased reimbursement will only result in increased profits for this largely for-profit industry. In addition, injecting professional nursing care into social services that are currently overseen by social workers can hardly be argued as a cost savings for consumers who must pay for these home care services out-of-pocket.

The problem with high turnover and burnout of low paid employees in home care is similar to the high turnover challenges in the long term care industry. The sponsors of AB 2850 (Rubio, 2018) cited these challenges in support of their recent legislation which would have created a new category of healthcare worker, “geriatric medication technicians.” Based on CNA’s strenuous objections to this proposal, the author and her sponsors deleted these provisions and instead addressed online training requirements.

The Journal of Nursing Regulation (JNR) reported in 2011 on a survey of states using medication technicians for the administration of medication in long term care facilities, finding:

A survey was developed with the goal of providing insight into the work settings, education, supervision, and work roles of medication aides. Results ... included

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9 Thomason, Sarah and Bernhardt, Annette, California’s Homecare Crisis: Raising Wages is Key to the Solution, Center for Labor Research and Education at UC Berkeley, November 2017, at 9.
46% of respondents reporting that medication aide training needed to be more challenging and 8% reporting they had no supervision. Of medication aides who had supervision, 19% said their supervisor was never on site. When asked about work roles, 21% said they were not given a job description that addressed the scope of their duties, 33% needed more information about their authorized duties, and 21% thought some of the tasks that they performed were beyond their scope. In terms of job duties, 29% indicated they were allowed to administer injectable medications, 80% were allowed to administer the first dose of a new medication, 67% were allowed to administer prn medication without an assessment by a licensed nurse, 49% were allowed to administer medications when the patient’s condition was unstable or had changing nursing needs, and 59% were allowed to crush medications without authorization by a licensed nurse.¹⁰

If this information is not sufficiently alarming, it is noteworthy that the three states with the most medication technicians, Maryland, Nebraska, and Texas had frighteningly high increases in the percentage of CMS survey deficiencies resulting in actual harm or immediate jeopardy to residents between 2010 and 2014, a period that covers the time of the survey (see Table 2). However well-intentioned the Commission may be, the reality shown in the long term care survey data is that there is an enormous gulf between regulation and practice which threatens patients’ safety in those states that approved the use of medication technician.

### Table 2.

<table>
<thead>
<tr>
<th>Medication Aides¹¹</th>
<th>All Facilities Changes in % of Deficiencies of Actual Harm or Immediate Jeopardy to Residents 2010-2014¹²</th>
<th>For-Profit Changes in % of Deficiencies of Actual Harm or Immediate Jeopardy to Residents 2010-2014¹³</th>
<th>Non-Profit Changes in % of Deficiencies of Actual Harm or Immediate Jeopardy to Residents 2010-2014¹⁴</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>0</td>
<td>-9.1%</td>
<td>-10%</td>
</tr>
<tr>
<td>National Average</td>
<td>-16%</td>
<td>-17.1%</td>
<td>-15.8%</td>
</tr>
<tr>
<td>Maryland</td>
<td>68,479</td>
<td>+14%</td>
<td>+37.4%</td>
</tr>
<tr>
<td>Nebraska</td>
<td>18,555</td>
<td>-0.4%</td>
<td>+7.4</td>
</tr>
<tr>
<td>Texas</td>
<td>10,457</td>
<td>+3.5%</td>
<td>+13.1</td>
</tr>
</tbody>
</table>

These statistics are particularly troubling when looking at the for-profit facilities in Maryland, the state with the most medication technicians, since they demonstrated a hugely increased rate.

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¹¹ Id. at 6-7.
¹² CMS, *Nursing Home Data Compendium 2015*, Table 2.7f: Change in Percentage of Nursing Home Surveys Resulting in a Health Deficiency of Actual Harm or Immediate Jeopardy to Residents by Type of Ownership: United States, 2010-2014, at 97.
¹³ Id.
¹⁴ Id.
of the deficiencies when compared to the non-profit facilities in the same state. That is relevant to California since we have the second highest for-profit ownership of certified nursing facilities in the nation (84% in 2016), according to data on the website of the Kaiser Family Foundation (KFF). Only Oklahoma, at 87%, has a higher percentage of for-profit ownership of these facilities.

Under the current regulatory environment, the for-profit industry in California has seen a 10% decline (See Table 2) in actual harm and immediately jeopardy citations during 2010 to 2014, which is less than the national for-profit average of a 17.1% decline but 47.4 percentage points higher than Maryland (See Table 2) with the greatest number of medication aides in the nation, according to the JNR survey article. And, the non-profit facilities in California demonstrated a 52.1% decline in deficiencies which far exceeds the 15.8% national average decline in all non-profits.

These arguments are illustrative, and not exhaustive, with respect to the problems associated with the efforts of the healthcare industry to have unlicensed staff engage in licensed care activities. The JNR survey opined (but without evidence), “Studies indicate that medication aides can perform these responsibilities safely, if free from distractions and other responsibilities.” Immediately following that puzzling pronouncement, the article explains:

The data from the current study imply that a disparity exists between regulation and practice in many nursing homes, long-term care facilities, and other institutions. Medication aides reported being required to take on responsibilities beyond their defined role.

Finally, recommendation 3.1 (as well as the Commission’s final draft report) also contains several references to “value-based reimbursement” or “pay for performance.” It is worth noting that this payment model has been criticized. As an example, this article in the New England Journal of Medicine Catalyst states:

There are numerous criticisms and challenges when it comes to Pay for Performance models in healthcare. Studies and actual cases have indicated that they harm and reduce access for socioeconomically disadvantaged populations

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15 Herrington, Charlene, Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2016, Table 5 at 33.
16 Id.
17 The KFF data includes Government owned facilities but they are not included because Maryland did not have comparable data for Government owned facilities.
18 Budden, supra note 10, at 12.
19 Id.
because, despite risk adjustments, providers who treat a larger share of low-income patients will not perform as well on P4P measures and therefore are incentivized to avoid treating them. Poorer patients struggle to pay for medications, follow-up care, and transportation and often engage in behaviors or unhealthy coping mechanisms that are detrimental to their health. Pay for Performance systems also reduce job satisfaction and intrinsic motivation for clinicians and cause doctors and administrators to game the system.

Additionally, costly administrative systems must be deployed to gather and verify the necessary metrics data and the patchwork of P4P models creates a confusing collection of measures and requirements with which providers must contend. Moreover, clinicians may skew their treatment schemes excessively toward P4P processes and practices, and away from care optimized to meet individual patient needs. Lastly, but not all-inclusively, it is challenging to accurately attribute performance outcomes given that patients attain care from multiple providers.  

In sum, forewarned is forearmed, the wise saying goes, and CNA believes that the Commission should heed that warning and maintain the current workforce in order to protect California’s frail elderly from profit-seeking entities that have monopolized geriatric care in California long-term care facilities and home care services. Moreover, CNA does not believe that the solution to changing the low status and low pay of home care workers is to increase their workload. CNA would encourage the Commission to instead direct its efforts towards raising the mandatory minimum wage for unlicensed healthcare workers so that a level playing field would exist that would require every home care agency to provide a living wage for home care workers.

CNA will continue to vigorously advocate for the protection of safe patient care in California, and we would strongly oppose the creation of this new and unnecessary category of UHCW and any related modifications to the Nursing Practice Act.

- **Recommendation 3.4 – Scale the Engagement of Community Health Workers and Promotores**

While this draft proposal appears to be focused on certifying a comprehensive, standardized curriculum for training programs for community health workers (CHWs) and promotores, CNA cautions the Commission that certification of training programs could potentially lead to the creation of obstacles to employment. First, CHWs and promotores are used extensively throughout California, and there does not appear to be a problem with their use. Second, certification of training (and presumably requirements that CHWs/promotores complete that training) could invariably increase the costs to become a CHW/promotore and thus erect barriers

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to employment, especially without funding assistance. CNA has historically had concerns with proposals—such as certification of unlicensed professionals—which can result in increased costs and obstacles to employment.

Furthermore, although this draft proposal does not suggest certification of unlicensed persons, certification of training is a step in that direction, and CNA has historically had concerns when certification involves an expansion of the role of the unlicensed person into the practice of licensed professionals.

- Recommendation 2.10 – Expand the Role of the California Community Colleges System and New Online College in Training the Future Health Workforce

This recommendation contains the following Proposed Action: “Explore the need for and options for increasing production of Bachelor of Science in Nursing (BSN) graduates.” First, it is important to note that very few employers actually require that nurses be BSN-trained. Second, CNA believes strongly that public Associate Degree Nursing (ADN) programs are essential to maintaining a diverse RN workforce in California. Students enrolled in public ADN programs are more diverse, more often the first in their families to attend college, and more likely to be from under-represented/under-served communities than students enrolled in private nursing school programs.

As a result, CNA believes it is important to protect the value of the ADN. CNA values all nursing degrees, and we believe that ADN-educated nurses are just as equipped to provide safe and quality patient care. All pre-licensure nursing programs in California have the same curriculum requirements that must be fulfilled by students in order to qualify to sit for the NCLEX. ADN nurses currently comprise the bulk of nursing program graduates, as well as California’s nursing workforce. They are the nurses who are more likely to provide bedside care to patients.

Despite the importance of the ADN and the prevalence of ADN graduates in the workforce, CNA has seen hospitals unfairly favor graduates and students from BSN programs over ADN programs in their hiring, promotion, and other practices. For example, one hospital that announced its closure would only permit those RN employees who had BSNs to transfer to a sister facility, leaving ADN nurses with decades of experience out in the cold. In another case, a hospital would only provide clinical placement slots to students in BSN programs and not students in ADN programs. As a result, these public ADN students were targeted for elimination.

from clinical sites during a time in which private for-profit nursing programs had rapidly expanded their programs and been granted disproportionate access to the hospital’s clinical rotations.

CNA believes diverse clinical educational experiences that prepare students for safe practice are a public good that contributes to the proper preparation of the RN workforce. Direct patient care experience is a requirement of nursing education. Public ADN programs are being squeezed out of clinical spots, creating an existential threat to them. And, health facilities rely upon RNs who are prepared for practice upon graduation and who have gained diverse clinical competencies that prepare them for employment with mixed patient populations. Health facilities receive federal and state funding for healthcare services and have an obligation to advance the proper preparation of their own future RN workforce by providing rich clinical experiences to students in California nursing programs.

Moreover, requiring an RN to obtain a BSN can mean saddling her/him with burdensome loans, additional debt, and delayed entry into the workforce. This requirement creates an occupational barrier that threatens the ability of students from disadvantaged backgrounds to enter the middle class workforce. Public ADN programs are much less costly than private BSN programs: while public ADN programs cost approximately $7,000-8,000 for in-state residents,22 private BSN program costs can run as high as $143,718.23 Public ADN programs in particular help diversify the nursing workforce so that California’s RNs are more reflective of its healthcare consumers.

CNA would also support the elimination of barriers to education for ADN registered nurses who choose to obtain a BSN in California’s public CSU or UC system. It is important, however, to ensure that it is truly a choice for students as to whether they enroll in an ADN program or an ADN/BSN program. CNA would be concerned if changes in admission standards would essentially require students to agree to dual enrollment in a baccalaureate program while enrolled in an ADN program. For example, any proposal to encourage this educational progression should not result in preferential treatment for clinical spots. It would be problematic if only ADN students who are enrolled in a dual enrollment program (ADN/BSN) were to get clinical placement slots. If the only way that an ADN student can obtain the required clinical placement experience is to be enrolled in an ADN/BSN program, then that student really doesn’t have a choice as to whether to enroll in an ADN program or an ADN/BSN program. CNA believes firmly that students who are enrolled in ADN-only programs should not be discriminated against.

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22 http://www.chabotcollege.edu/nursing/registered-nurse-program/ and Merrit College 2017 ADN program handbook at 62.
for clinical placements. In addition, it is important to ensure that any proposals on this issue are not cost-prohibitive and do not result in a significantly longer time to obtain a BSN, thereby delaying an RN’s entry into the workforce.

- **Recommendation 3.7 – Establish a California Health Workforce Technology and Data Center to Support the Adoption of Technologies that Increase Access to Quality Care**

This recommendation, which would establish a California Health Workforce Technology and Data Center, notes that one of the phases of implementation would be to “advance virtual care as a standard of care” and “realize a systemwide transformation to a virtual care model.”

Regarding the increased use of telehealth, CNA has consistently opposed any and all technologies used to supplant, instead of supplement, the skilled judgment of health care providers in face-to-face encounters. CNA also opposes any or all forms of automation which replace health care professionals with technology or interfere with the face-to-face, hands on “therapeutic touch” by health care professionals. We are deeply concerned about how artificial intelligence, for example, is interfering with the nurse-patient relationship in significant ways, potentially with very negative implications for patient health outcomes. These areas of concern are closely related, since the work of RNs cannot be separated from the outcomes and experiences of their patients.

Thank you for your consideration of CNA’s perspective on these important issues.

Sincerely,

**CALIFORNIA NURSES ASSOCIATION**
**NATIONAL NURSES UNITED**

[Signature]

Stephanie Roberson
Director, Government Relations