California Health and Human Services Agency

Improving Access to Mental Health Services for Persons with Alzheimer's Disease And Related Disorders

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California Health and Human Service Agency
Long Term Care Council

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INTRODUCTION

Scope of the Issue

Two trends mark California's current demographic growth:

- The rapid aging of the population. Currently the state has 3.5 million residents over age 65--the largest older adult population in the nation. By 2010, this age group will likely reach 4.5 million by the year 2010, a 23% increase since 2000. The greatest current and projected growth is among those aged 85 and over.

- The growing racial and ethnic diversity. Already no single ethnic group represents the majority of the state's population. A quarter of the state's residents are immigrants. The state's aging population is becoming more diverse and by 2040, the majority of the state's older adults will be from groups now considered ethnic minorities.

Coronary heart disease, cancer, and stroke currently account for 61% of all deaths in California. While mortality rates from coronary heart disease and stroke have declined overall in California, cancer mortality has remained relatively constant. Alzheimer's disease (AD) and other dementias represent increasingly prevalent conditions among older adults. Approximately 10% of persons aged 65 or older and 47% of those 85 years and older have AD, the most prevalent form of dementia.[1] Recent research indicates that African Americans and Hispanic older adults are more likely to have AD.[2]

While significant advances have been made in diagnoses and standards of care, no treatment is currently available to prevent or reverse AD or other forms of dementia.

Until breakthroughs occur, an increasing number of older Californians will develop dementia and a growing proportion of our family and community resources will be required to address the needs of this subpopulation. In 2000, an estimated 500,000 Californians had AD. By 2040, 1 million older Californians will likely have the disease.[3]

While estimates range broadly, from a third to a half of persons with dementia also exhibit psychiatric symptoms or behavioral disturbances and disorders ranging from delusions to severe depression. An estimated 86% of individuals

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[1] Albert MS, Drachman DA. Alzheimer's disease: What is it, how many people have it, and why do we need to know? Neurology 2000;55:166-168.

[2] Hargrave R, Stoeklin M, Haan M, Reed B. Clinical aspects of Alzheimer's disease in black and white patients. Journal of the National Medical Association 1998;90:78-84.

[3] Fox P, Kohatsu N, Max W, Arnsberger P. Estimating the costs of caring for people with Alzheimer's disease in California. Journal of Public Health Policy, 2001;:22:88-97.

diagnosed with dementia may demonstrate aggressive behavior at some point as the disease progresses.

Dementia is a devastating condition, affecting not only the individual, but also his or her entire social network. The physical, emotional, and economic toll of providing care to persons with dementia is immense. When dementia is complicated by co-occurring mental disorders or severe behavioral changes, the potential for caregiver frustration, burnout and injury; abuse; use of physical restraints; and institutionalization are exacerbated**.**

Care for individuals suffering from AD and other dementias and co-occurring mental disorders has traditionally been provided by family members or in institutions. Current research indicates that multi-disciplinary effective treatments can positively impact the course of the illness and improve the quality of life for individuals, family-members and other involved caregivers.

Where individuals with dementia receive treatment should be determined by assessing what setting can provide safe and effective treatment in the least restrictive environment. Professionals and family caregivers must be vigilant in monitoring changes in symptoms and behavior so that if a co-occurring mental disorder complicates dementia care, a different level or type of intervention can be found.

Legislative Charge

SB 639 (Chapter 692 Statutes of 2001), authored by Senator Deborah Ortiz, was signed into law by the Governor in October 2001 and became effective January 1, 2002.

The statute requires the California Health and Human Services (CHHS) Agency to develop a strategic plan for improving access to mental health services for treatable mental health conditions in persons with AD or related disorders. The plan is to be completed and submitted to the Governor and the Legislature by January 1, 2003.

The legislation required that the plan developed include the consultation and collaboration of individuals and organizations that have specific expertise in addressing the unique needs of this population, including the Agency's Alzheimer’s Disease and Related Disorders Advisory Committee, the California Mental Health Planning Council, the State Department of Mental Health, the California Department of Aging, the State Department of Health Services, the California Mental Health Directors Association, and the California Council of the Alzheimer's Association.

Developing the Strategic Policy Report

To gain input from a broad spectrum of stakeholders, including experts in dementia and geriatric mental health, the CHHS Agency solicited three levels of participation in this report's development. Stakeholders were invited to participate in: (1) a structured telephone interview or e-mail survey to identify key issues; (2) written input and/or comment on the draft working paper; and (3) participation in four formal Taskforce meetings.

Purpose of the Report

In responding to the legislative mandate of SB 639, this document:

- Presents key issues and concepts pertaining to dementia, the prevalence of co-occurring behavioral disorders and co-occurring psychiatric disorders;
- Identifies barriers that prevent persons with dementia, and who demonstrate severe behavioral or mental disorders, from accessing and receiving appropriate services that would potentially ameliorate some of their symptoms; and
- Recommends potential actions to overcome these barriers.

The CHHS Agency appreciates the time and commitment Taskforce members contributed to the development of this report. The Agency would like to acknowledge that there was great interest among Taskforce members in expanding overall geriatric mental health services and developing/expanding an older adult system of mental health services. There is equal interest in expanding services to persons with dementia who do not have mental health or severe behavioral issues. The legal issues surrounding conservatorship and institutional levels of care for persons diagnosed only with dementia as well as those dually diagnosed with dementia and mental illness are another area of strong interest.

Given the limited resources available and the timeframe involved, this plan discusses these more generic issues only if they have a unique and particular impact on access to mental health services for persons with dementia and co-occurring mental illness. In addition, given the state's current fiscal condition, many of the report's recommendations should be viewed as long term strategies that may be embraced in future years when state revenues improve or private funding sources become available.

SECTION 1 - OVERVIEW

Dementia

As used in this report, the term "dementia" refers to a neurological syndrome involving progressive decline in memory and other intellectual abilities. Dementia

is a syndrome, not a specific disease. It is a pattern of symptoms that can be caused by many different illnesses. There are numerous diseases and other factors known to cause or aggravate dementia.

Three key features characterize dementia:

(1) It is acquired;
(2) It is persistent; and
(3) It involves multiple impairments of intellectual functioning and can affect a person's ability to perform daily personal care activities and the many other tasks required to maintain independence.[4]

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (1994) established three criteria in a dementia diagnosis:

- Memory impairment;
- Cognitive disturbances in at least one other area of functioning (e.g., aphasia, apraxia, agnosia, or a disturbance in executive functions), and
- These cognitive impairments are severe enough to interfere with social or occupational functioning.

Among older adults, more than half of those diagnosed with dementia are classified as having AD, based on pathological findings at autopsy.[5] The prevalence of dementia caused by vascular disease has been estimated to be between 5%-20% based on postmortem studies.[6] Approximately 18% of AD patients also show evidence of cerebrovascular disease, which is referred to as "mixed" dementia. Parkinson's disease, Pick's disease, Diffuse Lewy Body disease, normal pressure hydrocephalus, Creutzfeldt-Jakob disease, frontal lobe dementia, brain tumors, HIV, and nutritional deficiencies are also disorders that result in dementia.

The particular pattern of dementia symptoms varies depending on the portion of the brain most affected by the underlying disorders. Cortical dementias reflect dysfunction in the cerebral cortex and are characterized by deteriorating basic intellectual processes including memory, language, judgement, and visual spatial skills. Alzheimer's and Pick's Diseases are classic examples of cortical dementia. Subcortical dementias, such as Parkinson's and Huntington's diseases, typically include a slowing of the cognitive processes and memory and an inability to spontaneously recall or integrate information. Mood disturbances and motor

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[4] Cummings, JL and Benson, DF. *Dementia: A Clinical Approach, Second E*dition. Stoneham, MA: Butterworth-Heinemann. 1992.

[5] Mortimer, JA and Hutton, JT: Epidemilogy and Etiology of Alzheimer's Disease. In Hutton JT, Kenney AD (Eds.): *Senile Dementia of the Alzheimer's Type.* New York: Liss. 1985: 177-196.

[6] Cummings, JL: Organic Delusions: Phenomenology, Anatomical Correlations, and Review. British Journal of Psychiatry 1985; 146:184-197.

difficulties are also more common in subcortical dementias. Vascular dementia can affect both cortical and subcortical regions.[7]

Potentially Reversible Dementias

An important aspect of a dementia evaluation is to identify whether this is a potentially reversible dementia. Conditions, which may appear to be symptoms of dementia, include:

- Tumors: both in the brain and peripheral tissues
- Metabolic disorders: thyroid disease, electrolyte imbalance, renal or hepatic failure
- Head trauma
- Poisoning: heavy metals, alcoholism, solvents, and insecticides
- Brain infections
- Autoimmune disorders: brain vasculitis, lupus erythematosus, multiple sclerosis
- Adverse effects of drugs
- Nutritional disorders: deficiency of vitamins $B_{12,}$ $B_{6,}$ $B_{1,}$ and folate
- Psychiatric disorders
- Normal pressure hydrocephalus
- Acquired immunodeficiency syndrome encephalopathy[8]

Mental Disorders

The DSM IV is a classification of neurological and mental disorders that groups these disorders into types based on criteria sets with defining features. Not all diagnoses in DSM IV are necessarily mental disorders nor does DSM IV inclusion imply that all listed conditions will benefit from traditional psychiatric intervention (e.g. mental retardation, substance abuse disorders, and dementias).

The introductory section of DSM IV states that: "no definition adequately specifies precise boundaries for the concept of "mental disorder". This caveat is included to assist and guide clinical decision making with regards to conditions on the boundary between normality and pathology. Each mental disorder is conceptualized as a clinically significant behavioral or psychological syndrome or pattern that occurs in individuals and is not the secondary to a general medical condition or substance abuse disorder [underline added for emphasis]. In addition to the presence of symptoms, there must also be present distress (a painful symptom) or disability (impairment in an area of life functioning) or a

[7] Zarit SH, Zarit JM: *Mental disorders in older adults*: *Fundamentals of Assessment and Treatment*. New York: Guilford Press. 1998.
[8] Mahoney EK, Volicer L, Hurley AC. Management of challenging behaviors in dementia. Baltimore: Health Professionals Press, 2000.

significant increased risk of suffering pain, death, disability, or an important loss of freedom.
Within the DSM-IV categorization structure, "cognitive disorders" include deliria, dementias, and amnestic disorders due to general medical conditions.

Welfare and Institutions (W&I) Code Section 5600.3(b)(2) defines a "serious mental disorder" to mean "a mental disorder which is severe in degree and persistent in duration, which may cause behavioral functioning which interferes substantially with the primary activities of daily living, and which may result in an inability to maintain stable adjustment and independent functioning without treatment, support, and rehabilitation for a long or indefinite period of time. Serious mental disorders include, but are not limited to, schizophrenia, as well as major affective disorders or other severely disabling mental disorders."

That W&I Code Section continues, stating that: "this section shall not be construed to exclude persons with a serious mental disorder and a diagnosis of substance abuse, developmental disability, or other physical or mental disorder."

Dementia and Co-occurring Mental Disorders[9]

Cummings and Coffey have noted that "AD and Parkinson's disease are examples of disorders traditionally considered as "neurological," whereas depression and obsessive-compulsive disorder have been thought of as "psychiatric." Neither of these assumptions proves to be true from the perspective of geriatric neuropsychiatry. AD and Parkinson's disease both have major behavioral manifestations, whereas depression and obsessive-compulsive disorder are increasingly well understood as brain disorders. It is ever more evident that designating disorders as "neurological" or "psychiatric"--although convenient for some administrative purposes--is arbitrary and may be misleading."[10]

For example, even though "the pattern of dementia is cortical in AD and subcortical in the dementia syndrome of depression, it can be impossible to distinguish one from the other clinically, and depression can aggravate the dementia in AD.[11] The delusions associated with AD are also often impossible to distinguish from that of organic or idiopathic disorders.

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[9] The presence of psychiatric symptoms alone does not necessarily warrant a secondary diagnosis of a co-occurring mental disorder. The DSM IV specifies that in diagnosing a co-occurring disorder, the professional must distinguish whether the symptoms are not better explained as the result of a medical or neurological disorder.

[10] Cummings JL, Coffey: Geriatric Neuropsychiatry. In Cummings JL, Coffey (Eds.): *Textbook of Geriatric Neuropsychiatry, Second Edition*. Washington, DC: American Psychiatric Press, 2000: 3-17.

[11] Dubovsky SL, Buzan R: Mood disorders. In Hales RE, Yudofsky SC, Talbott JA (Eds.): *The American Psychiatric Press Textbook of Psychiatry, Third Edition*. Baltimore, MD: American Psychiatric Press, Inc. 1999: 479-566.

Psychiatric disorders, including severe behavioral disturbances such as agitation, severe depression, delusions, hallucinations, and sleep disorders are quite typical in persons with dementia.

Among persons with dementia, an estimated 5%-20% have hallucinations, while 13%-33% have delusions.[12] An estimated 50% of persons with AD meet the criteria for major depression or dysthymia.[13] Depression is also extremely common in persons with vascular dementia.

The behavioral manifestations of depression in persons with dementia include restlessness, agitation, repetitive vocalization, irritability, and combative behavior. As dementia progresses, individuals may be less able to express their feelings of depression verbally. However, the depression may increasingly be expressed non-verbally through behavior and vegetative symptoms.

The most extreme form of functional impairment related to depression in persons with dementia is called "cocooning." Cocooning, a form of neurovegetative behavior, appears as the withdrawal from, or lack of interaction with, the environment. Symptoms may include refusing food and sleep abnormalities. While clinicians and family members may believe that this state of "cocooning" is the result of AD, it may be the result of profound depression. Researchers have noted that with the treatment of depression, functional ability, affective states, and cognitive capacity may also improve.

Behavioral Symptoms

Behavioral symptoms become problematic when they cause the individual significant distress, have the potential to cause loss of functional capacity or create a risk of harm to the individual or others. Behavior that is unusual, threatening or a nuisance often distresses families and care staff. Severe behavioral problems may exacerbate family caregiver burnout and/or lead to institutional placement.

Challenging behaviors have differing causes, emerging at different points in the disease process and take on a variety of manifestations. Problems may include anxiety, insomnia, wandering, and agitation.

Among persons with AD, agitation is even more common than depression. Agitation includes:

[12] Cummings JL. Dementia syndromes: Neurobehavioral and neuropsychiatric features. Journal of Clinical Psychiatry 1987;48(5 Suppl.):3-8.
[13] Pettracca G, Teson A, Chemerinski E: A double-blind placebo-controlled study of clomipramine in depressed patients with Alzheimer's disease. Journal of Neuropsychiatric Clinical Neuroscience. 1996; 8:270-275.

- Aggressive Behavior--including kicking, hitting, pushing, scratching, grabbing, and cursing;
- Physically Nonaggressive Behavior--including pacing, inappropriate robing and disrobing, repetitious sentences or questions; repetitious mannerisms; trying to get to a different place; handling things inappropriately, and a general restlessness;
- Verbally Agitated Behavior--including constant requests for attention, screaming, complaining, noise making and negativism (Kane, 103)

Treatment Interventions

In the past several decades, progress in both clinical and basic research has advanced our understanding of dementia. Although many dementias cannot yet be reversed, pharmacological advances now make it possible to slow the progression of AD and other drugs have been found effective in addressing co-occurring mental disorders. Persons with dementia exhibit specific behaviors based in part on how people respond to them and how their environment is structured. Those interactions and environments can be restructured to be more supportive.[14]

"Viewing the behavior of dementia patients as the outcome of an interaction creates the possibility for many types of intervention. Sometimes it is possible to intervene directly with the patient, for example, by using medications or even psychological interventions. More often, we can change how other people respond to the patient or make alterations in the environment that lead to better functioning. The main goal is to identify treatable or modifiable aspects of the situation."[15] Potential interventions include medications,[16] cognitive stimulation, and counseling with individuals and/or families.

For individuals with dementia and co-occurring medical disorders, a multi-disciplinary approach to treatment is appropriate, including neurological, medical, and psychiatric intervention as necessary. Ongoing thorough assessment is necessary to differentiate which symptoms are best managed by medical doctors and which are amenable to mental health intervention.

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[14] Zarit SH, Zarit JM: *Mental disorders in older adults*: *Fundamentals of Assessment and Treatment*. New York: Guilford Press. 1998.

[15] Ibid., p. 279.

[16] Medications for dementia can be divided into two broad categories: one to treat the underlying disease and those that treat associated mental health or behavioral problems. The former include cholinase inhibitors that attempt to partially regain lost function and/or delay the disease's progression. The latter includes neuroleptics, which treat agitation, aggressive behavior, restlessness, hallucinations, and delusions. Antidepressants, mood stabilizers and even beta blockers are successfully being used to treat behavioral disturbances. These newer neuroleptic drugs have very mild side effects compared to those that were prescribed 20 years ago.

The Guidelines for Alzheimer's disease Management identifies the following key steps in assessing and treating persons suspected to have AD:

- To facilitate an early intervention, health care professionals must distinguish the symptoms of dementia from delirium and depression.
- A key primary care physician (PCP) assessment goal should include recognizing depression as a treatable disorder.
- Consultation with and/or referral to a specialist (e.g. psychiatrist) is warranted if the presentation or history of depression is atypical or complex.
- Early stage depression should always be treated to alleviate additional confusion and feelings of helplessness.
- With or without efficacious drugs for treating the illness itself, the PCP should educate caregivers that there are steps that can be taken to manage the AD patient's mental symptoms.

Expanding Care Options

In the decades prior to the 1960's, fewer individuals than today live very long with dementia. Persons with dementia and**/**or psychiatric conditions were routinely committed to institutions. With the advent of the deinstitutionalization movement, home and community-based services have developed for various segments of the long-term care population. Families provide much of that care. In-home and day care services also provide assistance. That this report focuses on how to maintain persons with dementia and psychiatric/severe behavioral symptoms in a continuum of settings speaks to how far we have progressed. The recommendations identified in this report provide direction for continuing this progress.

Key Role of Primary Care Physicians

The SB 639 Taskforce meetings included focusing on how difficult it is for an individual to navigate the health care system in order to address dementia and other health issues as well as the mental health system if they have a co-occurring mental disorder.

Some Taskforce members felt that in order to simplify the process and increase access to mental health intervention the best strategy is to increase the skills of primary care doctors and medical specialists so that they can better identify and treat coexisting mental disorders and understand when to seek a psychiatric consultation.

The majority of older people who receive mental health services obtain them as a result of a primary care physician visit. So this approach is based on how families currently seek assistance when they recognize a health, functional or behavioral change. Especially given the significant projected growth of the

geriatric population that will develop dementia and a coexisting psychiatric disorder, this strategy emphasizes enhancing the role of the primary care practice. The growing shortage of mental health clinicians and the desire to provide care in a more holistic way also supports this approach.

However, primary care physicians generally receive very little geriatric or mental health training in assessing and treating dementia and psychiatric conditions. Many treatable health and mental health conditions are misdiagnosed as "early Alzheimer's" and many dementias are not recognized early on by primary care physicians. A recent study of 250 primary care physicians found that only half of the physicians surveyed believed that their colleagues can adequately treat a number of common geriatric conditions, including memory loss.[17]

An alternative strategy is to train primary care physicians to identify and refer patients to mental health specialists for treatment of their psychiatric or behavioral condition. The rationale for this approach is the belief that most primary care physicians will not have the necessary time with patients to develop the clinical skills required to provide appropriate geropsychiatric care.

The lack of consensus among Taskforce members reflects the divergent opinions of clinicians, researchers and policymakers on the appropriate role for primary care physicians. But adherents of both perspectives are in agreement that in order to address the needs of a growing aging population, primary care physicians need additional training to make a correct dementia diagnosis and, at a minimum, to determine whether a referral to a mental health specialist is appropriate. Opportunities should also be developed for primary care physicians to consult with mental health specialists in making a diagnosis, prescribing neuroleptic medications, and in providing on–going treatment.

Emerging Collaborative Models

In many parts of the state, counties, local agencies, and providers have or are developing collaborative models to address the issues summarized in the following sections.

In the process of developing this plan, the Taskforce became aware of some of these innovative approaches. Several of these are discussed in Appendix 3. Several counties discussed have made innovative service delivery changes without additional funding by pooling funding across departments.

However, no clearinghouse or network for the sharing of these practices or expanding them based upon the lessons learned currently exists. Nor is there a

[17] Barry, P (March 26 2002) Doctors Need More Information on Treating Older Americans. Merck Institute of Aging and Health. retrieved December 5, 2002, from http://www.miahonline.org/resources/survey/content.

network that would encourage and assist counties that have not developed these strategies to do so.

SECTION II—FIVE KEY ISSUES

Improving access to mental health services for persons with dementia is a complex topic. The interaction between service providers, funding streams, and care facility and service licensure categories is not simple. In examining these issues, it is challenging to isolate particular aspects of the barriers because so many factors are interactive and shape each other. For example, financing mechanisms certainly shape service delivery options. The perceived efficacy of mental health treatment for older persons and/or persons with dementia also shapes the financing structure.

That said, our research identified five main clusters of issues that specifically impede access to mental health services for persons with dementia. These issue areas include the following:

- Stigma associated with seeking mental health services and/or dementia services, including caregiver/family perceptions**.**

- Difficulty in distinguishing treatable behavioral issues or psychiatric conditions from the dementia. Families, service providers, and many "front line responders" may not have the skills required to distinguish whether behavioral issues would benefit from mental health services. This may cause delays in or a failure to access needed care in a timely manner**.**

- Reimbursement incentives. Reimbursement mechanisms do not equitably cover services for individuals diagnosed with dementia and co-occurring mental disorders or do not adjust for the more intensive staffing ratios, skills, and environmental factors required to appropriately care for persons who have dementia and co-occurring mental disorders. This limits access to appropriate mental health interventions and/or provider willingness to serve this segment of population.

- Continuum of appropriate services and care settings. Identifying the appropriate service or the most appropriate care settings for some individuals who have dementia and co-occurring mental disorders, and who may also exhibit or develop severe behavioral conditions can be challenging, particularly if the individual exhibits uncontrollable aggressive behavior which creates a liability risk for the provider.

- Involuntary treatment issues. If an individual appears to lack the capacity to agree to treatment but is still deemed competent by a professional with the authority and training to make that decision, the individual may refuse treatment. If they refuse treatment as a result of their dementia and/or a mental illness, providers and caregivers often have very few viable options for getting a person into treatment.

Key Issue 1 Reduce stigma associated with seeking help.

Particularly for older adults, considerable stigma is still attached to seeking mental health services. As a result, many older adults are reluctant or refuse to accept services that could significantly improve the quality of their life. When an individual begins to exhibit symptoms of cognitive decline, he or she may be ashamed or embarrassed by their inability and seek to hide this condition from family. Family members frequently do not want to acknowledge the cognitive loss that they see. They, too, may be embarrassed that this is happening to their loved one; do not realize that there are now interventions that may help delay the dementia's progress if diagnosed early enough; be unaware that options are available for the treatment of both dementia and co-occurring mental disorders; and may not know where to turn for assistance.

The stigma associated with dementia or mental health symptoms is linked to cultural beliefs and values. California's older population is increasingly non-white. Minorities age 60 and over will increase by 350 percent between 2000 and 2040. Limited understanding of these illnesses and symptoms, access to information and resources, availability of culturally appropriate services, and comprehensive health insurance often create barriers for minority or immigrant families in understanding the cause of a loved one's behavior and in accessing needed services.

As noted earlier in the report, the recommendations that follow should be viewed as long-term strategies and not as an implementation plan.

Key Issue 1 Reduce stigma associated with seeking help

Recommendation 1A: Campaign to combat the stigma associated with seeking dementia and/or mental health treatment.

Strategies: Piggyback on the Campaign for Mental Health and National Association for the Mentally Ill (NAMI), at the federal level, in addressing the stigma associated with seeking mental health services.

Recommendation 1B: Provide more community outreach and information to help people understand the symptoms and behavior associated with dementia and co-occurring psychiatric conditions. Address family member concerns that they may also develop this condition.

Strategies: Develop and implement an outreach plan, if and when, resources become available.

Recommendation 1C: Strengthen information and referral system so that clients/family caregivers are linked to information and services.

Strategies: Develop and implement a plan to educate medical professionals regarding options to which they can refer clients and families, if and when, resources become available.

Key Issue 2 Skill building for appropriate diagnosis and treatment

In some individuals, dementia follows the "classic" progression of symptoms without development of a co-occurring psychiatric condition. In this circumstance, the initial diagnosis is not too challenging. In other individuals, both dementia and co-occurring mental disorders may appear suddenly. Individuals who have had a history of mental illness may also begin to exhibit symptoms of cognitive decline related to dementia as they age.

Particularly in crisis situations, it can be very difficult for treatment providers to diagnose whether the individual is suffering from an exacerbation of their dementia symptoms or from a psychiatric disorder. Since the individual may not be able to verbally communicate what he or she is feeling or provide much medical history, the diagnostic evaluation may take longer and be more complicated.

Families receive very limited training or support in caring for a family member diagnosed with either or both dementia and mental illness. As a result, if behavioral symptoms change significantly, they may accept this as just the progression of the dementia.

Family caregivers are frequently so stressed just trying to provide care from day-to-day that they do not know how to pursue obtaining mental health services for their family member or they do not have the energy to pursue the authorizations, appeals, etc. that may be required to obtain services. There are no specific mental health advocacy groups or ombudsmen that families can call for help in learning how to "work" the system.

Caregiver support services, offered by public and private agencies, such as the Caregiver Resource Centers, the Alzheimer's Association, other agencies receiving family caregiver support funding from the local area agencies on aging, etc. do not reach all areas of the state. These programs have limited ability to provide respite or other needed services to support caregivers. The Caregiver Resource Centers and the Alzheimer's Association both have good fact sheets on dementia behavioral issues (e.g. aggressiveness, paranoid ideas, etc.) that could benefit many more families.

Family members are by no means the only caregivers lacking the skills to assess the differences between dementia and psychiatric conditions. Primary care physicians, neurologists, psychiatrists, social workers, psychologists, direct care staff in all long term care settings, county mental health workers, adult protective service staff, emergency room nurses and doctors, conservators, and local law enforcement may also need education to recognize and seek treatment for mental conditions; tools to aid in accurate assessments; and standards of care to assure more effective intervention and on-going care.

Some health and mental health professionals consider it a waste of precious resources to provide more than minimal intervention in caring for a patient with AD or a related dementia.

Currently, only a small cohort of clinicians has the required skills to accurately assess and treat individuals exhibiting dementia and co-occurring mental disorders. The American Psychiatric Association has developed guidelines for the psychiatric treatment of patients with dementia and the American Association for Geriatric Psychiatry has been very involved in these issues. Those efforts are helping to shape the consensus on the standard of care for persons with dementia and mental health needs. But until all treating physicians are trained and using those standards:

- Other medical conditions may be mistakenly diagnosed as dementia;
- Other mental health conditions may be mistakenly diagnosed as dementia;
- Individuals with dementia, who have co-occurring psychiatric conditions and significant behavioral problems, may be overmedicated or placed in higher levels of care than necessary in order to control their behavior when treatment at a lower level of care could have provided a more effective intervention;
- Individuals suffering from mental illness who develop dementia may need a different level of care if the symptoms of dementia outweigh the symptoms of the psychiatric disorder. Appropriate long-term care needs may not be addressed; and
- Some individuals with both dementia and co-occurring mental disorders may develop behavioral problems leading to injury to themselves or to others, which may result in incarceration if their health and mental health conditions are not recognized or if there are no emergency alternatives available in the community.

The California Alzheimer's Disease Management Guidelines provide an outline of the training needed by health care professionals who serve these clients. The supporting report provides detailed information on several symptoms of mental disorder and behavioral challenges common among persons with dementia. In 1999, the Alzheimer's Association of Los Angeles developed a training manual and workshop that teaches care managers how to conduct a differential diagnosis of dementia, delirium, and depression in older adults. While those guidelines have been nationally recognized, additional dissemination of this information within the state through provider training is the appropriate next step.

As noted earlier in the report, the recommendations that follow should be viewed as long-term strategies rather than as an implementation plan.

Key Issue 2 Skill building for appropriate diagnosis and care.

Recommendation 2A: Create a family caregiver educational campaign. This campaign should widely disseminate materials/training that (1) helps caregivers understand dementia and co-occurring mental disorders; (2) provides communication tools to be used in caring for a person who is losing/has lost their prior modes of communication; (3) addresses dealing with difficult behaviors; (4) includes links to additional community resources, and (5) is responsive to the state's cultural and ethnic diversity.

Strategy: 2A(1) Review existing materials and partner with these organizations to increase the dissemination of effective materials.

Recommendation 2B: Increase training for clinicians on diagnosing and treating persons with dementia and dementia-related psychiatric and behavioral symptoms.

Strategies**:** 2B(1) Establish minimum continuing education courses in geriatrics for primary care physicians and licensed mental health providers.

2B(2) Explore the cost benefit of providing a discount on license fees for individuals in targeted professional groups to increase their competence in treating persons with dementia and co-occurring psychiatric conditions or severe behavioral issues.

2B(3) Given that the California Alzheimer's Disease Management Guidelines have recently been updated, explore efforts to identify and train a cadre of trainers who would provide instruction on the guidelines in their specific geographic area to their peers.

Recommendation C: Create a training program for all "first responders" (e.g., law enforcement, fire department, paramedics, etc.) on strategies for identifying and interacting with persons who may have dementia and/or psychiatric conditions.

Strategies: 2C(1) Create or adopt existing training modules for use by first responders and identify appropriate trainers.

Key Issue 3 Service Delivery and Reimbursement Mechanisms

One of the most fundamental barriers to comprehensive care for individuals with dementia and treatable mental health conditions is the huge fiscal exposure for county mental health systems if they cannot find a payer/provider for needed long term care services. County Mental Health Departments could provide appropriate mental health services to persons with dementia who meet medical necessity criteria and have treatable mental health conditions. But, if long term care providers are not willing to accept these individuals when they are stabilized, the county mental health program must pay not only for the cost of their mental health services but for their custodial long term care expenses as well.

At the same time, long term care providers may be hesitant to accept these clients because they fear that these individuals may require mental health services beyond their potential capacity, etc. and they do not want to be at risk for these costs. A reoccurring theme heard throughout the Taskforce's meetings was that unless both sides of the risk equation are addressed in unison, an effective solution will not be reached.

Until an effective risk sharing arrangement between mental health and long term care payers is created, many geriatric professionals state that persons with dementia and co-occurring mental disorders will be screened out of the mental health system on the basis of their "dementia" diagnosis.

Medicare provides health insurance to 95% of Americans age 65 and over. The program also serves 5 million non-elderly persons with disabilities.[18] So most individuals who have dementia and mental health and/or severe behavioral issues are Medicare beneficiaries as a result of their age and/or disability. A smaller percentage of these individuals are Medi-Cal beneficiaries as a result of their income level and need for medical assistance.

This section provides an overview of the source of reimbursement available to Medicare and Medi-Cal beneficiaries who have dementia and co-occurring mental illness which are amenable to mental health treatment.

Medicare

Medicare data analyses indicates that 63% of Medicare expenditures for individuals with AD is for inpatient hospital care.[19] A recent study indicates that

[18] U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services, Office of the Actuary, June 2002.

[19] Weiner M, Powe N, Weller WE, Shaffer TJ, Anderson GF: Alzheimer's disease under managed care: implications from Medicare utilization and expenditure patterns. Journal of the American Geriatric Society 1998; 46:762-770.

patients with dementia are admitted for different reasons than patients without dementia and appear to have longer stays, resulting in higher costs. This study identified an average 15-day hospital length of stay for persons with dementia versus 6.5 for comparable geriatric patients without dementia.[20] While this study suggests that many of the conditions that lead to hospitalization could have been avoided or treated in another setting, some of the care systems that would likely provide that early intervention for persons with AD and co-occurring mental conditions may not be Medicare providers (e.g., county mental health departments, area agencies on aging, etc.) Given these fragmented funding structures, the fiscal incentives have not aligned strongly enough to incentivize Medicare or non-Medicare providers to globally develop alternative models of care for this subpopulation.

In 1990, Medicare Part A expenditures included $1billion for inpatient psychiatric services and $370 million in Medicare Part B claims payments to mental health providers for inpatient, partial, or outpatient services. While Medicare mental health expenditures have increased, this spending represents less than 3% of total Medicare expenditures.

Numerous studies, committees and commissions have recommended that Medicare develop and expand its mental health benefits to promote mental health and prevent mental illness. As a result of federal budget action in 1987 and 1989:

- The Medicare lifetime limit on inpatient psychiatric hospital care was expanded to 190 days;
- The annual Medicare reimbursement limit for outpatient mental health services was rescinded; and
- The Medicare list of qualified mental health providers was expanded to include licensed clinical psychologists and licensed clinical social workers.

Medicare does not cover custodial long-term care assistance. While Medicare has a limited nursing facility and home health care benefit, it will not pay for personal care assistance or instrumental activities of daily living (e.g., cooking, cleaning, bill paying, etc). As a result, Medicare does not cover much of the assistance required by persons with AD or other forms of dementia.

Aspects of the current Medicare mental health benefits that have been identified as barriers to mental health services include:

- A bias toward general health care settings rather than specialized mental health service organizations (e.g., there is a 190-day lifetime limit on inpatient care within psychiatric hospitals but no comparable restriction for specialty psychiatric units within general hospitals; a daily reimbursement limit on

[20] Lyketsos CG, Sheppard JE, and Rabins, PV: Dementia in Elderly Persons in a General Hospital American Journal of Psychiatry 2000;157: 704-707.

psychiatric services but none on general practitioners providing services to beneficiaries with mental illness, etc.);

- The lack of parity in co-payments for Medicare health and mental health services (a 50% co-payment for non-medical psychiatric services, compared to a 20% co-payment for medical treatment);

- The absence of a Medicare out-patient pharmacy benefit results in less than optimal treatment outcomes if a beneficiary has been stabilized in an acute psychiatric unit, but cannot afford to continue taking those medications once discharged back to the community;

- The remaining Medicare + Choice plans have severely restricted their prescription drug benefit, often to generic drugs. This has resulted in many Californians who were receiving pharmacological interventions for dementia and/or mental health problems not being able to afford these brand name drugs on an on-going basis. Generic equivalents are not available for many of the newer drugs.

- The routine rejection of mental health payment claims by the Medicare fiscal intermediaries (FIs), particularly if the beneficiary had also been diagnosed with dementia.

Recently, the Centers for Medicare and Medicaid Services (CMS) instructed the fiscal intermediaries (FIs) that they should review Medicare payment claims for services including physical, speech, and occupational therapy on a case-by-case basis rather than automatically denying the claim if the beneficiary had been diagnosed with dementia. The Alzheimer's Association and the American Bar Association persuaded CMS that many individuals are now diagnosed early enough to gain significant benefit from rehabilitative therapies. However, an informal survey of some Los Angeles mental health providers found that this CMS clarification would not change their practice. Fearful of CMS audits or disallowances, these providers said they would continue to provide services to persons diagnosed with psychiatric symptoms and not mention a coexisting dementia diagnosis.

A recent research study found that the most Medicare beneficiaries do not even know that they have a mental health benefit much less know that Medicare has a 50% co-payment for outpatient mental health services.[21]

[21] Bulot, J. and Jakubiak, C Elderly Medicare Beneficiaries' Knowledge of Mental Health Benefits. Presented at the 2002 Annual Conference of the National Council on Aging and the American Society on Aging, Denver.

Medi-Cal

Medicaid is a health care program for low-income families, children, and the aged, blind, and disabled established and funded through state and federal partnership. States design their programs within federal requirements through their state plans or federal waivers requests. Federal law describes the services which may be considered "medical assistance" and included in the state plan. Medical assistance includes: inpatient hospital and physician services, and provides options for targeted case management and rehabilitative services. The California Medicaid program, known as Medi-Cal, is administered by the Department of Health Services (DHS). The program includes rehabilitative mental health services and targeted case management for beneficiaries who have a mental health diagnosis which meets the criteria for medically necessary services. The Medi-Cal program provides more flexibility than the Medicare program, (described above), particularly with regard to the responsibilities of licensed professionals, and in the services which can be provided by non-licensed professionals as supervision of services by other individuals, and in the sites where services can be provided.

Medi-Cal's reimbursement rates for adult day health care and nursing facility (NF) care is a per diem, cost settled rate, with certain ancillary services included in the per diem. Under such a system, providers may not see an incentive to accept or retain clients with dementia and psychiatric or severe behavioral symptoms if these residents require additional staff time and individualized care.

AB 1731 (Shelley), Chapter 451, Statutes of 2000, and AB 430 (Cardenas), Chapter 171, Statutes of 2001, require DHS to review the current Medi-Cal reimbursement system to evaluate, among other things, the extent to which the methodology effectively ensures individual access to appropriate long-term care services and promotes quality resident care. AB 1075 (Shelley), Chapter 684, Statutes of 2001, requires DHS to implement a facility-specific rate methodology by August 1, 2004, that reflects the costs and staffing levels associated with quality of care for residents of nursing facilities. Status reports on the implementation are due to the Legislature on April 2002, 2003, and 2004.

Mental Health Services

The California Department of Mental Health (DMH) originally provided long-term mental health services through 14 inpatient state psychiatric hospitals (SPHs) across the state. All California residents were eligible for inpatient care. Individuals admitted to the hospitals had the most serious and persistent forms of mental illness. In 1957, California passed legislation creating the Short-Doyle Program in order to provide community-based alternatives to such care. This program required counties to provide mental health services to specific target populations through a system of state operated and contract providers.

In July 1965, Congress passed two major amendments to the Social Security Act (the Act) that expanded the scope of health benefits to persons eligible for federal grants: Title XVIII, the Medicare legislation for persons 65 years of age and over, and Title XIX, the Medicaid legislation that provided federal matching funds to states that implemented a comprehensive health care system for the poor under the administration of a single state agency.

In 1966, legislation was passed establishing the California Medical Assistance Program (Medi-Cal), based on the provisions of Title XIX, for medical services to eligible federal cash grant welfare recipients. The specialty mental health services reimbursed by this program included psychiatric inpatient hospital services, nursing facility care, and professional services provided by psychiatrists and psychologists.

In 1971, state legislation added Short-Doyle community mental health services to the Medi-Cal scope of benefits. This change enabled counties to obtain federal matching funds for their costs of providing Short-Doyle community mental health services to persons eligible for Medi-Cal. At this point, the Medi-Cal program was split into two mental health delivery systems. The original program continued as the Fee-for-Service/Medi-Cal (FFS/MC) system. The counties became the providers of the new Short-Doyle/Medi-Cal (SD/MC) services benefit. SD/MC services included many services provided by the Short-Doyle program, but not all (e.g., socialization and vocational programs were not covered). But the SD/MC program provided a much broader range of mental health services, using a wider group of service delivery personnel, than were offered under FFS/MC.

A Medicaid State Plan Amendment, implemented in October 1989, added targeted case management to the scope of benefits offered under the SD/MC system. Another State Plan Amendment, implemented in July 1993, added services available under the Rehabilitation Option to the SD/MC scope of benefits and broadened the range of personnel who could provide services and the locations where services could be delivered.

Based on approval of a Section 1915(b) waiver, effective March 17, 1995, California consolidated the FFS/MC and SD/MC psychiatric inpatient hospital services at the county level. County mental health departments became responsible for both FFS/MC and SD/MC psychiatric inpatient hospital systems for the first time. CMS approved State Plan Amendment 95-016, which described the reimbursement methodology used for psychiatric inpatient hospital services under the consolidated program. A separate Section 1915(b) waiver was also approved for the Medi-Cal Mental Health Care Field Test in San Mateo County in 1995.

In 1997, CMS renewed the Medi-Cal Psychiatric Inpatient Hospital Service Consolidation Waiver, which had been modified to include both inpatient hospital and professional specialty mental health services under the responsibility of a single mental health plan (MHP) in each county. The modified waiver was renamed the Medi-Cal Specialty Mental Health Services Consolidation waiver.

Implementation of the renewed waiver, referred to as “Phase II" implementation, occurred at various times in each California county between November 1, 1997, and July 1, 1998, depending on the readiness of the MHP in each county. During the first waiver renewal period, MHPs became responsible for authorization and payment of professional specialty mental health services that were previously reimbursed through the FFS/MC claiming system. At that time, both inpatient hospital and professional Medi-Cal specialty mental health services previously reimbursed through FFS/MC and SD/MC claiming systems became the responsibility of a single entity, the MHP, in each county.

As of 1995, the MHP in each county became responsible for authorizing psychiatric inpatient hospital services. Between November 1997 and July 1998, MHPs also became responsible for outpatient and inpatient professional specialty mental health services. Under the current waiver, which expires November 19, 2002, all MHPs are county mental health departments, although if a county elects not to participate in the program, another entity may be designated the MHP.

There are currently four state hospitals. The patients served by the DMH are often classified on the basis of the legal class or type of commitment proceeding that resulted in their placement in a state hospital. There are two basic types of commitments to state hospitals: patients may be committed as a danger to self or others, gravely disabled, under civil statutes commonly referred to as Lanterman-Petris-Short (LPS) commitments; or they may receive a forensic (criminal) commitment from the courts, Board of Prison Terms, or the California Department of Corrections. Forensic commitments include: Not Guilty by Reason of Insanity (PC 1026), Incompetent to Stand Trial (PC 1370), Mentally Ill Inmates (PC 2684), Mentally Disordered Offenders (PC 2960-72), and Sexually Violent Predators (WIC 6600).

Eligibility

To the extent 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. The eligibility and targeting of mental health services for adults and older adults are contained in the Welfare and Institutions Code, Section 5600.3(b)(3) which states:

“(3) Members of the target population must meet all of the criteria:

(A) The person has a diagnosis of a mental disorder as identified in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, other than a substance abuse or developmental disorder or acquired traumatic brain injury pursuant to subdivision (a) of Section 4354 unless that person also has a serious mental disorder as defined in paragraph (2) the statute;

(B) (i) As a result of the mental disorder the person has substantial functional impairments or symptoms, or a psychiatric history demonstrating that without treatment there is an imminent risk of decompensation to having substantial impairments or symptoms;

(ii) For purposes of this part, "functional impairment" and circumstances the person is likely to become so disabled as to require public assistance, services, or entitlements.

(C) As a result of a mental functional impairment and circumstances the person is likely to become so disabled as to require public assistance, services, or entitlements.
(4) For the purpose of organizing outreach and treatment options, to the extent resources are available, this target population includes, but is not limited to, persons who are any of the following:
(A) Homeless persons who are mentally ill.
(B) Persons evaluated by appropriately licensed persons as requiring care in acute treatment facilities including state hospitals, acute inpatient facilities, institutes for mental disease, and crisis residential programs.
(C) Persons arrested or convicted of crimes.
(D) Persons who require acute treatment as a result of a first episode of mental illness with psychotic features.
(c) Adults or older adults who require or are at risk of requiring acute psychiatric inpatient care, residential treatment, or outpatient crisis intervention because of a mental disorder with symptoms of psychosis, suicidality, or violence.
(d) Persons who need brief treatment as a result of a natural disaster or severe local emergency.

An individual with dementia would not be excluded from receiving mental health services as long as he or she also meet medical necessity criteria for medically necessary mental heath services.

Medical Necessity criteria are described in Title 9, Chapter 11, Section 1830.205. Medical Necessity Criteria for MHP Reimbursement of Specialty Mental Health Services.

a. The following medical necessity criteria determine Medi-Cal reimbursement for specialty mental health services that are the responsibility of the MHP under this subchapter, except as specifically provided.

b. The beneficiary must meet criteria outlined in (1), (2), and (3) below to be eligible for services:

(1) Be diagnosed by the MHP with one of the following diagnoses in the Diagnostic and Statistical Manual, Fourth Edition, published by the American Psychiatric Association:
(a) Pervasive Developmental Disorders, except Autistic Disorders
(b) Disruptive Behavior and Attention Deficit Disorders
(c) Feeding and Eating Disorders of Infancy and Early Childhood
(d) Elimination Disorders
(e) Other Disorders of Infancy, Childhood, or Adolescence
(f) Schizophrenia and other Psychotic Disorders
(g) Mood Disorders

(h) Anxiety Disorders
(I) Somatoform Disorders
(j) Factitious Disorders
(k) Dissociative Disorders
(l) Paraphilias
(m) Gender Identity Disorder
(n) Eating Disorders
(o) Impulse Control Disorders Not Elsewhere Classified
(p) Adjustment Disorders
(q) Personality Disorders, excluding Antisocial Personality Disorder
(r) Medication-Induced Movement Disorders related to other included diagnoses.

(2) Must have at least one of the following impairments as a result of the mental disorder(s) listed in subdivision (1) above:
(a) A significant impairment in an important area of life functioning.
(b) A probability of significant deterioration in an important area of life functioning.
(c) Except as provided in Section 1830.210, a probability a child will not progress developmentally as individually appropriate. For the purpose of this section, a child is a person under the age of 21 years.

(3) Must meet each of the intervention criteria listed below:
(a) The focus of the proposed intervention is to address the condition identified in (2) above.
(b) The expectation is that the proposed intervention will:
(1) Significantly diminish the impairment, or
(2) Prevent significant deterioration in an important area of life functioning, or
(3) Except as provided in Section 1830.210, allow the child to progress developmentally as individually appropriate.
(c) The condition would not be responsive to physical health care based treatment.

c. When the requirements of this section are met, beneficiaries shall receive specialty mental health services for a diagnosis included in subsection (b)(1) even if a diagnosis that is not included in subsection (b)(1) is also present.

NOTE: Authority cited: Section 14680, Welfare and Institutions Code.
Reference: Section 5777 and 14684, Welfare and Institutions Code.

It should be noted that this medical necessity criteria does not include the DSM-IV “Cognitive Disorders” category, which includes dementia due to general medical conditions. An individual with dementia may exhibit a mental disorder that meets the medical necessity criteria (e.g., mood disorder, anxiety disorder, etc.). But the DSM evaluation criteria also includes a determination that this mental disorder is not better accounted for by another disorder. This criteria component can be used to argue that the disease causing the dementia (e.g., Alzheimer’s, Parkinsons, etc.) better accounts for the depression, delusions, etc.). Such an evaluation would result in the individual not meeting the medical necessity criteria for mental health services.

Medical necessity is determined by mental health professionals who may be County staff or contracted providers. If an individual is not satisfied with the clinical decision regarding eligibility for specialty mental health services, a second

opinion maybe requested and/or the beneficiary can register a complaint, file a grievance, or request a state fair hearing.

As evidenced at the SB 639 Taskforce meetings, there is considerable confusion among counties and mental health providers on the interpretation of these eligibility criteria. As noted at those meetings, a similar confusion exists with respect to with developmental disabilities and exhibit mental health disorders.

Services Provided. County mental health plans (MHP) can authorize or provide, to the extent resources are available, a broad array of services as described in W&I Code including: crisis care, 24-hour emergency services, evaluation and assessment, individual and group psychotherapy, individual treatment planning, medication management, rehabilitation and support services, services for the homeless, and targeted case management.

SPECIALIZED DEMENTIA SERVICES

Many Californians with AD or other forms of dementia may receive assistance from "generic" (i.e., not specifically designed for persons with dementia) in-home, community-based, residential or institutional services. However, three state-funded programs provide specialized services to persons with dementia and their caregivers. These programs assist family caregivers in understanding dementia and provide tips on dealing with difficult behaviors; provide training on dementia diagnosis and care planning; and provide day services for persons with moderate to severe dementia.

Alzheimer's Disease Program

The California Department of Health Services Chronic Disease Program administers ten Alzheimer's Research Centers, located in university medical centers throughout the state. These centers primarily conduct research, but also provide diagnostic treatment; information and referrals to community health and social services; caregiver support groups; and training and education for professionals in that geographic area.

Each center is required to evaluate at least 100 persons annually. While there is no financial eligibility requirement for this service, the individual to be evaluated must exhibit symptoms of memory loss, disorientation, and confusion.

This program is completely supported with state general funds. In FY 2000, total state expenditure for this program was approximately $3,875,000.

Alzheimer's Day Care Resource Centers

Alzheimer's Day Care Resource Centers (ADCRCs) provide respite and support for caregivers. They serve as models of day care services for persons with

dementia. They also provide training opportunities for persons involved in dementia care and treatment and seek to increase public awareness and knowledge about AD and related disorders.

These centers serve individuals with AD or a related dementia, without regard to age or income. The centers target individuals with moderate to severe dementia, who may be difficult to serve in another day care setting.

Over the last 13 years, the number of ADCRCs has expanded from 8 to 54 sites throughout the state. Currently, there is at least one center in each of the 33 Area Agencies on Aging planning and service areas. Each center receives an annual grant of up to $80,000 in state general funds for program operations. Applicants, who can afford to do so, may also pay for services on a sliding scale. In FY 1999, 7,397 individuals were served by these centers and the total state expenditures were $3,764,000.

Caregiver Resource Centers

In 1984, the Comprehensive Act for Families and Caregivers of Brain-Impaired adults was established to support families and other caregivers of individuals with adult-onset brain disorders. These disorders include Alzheimer's, multi-infarct diseases and other dementias; cerebrovascular diseases (stroke or aneurysm); degenerative diseases such as Parkinson's, Huntington's, multiple sclerosis and amyotrophic lateral sclerosis; brain injury due to trauma or infection; brain tumor; and HIV related dementia.

Eleven Caregiver Resource Centers throughout the state provide the following assistance to caregivers: information, advice and referral; needs assessment; long-term planning and consultation; legal and financial consultation; mental health intervention (counseling, support groups, psychoeducational groups); education and training; and respite services.

In 1998, approximately 10,200 families were served annually by these centers. Funding to support these programs comes from the state general fund ($5,046,995), private donations, and fund raising efforts.

The San Francisco-based Family Caregiver Alliance is the model for the 10 other Caregiver Resource Centers (CRCs) and also serves as the Statewide Resource Consultant, assisting the California Department of Mental Health.

Implementation

As noted earlier in the report, the recommendations that follow should be viewed as long-term strategies and not as an implementation plan.

Key Issue 3 Service Delivery and Reimbursement Mechanisms

Recommendation 3A: Identify potential Medi-Cal home and community-based rate options that would encourage providers to develop and provide services to individuals with dual diagnoses and more complex care needs.

Strategy: 3A(1). Based on the findings from the AB 1731 and 1075 Medi-Cal NF rate study, determine whether restructuring the current Medi-Cal payments to some home and community based LTC services would encourage providers to accept and/or retain clients who have higher level of care needs or who have severe behavioral problems.

Recommendation 3B: Clarify eligibility for county mental health services when an individual is suspected of having or has been diagnosed as having dementia and is suspected or diagnosed as having a treatable mental health symptoms as well.

Strategy: 3B(1) Clarify eligibility for mental health services when an individual is assumed or has been assessed to have some form of dementia; responsibility for conducting this type of assessment; and include a requirement that a care plan which would specify what services might be Medi-Cal reimbursable be developed as part of the assessment.

Key Issue 4 Continuum of Appropriate Services and Care Settings

A Children's System of Care (SOC) was created as a multi-agency, multi-disciplinary approach to providing services to children's problems frequently affect many aspects of their lives. SOCs are formed to create collaborative, cooperative working relationship among various agencies and systems in order to better meet the client's needs.

Recently, some counties have begun efforts to develop a SOC approach to serving older adults to ensure the access, availability, and appropriateness of needed services. An older adult SOC strategically seeks to keep clients in the most independent community setting possible. (A model "Older Adult System of Care Framework" developed by the California Mental Health Directors Association is included in Appendix 3.).

Many counties have utilized one of two agency models:

- Integrated Service Agency Model (ISA)--involves voluntary participation of clients in the services identified in a personal care plan. Services are provided on a capitated 24-hour basis in order to meet all of the client's needs. These services can include: housing, socialization, rehabilitation, legal assistance, money management, mental health treatment, physical health, and dental care. Each ISA also provides information, counseling, and respite services.

- County Interagency Demonstration model—is similar in philosophy to the ISA model but uses interagency collaboration, which may include an Adult Protective Services worker, psychiatric nurse, social worker, and even a psychiatrist, in order to provide needed services to clients. These outreach and crisis intervention multidisciplinary teams often make house calls in order to defuse and resolve an escalating episode before it results in an emergency room visit.

A growing number of clinicians believe that the implementation of older adult SoCs can:

- Significantly increase the percentage of older adults, that meet the mental health medical necessity criteria**,** seeking and receiving community-based mental health services; and

- Reduce the number of individuals with dementia and coexisting mental health conditions from being admitted to acute care and psychiatric hospitals and the associated expenditures through timely, multi-disciplinary community intervention.

Appendix 3 includes a description of Older Adult System of Care models from two counties.

Crisis Response Services

When an individual with dementia has a crisis or develops severe behavioral changes, frequently there is no appropriate emergency response provider nor is there emergency shelter available to house the individual while they are being stabilized. In-patient psychiatric units (need to specify what type of licensed facility) that house multiple age groups and do not have the ability to provide needed geriatric health and long term care services are not considered appropriate for these older adults. These units are intended for cognitively intact individuals requiring hospitalization to be stabilized.

Appendix 3 includes a description of the multidisciplinary teams that two counties have developed to evaluate and stability older adults with dementia and psychiatric conditions or severe behavioral problems.

Acute Care Hospitals/Emergency Room Departments

Acute Hospital Settings

Many acute hospital patients are admitted with dementia and/or psychiatric conditions, an environment that at times is "confusing and hostile to them." [22] Persons with dementia are prone to decompensate when hospitalized, exhibiting delirium and loss of functional capacity which complicates compliance and recovery. Delays in securing post-acute placement may also add to the length of stay. Urinary tract infections, drug psychosis, senile organic psychotic conditions, and behavioral, functional or social complications of dementia--conditions prevalent in admitted patients with dementia--could potentially be prevented, identified earlier, and treated in another setting.[23]

Appendix 3 includes a description of an acute hospital dementia care unit pilot program. That appendix also includes guidelines developed by a managed care plan for its social workers to use in planning the discharge for medically stable hospital patients whose behavior is a barrier to transferring to a lower level of care.

Emergency Room Departments

Emergency rooms (ERs) are often the provider of last resort for persons with dementia and psychiatric problems who develop severe behavioral problems. Generally, ERs are very poorly equipped to respond to the needs of any psychiatric patient or geriatric patients with dementia:

[22] Lyketsos 704-707.
[23] Ibid.

- Patients may have to wait a long time to be seen by a physician, which may exacerbate behavioral problems.
- The resources and staff of emergency room departments and mental health units are typically not equipped to treat persons with dementia and psychiatric disorders who develop severe behavioral symptoms and are frequently overextended in trying to care for these patients. It was noted that emergency room staff may administer psychotrophic medications in order to manage the patient's behavior. However, providing f such medication to an older individual who may have several other health conditions and be taking other types of medication could put their physical health at risk.
- Emergency room and hospital environments and routines tend to increase confusion, agitation, and aggressive behavior in persons with dementia and co-occurring mental disorders.
- Most cities do not have in-patient psychiatric facilities located within an acute medical hospital. As a result, older adults with psychiatric conditions and dementia are frequently admitted to the acute medical facility, which is not well equipped to address co-occurring mental disorders.

Acute Care Psychiatric Hospitals

- With the exception of Los Angeles, there is a statewide shortage of in-patient psychiatric hospital beds, particularly those with a geriatric specialty;

- Like emergency rooms, acute care psychiatric hospitals are often the option of last resort for persons with dementia exhibiting very aggressive behavior. In-patient psychiatric hospitals do not have the medical staff and expertise to meet the acute and chronic health care needs most older patients have. Frail, confused older adults may not be safe in a mixed setting with psychotic patients.

- Because so few long term care placement options exist for persons with dementia who are in crisis, once an older individual is admitted and stabilized, it is very difficult to find discharge options for them. Family members may no longer feel capable of providing needed care or may have become too exhausted to do so. Liability issues (discussed later in this section) and the lack of a financial incentive to care for this heavier care client frequently results in skilled nursing facilities, residential care facilities (commonly referred to as "assisted living" facilities), adult day care facilities and home care providers not being willing to accept individuals who have had a history of combative or difficult behavior.

  As a result, older adults with dementia who are stabilized in in-patient psychiatric facilities may remain there much longer than is clinically warranted on "administrative" days. When this occurs, the older person is not being returned to the most appropriate level of care; they are being cared for at a

cost higher than is required once they are stabilized; and those in-patient psychiatric hospital beds are not being used by persons who do need that level of care.

- There are very few geriatric in-patient psychiatric units, the setting that would provide the optimal blend of specialized geriatric psychiatric services in an appropriate environment for persons with dementia and with acute psychiatric, health and long term care needs.

Provider Liability Issues

It can be difficult to predict when an individual with dementia who has not previously been aggressive may suddenly become so. Changes in an individual's behavior may be related to further progression of the disease into different portions of the brain, or may be triggered by an external sight, sound, or condition that may confuse or frighten the individual.

All health facilities, residential care facilities, and adult day health care programs are required to provide an environment that optimizes the health and safety of staff and clients, including protecting clients from other potentially aggressive clients. If a client injures another, the facility could face a citation by the licensing entity for failing to take reasonable measures to prevent the occurrence.

Nursing Facilities (NFs)

Preadmission Screen Resident Review (PASRR). The Omnibus Budget Reconciliation Act (OBRA) of 1987 revised federal laws governing nursing facilities (NFs). OBRA required that all individuals initially entering a NF must be screened to determine if they have a developmental disability or serious mental illness. On initial application for admission to a nursing facility (NF), the admitting NF must perform a Level I PASRR screening of all resident expected to stay 30 days or more to identify potential residents with a developmental disability or serious mental illness. The admitting NF is also responsible for making the referral for a Level II evaluation when appropriate.

The PASRR Level II evaluation for residents identified as potentially having a serious mental illness is performed by the California Department of Mental Health (DMH). The DMH contracts with independent clinical evaluators throughout the state to conduct these evaluations. The Level II review evaluates the appropriateness of the setting and/or treatment; may recommend specialized or less than specialized mental health services; and may recommend certain interventions or strategies in providing treatment to the resident. The Level II contract evaluators will frequently provide consultation to the NF, making care plan recommendations that address problematic behaviors; encourage therapeutic activities, etc.

Residential Care Facilities for the Elderly

In California, small or large facilities that provide residential and personal care services to the elderly are technically referred to as Residential Care Facilities for the Elderly (RCFEs). Most people commonly refer to these types of residences as assisted living, board and care or adult foster care facilities.

Medi-Cal does not currently provide reimbursement for RCFE services. As a result, Medi-Cal beneficiaries who could be appropriately cared for in a specialized residential setting may be admitted to a NF that accepts Medi-Cal payment. AB 499 (Aroner) Chapter 557, Statutes of 2000, requires the DHS to develop the necessary Medi-Cal waiver(s) to conduct a Medi-Cal assisted living pilot project.

Appendix 3 describes a residential care facility providing geropsychiatric services in a regional rural area.

Respite Services

Family caregivers struggle to care for their relative as long as possible. Providing that care frequently exacts a heavy toll on the caregiver emotional, financial, and physical.

It is difficult for family caregivers to find dependable respite providers if their relative has dementia; it becomes much more challenging if the relative also has mental health and/or severe behavioral problems.

Other Care Systems Issues

Transportation costs to and from day care or other services, including mental health services, can be unaffordable for the elderly. Public transportation is not always easily accessible or an appropriate option for individuals with dementia.

Rural areas often lack the home and community-based long-term care service options available in urban settings. Frequently individuals must move to a more urban area to receive appropriate care. This is a burden for individuals who are unable to or who must travel great distances to visit a family member receiving treatment in a larger town or city. The lack of economic efficiencies in rural areas results in higher costs per unit of service and limits the services that can be provided.

Telemedicine could be used to bring specialized diagnosis and treatment services into rural areas and to provide consultation to primary care physicians on dementia and dual diagnosis differentiation and treatment. In 1999, an estimated 74,000 telemedicine visits occurred in the United States. Telemental

Health/Telepsychiatry services have consistently been among the most used telemedicine services due to the scarcity of psychiatrists and other mental health professionals in rural and urban underserved areas as well as the traditional dependence on primary care settings for mental health related services.

With careful planning, telemedicine technology could be used to address numerous issues facing county mental health plans. For example, TM can be used to provide cultural and linguistic competencies that may be unavailable in the local area, thus compensating for staff shortages and gaps in provider networks. TM can include office, home and hospital-based procedures; individual, group and family assessments; therapeutic intervention; medication evaluation and monitoring; emergency evaluations; case management; distance learning and training; and supervision, case conferencing, and consultation.

Fee structures and reimbursement mechanisms to compensate the consulting specialists and to pay for the technology must be developed before telemedicine becomes a viable mainstream treatment option.

Implementation

As noted earlier in the report, the recommendations that follow should be viewed as long-term strategies and not as an implementation plan.

Key Issue 4 Continuum of Appropriate Services and Care Settings

Recommendation A: Emergency Crisis Interventions: As a component of its comprehensive plan, each county should include a component on emergency crisis intervention options for individuals with dementia who are exhibiting severe psychiatric and/or behavioral symptoms. This would potentially alleviate some emergency room visits and hospitalizations and inappropriate incarceration in jails.

Strategies: 4A(1) Encourage county mental health departments to provide services in urgent situations through (a) development of mobile geriatric multidisciplinary teams and (b) training to new or existing multidisciplinary teams on dementia and mental health issues. County consultative services to providers following a crisis intervention should also be included.

4A(2) Identify and evaluate promising practices already being used in some counties to provide emergency shelter, use mobile crisis teams, and provide consultation services; (2) convene county mental health directors and key staff to present these findings; and (3) facilitate a 1-2 year facilitated "coaching" program in which counties that have implemented these strategies assist other counties in developing them.

Recommendation B: Encourage hospitals, particularly emergency departments, to evaluate environmental and clinical treatment changes to minimize the negative impact that hospitalization frequently has on persons with dementia and behavioral and/or co-occurring mental disorders.

4B(1) (a) Identify and evaluate promising practices already being used in hospitals and emergency rooms to mitigate increased confusion, delusions, and agitation among persons with dementia and co-occurring mental disorders; (b) share these findings with key hospital and emergency room decision makers; (c) provide a facilitated 1-2 year "coaching" program in which selected hospitals are assisted in implementing new practices to address this problem; (d) evaluate and share outcomes with stakeholders.

Recommendation C: In developing the Medi-Cal assisted living waiver, consider including a tiered reimbursement tied to the acuity of resident need, to provide another option on the care continuum for persons with dementia and psychiatric/behavioral symptoms.

Strategy: 4C(1) AB 499 requires the DHS to develop an assisted living waiver pilot program. Include in the assisted living waiver pilot program incentives for providers to accept and retain persons with dementia and psychiatric/behavioral issues that could be appropriately cared for in a more residential care setting.

Recommendation D: Explore options that would stimulate development of specialized day care services for persons with dementia and psychiatric/behavioral symptoms.

Strategies: 4D(1). Evaluate whether a tiered Medi-Cal Adult Day Health Care reimbursement structure would create sufficient provider incentive to serve these individuals.

4D(2) Evaluate whether a specialized day care program for persons with dementia and psychiatric/behavioral symptoms is needed and could better meet the needs of this subpopulation.

Recommendation E: Encourage home care agency specialization in geriatric psychiatric services.

Strategy: 4E(1). Study whether encouraging home health care agencies to specialize in geriatric psychiatric services, using geriatric clinical nurse specialists, could be an economically viable model.

Recommendation F: Require agencies that provide respite funding to family caregivers to develop and maintain a registry of respite providers.

Strategy: 4F(1). At the local level, coordinate a registry of respite providers to help families locate caregivers who have experience in caring for persons with dementia and psychiatric/behavioral symptoms. Private pay individuals should have access to the registry and individuals should also be identified on the registry that have skills and training in caring for persons with dementia and mental health conditions.

Recommendation G: Telemedicine as an Option for Mental Health Specialty Consultation in Rural and Urban Areas.

Strategies: 4G(1) Permit telemedicine as a provided service of the AD Research Centers, which would permit them to provide not only direct client assessments but consultative services to primary care physicians and other clinicians to improve the evaluation and treatment of persons with dementia and co-occurring mental disorders.

4G(2) Include telemental health/telepsychiatry among the consultation services identified and included in Strategy 4A(2).

Key Issue 5 Involuntary Treatment Issues

County Adult Protective Service (APS) agencies often receive reports of self-neglect. After investigation, APS may determine that the individual can no longer remain in that living situation without being a serious threat to him/herself or others. However, an individual with dementia and a co-occurring psychiatric or behavioral condition can refuse recommended services. APS cannot force these services on the individual. At that point, APS may contact the county mental health department for an assessment and evaluation to determine whether the person is appropriate for a 72-hour involuntary mental health placement.[24]

However, many individuals with dementia and co-occurring mental disorders do not meet the criteria for a "5150" hold. Even if they are placed for 72 hours, that is a very short timeframe to complete and evaluation based on the presenting dementia, behavioral and/or mental disorders being exhibited. Once the 72-hour hold expires, facility and APS staff will attempt to find the most appropriate service environment possible. The limitations in securing those options have been discussed in earlier sections of this report.

Conservatorship Options

A conservatorship is a judicial procedure in which an individual or an agency (the 'conservator') is appointed to manage another person's (the 'conservatee's') health, financial, and/or personal affairs when the individual is no longer able to manage those decisions and affairs independently and there is no viable alternative method of delegating these duties to another (either through a durable power of attorney, living trust or other means). A relative, friend or public official may petition the court for appointment as a conservator.

Welfare and Institutions Code Section 5350 establishes the Lanterman-Petris-Short (LPS) Act Conservatorship. An LPS Conservatorship is a court proceeding in which a conservator is appointed for an individual found to be "gravely disabled" as a result of a mental disorder and can be used to involuntarily commit an individual to a mental institution for treatment. It is used for person with serious mental disorders who refuse voluntary mental health treatment and may be used for those impaired by chronic alcoholism (although this is rare since there are no involuntary alcohol treatment facilities). The County Mental Health Director must initiate an LPS Conservatorship. It has a one-year term unless a renewal is filed and approved.

An LPS Conservator can:

- oversee and consent to all appropriate mental health treatment;

[24] This involuntary mental health placement is frequently referred to as a "5150," based on the Welfare and Institutions Code Section that establishes the situations in which involuntary placement for treatment and evaluation can be authorized.

- monitor the conservatee's physical health, safety, emotional and social well-being;
- arrange for transportation, recreation, and health care; and
- manage the conservatee's estate.

An LPS Conservator cannot be granted general medical consent authority, but may be granted limited medical consent authority for an existing medical condition. Funding for LPS conservatorships comes from county mental health funding, targeted case management, and conservatorship fees. Local county social service agencies acknowledge that this funding patchwork results in a triaging such that only the most severe of the gravely disabled have an LPS conservatorship.

Probate Conservatorship

A probate conservatorship is a legal (not medical) determination based on facts showing a course of conduct that proves inability to "properly provide" for personal needs and/or a "substantial" failure to manage financial resources, and/or inability to resist undue influence. Referrals can be made by anyone in any setting. A private party or the Public Guardian/Conservator can petition for conservatorship and be appointed as a probate conservator. The court determines whether a conservatorship is required and what types of powers the conservator will be granted (e.g., financial, health care, residency decisions, etc.) Under a probate conservatorship, the conservator may not place the conservatee into a locked mental institution.

Because many individuals with dementia would not meet the very strict LPS conservatorship criteria, and probate conservatorship provisions prohibit involuntary placement in a locked facility, Probate Code, Section 2356.5 was added granting special powers to a probate conservator, when the conservatee has dementia. These include the power to authorize:

- Medication for dementia treatment and/or to affect behavior, cognition or mood;
- Placement in a residential care facility with a secured perimeter; or
- Placement in a locked or secured nursing facility specializing in the care of persons with dementia (placement in an Institution for Mental Disease is specifically prohibited).

Issues

The Taskforce did not develop specific recommendations on conservatorship for persons with dementia and coexisting psychiatric or behavioral conditions. However, several important issues were raised, including:

- The purpose of an LPS conservatorship is to provide involuntary mental health treatment. The implication is that the mental disorder results in a grave disability that is treatable and that treatment will improve the conservatee's ability to function in the community. Given the statute's intent, an LPS conservatorship for persons with dementia who also have coexisting psychiatric and behavioral conditions may not be an appropriate approach;

- The cost of LPS conservators and extended involuntary placements is primarily borne by county mental health departments, which were never funded to treat dementia. So, if an individual whose primary condition is dementia is placed on LPS conservatorship, funding is essentially being diverted from treating other gravely disabled mentally ill persons since county mental health systems are already under significant financial strain.

- Probate conservatorships do not provide funding for treatment. Even if an individual under probate conservatorship exhibits symptoms and behavior that can be best managed in a residential care facility with a secured perimeter or a secured/locked nursing facility specializing in dementia care, these facilities are usually very expensive, and unless the conservatee's estate has significant financial resources, they will not be able to afford this type of care;

- Because a conservatorship is a court supervised proceeding, substantial costs may be involved in establishing and maintaining it (e.g., court filing fees, legal fees, investigator fees and the conservator's fees). Many individuals cannot afford this process.

- The Probate Conservatorship process can be a cumbersome means of managing a person's health or financial affairs since the conservator must return to court for approval of certain transactions or decisions. This requires additional attorney's fees and can create delays in completing the transaction.

- Establishing a public probate conservatorship is not a quick process. The office of the Public Guardian/Conservator in most counties is not well funded and has very few staff, which limits their ability to quickly perform an initial investigation assessing the need for conservatorship. In Sacramento County, for example, it takes an average of 47 days to obtain a temporary conservatorship from the day the referral is accepted. [25] Access to public probate conservatorship varies across counties due to limited resources. In some counties, if a client's estate is not sufficient to cover the administrative costs of the conservatorship, the referral may not be accepted.

[25] County of Sacramento Board of Supervisors Meeting, July 31, 2001. "An Informative Glance at LPS and Probate Conservatorship" presented by RoseMary Vaske, Steve Petree and Scarlet Hughes.

- There are no statutory provisions that permit health care providers to provide treatment to individuals who have dementia or have mental health conditions and lack the capacity to give informed consent if there is no available surrogate decision-maker, such as a spouse, adult child or other person designated to be a surrogate prior to the individual's loss of mental capacity. If the individual can afford a probate conservatorship, it can take well over a month before the court can approve that request. In the meantime, unless the individual is appropriate for a "5150," mental health, social service and health care providers cannot treat the individual.

- Extended deliberations in determining whether a probate conservator or an LPS conservator is most appropriate can extend an individual's stay in a psychiatric facility longer than clinically necessary, a cost borne by the county's mental health system.

- The current conservator options can be described as "all or nothing." Unless the individual's decision-making and self-management capacity is so severely limited, the court is not likely to approve a conservator. But many individuals in the early to mid-stages of dementia have the capacity to make some decisions, but not others. What is needed is a mechanism that protects an individual's rights in domains where capacity still exists. But that process should be adjustable as capacity decreases, timely, and affordable to administer so that it is responsive to the progressive nature of the disorder.

- Some conservators are not familiar with dementia and/or psychiatric treatment issues and, therefore, may not make optimal decisions for their conservatee. They, too, need education and training on these issues to support the conservatee in the most appropriate and least restrictive setting possible.

APPENDIX 1—SB 639

BILL NUMBER: SB 639 CHAPTERED
BILL TEXT

CHAPTER 692
PASSED THE SENATE SEPTEMBER 13, 2001
PASSED THE ASSEMBLY SEPTEMBER 10, 2001
AMENDED IN ASSEMBLY SEPTEMBER 6, 2001
AMENDED IN ASSEMBLY AUGUST 28, 2001
AMENDED IN ASSEMBLY AUGUST 20, 2001
AMENDED IN ASSEMBLY JULY 9, 2001
AMENDED IN SENATE JUNE 4, 2001
AMENDED IN SENATE APRIL 16, 2001

INTRODUCED BY Senator Ortiz

FEBRUARY 22, 2001

An act to add and repeal Chapter 7 (commencing with Section 4099) of Part 1 of Division 4 of the Welfare and Institutions Code, relating to mental health, and making an appropriation therefor.

(Approved by Governor October 10, 2001. Filed with Secretary of State October 10, 2001.)

I am signing Senate Bill 639, which would require the California Health and Human Services Agency to develop a strategic plan for improving access to mental health services for persons with AD or related dementia. However, given the rapid decline of our economy and a budget shortfall of $1.1 billion through the first three months of this fiscal year alone, I have no choice but to oppose additional General Fund spending. I am directing the Health and Human Services Agency to develop the strategic plan within existing resources.

GRAY DAVIS, Governor

LEGISLATIVE COUNSEL'S DIGEST

SB 639, Ortiz. Alzheimer's disease and related disorders: demonstration projects. Existing law establishes a number of mental health programs administered by various state or local entities. This bill, until January 1, 2003, would require the California Health and Human Services Agency to develop a strategic plan for improving access to mental health services for people with Alzheimer's disease or related dementia and to complete the plan and submit a report to the Governor and the Legislature no later than January 1, 2003.

This bill would also appropriate, without regard to fiscal years, $85,000 from the General Fund to the agency for the purpose of implementing the bill. Appropriation: yes.

THE PEOPLE OF THE STATE OF CALIFORNIA DO ENACT AS FOLLOWS:

SECTION 1. Chapter 7 (commencing with Section 4099) is added to Part 1 of Division 4 of the Welfare and Institutions Code, to read:

CHAPTER 7. STRATEGIC PLAN FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS

4099. The Legislature finds and declares all of the following:

(a) There is no cure for Alzheimer's disease, a progressive neurological disease that slowly robs its victims of their cognitive and physical abilities.

(b) Seventy percent of persons with Alzheimer's disease reside at home in the community and rely on both formal and informal support to maintain dignity and independence.

(c) The predictable progression of the disease eventually leads to cognitive, behavioral, and personality changes that may include psychiatric symptoms such as anxiety, depression, hallucinations, delusions, and agitation.

(d) Both formal and informal caregivers must address increasingly complex needs that arise from the effects of the disease on the person and frequently find themselves faced with a crisis of care.

(e) Persons who suffer from Alzheimer's disease and individuals whose symptoms are suggestive of a dementia-related condition, when in crisis, often present themselves in overcrowded emergency rooms, while others are identified by law enforcement, who do not have the training or expertise to assess the medical and cognitive condition of the individual and who do not have access to expert assistance.

(f) There are numerous examples of avoidable incarceration, hospitalization, or placement in unnecessarily expensive and inappropriate institutional settings as a result of an episode that could have been stabilized with a rapid, interdisciplinary and coordinated crisis response.

(g) Alzheimer's patients often encounter barriers to accessing effective services in the appropriate setting due to uncoordinated, limited, and exclusionary funding streams.

(h) It is in the interest of the state to design and encourage more humane, effective, and efficient solutions to the significant caregiving crisis that arises from the progression of Alzheimer's disease and other related disorders.

4099.1. For purposes of this chapter, the following definitions apply:

(a) "Alzheimer's disease or related dementia" means persons with Alzheimer's disease or related dementia or individuals whose symptoms are suggestive of a dementia-related condition.

(b) "Caregivers" means both formal and informal caregivers.

4099.3. The California Health and Human Services Agency shall develop a strategic plan for improving access to mental health services by persons with Alzheimer's disease or related disorders, for treatable mental health conditions. The agency may use consultant services for this purpose. The plan shall be developed with consultation and collaboration with the agency's Alzheimer's Disease and Related Disorders Advisory Committee, the California Mental Health Planning Council, the State Department of Mental Health, the California Department of Aging, the State Department of Health Services, the California Mental Health Directors Association, the California Council of the Alzheimer's Association, and other departments and organizations, as deemed appropriate by the agency, with expertise and experience in the unique needs of this population. The plan shall be completed and a report submitted to the Governor and the Legislature no later than January 1, 2003.

4099.4. (a) This chapter shall become inoperative on January 1, 2003, and as of that date is repealed, unless a later enacted statute that is enacted before January 1, 2003, deletes or extends the dates on which it becomes inoperative and is repealed.

(b) This chapter shall be implemented only to the extent that funds are appropriated for this purpose.

APPENDIX 2 SB 639 Taskforce Members

Lin Benjamin	Benjamin Gero-Psych Consulting
Ann Burns Johnson	CA Association of Homes and Services for the Aging
Susan DeMarois	CA Council of the Alzheimer's Association
Cordula Dick-Muehlke	Chair, CHHS Alzheimer's Disease Advisory Committee
Patrick Fox	UCSF Institute for Health and Aging
Joyce Fukui	CA Department of Aging
Ed Long	CA Department of Aging
Mary Lamar-Wiley	CA Department of Health Services, Medi-Cal Policy Division
Rita McCabe-Hax	CA Department of Mental Health, Managed Care
Sara McCarthy	Senator Ortiz Staff
Lydia Missaelides	CA Association for Adult Day Services
Carol Motylewski-Link	CA Department of Health Services, Center for Gerontology
Marie Nitz	Catholic Healthcare West Geriatric Network
Esther Novak	Catholic Healthcare West, Geriatric Psychiatrist
Laura Trejo	Los Angeles County Department of Mental Health
Heather Walters	CA Mental Health Directors Association
Barbara Yates	CA Department of Mental Health, Mental Health Planning Council

<u>Taskforce Staff</u>

Melissa Borrelli	CA Health and Human Services Agency, Executive Fellow
Lora Connolly	CA Department of Aging
Rob Schladale	CA Health and Human Services Agency

APPENDIX 3 Promising Practices

COUNTY OLDER ADULT SYSTEM OF CARE MODELS

Butte County

In 1999, several older adult caregivers sought help in crisis, only to have their family members jailed when local resources were inadequate. In one instance, an 83-year old Paradise woman with AD was arrested and jailed for four days for allegedly physically abusing her husband. In another situation, a elderly man with AD was arrested for domestic violence and jailed for two weeks for hitting his wife with a telephone, bruising her arm. These events, widely publicized within the county, demonstrated serious unmet needs for elders in the county, especially during crisis situations.

Ad-hoc local efforts lead to the development of an Elder Services Taskforce. With funding from the Governor's Aging with Dignity Long Term Care Innovation Grant Program, the County created an Elder Services Coordinating Council, with subcommittees to address crisis intervention, developing a resource directory, disaster preparedness, prevention, training and education, and advanced illness planning. The Taskforce's goal was to increase the capacity, quality and accessibility of the County's older adults system of care.

Over 75% of respondents to a county needs assessment identified mobile crisis teams, emergency dementia evaluation and care, and emergency mental illness evaluation and care as unmet needs.

A crisis multidisciplinary team, which includes representatives from Adult Protective Services, Butte County Behavioral Health, and other appropriate agencies, has been established. A geriatric psychiatrist now facilitates a family caregiver group that discusses strategies for caring for an individual with dementia, crisis intervention resources and strategies, and mental disorders associated with dementia and provides consultations on these issues to treating professionals.

The Crisis Intervention Subcommittee continues to convene staff from county agencies, hospitals, law enforcement, community-based long-term care organizations and home health care agencies to discuss roles, responsibilities, resources, and protocols in serving elders in crisis.

The Subcommittee has recommended creation of a mobile multidisciplinary team, comprised of crisis response staff from across agencies and disciplines, to immediately assess the situation, develop a plan to assure the elder's immediate safety, reassure family members, and take the elder to another placement if

needed. The group is also exploring crisis shelter options since this is a critical unmet needs.[26]

For more information, contact Diane Cooper, Co-chair of the Butte County Elder Service Coordinating Council (530) 342-2345.

Los Angeles County--Genesis Program

An example of an Older Adult System of Care based on a county interagency demonstration model is the Geriatric Evaluation Networks Encompassing Services, Information and Supports (GENESIS). This program was jointly created and funded by the Los Angeles (LA) County Departments of Aging (using Older Americans Act Title III-F funding) and Mental Health in the 1980's. The program paired public health nurses with licensed clinical social workers to provide rapid response in-home evaluations, care planning, linkage to existing community resources, and intensive (if necessary) short-term care management for older adults with persistent mental illness or dementia.

By intervening early (to avoid symptoms from escalating and/or reaching a crisis point that requires institutionalization), maintaining the individual in their own home, and using well-trained experienced staff, the program found that only 3% of their clients required hospitalization (compared to a 60% hospitalization rate in their other program) and resulted in $2 million cost avoidance for the county, factoring in the GENSIS program costs. While some initially feared that short-term intervention would not be sufficient, 60% of their clients meet their clinical goals within the first six months and are discharged from the program. Today, the GENESIS program has 8 teams working throughout the county.[27]

For more information, contact Barbara Massey, GENESIS Program Co-ordinator, LA County Department of Mental Health (213) 351-5103.

Orange County Older Adult Services Program

Under their Older Adult System of Care, Orange County has developed three multidisciplinary teams to respond to the particular needs of these subpopulations.

The Crisis Response Team is comprised of 7.5 clinicians: 1 supervisor, 0.5 geriatric psychiatrist and 0.5 pharmacist. This group is principally a Crisis Response team, receiving about 1600 calls annually; 40% are from Adult Protective Services. These clinicians all have formal trained and have experience in mental health and geriatrics. The team accepts calls from consumers, family members or caretakers, professionals, the Office on Aging, community organizations and any groups serving seniors.

[26] Extracted from the Butte County Elder Services Coordinating Council Strategic Plan, June 2002 and from a presentation by Council members at the SB 639 meeting (May 22, 2002).
[27] Trejo, L. personal communication (December 9, 2002).

All consumers are visited and assessed, usually within a 5-day period. No one is denied these services for lack of insurance or public benefits. (This is often difficult to determine initially anyhow.) The team does thorough assessments for mental health issues, cognitive conditions, and takes a careful history of medical issues. They work intensively with family members and caretakers to assure the consumer remains in the safest and least restrictive level of care, including residence. Consumers are referred to the most appropriate venue for ongoing service delivery, whether in a County clinic for mental health services or in the community. The psychiatrist acts as a resource for clinician consultations and performs QI functions. The pharmacist does "brown bag" educational programs for seniors and their families in senior centers or in their homes. He educates them about the appropriate use of their prescription medications, alerts them to possible drug interactions and discusses the use of over the counter preparations and herbal remedies.

The Substance Abuse and Recovery Team (START) is comprised of 2 clinicians, 1 Public Health Nurse and 0.5 pharmacist. The group is a mobile team, providing services to consumers in their homes or in Senior Centers throughout the County. This program is unique in that it partners Public Health and Behavioral Health to provide assessment and service delivery to consumers who are abusing alcohol, drugs and/or prescription medications. The team focuses on harm reduction rather than total abstinence to better gain client cooperation. They carry ongoing caseloads of approximately 50 clients. The pharmacist performs similar duties outlined in the Crisis Response program above.

The Senior Health Outreach Prevention Program (SHOPP) is just one year old, but has already been a huge success. The program was patterned after the START program in that it joins together Behavioral Health and Public Health services. However, because so many of the START clients had coexisting or precipitating physical health conditions, the need for a broader team that could address all of the individual's physical and behavioral issues.

The team consists of 4 Behavioral Health clinicians and 8 Public Health Nurses. The pharmacist and the geriatric psychiatrist also provide some of their time to this program. A geriatric educator acts as liaison to the community partners, providing education and development to their paraprofessional staff; doing outreach and acting as liaison to community organizations; promoting communication and education between BH and PH staff and doing outreach and education with the senior population, their family members and caretakers.

Over 600 clients were visited in their homes or place of residence in the last year. Many lives have been saved due to the team's intervention. The services are short term and linkage is made to other community resources, as appropriate. But the program has been widely embraced and acclaimed within the County.

For more information on these Orange County programs, please contact: Christine Basterrechea, RN PsyD, Interim Program Manager II, Centralized Services (714) 834-4796.

GUIDELINES FOR DISCHARGE PLANNING

Kaiser Behavioral Transition Program--Sacramento has developed guidelines for its discharge planners targeted to hospitalized patients who are medically stable but whose behavior is a barrier to transfer to a lower level of care. These behaviors include agitation, elopement, aggression, intrusiveness, and yelling. These may be hospital patients that have required sitters or restraints.

The Transition Program's goal is to de-escalate and stabilize the behavior of these patients through an intensive, short term behavior management program in a skilled nursing facility setting, so they can be integrated comfortably into a regular custodial, residential or home environment.

The skilled nursing facility's (Norwood Pines) uses a team approach combining monitoring and analysis; developing effective individual non-pharmacological behavioral management strategies (environmental, staff approach and interaction, identification of triggers, etc.); and medication management. Kaiser team members include a geropsychiatrist, geropsychiatric nurse, nurse care coordinator, geriatrician and geriatric nurse practitioner. The nursing facility team includes a behavioral specialist and nursing staff with specialized training and experience, along with the facility's regular recreation, social work and therapy staff.

For more information, contact Dave Bundgard at Norwood Pines Alzheimer's Center, 500 Jessie Avenue, Sacramento (916) 922-7177.

SPECIALTY RESIDENTIAL CARE

Willow Glen Care Center--Yuba City is a non-profit 60-bed long term residential care facility for the elderly (RCFE), licensed by the CA Department of Social Services Community Care Licensing Division and its program is certified by the CA Department of Mental Heath (Short Doyle Medi-Cal for Day Rehabilitation). The Center specializes in serving elderly and other adults with dementia and other mental health conditions.

The Center operates a 24-hour residential care facility and a day rehabilitation program for the elderly and other adults with identifiable mental health conditions. The primary focus of the program is continuous diagnostic assessment of the individual's mental status, prevention of mental health crisis, stabilization and maintenance of the client's mental health, rehabilitation and improvement of the individual's functioning, and transition planning with appropriate referrals.

The program is intended for individuals with an identifiable DSM IV psychiatric diagnosis or crisis requiring temporary or long term placement outside of their home or other living environment and who have rehabilitation potential.

For more information, contact Thomas Ortner at Willow Glen Care Center, 2290 Forrest Lane, Yuba City (530) 755-0992.

ACUTE HOSPITAL DEMENTIA CARE UNIT

In 1999, Cabrini Medical Center in New York City received a local grant to develop an eight bed, family centered acute care unit for patients with dementia within the 500 bed hospital. By redesigning the unit's layout, creating a very quite environment, developing and training a multi-disciplinary team, and including family members in the care planning and problem solving process, care for individual's with dementia was measurably improved. Grant funds were only used for remodeling cost. All other changes were made within the existing staffing levels. Patient functional loss and length of stay were reduced; family caregiver satisfaction has increased. The project's initial phases did not include the ER. With additional grant funding, they hope to include that department in the project's next phase. Further information on this program is available on line.[28]

[28] Nichols, JN (2001) Window to the Heart: Creating an acute care dementia unit: An interview with Jeffrey Nichols, by KS Heller. [electronic version] Innovations in End-of-Life Care, 3(2) from http://www.edc.org/lastacts.

APPENDIX 4 Older Adult System of Care Framework

Adopted by CMHDA, March 15, 2001

INTRODUCTION

The California Mental Health Directors Association has designed this framework to articulate our vision of a fully funded, culturally and linguistically competent, age-appropriate, and gender sensitive Older Adult System of Care (OASOC). This framework identifies the values and beliefs, structural elements, population definitions, and service delivery mechanisms necessary to deliver optimal specialty public mental health services to older adults throughout California. This framework will provide guidance to both policy makers and service providers on policy and program development at the state, regional, and local levels of service delivery.[29]

As a publicly funded mental health system for the state of California, the framework must address the current shifts in our state demographics. With the influx of recent immigrants, there has been a dramatic increase of elders with traditional beliefs and practices, which will affect the utilization of mental health services. The framework also needs to address the indigent older adult population to the extent that resources are available.

A fully funded and implemented OASOC would require a priority for significant funding increases from the State and local governments, particularly for outreach to ethnic and other underserved older adult populations. This document can be useful without additional fiscal resources**,** both as a template for counties searching for ways to identify structural modifications that will enhance their mental health services delivery systems for the target population, and as a template that State policy makers can use to identify funding shortages and critical policy issues.

This framework upholds improving a person's quality of life. It establishes service delivery designs that support effective, high quality, culturally competent, linguistically appropriate, recovery oriented services for older adults, which can be used independently and in tandem with community-based supports. The needs of older adults in recovery/habilitation from mental illness drive the access to and duration of services that are designed to assist them to negotiate multiple physical, socioeconomic, social and age-related stigmas and barriers. This dynamic framework allows older adults to enter, access, re-enter or exit the system at any point, depending on their needs. Services do not follow a

[29] This framework is designed to be flexible, and recognizes that even if it were possible to implement an OASOC in all counties, not all public mental health systems would need or desire to implement all of the service elements that are included in this framework. In order to provide for such flexibility, and in view of prevailing inadequacy of resources, it is important to emphasize that this document is not a set of regulations or review standards to be imposed on local government. It is, rather, an articluation of values and goals to which mental health directors are strongly committed.

particular order, but build bridges with the community in which the consumers and their families live.

Mental health promotion, education and prevention, and wellness activities increase community awareness about mental health issues and the resources available for older adults. To dispel myths and stigmas commonly associated with accessing the public mental health system by older adults, the public mental health system must reach and establish collaboration and partnership with community and faith-based organizations for cross-training to address discrimination issues (such as ageism, racial/ethnic prejudice and the stigma of mental illness).

ISSUE STATEMENT

The current public specialty mental health delivery system is one of uneven distribution and development. Some of these issues include multiple public and private health insurance plans, disparate and unreliable funding streams, multiple entry points, multiple third party payors, and an incomplete patch-work of state and local laws and policies that are frequently in conflict. Often, exclusionary rules and payor policies involving diagnosis or service restrictions complicate efforts to provide services to older adults, and result in increased service demands without additional dedicated resources. In addition, multiple socioeconomic, cultural, linguistic, disabilities and age related stigmas further confound efforts to redress the barriers faced by older individuals in recovery or habilitation from mental illness.

The costs of health care to the public and to older adults are staggering. Increases in the rate and severity of mental illness are due to underutilization of publicly available mental health resources (often as a result of fear and perceived stigma) and/or unrecognized, untreated or misdiagnosed mental disorders. This is especially true when combined with cultural and linguistic barriers which ethnic populations and their families encounter in seeking mental health services. These factors result in an increase in the rate of institutionalization, long term care, medical services, hospital, and emergency services, as well as in the rate and incidence of morbidity, mortality and emotional suffering due to untreated mental illness.

OASOC PHILOSOPHY

An OASOC is a seamless system of services for older adults with mental health issues. It establishes collaborative and cooperative relationships between county public specialty mental health systems in partnership with older adults and their families. Service planning and delivery partners must include CBO's, faith-based organizations, grass roots organizations, and the aging network. OASOC focuses on developing a comprehensive, age appropriate, culturally competent, accountable system of public supports that consumers can readily access and

negotiate to help facilitate their recovery or habilitation, as they themselves define it. The ultimate goal of an ASOC is to achieve quality of life as defined by the elder in partnership with their natural relationships (i.e., family, community, etc.) in his or her life.

The concepts of recovery and habilitation are used in mental health policy and program design and are the means for enhancing quality of life. Though competing definitions exist for each, we have chosen the following definitions as they most nearly approximate our understanding of these concepts. “Recovery” is a personal process through which an individual can choose to change his or her goals, with the ultimate objective of living a healthy, satisfying, and hopeful life despite limitations and/or continuing effects caused by his or her mental illness. “Habilitation” is a strength-based approach to skills development that focuses on maximizing an individual's functioning. The services that consumers require for their recovery and habilitation are unique to every older adult.

Refocusing mental health service delivery on recovery or habilitation represents a profound shift from previous understandings of the service provider and client roles. Although the service elements of every OASOC are manifested differently to reflect geographic goals and realities, they all reflect common elements such as consumer ownership, cultural competency, and flexible service delivery. A comparison of the old mental health model and the new older adult system of care model is illustrated in Table 1.

COMPARISON OF MENTAL HEALTH MODELS	
Old Model	OASOC Model
(Done to/for)	(Done with)
Individual focus	Client/Family/caregiver/community focus
Aging as pathology	Healthy Aging
Emphasis on deficits and pathology	Emphasis on strengths, options and quality of life
Office based	Community based
Individual clinician	Geriatric Multiple Disciplinary Team
Mental Illness symptom reduction focus	Holistic approach (Bio-psycho-social) and spiritual Improve quality of life and regain personally meaningful social roles
Services delivery to client	Services planned collaboratively with client
Providing Advocacy	Consumer and community empowerment, shared responsibility between consumers, families and providers
Quantitative Accountability	Outcome accountability
Service delivery in isolation	Emphasis on cooperation, collaboration, a partnership with other agencies & community
Deny ethnic and cultural differences	Value diversity of ethnic and special populations

Table 1: Older Adult System of Care Paradigm Shift

VALUES AND BELIEFS

1. Mental illness can occur at any age within a person's lifespan.
2. Consumers of all ages (and diagnostic categories) can and do recover. Human beings are resilient. Support and challenge are both important to reestablish quality of life.
3. Consumers and providers enjoy a relationship in which power is a shared responsibility. The power enjoyed by each balances their relationship, and enhances service quality and delivery.
4. OASOC values the unique role that an older adult has in a family and community system, which acknowledges their wisdom, knowledge and ceremonial functions and ability to transmit healthy traditional beliefs and practices.
5. An OASOC is a continuum of services that includes prevention, intervention, treatment and recovery services. These services are delivered in the older adult preferred language.
6. Services are consumer-driven and governed by consumers' choices. They maintain consumer rights, dignity, and respect, and recognize the unique experiences and worldviews that each older adult brings to a system of care.
7. Older adults are more likely than other adults to have co existing medical conditions, possible addictions, multiple losses, cultural isolation, socio-economic stressors, transportation problems, ageism issues and stigma.
8. OASOC system of services seeks to overcome access/services barriers associated with age, race, national origin, gender, sexual orientation, religion, and/or physical disability.
9. Targeted outreach in natural community settings is a critical component to access services to older adults, especially for ethnically diverse populations.
10. Critical components of the recovery/habilitation process must be supported by appropriate resource allocation in order to access quality clinical care, housing, transportation, education, employment or volunteer opportunities, meaningful activities, access to physical health care, and an array of community supports.
11. Quality of life (recovery/habilitation) is supported by access to high quality clinical services, delivered by skilled and motivated clinical personnel who can use culturally based practices and recognize the importance of integration into the older adults components of quality of life.
12. The OASOC makes an effort to work with the family and understand the impact of acculturation process in determining the primary caregiver responsibilities and the level of care needed for the older adult.
13. Quality of life (recovery/habilitation) is anchored in a range of interpersonal relationships, including families, caregivers, peers, friends, significant others and community supports.
14. Service agencies must create a culture of mutual respect and support, which empowers staff to work effectively together to provide quality care. This includes empowering and supporting each other in the workplace and

creating the kinds of organizational environments that support recovery/habilitation for older adults we serve.

15. Services are strength-based, recognizing that consumers with varying strengths, symptoms, life situations, experiences, and cultural values have unique goals and approaches to their recovery/habilitation processes.
16. Effective clinical services are supported by on-going training, consultation, and technical assistance.
17. Service quality requires development of appropriate benchmarks and accountability, with ongoing monitoring for consumer satisfaction and relevant clinical structures, processes and functional outcomes
18. Attention to problems of elder abuse and neglect, including self-neglect, needs to be identified and addressed.
19. Research and evaluation policies need to be developed that include diverse ethnic populations.

OLDER ADULT SYSTEM OF CARE DEVELOPMENT

This parameter defines the aspects of a System of Care's organizational infrastructure that are required to transform diverse services into a gender-sensitive, culturally and linguistically competent continuous and comprehensive system. The aspects to which we refer are collaboration and partnership, transition, governance and organizational structure, outreach, education and advocacy, strategic planning, community and human resource development, and accountability.

Collaboration and Partnership

The success of a recovery-based system of care is anchored in providers collaborating with consumers, families, and community, requiring inter-organizational, inter-agency, and intra-county collaboration as well. Collaboration must occur between agencies and/or individuals that are involved in a consumer's life in terms of policy, planning, and service delivery. Collaboration across individual, family, and community systems is needed to identify older adults who would benefit from public mental health services.

Families, the community and caregivers are at the core of a successful partnership in recovery. 'Family members' is defined broadly to include relatives, caregivers, peers, friends, and significant others as determined by the individual consumers. Services will include consumer-driven quality of life plans that honor and protect consumer privacy and choice with regards to the involvement and re-involvement of family members and caregivers.

Local inter-agency collaboration begins with and is supported by state level inter-agency collaboration. State agency commitments must be clearly communicated to local agencies. Many mental health departments rely on relationships with other government agencies to offer access to important services and supports

like housing, transportation, health care, employment, and education. Collaboration will be stronger if requirements and incentives to collaborate are similar across local agencies, and this in turn will require commitment and collaboration by state departments and agencies. The role of the State Mental Health Department includes assisting local agencies in designing the right kind of supportive services that will accommodate consumer needs, and in establishing collaborative relationships that work.

For many mental health departments, formal and informal collaboration with community-based and faith-based organizations is required to build the organizational infrastructure necessary to ensure that consumers have access to a wide variety of therapeutic and support services and opportunities for community integration. Contracting partnerships with community-based organizations can offer rich and seamless services for consumers with the goal of including community partners in the healing process. Bridges built between mental health departments and a variety of local social service and peer support, health care, and aging networks give consumers in recovery/habilitation broader opportunities to settle into appropriately designed community supports. Abuse/neglect prevention and education need to be addressed across the systems of care serving all age groups.

Transition Services

Formal, system-embedded transition services into and out of age-based OASOC should be strong, specific, planned, and collaborative.

Transition Age Older Adults: Specific planning must occur between ASOC and OASOC to develop individual transitions for adults who might need to access the specialized services of the OASOC. The purpose of integrated joint planning is to build a bridge between adult system services and the services to meet special needs of older adults. Integrated planning should begin based on the functionality of the individual, the likelihood that the person will need the intensive linkage to health and support services available under OASOC and the desire to provide continuous care during the transition. Services to older adults during this period may include:

- Identification of specialized residential facilities that can serve linguistically and ethnically diverse client population for intensive care and security.
- Consultation to other agencies and providers with a focus on assisting with culturally appropriate and differential diagnosis and identifying existing co-morbid conditions
- Strengthening linkages to health care providers
- Intensive work with families and caregivers, focused on education regarding mental health needs and advocacy for appropriate linkage to other community supports

- Assessments of the need for alternative care options.

Governance and Organizational Structure

The county mental health department is responsible for taking the leadership role in the development of the OASOC. This entity has the authority at the policy, program, and funding level to coordinate services that may be provided by the local mental health department (i.e. therapeutic and support services) and responsibility for linkages with services and supports provided by other local agencies, and/or local service and support organizations (i.e. housing, education, employment, peer support networks, and health care providers).

System of Care Councils must be established that represent two levels of input and collaboration - one for resource and policy development and a second to coordinate hands-on delivery of services. Both should reflect the ethnic and cultural diversity of the community.

- Develop written operational guidelines which would address cultural competency
- Develop, disseminate and maintain a local OASOC plan
- Coordinate with local boards and commissions

Outreach, Education, and Advocacy

Outreach, education and advocacy are pivotal to a system of care. Targeted community outreach, education, and advocacy efforts, focused on system of care values and beliefs, should be part of every mental health department's strategy. Older adults are affected by stigma, ageism, discrimination, and cultural and linguistic isolation that greatly impact their ability to access and utilize mental health services. Effective outreach, education, and advocacy may be provided through the use of home and/or community based activities, mass media, peers, and families and must address all ethnic communities in the target service population.

Strategic Planning

County mental health departments must assemble the partners to develop a framework for long-term planning and organizational development for the Older Adult System of Care. This framework will guide regional and local resource allocation, and will allow utilization of funds to build the essential elements of a culturally competent, value-based, treatment-effective, and coherent OASOC.

Human Resources Development

Recruitment and retention of geriatrically trained staff who are culturally competent and ethnically diverse is a large and growing problem in the public

mental health system. Strategies for recruitment and development of staff must be a part of OASOC design and implementation. Training of current and new staff in the values and strategies of a recovery/habilitation-based OASOC is needed for organizational development. Training is also needed for ongoing system operation. Training must be a regular part of every OASOC project and must include staff, consumers, family members, faith-based, community-based, grassroots organizations, health and social service providers, the public, collaborative partners, academic and research institutions, and the recovery/habilitation community. OASOC programs must have a human resource component that includes:

- Identification of staff with expertise in aging who are representative of the ethnic and linguistic needs of consumers
- Development and implementation of a retention plan for these highly trained staff
- Training specifically designed to provide geriatric competency across cultures

Accountability

Accountability and service quality must be guaranteed through development of policy, procedures, and performance outcome data that ensure:

- Age-specific service quality indicators
- Cultural and linguistic congruence
- Clear documentation of medical necessity for clinical services
- Clear accounting of all funding sources and expenditures
- Ongoing monitoring of consumer and caregiver satisfaction
- Ongoing monitoring of individual and aggregate outcomes
- Sharing of outcomes and other relevant information with local collaboratives, and
- Use of outcomes to improve service quality

Best Practices

Identification, development, promulgation, and adoption of best practices guidelines for care must be an integral part of ongoing OASOC design and modification. These guidelines should be regularly reviewed and modified based upon field-practice and experience, state and national system outcome measurement results and advances in knowledge and technology.

SERVICE POPULATION DEFINITI0N

The OASOC service population includes persons 60 years and older, who, due to a mental disorder, have a reduction in personal or community functioning, and are best served in the public specialty mental health system. This includes persons with co-occurring disorders who have primary diagnoses of mental

illness. The system of care acknowledges its leadership role in facilitating services needed by other populations through cooperation and collaboration.

Services will be provided until the individual recovers or no longer accepts services, or until client outcomes would be better served outside the public specialty mental health system.

Older Adults

The OASOC recognizes that older adults present unique needs, challenges, and opportunities that may include:

- Biological changes associated with normal aging
- Multiple losses
- Cultural values, world view and beliefs as they relate to the role of an older adult, their place in the family and care-giving expectations
- Increased risk of cognitive impairment, physical illness, and functional disability
- Language needs that predispose older adults to linguistic isolation
- Recognition of merits of survival resilience

The Older Adult System of Care service population includes three broad service-based consumer populations:

- Older Adults 60 - 64 "Young Old"
- Pre-retirement age
- Working age (may lack SSI and Medicare eligibility)
- Transitional age adult into older adult
- Language needs that predispose older adults to linguistic isolation

- Older Adults 65–84 "Middle Old"
- Retirement age
- Access to SSI and Medicare and other pension systems
- May have increased risk of loss in social support, physical health and income
- Highest risk group for completing suicide
- Recognition of merits of survival/resilience

- Older Adults 85+ "Oldest Old"
- Fastest growing segment of the older adult population
- Highest risk for cognitive impairments, physical, social and financial problems
- Cohort differences, especially in relation to definition of self, illness and society (e.g. role, identity changes)

The age ranges stipulated in the foregoing population definitions do not imply actual or expected service delivery requirements, but are included here for planning, and to delineate three broad subsets of the population along a continuum of service needs. OASOCs recognize that every consumer is unique, and that each must make individual choices about his or her service needs.

SERVICE ELEMENTS

The following service elements reflect the vision of an age-specific culturally and linguistically competent, recovery/habilitation-oriented OASOC. This "menu" of service elements has been developed as though full funding would be made available. The full menu may not be achievable for every locality immediately. The list of service elements is intended to serve as a guideline for counties in creating comprehensive systems that are responsive to the diverse needs of local communities.

Service elements will reflect the needs of the populations served. That is, services should be age-specific, culturally competent and linguistically appropriate for the demographics of the geographic area served. Sites targeted for outreach and services should be the natural gathering places or homes of older adults as often as possible.

Multi-disciplinary teams have been demonstrated to be effective, especially when available on a mobile basis, and may include professionals, para-professionals and consumers. The delivery service of the team may require services to be rendered at the home, alternate service-sites, shopping malls, and in the community. It is through the activities of the team that services become truly seamless and accessible.

Access to and duration of services are individually determined and directed by the consumer. The framework is designed to be dynamic so that individuals can enter/access services and can exit or re-enter the system at any service point, depending on their needs.

The standard for an OASOC is to be "recovery/habilitation" focused and designed to provide services across four primary dimensions:

1. **Prevention, promotion, and wellness**
2. **Entry/Access**
3. **Therapeutic/Recovery/Habilitative Services**
4. **Services provided by integrated agencies and/or with community collaboration and partnership**

1. **Prevention, promotion, and wellness** These activities complement direct service and recovery/habilitation activities by increasing community awareness about mental health issues and the resources available within

Systems of Care as well as other community resources. Specific elements are as follows:

- Education to dispel the myths and stereotypes commonly held by the elderly about mental illness.
- Anti-stigma education (e.g. mental illness and ageism)
- Behavioral health screenings
  - Bio-psycho-social screenings
  - Alcohol/Drug screenings
  - Depression screenings
- Community education and training (e.g., law enforcement, adult protective services, aging network, family caregiver resource, health care provider)
- Community mental health consultation (e.g.. liaison with government and other organizations; problem-solving around community mental health issues and older adults)
- Abuse/neglect prevention and education options (e.g. Multidisciplinary Teams, CARE Teams, and FAST Teams.)
- Information referral and linkage to appropriate community resources
  - Community resources
  - Assisting in accessing appropriateness of community resources

2. <u>Entry/Access</u>

The OASOC should minimize barriers and create services that are easily identifiable and available throughout the community.

- Consumer, family, and caregiver training on how to access services
- Linkages to health services (i.e. medical, dental, placement; community residential options)
- Assertive mobile outreach to older adults' natural settings, such as senior centers, mobile home parks, senior education classes, recreation centers, and residential settings in collaboration with the community.
- Communication among social and health service providers working with older adults.
- Transportation-identify and overcome barriers to adequate transportation systems in both rural and urban areas.
- Engagement - problem resolution of consumer-identified needs (for example, housing assistance, physical and dental health care, educational services and other community resources) (These should include linguistically competent, age-sensitive approaches.)
- Screening and/or initial assessments by mental health professionals trained in age specific issues, cultural competency, and respecting older adult values and beliefs

- Advocacy for historically underserved groups
- Family, caregiver support, and community consultation and collaboration
- Assertive involvement with discharge planning (e.g. education on symptom management support services in the community)
- Enter/Exit System – any service point depending on consumer's needs
- Continuity of care /older adult services – age appropriate services delivered by specially trained staff across the continuum of need, including in-home care and assistance with activities of daily living

3. **Therapeutic/Recovery/Habilitative Services**

The OASOC is a continuum of care and works in cooperation with other community resources. These mental health services may include case/care management, assessment/evaluation, outpatient/inpatient treatment, and residential care, etc. The following services may be provided by other agencies and coordinated by the case/care management teams.

- Comprehensive assessment including a clinical assessment as well as assessment for non-clinical support needs such as housing, occupational, recreational, or volunteer involvement, income, social supports, education, dual diagnosis needs, health care, in-home supportive services, etc.
- Care management and coordination (linkage, brokerage and advocacy, SSI, Medi-Cal, food stamps, physical health care) consultation and referral services
- Crisis services (includes mobile crisis as appropriate)
- Stabilization services
- Comprehensive services for recovery/habilitation of persons with dual disorders
- Psychotherapy/Counseling (Individual, Group, Family)
- Mental health education
- Medication stabilization and maintenance
- Forensic mental health services
- Acute and long term inpatient care
- Residential care with a therapeutic environment tailored to the needs of older adults
- Home care assistance, including training of caregivers and providers about enhancing the 'therapeutic environment' of the home
- Skill building (e.g., relapse prevention/WRAP, stress management)
- Clinical management related to somatic treatments, including collaboration with general medical providers

4. Services Provided by Integrated Agencies and/or with Community Collaboration

Collaboration is key to successfully providing mental health services to older adults and their families. OASOCs must emphasize formal and informal collaboratives, and promote integration of service provision in their communities.

- Supportive and independent housing
- Supportive and independent employment or personal growth opportunities
- Supportive and independent education
- Peer supports (peer recovery/habilitation network, drop-in centers**,** day centers, etc.)
- Family and caregiver support and consultation
- Exit planning and successful linkage to other supports
- Cultural and ethnic services
- Gender and sexual orientation based services
- Senior centers
- Freestanding wellness recovery/habilitation centers
- Residential care facilities for elderly with therapeutic environments (including a supplemental rate for mental health services
- Physical health care
- Senior legal aid
- Faith based organizations and spiritual groups
- Dispute resolution
- Traditional healers
- Senior peer counseling
- Intensive case management
- Family advocate
- Adult day health care
- Adult day care
- Partial hospitalization
- Geriatric assessment centers
- Private caregiver resource centers
- Senior nutrition centers
- Adult Protective Services
- In-home Supportive Services
- Multi-Service Senior Programs
- Senior volunteer programs
- Foster Grandparents
- Shared housing
- Veterans Services
- Transportation services
- Fitness centers

- Community colleges
- Public Guardian: LPS and probate guardianships
- Regional Centers
- Consumer support groups
- Grief/loss support groups
- Self-help groups (i.e. COPD, Overeaters Anonymous, Hospice, cancer, asthma, pain, Parkinson's, Alzheimer's, Alanon, AA, NA.)
- Multigenerational family consultation
- A full array of outpatient services specializing in geriatric diagnosis and treatment

The CMHDA acknowledges the many contributions that older adults have made, and continue to make to society. It is in recognition of these many contributions that this framework is dedicated.