Mental Health Services for Californians with Alzheimer's Disease

Prepared for the Alzheimer's Association
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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.

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.

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. A "triple-whammy," this complex stigma penetrates the entire health care system, creating barriers in attitude, perception, access, and treatment. Recognizing these multiple detrimental impacts on people with Alzheimer's disease, the California State Plan for Alzheimer's Disease set eliminating stigma as its highest priority.

Within this larger societal context, California's mental health system is perpetuating significant and unjust gaps in much-needed services for people with dementia. Currently, Medi-Cal managed care and county mental health plans share responsibility for providing mental health services. As described in this paper, Medi-Cal plans are responsible for serving persons who are classified as having mild-to-moderate impairment due to a mental health disorder under one definition of medical necessity, while county mental health plans are responsible for serving those with severe impairment (i.e., the seriously mentally ill) using a separate set of eligibility criteria as found in the California Code of Regulations, Title 9, 1830.205 and 1820.205. 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 inconsistently – 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).

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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, 2016; Zeller, 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.

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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.

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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).

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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.

Worsening behavior – that becomes intolerable and unmanageable for family caregivers – is a primary precipitant of placement.

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 – whether for lack of resources or lack of knowledge about dementia, or both – people with Alzheimer's disease are not receiving needed mental health services, as illustrated 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 pre-date 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 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 his wife 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, ineligibility 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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