

2020 FORESIGHT:

San Francisco's Strategy For Excellence In Dementia Care

Research, recommendations, and an action plan to address the growing crisis in dementia care, and an economic analysis of that care.



Part One of Two

- Plan Purpose and Historic Context
- The Planning Process
- Mission, Values & Vision
- The Nature of the Crisis
- Improving the Service Network
- Objectives
- Recommendations
- Action Plan
- Impact of 2009-2010 State Budget

By Alzheimer's/Dementia Expert Panel

For Department of Aging and Adult Services

December 2009

THE HUMAN FACE OF DEMENTIA

This *Strategy for Excellence in Dementia Care* is dedicated to ensuring that services and supports in San Francisco are organized around the needs of people with Alzheimer's and related dementias and their caregivers, and not around organizational or service provider needs. Below are examples of people with dementia who might require care and support in San Francisco – now and in the future.

Vignette #1: MaeLynn Chang and Janice Lee

MaeLynn, age 74, has lived alone in her home in the Sunset district since her husband, MingTong, died several years ago. Her daughter, Janice Lee, lives in Antioch. While she sees her mother several times a week, the strain of getting back and forth to the City takes its toll. Of late, she has noticed that her mother has been unusually forgetful, last month failing to recall her birthday. More alarming, MaeLynn recently started the stove to make tea and then went to bed without turning off the burner, only to be awakened by the smoke alarm and the scent of a scorched pan.

Vignette #2: Roberto Gonzalez

Roberto Gonzalez is 81 years old and has lived alone for over 20 years since his wife, Maria, left him. He has no children and his closest relatives, two cousins, live in south Los Angeles. He rarely communicates with them, as there has been a history of family conflict. Until recently he had been active in the City of Refuge United Church of Christ near his single room occupancy hotel unit on Folsom Street in the South of Market neighborhood. Members of the church have been concerned about his behavior of late, including his missing services or appearing for services on odd days. One church member visited to speak with him and the resident manager only to discover Roberto's normally meticulously neat room to be in disarray. The resident manager noted that Roberto had recently forgotten to pay his rent and when reminded, seemed confused. Despite living on a fixed income, Roberto had never failed to pay his rent on time.

Vignette #3: Richard Brown and Damien Thomas

Richard Brown and Damian Thomas have lived together for over 25 years. Richard is 14 years older than Damian and at 69 is beginning to show signs of memory loss. Richard is an artist and he is often alone as part of his creative process. Lately, however, he has begun to feel isolated. He recently had great difficulty figuring out how to operate the remote control for the television, a tool he had been using for many years. When trying to turn the sound to mute, Richard looked at Damian with a confused expression and then simply gave up. Damian works as a program manager at the Department of Human Services and is becoming concerned that Richard may be developing Alzheimer's or some other form of dementia.

These vignettes provide examples of the kinds of San Francisco residents entering the world of cognitive impairment and dementia. They demonstrate the need for expanded community education; enhanced workforce training; improved service coordination; early diagnosis and improved access to treatment, care and services; and the need for ongoing caregiver support. This *Strategy* offers many recommendations to address these situations. When implemented, the recommendations will improve access to a full range of services for the increasing number of people with cognitive impairment and dementia, and to a variety of resources and supports for their caregivers.

TABLE OF CONTENTS

SECTION	TITLE	PAGE
	Executive Summary	1
	Letter From Mayor Gavin Newsom	8
	Message From Expert Panel Co-Chairs	9
	Message From DAAS Executive Director	10
	Expert Panel Members & Affiliations	11
	Subcommittee Members & Affiliations	12
	Acknowledgements	13
I	Background	14
I.A.	Plan Purpose & Historic Context	14
I.B.	The Planning Process	16
I.C.	Mission, Values & Vision	18
II.	The Nature of the Crisis – A Demographic & Fiscal Imperative to Act	22
II.A.	Background on Dementia	22
II.B.	San Francisco’s Demographic Factors	24
II.C.	Projections of Population Growth & Costs of Dementia Care	28
III.	Improving the Service Network	36
III.A.	Literature Review	36
III.B.	San Francisco’s Assets & Challenges	38
III.C.	Existing Services & Supports: Key Challenges	41
IV.	Recommendations for Excellence in Dementia Care: In the Short Term & in the Future	47
V.	Action Plan & Next Steps	73
VI.	Impact of 2009-2010 State Budget	92
VII.	Conclusion	95
 APPENDICES		
I.	Evidence Based Practice & Emerging Research	3
II.	Inventory of Services and Supports	56
III.	Education & Prevention Recommendations	69
IV.	Finance Detail	98
V.	Inventory of Plans in Other Jurisdictions	100
VI.	California Guideline for Alzheimer’s Disease Management	116
VII.	United Kingdom National Dementia Strategy	117
VIII.	Additional Standards and Guidelines	118
IX.	Managed Chronic Care Demonstration Project Requirements	120
X.	Key Informant Interviews	121
XI.	Bibliography	123
XII.	Challenges in San Francisco: Caregiver Issues (Dementia Summit Powerpoint Presentation)	131
XIII.	External review team comments from: (1) Andrew Scharlach, PhD, School of Social Welfare, UC Berkeley; & (2) Kristine Yaffe, MD, Chief of Geriatric Psychiatry and Director of the Memory Disorders Clinic at the San Francisco VA Medical Center	145

EXECUTIVE SUMMARY

San Francisco is facing a crisis in dementia care. In the Bay Area, one out of every two people 85+ has some type of dementia. Between now and 2020, San Francisco will experience a dramatic increase in the number of its citizens with Alzheimer's disease and other dementing illnesses. Between 2010 and 2030, there will be a 49% increase in the number of people with Alzheimer's related dementias (from 23,445 to 34,837). This does not include the increase in the number of people with other forms of dementia and mild cognitive impairment (MCI).

An Alzheimer's/Dementia Expert Panel, formed by Mayor Gavin Newsom in November 2008, investigated the growing crisis in dementia care. The Expert Panel was charged with developing a plan to address the demand for services related to Alzheimer's/dementia care between 2010 and 2020, and an economic analysis of that care.

Background: The Department of Aging and Adult Services (DAAS) led and managed this initiative. In September 2008, DAAS retained the services of a research team consisting of Gibson & Associates, Resource Development Associates, and the Mental Health Association of San Francisco. This research team worked with the Expert Panel and DAAS staff to undertake an evaluation of San Francisco's current dementia care services, project the need for additional services, and with guidance from the Expert Panel, prepare a plan and recommendations to address the needed services during the next 10 years (2010 to 2020). The work of the Expert Panel took place between December 2008 and May 2009. There were six Expert Panel meetings. Four sub-committees researched specific topics and reported back to the Expert Panel to assist in its deliberations. Each subcommittee met approximately five to seven times.

From the outset, the Expert Panel sought to create a *Strategy for Excellence in Dementia Care* that could serve as a road map, providing policy makers with short-term and intermediate recommendations that can be implemented within the current network of care as well as long-term recommendations that incorporate significant reforms. As the values and vision developed by the Expert Panel describe, as was evident in the research, and as was expressed by Panel members from the first meeting: service providers continuing to operate in silos (separate organizational structures) is no longer acceptable and a more integrated model of care is needed. *San Francisco's Strategy for Excellence in Dementia Care* points to a future approach to service delivery that is characterized by:

- Expanded community education and training;
- Improved service coordination;
- Shared client information;
- Team-based care;
- Promotion & dissemination of the most current standards and guidelines for care;
- Education & training for service providers to implement those standards and guidelines; and
- Improved access to resources and services in the early stages of this disease and, hopefully, a delay in the need for more intensive services in later stages.

It is the Expert Panel's hope that even its most visionary recommendations may in time be realized, as state and national health policy reform becomes more aligned with San Francisco's historically progressive approach to the delivery of health care and social services. Panel members also made recommendations that could emerge without major policy changes at state or national levels, or without a massive infusion of financial resources. The resulting plan strikes this balance, including:

(1) low cost initiatives for education and training, and improved access to services, that could be implemented relatively easily; (2) a pilot project to improve care coordination; (3) promotion of guidelines and standards that, while challenging to implement, do not require significant new funding; (4) advocacy and policy recommendations that could enable the City to better manage its resources and invest in services that might reduce the use of more intensive, higher cost services; and (5) demonstration projects that require varying levels of public and private investment, but once established could lead to broad replication of research-based approaches.

The following objectives and recommendations are intended to address the growing crisis in dementia care, from early memory loss, to the progression to mild, moderate, and advanced dementia. However, if San Francisco could: (1) help people to learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment; (3) offer training and support for caregivers and service providers; and (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, the need for more intensive and costly services could be delayed.

The advance of the disease cannot currently be halted. This being the case, we should provide comprehensive, compassionate care for people with dementing illnesses and their care partners at each stage. Until there is a cure or treatment for cognitive decline, achieving these objectives and implementing these recommendations will allow us to better manage each individual's complex medical conditions along with their cognitive impairments in a way that will improve quality of life.

OBJECTIVE 1: Improve capacity to meet the needs of the whole person by delivering integrated care.

RECOMMENDATION 1-1. Dementia care should be integrated into San Francisco's existing long term care service delivery network, which emphasizes ongoing chronic care management. This will enable the needs of the whole person to be considered and addressed.

RECOMMENDATION 1-2. All agencies and programs delivering services in the long-term care service delivery network as well as first responders and urgent care clinical settings should become dementia capable. This will require education, training, and support for service providers and families. Agencies and programs serving people with dementia will need to consider the stigma related to dementia, the concerns of existing clients, and the dignity of new clients experiencing cognitive impairment or dementia.

OBJECTIVE 2: Improve public and professional awareness and understanding of dementia.

RECOMMENDATION 2-1. Public education should be expanded and enriched and should target those experiencing memory loss and those newly diagnosed with Alzheimer's and related dementias, and their caregivers, as well as service providers, care managers, and health care professionals. Funding should be sought and obtained to enable the provision of this expanded public education.

Public education and training should be available on the following topics:

- Risk Reduction;
- Early Identification of Alzheimer's and Related Dementias;

-
- ❑ What To Expect as the Disease Progresses;
 - ❑ Services and Resources;
 - ❑ Caregiver Wellness and Support;
 - ❑ Disease Management - Mild, Moderate & Advanced Dementia;
 - ❑ Advanced Care Planning;
 - ❑ Ethical Issues; and
 - ❑ Emergency Preparedness and Safety.

OBJECTIVE 3: Develop an informed and effective workforce for people with dementia.

RECOMMENDATION 3-1. The most current guidelines and standards for dementia treatment and care should be identified, promoted, and disseminated to professionals on a regular basis.

RECOMMENDATION 3-2. Training for professionals, including community-based service providers and care managers, should be expanded to facilitate implementation of the most current guidelines and standards for dementia care. Funding should be sought and obtained to enable the provision of this expanded training.

RECOMMENDATION 3-3. Targeted training for primary care physicians, hospitalists, and the medical staff of primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente should be expanded related to medication prescriptions, diagnosis, end-of-life care, and managing difficult behaviors and critical crisis care issues.

RECOMMENDATION 3-4. An electronic medical record (using a “patient dashboard”) should be researched and developed for the use of health and social service staff which will: (1) enable cross-system information sharing; and (2) improve service coordination.

OBJECTIVE 4: Expand capacity to deliver high-quality early diagnosis and intervention for all.

RECOMMENDATION 4-1. Diagnosis of mild cognitive impairment (MCI) should be encouraged and facilitated with clearly established diagnostic criteria.

RECOMMENDATION 4-2. A standardized screening tool for chronic conditions and illnesses, which encompasses cognitive function, mood, activities of daily living, and caregiver or family observations, should be selected or developed. This should be used by health care professionals (primary care physicians, physician assistants, nurses, nurse practitioners, social workers and clinics) and psychologists, to assess the need for a comprehensive evaluation for adults with memory complaints or cognitive change, possibly including referral to a specialist for thorough diagnosis.

RECOMMENDATION 4-3. A range of clinical geriatric fellowships should be developed at UCSF for physicians, nurses, and social workers training in geriatric practice, with fellows committing to a number of years working in community health services (primary care health centers and clinics operated by the Department of Public Health and the San Francisco Community Clinic Consortium), performing assessments, and managing the care of people with Alzheimer’s and related dementias.

RECOMMENDATION 4-4. Barriers and financial disincentives in medical care should be removed that deter physicians from providing geriatric assessments, diagnoses, and ongoing care by increasing reimbursement rates for these services.

RECOMMENDATION 4-5. Barriers and financial disincentives should be removed that limit access to services that are based on a single diagnosis.

OBJECTIVE 5: Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and for their caregivers.

RECOMMENDATION 5-1. To enable easy access to quality information, people with cognitive impairment and dementia as well as their caregivers will benefit from the professionally staffed “central door” of San Francisco’s “no wrong door” approach.

OBJECTIVE 6: Create expanded and easy access to care, support and advice following diagnosis.

RECOMMENDATION 6-1. A team approach to dementia care and service delivery should be piloted, employing care managers with dementia expertise operating as the “single-point-of-contact” for people with dementia using primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente. This will result in a better informed and coordinated delivery of services.

RECOMMENDATION 6-2. Structured peer or volunteer support and learning networks should be developed for people with dementia and their caregivers, especially in early and mid stages. The establishment and maintenance of such networks will provide direct informal support delivered by trained volunteers. These networks can also provide practical and emotional support, reduce social isolation, and promote self-care.

OBJECTIVE 7: Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.

RECOMMENDATION 7-1. Immediately upon a diagnosis of dementia being made, a practice should be established where doctors and their staff refer caregivers as well as family members to supports, such as education, counseling, caregiver assessment, and services.

RECOMMENDATION 7-2. Additional respite care services should be developed for people with Alzheimer’s and related dementias. Increased respite care should be part of the supports (that include education, counseling, assessment, and services) for caregivers and family members. Funding should be sought for additional respite care.

OBJECTIVE 8: Improve the quality of hospital and nursing home care for people with dementia.

RECOMMENDATION 8-1. A meeting of acute care hospitals should be convened to review all existing care plans for patients with any type of dementia, identify best practices for the care of hospitalized adults with dementia, and implement best practices to improve their care.

RECOMMENDATION 8-2. Nursing home placement should not only be for the purpose of safety and containment of dementia related behaviors, but also for person-centered care with an array of services that address all of the needs of the person and not solely the diagnosis of dementia.

OBJECTIVE 9: Expand and improve the quality of community-based care for people with dementia.

RECOMMENDATION 9-1. An expanded range of community-based services should be developed for people in the early stages of cognitive impairment or Alzheimer's and related dementias, based upon evidence-based practice and emerging research.

RECOMMENDATION 9-2. The full range of adult day services (Adult Day Health Care, Social Day Care, and Alzheimer's Day Care Resource Centers), appropriate for people at different stages of the disease, should be expanded and improved. Day care programs and staff should be informed, trained, and capable of addressing the needs of individuals with cognitive impairment or Alzheimer's and related dementias and their caregivers.

RECOMMENDATION 9-3. Services and supports should be developed for people with cognitive impairment or Alzheimer's and related dementias who have no family, or who do not have family members living in close proximity to San Francisco.

RECOMMENDATION 9-4. A crisis intervention and assessment setting should be developed for the placement of people with cognitive impairment or Alzheimer's and related dementias who are no longer safe in their own environments and/or who have behavioral issues.

RECOMMENDATION 9-5. Advocacy for changes in the mental health system should be undertaken at the local and state level to eliminate the carve-out of mental health services for people with a primary diagnosis of dementia. San Francisco's mental health system and medical/health care system should be encouraged to collaborate more effectively in serving clients with both dementia and mental illness, or those with Alzheimer's who develop mental health related conditions.

RECOMMENDATION 9-6. A plan should be developed to provide and fund services, particularly respite care, for people with Alzheimer's and related dementias who are above Medi-Cal eligibility. The needs of these individuals, who are often unable to get the services they require, should be addressed.

OBJECTIVE 10: Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.

RECOMMENDATION 10-1. A range of residential care settings should be developed for people who require both residential and nursing care services.

RECOMMENDATION 10-2. Residential care settings should be designed and operated not only to ensure individual safety and contain dementia-related behaviors, but also to offer person-centered care with an array of services that address the whole person.

OBJECTIVE 11: Improve access to end of life care for people with dementia.

RECOMMENDATION 11-1. Advocacy should be undertaken for changes in local, state and national policies to enable individuals with late stage Alzheimer’s and related dementias to be able to more easily access hospice care. This will require establishing diagnostic criteria that are more in line with the progression of late stage dementia, allowing for the extension of time limits, and ensuring palliative care is available to people with dementia.

OBJECTIVE 12: Advocate for effective state and national support for the implementation of this *Strategy*.

RECOMMENDATION 12-1. Education and advocacy for universal coverage for long-term supports and services should be undertaken so that this is part of national health care reform. Work to assure that Medicare and Medicaid regulations are coordinated to allow for the best possible patient care.

RECOMMENDATION 12-2. The City should advocate for legislation that would require the State Department of Health Care Services and State Department of Social Services to develop expertise in dementia care.

RECOMMENDATION 12-3. The City should explore federal waivers for assisted living programs to enable the retention of Medi-Cal funds for these services and the ability to manage them locally.

RECOMMENDATION 12-4. An enhanced nursing home diversion services project should be considered. This project would be developed in collaboration with the California Department of Aging, funded by a grant from the federal Administration on Aging.

RECOMMENDATION 12-5. The feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including those with Alzheimer’s and related dementias, should be explored.

OBJECTIVE 13: Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.

RECOMMENDATION 13-1. Efforts should be undertaken to make San Francisco more accommodating of people experiencing forgetfulness and cognitive impairment. These efforts should be connected to the local, national, and international movements toward creating age and disability friendly communities.

OBJECTIVE 14: Facilitate and support an Oversight Committee responsible for implementing this *Strategy*, and advocating for improvement of prevention, education and services related to dementia.

RECOMMENDATION 14-1. A *Dementia Care Excellence Oversight Committee* should be established for: (1) overseeing the implementation of this Strategy and its recommendations; (2) monitoring the progress of workgroups, (3) monitoring the participation of partners; (4) undertaking advocacy efforts to influence state and national legislation; (4) overseeing the exploration and initiation of pilot projects and demonstration projects; (5) identifying guidelines and standards of care for all components of the network of services for individuals with dementia; and (6) fostering adherence to these standards by all appropriate service providers.

ACTION PLAN AND NEXT STEPS

(See complete Action Plan on page 73)

San Francisco's response to the growing crisis in dementia care should be comparable to the City's comprehensive and effective response to the AIDS epidemic back in the 1980s. To be successful, the implementation of this *Strategy for Excellence in Dementia Care* will require a unified, proactive, long term response. This effort should not be the responsibility of any single city department. Should this be the case, implementation will falter or fail. Instead, this effort will require the involvement of many city departments, non-profit agencies, social service agencies, health care providers, residential care and institutional care providers, and advocacy groups. Success will also require that ongoing staffing for the seven recommended workgroups is provided by several different city departments.

Leadership required to advance this *Strategy*

Visible leadership will be required to make this *Strategy* a reality. The overarching leadership and direction for its implementation across city departments should come from the Mayor's Office. A *Dementia Care Excellence Oversight Committee*, whose members should be appointed by the Mayor, will oversee all implementation activities. The Department of Aging and Adult Services will take part of the leadership role. However, other city departments, agencies, and organizations will need to be actively involved and commit resources, staffing, advocacy, and time to this effort.

Other city departments, agencies, and organizations recommended for participation and leadership include: the Department of Public Health, University of California at San Francisco (UCSF), the Alzheimer's Association of Northern California and Northern Nevada, Family Caregiver Alliance, San Francisco Medical Society, Sutter Health, Catholic HealthCare West, Brown & Toland Physicians Medical Group, Hill Physicians Medical Group, On Lok Lifeways, Kaiser Permanente's national office in Oakland, and the Long-Term Care Coordinating Council. Expert consultation on specific issues will be required from members of the Expert Panel periodically for a limited time. For example, they may need to provide access to the UCSF Department of Medicine.

Recommended workgroups required to implement this *Strategy*

1. Training And Education
2. Guidelines And Standards
3. Additional Services And Settings
4. Medical Resources
5. Shared Electronic Medical Records System
6. Waivers, Pilot Projects, And Demonstration Projects
7. Advocacy

Conclusion

There is no cure for dementia on the immediate horizon. A wave of baby boomers is approaching the age where Alzheimer's and related dementias will begin to emerge. There will be a crisis in dementia care and San Francisco must respond. The Alzheimer's/Dementia Expert Panel spent months deliberating on research, local data, and input from caregivers and other stakeholders. The recommendations provided in this report are the product of that focused and intensive work. San Francisco must act with urgency, move forward to implement these recommendations, and realize our vision of care for people with dementia so that they can live in dignity and thrive.



October 2009

Dear Citizens of San Francisco,

The City and County of San Francisco has long been a leader of innovation in services and support for seniors and persons with disabilities. Today, we need that spirit of innovation more than ever as the approaching "age wave" may bring a potential crisis in Alzheimer's and dementia care to our county.

San Francisco has the highest percentage of seniors of any county in California and the highest portion of seniors living alone. I know that many caregivers give their lives to care for a loved one with dementia. Last year, in June 2008, based on the findings and recommendations of the Long Term Care Coordinating Council, I put money in the budget to fund a comprehensive assessment of the demand for services related to Alzheimer's and dementia care, and to assess the need for support for caregivers. In November 2008, I appointed an Alzheimer's/ Dementia Expert Panel charged with investigating this pending crisis and helping San Francisco to plan for the future. I want to express my gratitude to the many leaders and experts who helped produce the incredible analysis and thoughtful recommendations that follow.

I invite you to join me so that we can work together to implement some very practical and innovative solutions. We value your involvement and need your commitment as we address this public health challenge.

It is my hope that *San Francisco's Strategy For Excellence in Dementia Care* is something that can be shared throughout California and across the rest of the country.

Sincerely,

Gavin Newsom
Mayor

November 2009

**MESSAGE FROM ALZHEIMER'S/DEMENTIA EXPERT PANEL
CO-CHAIRS**

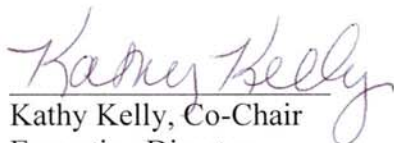
The Alzheimer's/Dementia Expert Panel, appointed by Mayor Newsom in November 2008, was charged to undertake an evaluation of San Francisco's existing dementia care services as well as to provide a plan and recommendations for service improvements and for additional services required over the next 10 years, from 2010 to 2020. The Mayor also requested that our planning include an economic analysis of this care and support.

Our first meeting took place in December 2008 and we concluded our deliberations in May 2009. Early in our work, the Expert Panel members were told that we should provide our best recommendations for improvements in dementia care that could be made in the short term and for longer term improvements based on opportunities that may exist in the future, regardless of the extremely challenging financial situation in FY 2009-10 confronted by San Francisco and by the State of California.

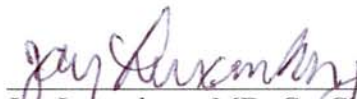
We believe our plan and recommendations, which we call a *Strategy for Excellence in Dementia Care*, meets our charge from Mayor Newsom. It has been an honor and a pleasure to work on this vitally important effort with all of the Expert Panel members, which included family caregivers, advocates, long term care experts, aging experts, Alzheimer's experts, labor, care coordination experts, medical care providers, researchers, as well as public and non-profit service providers.

Accordingly, on behalf of the Alzheimer's/Dementia Expert Panel, we are very pleased to present *San Francisco's Strategy for Excellence in Dementia Care*. We have provided 14 objectives and 35 recommendations that, when implemented, will significantly improve services and respond to the growing crisis in dementia care. It is our hope that this *Strategy* will guide most or all of the improvements that we have recommended over the next 11 years.

San Francisco has a history of innovation in terms of providing long term services and supports for older adults and adults with disabilities. We envision this undertaking to improve dementia care as the logical next step in meeting the needs of the most vulnerable among us. This is the compassionate thing for San Francisco to do.



Kathy Kelly, Co-Chair
Executive Director
Family Caregiver Alliance



Jay Luxenberg, MD, Co-Chair
Medical Director and Geriatrician
Jewish Home, San Francisco

November 2009

**MESSAGE FROM THE EXECUTIVE DIRECTOR,
DEPARTMENT OF AGING AND ADULT SERVICES**

It is with great pleasure that the Department of Aging and Adult Services joins the Alzheimer's/ Dementia Expert Panel to present *San Francisco's Strategy for Excellence in Dementia Care*, which will guide greatly needed improvements in services and supports for people with Alzheimer's disease and related dementias, and for their caregivers.

With this *Strategy*, we intend to: (1) help people to learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment, and for their caregivers; (3) offer training and support for caregivers and service providers; (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, so that the need for more intensive and costly services could be delayed; and (5) improve the residential and nursing care options for those with late stage dementia and for their caregivers, so that they both may live with dignity throughout their lives.

Among the many recommendations included, I believe that:

- An expansion of community education can increase public and professional awareness, enhance understanding and reduce stigma, remove some of the barriers to seeking treatment, and create a more compassionate community environment in which people with dementia can live and thrive.
- Providing training and education to those who work with and treat people with dementia, including professionals (home care workers, assisted living staff, nursing facility staff, physicians, and other health care providers), community-based service providers, and care managers, can help to improve skills to enable the delivery of effective, responsive and compassionate care.
- A strategic investment in early intervention, and in caregiver education and support, can significantly delay the need for high-end services and supports that are costly and in short supply.
- Expanded community-based services, and improved coordination and integration of services can make possible timely access to care, and transitions between levels and types of care less disruptive.
- Changes in restrictive policies and fiscal regulations can result in greater flexibility, which can enable a more person-centered range of services.
- Implementation of the most current guidelines and standards can improve the degree to which service providers deliver the highest quality services, and can make a significant difference in the lives of people with dementia, and their caregivers.

I am very proud of the hard work accomplished by San Francisco's Expert Panel members, which produced this *Strategy*. I am also truly excited that its implementation will make a great difference in the lives of people who have Alzheimer's and related dementia as well as in the lives of those of us who care for them. The work continues and implementation begins.



Anne Hinton
Executive Director
Department of Aging and Adult Services

Alzheimer's/Dementia Expert Panel Members

1. Department of Public Health:
 - o Laguna Honda Hospital **Gail Cobe**, RN, Clinical Nurse Specialist, Dementia Program
 - o San Francisco General Hospital **Edgar Pierluissi**, MD, Medical Director, ACE Unit
 - o Community Behavioral Health Services **Robert Cabaj**, MD, Director, Community Behavioral Health Services
2. Department of Aging and Adult Services **Anne Hinton**, ED, Department of Aging and Adult Services
3. Family Caregiver Expert **Kathy Kelly**, ED, Family Caregiver Alliance, CO-CHAIR
4. Long Term Care Ombudsman **Benson Nadell**, Ombudsman, Family Service Agency
5. PACE Model Experts **Robert Edmondson**, ED, On Lok, Inc
David Werdegar, President & CEO, Institute on Aging
6. Homecare Expert **Margaret Baran**, ED, IHSS Consortium
7. Labor **Richard Thomason**, Policy Director, SEIU United Healthcare Workers West
8. Aging Experts **Anni Chung**, ED, Self Help for the Elderly
Gay Kaplan, RN, Director of Services, Curry Senior Center
Martin Lynch, ED, LifeLong Medical Care, Berkeley
9. Care Coordination Experts **Susan Garbuio**, Director, Community Living Fund, Institute on Aging
Linda Fodrini-Johnson, Founder & ED, Eldercare Services (Geriatric Care Management)
10. Economic Expert **Patrick Fox**, PhD, Co-Director, UCSF Institute for Health & Aging
11. Alzheimer's Experts **Bruce Miller**, MD, Director, UCSF Memory & Aging Center
Ruth Gay, Director, Public Policy & Advocacy, Alzheimer's Association of Northern California and Northern Nevada
Nader Robert Shabahangi, PhD, President & CEO, Age Song Therapeutic Environments
12. Foundation **Carmen Mendieta**, Director, Brookdale National Group Respite Program, focusing on enhancing quality of life for people with dementia and their families
13. Long Term Care Coordinating Council **Vera Haile**, Co-Chair, Behavioral Health Access Workgroup
14. Caregiver/Partner/Consumer **Willard Harris**, RN, caregiver and older adult
15. Medical Care Provider **Jay Luxenberg**, MD, Director & Geriatrician, Jewish Home, CO-CHAIR
16. Researcher **Adam Boxer**, MD, PhD, Alzheimer's Disease Researcher & Assistant Professor of Neurology, UCSF Memory & Aging Center, Director, UCSF Alzheimer's Disease and Frontotemporal Dementia Clinical Trials Program

Subcommittee Members

Evidence-Based Practices & Emerging Research Subcommittee

Ruth Gay, Director, Public Policy and Advocacy, Alzheimer's Association of Northern California and Northern Nevada, CHAIR

- **Bruce Miller**, MD, Director, UCSF Memory & Aging Center
- **Marilyn Williams**, RN, Kaiser Permanente
- **Karyn Skultety**, PhD, Institute on Aging
- **Eva Schmitt**, PhD, Institute on Aging
- **Sherrie Matza**, Family Caregiver
- **Vera Haile**, Long Term Care Coordinating Council
- **Carmen Mendieta**, Director, Brookdale National Group Respite Program
- **Kathy Kelly**, ED, Family Caregiver Alliance
- **Jay Luxenberg**, MD, Director & Geriatrician, Jewish Home
- **Cindy Barton**, RN, VA Medical Center
- **Adam Boxer**, MD, PhD, UCSF Memory & Aging Center

Services & Systems Subcommittee

Cindy Kauffman, Institute on Aging, Vice President, Adult Day Programs and Health Services, CHAIR

- **Patty Clement**, Program Director, Catholic Charities CYO
- **Gail Cobe**, RN, Laguna Honda Hospital, Dementia Program
- **Benson Nadell**, Long Term Care Ombudsman, Family Service Agency
- **Bob Cabaj**, MD, Community Behavioral Health Services, DPH
- **Karen Garrison**, Senior Services Director, Bernal Heights Neighborhood Center
- **Anni Chung**, ED, Self Help for the Elderly
- **Linda Fodrini-Johnson**, Founder & ED, Eldercare Services
- **Donna Schempp**, Program Director, Family Caregiver Alliance
- **Margaret Baran**, ED, IHSS Consortium
- **Willard Harris**, RN, Caregiver
- **Susan Garbuio**, Director, Community Living Fund, Institute on Aging

Finance Subcommittee

Patrick Fox, PhD, Co-Director, UCSF Institute for Health & Aging, and expert in the economic costs of illness, CHAIR

- **Brooke Hollister**, PhD, Assistant Professor, UCSF Institute for Health & Aging
- **Tom Mesa**, Community Behavioral Health Services, DPH
- **Martin Lynch**, ED, LifeLong Medical Care, Berkeley
- **Martha Peterson**, Senior Budget Analyst, Human Services Agency
- **Steve Shane**, Deputy Director, IHSS Consortium
- **Rick Zawadski**, PhD, Founder & Director, RTZ Associates

Education & Prevention Subcommittee

Elizabeth Edgerly, PhD, Program Director, Alzheimer's Association of Northern California and Northern Nevada, & National spokesperson for the Maintain Your Brain program, CHAIR

- **Alvaro Fernandez**, CEO & Co-Founder of SharpBrains
- **Bonnie Bollwinkel**, Alzheimer's Association
- **Nancy Brundy**, Director of External Affairs, Institute on Aging
- **Nelu Zia**, San Francisco Adult Day Services Network
- **Bridgett Brown**, Independent Living Resource Center
- **Leslie Kernisan**, MD, Division of Geriatrics, UCSF, VA Medical Center

Acknowledgments

Project Leadership:

**Anne Hinton, Executive Director
Department of Aging and Adult Services**

Project Management:

**Bill Haskell, Long Term Care Principal Investigator
Department of Aging and Adult Services**

Project Editors:

**Diana Jensen, Senior Planning Analyst
Human Services Agency**

**Fanny Lapitan, Long-Term Care Operations Analyst
Department of Aging and Adult Services**

Research Team:

**Paul Gibson, President and Founder
Gibson & Associates**

**Patricia Marrone Bennett, Principal and CEO
Resource Development Associates**

**Belinda Lyons, Executive Director
Mental Health Association of San Francisco**

Special Acknowledgement and Thanks
for her vision and unflagging support of this initiative:

**Catherine Dodd, Former Deputy Chief of Staff
Office of Mayor Gavin Newsom**

Photographs:

The photographs included throughout this report were generously provided by the Alzheimer's Association of Northern California and Northern Nevada

I. BACKGROUND

I.A. PLAN PURPOSE & HISTORIC CONTEXT

Plan Purpose

San Francisco is facing a crisis in dementia care. In the San Francisco Bay Area, one out of every two persons 85+ has some type of dementia. Between now and 2020, San Francisco will experience a dramatic increase in the number of its citizens with Alzheimer's disease and other dementing illnesses. An Alzheimer's/Dementia Expert Panel, formed by Mayor Gavin Newsom in November 2008, investigated this growing crisis between December 2008 and May 2009. The Expert Panel was charged with developing a plan and recommendations that respond to the need for services between 2010 and 2020, and an economic analysis of that care.

Historic Context

Dementia is expected to skyrocket in coming decades. Barring a medical breakthrough, the 2009 World Alzheimer's Report projects that dementia will nearly double every 20 years. The report puts North America's total cases at 4.4 million, although the Alzheimer's Association of the United States estimates that more than 5 million people in this country alone are affected.

While advances are being made for the treatment of Alzheimer's disease and related dementias, currently there is no cure and treatments can only slow dementia's progression, not stop it or ease its symptoms, and not eliminate them. The human and fiscal burdens imposed by dementia are extraordinary. Demographic projections make clear that as the oldest segment of our adult population doubles over the next 20 years, the demand for services and supports will far outstrip our current capacity. To avoid a catastrophic human and fiscal crisis of unparalleled scope, significant changes in education and training, caregiver support, diagnosis, service delivery, fiscal regulations, and policy are essential.

This plan has been designed to serve as a roadmap for local policy makers, administrators, advocates, service providers, and caregivers. The framers of this plan were keenly aware of the national, state and local fiscal crisis that for the foreseeable future will limit investments in health, education, infrastructure and other public initiatives. However, *dementia will not wait for the City's fiscal house to be restored*. The demographic bubble, with thousands more aging adults in need of services, is not going to wait for our fiscal crisis to recede. Therefore, this plan must not collect dust or by 2020 we will have hundreds of individuals with dementia underserved, many becoming homeless, caregivers overburdened and exhausted, and our health and social service systems awash in red ink. It doesn't have to be this way.

Our understanding of the nature of the crisis in dementia care emerged in 2007 from the initial investigation of dementia by the Behavioral Health Access Workgroup, a subcommittee of the Long Term Care Coordinating Council (LTCCC). This investigation, and the Workgroup's subsequent findings and recommendations to the LTCCC, including the recommendation that the Mayor's Office "establish a Dementia Care Task Force to evaluate service needs and make recommendations

for how to address the demand for additional services”, provided a great amount of information and formed the foundation for this more detailed investigation.

Living with Dignity (LWD) Strategic Plan, 2009-2013. This strategic plan examined current long term care services, and the need for program development and policy reform to better meet the needs of older adults and adults with disabilities suffering from chronic illnesses and chronic conditions. During the strategic planning process, as a result of the initial investigation into dementia referenced above, the LTCCC identified a critical need to focus on the unique issues of people with dementia, and their caregivers, and the services available to address those needs.

San Francisco Baby Boomers – A Breed Apart? This study, released in July 2008, conducted on behalf of the Department of Aging and Adult Services (DAAS), projected a growing baby boomer population bubble about to explode in San Francisco. It is now expected this population will be creating an ever larger aging population at significant risk of developing dementia.

The baby boomer study used data from the July 2007 State Department of Finance projections, which estimate that the population of “older old” seniors in San Francisco (age 85+) is projected to nearly double by 2030. The report estimates:

- By 2020, the projected number of San Franciscans with dementia will increase by approximately 36% or 7,000 people, with roughly 5,000 of these being over 85 and most likely to be suffering from advanced dementia, requiring more services, supports and institutional care.
- By 2030, the aging baby boomers in San Francisco will swell the population age 65 to 85 from 13 to 18%, as compared to 2000 Census figures. Specifically, the population of “older old” seniors in San Francisco (age 85+) is projected to nearly double by 2030.

Given that prevalence data projects more than 50% of people over 85 are likely to have some form of dementia, these projections indicate a significant and growing demand is developing for more extensive services and supports. When dementia prevalence projections are applied to this population increase, it is evident a growing number of San Franciscans will need a range of services and supports either because they are cognitively impaired or are caring for a loved one who is.

Collectively, these documents raised concerns that a human and fiscal crisis of staggering proportion related to dementia care is imminent. Accordingly, in June 2008, the Mayor provided funding to DAAS to support the formation of an Alzheimer’s/Dementia Expert Panel. The charge for this Panel was to evaluate current dementia care services, assess the need for additional services, investigate national and international research and best practice models, and develop a plan and recommendations to address the need for services during the next 11 years (to 2020), including an analysis of projected costs.

Many of the recommendations found in this plan are not expensive and are possible even today. However, some of the recommendations proposed may be quite costly and will require policy changes, changes in funding regulations (waivers), and/or significant investments that may not be realistic today. Even for the long-term recommendations, if they are to be implemented, there is groundwork to be done in the next few years.

I.B. THE PLANNING PROCESS

The Department of Aging and Adult Services (DAAS) led and managed this planning process. In December 2008, DAAS convened the Alzheimer's/Dementia Expert Panel appointed by Mayor Newsom, comprised of Alzheimer's experts, aging experts, medical providers, community-based service providers, advocates, researchers, economic experts, public agency administrators, and family caregivers. The diversity of the Panel ensured varied perspectives were incorporated throughout deliberations. San Francisco is blessed with an extraordinary level of local dementia-related expertise respected throughout the nation, with experts in research, policy, public administration and service provision, which has been a great benefit to the planning process and the resulting plan.

The Expert Panel created four subcommittees where more substantive discussion of a wide range of issues could occur, with the subcommittees reporting their findings back to the full Panel. The four subcommittees included:

- ***Evidence Based Practice & Emerging Research***, which reviewed findings from the most recent research regarding dementia, including: (1) evidence-based best practices for: dementia care services, treatment, and prevention; (2) the role of the family and the larger community; (3) strategies to provide caregivers with support; (4) protective factors and prevention strategies; and (5) promising practices and emerging trends. This involved a national and international literature review. See key findings from the literature review on page 36 and the comprehensive research summary in Appendix I.
- ***Services & Systems***, which enumerated San Francisco's existing dementia care services and supports (for mild, moderate and advanced levels). The subcommittee considered additional services needed to care for adults with dementia. Categories of services enumerated include: (1) adult day services; (2) advocacy and protection; (3) care management; (4) caregiver services and supports; (5) diagnostic assessment; (6) education; (7) information and referral; (8) in home supportive services; (9) legal services; (10) mental health services; (11) money management services; (12) nursing care and hospital services; (13) ongoing medical treatment; (14) public policy; (15) research and development; (16) residential care; and (17) respite care. See discussion of services and supports on page 41 and the full list of services and supports in Appendix II.
- ***Finance***, which examined the cost of operations of the current network of dementia care services and supports. It considered the costs to: (1) expand existing services; and (2) implement new initiatives and services currently not in place. It then projected these costs forward 10-12 years to anticipate how the costs might change to meet the needs of the expanding population. The subcommittee also identified a range of funding resources that could be accessed to support the recommended model system of dementia care services. See discussion of the costs of dementia care on page 28 and additional detailed financial information in Appendix IV.
- ***Education & Prevention***, which developed a range effective educational programs for community members regarding dementia. Protective factors including brain fitness and risk factors, early identification and early access to services were evaluated. Nine content areas were identified to be part of a comprehensive education and prevention effort. Many content areas are intended to address issues related to stigma regarding dementia. The subcommittee also addressed the need for educating professionals (e.g. doctors, psychiatrists, social workers, nurses, caregivers-paid and family), and others who find themselves dealing with those who should be providing more in terms of care. See a summary of education and prevention recommendations on page 50 and the considerably detailed findings and recommendations in Appendix III.

Each of the subcommittees met between five to seven times, with each producing a summary of its deliberations and reporting to the Expert Panel during the seven-month process. The Expert Panel met six times, reviewing the work products of the four subcommittees and incorporating them into the components of this plan and recommendations.

Earlier, in September 2008, DAAS retained a research team consisting of: (1) Gibson & Associates, (2) Resource Development Associates, and (3) the Mental Health Association of San Francisco. This team worked with the Expert Panel and DAAS staff to research best practice models for dementia care, undertake an evaluation of the City's dementia care services, explore the need to improve existing services, and prepare a plan and recommendations to address the demand for services during the next 10 years (2010 to 2020). Specifically, the research team:

- Facilitated all Expert Panel meetings;
- Supported the work of all subcommittees;
- Compiled a review of the literature, identifying evidence-based research, promising practices, and emerging trends, for each type of dementia-related service, and facilitated the Evidence-Based-Practice and Emerging Research Subcommittee's consideration of these findings;
- Conducted 42 key informant interviews with policy-makers representatives of public and private agencies and more than 25 caregivers and caregiver organizations. Through this work, and the work of the Services & Systems Subcommittee, assisted in the development of a comprehensive inventory of current services and supports for each stage dementia;
- Analyzed a variety of statistical models for capturing current costs and projecting future costs of caring for individuals with dementia; and
- Prepared the initial draft of this report, in collaboration with DAAS staff.

Over the seven month planning process, the Expert Panel discussed the strengths and weaknesses of the current service delivery network, identified principles and concepts that should characterize how San Francisco addresses the crisis in dementia care, and

- Developed a mission statement and vision statement, and a list of core values that are to guide implementation of the plan;
- Reviewed the summary of the research developed by the research team and vetted by the Evidence-Based Practice & Emerging Research Subcommittee;
- Evaluated an analysis of current costs for services and projected costs as the population of older adults grows over the next 20 years completed by the Finance Subcommittee;
- Learned from the Services & Systems Subcommittee about its summary of the current available dementia services and supports;
- Reviewed the report from the Education & Prevention Subcommittee with recommendations for extensive training and education; and
- Made program and policy recommendations to improve dementia care services and develop new services as necessary.

DAAS staff and the research team used notes from all Expert Panel and subcommittee meetings to generate a preliminary list of 25 recommendations that was considered and revised by the Expert Panel in April 2009. Subsequently, 12 additional recommendations were proposed as a result of the

Expert Panel breaking into small groups in May 2009, with all but one being advanced to this report. Once the recommendations were approved, DAAS staff and the research team worked collaboratively in developing the initial draft of *San Francisco's Strategy For Excellence in Dementia Care*, identifying models cited in the literature review, considering necessary implementation steps, and proposing partners and resources necessary to implementing each recommendation.

Following the completion of the Expert Panel's deliberations in May 2009, the recommendations were presented at an Alzheimer's/Dementia Summit, held in City Hall in July 2009. This offered an opportunity for the community to learn about the crisis in dementia care and to provide additional input into the recommendations prior to the completion of the initial draft *Strategy*.

Subsequently, the initial draft *Strategy* was revised, edited, formatted, and completed by DAAS staff, with continuing participation from research team members. This draft was reviewed and edited by internal review team consisting of DAAS leadership and Expert Panel members: (1) Ruth Gay, Director of Public Policy and Advocacy, Alzheimer's Association of Northern California and Northern Nevada; and (2) Adam Boxer, MD, PhD, Alzheimer's Disease Researcher and Assistant Professor of Neurology, UCSF Memory and Aging Center, and UCSF Alzheimer's Disease and Frontotemporal Dementia Clinical Trials Program. It was also examined by an external review team consisting of: (1) Andrew Scharlach, PhD, School of Social Welfare, UC Berkeley; and (2) Kristine Yaffe, MD, Chief of Geriatric Psychiatry and Director of the Memory Disorders Clinic at the San Francisco VA Medical Center. Input from the internal and external review teams was incorporated before the final version of *San Francisco's Strategy for Excellence in Dementia Care* was published.

I.C. MISSION, VALUES & VISION

The Mission:

The mission of this *Strategy* is to improve the quality of life for people with Alzheimer's disease and related dementias and for their caregivers, through an easily accessible, coordinated network of formal and informal, non-judgmental services and supports that will address the chronic care management needs of both older and younger individuals throughout the course of cognitive decline.

The Values emphasize:

- Services and supports that will be developed and delivered using a person-centered and family-centered approach, based on an assessment of the unique needs and preferences of the person and their loved ones, and that enable each of them to thrive.
- The importance of chronic care management*, through home and community-based services as well as institutional services, that will offer a new framework for providing care and support for people with Alzheimer's and related dementias.



-
- ❑ That the most appropriate dementia care, services and support will be provided in the least restrictive and most integrated setting, depending on need and choice.
 - ❑ That people with dementia will remain integral members of their communities, as appropriate to their health and safety.
 - ❑ The importance of caregivers, both informal unpaid caregivers (family, partners, friends, neighbors, community members) and formal paid caregivers (homecare workers, home health care workers).

- ❑ That dementia care today places an undue burden on women as informal unpaid caregivers. We value the lives and contributions of women beyond care giving and we seek to reduce this burden.



- ❑ The need to ensure high quality, culturally and linguistically appropriate dementia care, services and support.

- ❑ That Alzheimer’s and related dementias impact the whole person and their actual or chosen family. With this in mind, the physical, mental, and spiritual issues of persons with dementia and their caregivers need to be attended.

The Vision:

Our vision is to create a better-coordinated, more integrated network of services and supports that will enable people with mild cognitive impairment (MCI), Alzheimer’s and other dementias, and their loved ones, to flourish throughout the progression of these disorders. San Francisco will develop and promote an integrated model of dementia care, in which the needs of people with dementia and their caregivers will be addressed within the full range of medical, health, social, and caregiver needs of all older adults and adults with disabilities.

Services and support for people with MCI, Alzheimer’s and other dementias, and for their caregivers, will be integrated into San Francisco’s existing long-term care service delivery network, which includes a range of home, community-based, and institutional services. Within this structure: (1) existing services will become dementia capable through education and training; (2) specific dementia care services will be expanded or developed as needed; (3) existing systems will provide services, care and support particularly for people with moderate and advanced dementia; and (4) new chronic care service delivery systems will be specifically designed and developed for older adults that will also address dementia care.

The community will be provided with training and education about dementia care resources, and about activities and other opportunities for risk reduction. The community will be well educated, sympathetic and supportive of people with Alzheimer’s disease and related dementias, and their caregivers. Information will be easily accessible in each neighborhood throughout the city.



This vision goes beyond providing what dementia care, services and supports that people with dementia and their caregivers need, to a broader, more fundamental issue: what people require for a good life. This includes: (1) the formation of personal and social support networks that promote the contributions of people with dementia, with the goal of strengthening our neighborhoods and communities; and (2) the creation of age- and disability-friendly communities that offer accessible and affordable housing, improved public safety, improved access to parks and recreation, and opportunities to be meaningfully engaged in the community.



Key Concepts

Chronic Care Management:

A central concept throughout the *Strategy* is a commitment to a shift in how dementia services are delivered, moving toward the development of a strengthened capacity to serve individuals in the community and relying less on institutionalization. Chronic care management is an approach to community-based care that captures this approach.

Widespread recognition of the need for ongoing chronic care management through home and community-based services is relatively new in the long term care arena. As older adults and adults with disabilities are living longer with functional impairments and chronic illnesses, they increasingly prefer to receive services in a community setting rather than an institutional setting. The evolving approach to chronic care management across the country, which relies substantially on community-based services and less on institutionalization, offers a new framework for thinking about how to provide services to people with chronic conditions.

The Community-Based Long Term Care Report of 1998 identified chronic illness as “an illness or disability that persists for a long time, whether or not it causes death.” Furthermore, they are “ongoing and not amenable to cure. They may range from mild to manageable to severe (potentially life threatening) physical or mental conditions. However, chronic conditions are changeable, so prevention of actual episodes and maintenance of functional ability are the primary goals. Those who may need help range from young spinal cord injury survivors to older adults with Alzheimer’s disease.” The report identified a new approach for long term care service provision as one that lends traditional medical and social models in recognition that managing an illness or a disability over time requires an integrated approach with the consumer as the focus.”¹

System versus Network:

In early meetings, the Expert Panel members considered the merits of working toward a system of services versus a network of services regarding Alzheimer’s/dementia care. A *system* is all-inclusive and can accommodate the needs of the individual or other entity in some facet at various levels of service. All users are served through connectiveness of these levels of service. Systems are often closed to outside input to their structure with the exception of laws, regulations and government constraints. A *network* is a relationship between individual service providers and systems that serves a common group or classification of individuals. Each has its own structure, standards of practice and operational modality. The network communicates on the common ground between each of its members. The network serves to be a communication link between entities that expand the knowledge base of all groups connected thus the effectiveness of each separate party. The connectiveness of all the participants makes the whole a stronger entity. The network can advocate for the needs of the classifications it represents.

The final decision was that a network structure is the better choice for Alzheimer’s/dementia care in San Francisco. The Expert Panel believes it provides options for more creativity and enables building on existing strengths. It can be tailored to neighborhoods, diverse geographies, and differing populations. Furthermore, systems can operate within a network. Accordingly, dementia care services and supports in San Francisco either already are or will become an integrated part of the larger long term care service delivery network.

II. THE NATURE OF THE CRISIS – A DEMOGRAPHIC AND FISCAL IMPERATIVE TO ACT

There is no cure available for Alzheimer’s disease and other forms of dementia nor is one expected in the near future. Only a limited number of interventions are available to delay the onset of dementia, leading us to focus on methods to slow the progression of the disease, avoid preventable co-morbid conditions or at least treat them more effectively. This section describes the demographic and fiscal crisis that looms in San Francisco. It provides **background information about mild cognitive impairment (MCI), Alzheimer’s disease and other forms of dementia**, including descriptions of various stages of impairment. It then describes **San Francisco’s unique demographic risk factors** as they relate to the dementia crisis. Finally, it provides **projections of dementia-related population growth and of associated local costs of care**.

II.A. BACKGROUND ON DEMENTIA

Throughout this plan we refer to dementia, MCI, and the various stages of Alzheimer’s disease, and also make periodic reference to other forms of dementia. It is important to define these terms so the reader is able to understand how dementia develops and the various forms it can take.

Dementia is an acquired, persistent, intellectual impairment involving multiple cognitive domains, such as:

- ❑ *memory*, usually the ability to remember events, facts, people or locations that were experienced recently;
- ❑ *executive function*, which includes the ability to think abstractly, make sound judgments and plan and carry out complex tasks;
- ❑ *language*, such as the ability to generate coherent speech or understand spoken or written language;
- ❑ *visuospatial function*, or the ability to recognize or identify objects, people or places or to navigate through well known locations; and
- ❑ *behavior*, such as lack of motivation, depression, hallucinations, delusions or personality changes.

Impairments in these cognitive abilities must be severe enough to cause a decline in an individual’s day to day function, such as performing duties necessary for work, household chores or even self-care. Dementia can be caused by a variety of diseases and conditions that result in dysfunction and damage to brain cells.

Alzheimer’s disease is the most common form of dementia, accounting for approximately 59 - 75% of all cases. It is a progressive and fatal brain disease. As many as 5.3 million Americans are living with Alzheimer’s disease. Alzheimer’s destroys brain cells, causing problems with memory, thinking and behavior severe enough to affect work, lifelong hobbies or social life. There are medical treatments and other interventions that benefit people with Alzheimer’s disease. However, inevitably, Alzheimer’s gets worse over time, and is fatal. Today it is the sixth-leading cause of death in the United States.

There are many other causes of dementia other than Alzheimer’s. These include the following:

-
- ❑ Vascular dementia (also known as multi-infarct dementia) is the second most common form of dementia; individuals often experience sudden deterioration, which may progress over time.
 - ❑ Parkinson's disease and related disorders, in which individuals develop severe problems of movement and balance, sometimes including cognitive and behavioral impairments.
 - ❑ Huntington's disease, a hereditary disease often appearing in early adulthood, passed on from parent to child, the symptoms of which include quick jerky movements of the face, limbs, and trunk, cognitive and psychiatric impairments.
 - ❑ Dementias associated with physical disorders such as diabetes, thyroid disease, brain tumors, or Acquired Immune Deficiency Syndrome (AIDS).
 - ❑ Dementias related to alcohol or substance abuse; these may be a combination of direct chemical damage to the brain combined with nutritional or vitamin deficiencies.

Although advancing age is recognized as the strongest risk factor for developing dementia, **Early (Younger) Onset** forms of dementia are increasingly being recognized and can be particularly devastating as they affect individuals at the height of their careers or when they have caregiving responsibilities for young children or elderly parents. The term younger-onset refers to dementia that occurs in a person who is under age 65 when symptoms begin. People who have younger-onset dementia may be in any stage of dementia – early, middle or late. Experts estimate approximately 500,000 Americans in their 30s, 40s and 50s have Alzheimer's disease or another dementia. In this age group, a different dementia called frontotemporal dementia is as common as Alzheimer's.

All forms of dementia advance in stages. While the exact progression and symptoms vary depending upon the form of dementia, the stages are generally characterized as moving from very early (or MCI) to mild to moderate to advanced or late stages.

Mild Cognitive Impairment (MCI) is a less severe, or very early stage of illnesses which can cause dementia. Individuals with MCI have an acquired intellectual impairment that is *NOT* sufficient to cause a decline in function, for which an individual can compensate. Some people with MCI go on to develop dementia, but many do not. Because some causes of dementia are reversible, MCI represents a window of opportunity during which interventions that stall or prevent the onset dementia may be initiated.

A person with MCI may have problems with memory, language or another essential cognitive function that are severe enough to be noticeable to others and show up on tests, but not severe enough to interfere with daily life. A common form of MCI is characterized by short-term memory problems, but few other symptoms of dementia (e.g., problems with language, judgment, changes in personality or behavior) that impair a person's daily functioning.

Stages of dementia. Experts have documented common patterns of symptom progression that occur in many people with Alzheimer's disease and have developed several methods of "staging" based on these patterns. Staging provide a useful frame of reference for understanding how the disease may unfold and for making future plans. But it is important to be aware that not everyone will experience the same symptoms or progress at the same rate. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.

People with non-Alzheimer's dementias will progress differently and may not adhere to stages in the same way as people with Alzheimer's might. However, all dementia diseases are progressive and people will continue to be impacted by the disease, even though they may transiently stabilize in the course of any of these diseases. It is hoped that with the development of new treatments, some of the symptoms, or even progression of the disease may be altered or arrested.

The stages below apply specifically to what is recognized for people with Alzheimer's disease.

Early Stage: Early-stage is the part of Alzheimer's when problems with memory, thinking and concentration may begin to appear in a doctor's interview or medical tests. People in the early-stage typically need assistance with simple daily routines. At the time of a diagnosis, an individual is not necessarily in the early stage of the disease; he or she may have progressed beyond the early stage.

Moderate or mid-stage Alzheimer's: Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may be unable to recall their own address or phone number or the high school or college from which they graduated; become confused about where they are or what day it is; have trouble with less challenging mental arithmetic; need help choosing proper clothing; still remember significant details about themselves and their family and still require no assistance eating or using the toilet.

Moderately severe Alzheimer's: Memory continues to worsen, personality changes may take place and individuals need significant help with daily activities. The person may: lose awareness of recent experiences as well as their surroundings; remember their own name but have difficulty with their personal history; distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver; need help dressing properly; experience major changes in their sleep patterns; need help handling details of the toilet; have increasingly frequent trouble controlling their bladder or bowels; experience major personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior; and tend to wander or become lost.

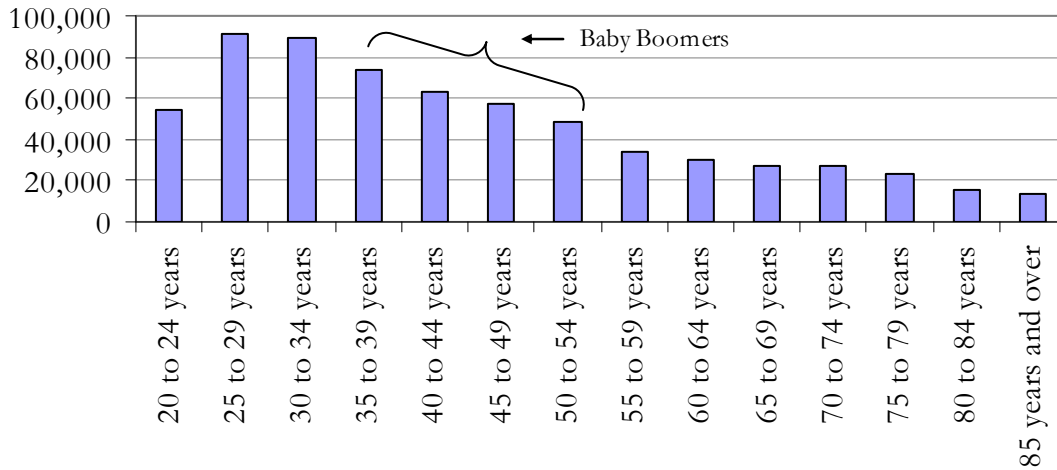
Severe, or late-stage Alzheimer's: In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation and, eventually, to control movement. At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal, muscles grow rigid and swallowing is impaired.

II.B. SAN FRANCISCO'S DEMOGRAPHIC FACTORS

Developing a plan to serve people with dementia and their caregivers must be founded on an understanding of the characteristics of the community. The *Strategy for Excellence in Dementia Care* calls for a variety of community-based services, structures to support caregivers, and community education. Each of these must be designed to be responsive to the unique character and the variety of cultures that define the City. As such, a brief analysis of the City's demographics is presented.

Age. Age is the strongest risk factor for the development of dementia. More than any factor, age also drives the emerging crisis in dementia care. San Francisco has a reputation for being a young and vibrant city, but in reality has one of the lowest proportions of children of any city in the country. San Francisco is increasingly becoming a city of senior citizens as baby boomers become seniors and the exorbitant cost of living drives young families out of the city in search of affordable housing. Seniors make up a higher proportion of the city's population (17.6% at the time of the 2000 Census) than they do statewide or nationally (14% and 16.5%, respectively).

**San Francisco Adults by Age
(Census 2000)**



As they age, current projections indicate that San Francisco’s baby boomers¹ will cause a significant increase in the senior population that mirrors a national trend. Growth projections from the California Department of Finance estimate that the aging of the baby boomers will swell San Francisco’s population age 65 to 85 from 13 to 18% by 2030 as compared to 2000. The population of “older old” seniors in San Francisco (age 85+) is projected to nearly double in the same time frame. This dramatic increase in the older population is projected to increase the number of San Franciscans who have dementia by 77% between the year 2000 and 2030, taxing an already over-extended network of providers.²

High Cost of Living. San Francisco is among the wealthiest and most highly educated cities in the United States, but wealth and educational attainment are not evenly distributed throughout the community. San Francisco is also among the most expensive cities in the United States in which to live. According to the 2006 ACCRA Cost of Living Index, San Francisco is the second most expensive urban area in the nation, and has the country’s second highest median housing prices. The high cost of living exacerbates the added significant costs of dementia care for poor and even moderate income San Franciscans.

Poverty. In 1999, 11.3% of the City’s residents had incomes below the poverty line. Furthermore, the California Health Interview Survey reported that 20.4% of San Franciscan adult respondents indicated that they are



¹ “Baby boomers” are the generation of adults born between 1945 and 1964.

² This projection applies age-based Alzheimer’s Association prevalence rates for Alzheimer’s disease to California Department of Finance population projections for San Francisco. A detailed table showing those projections can be found on page 31 of this report.

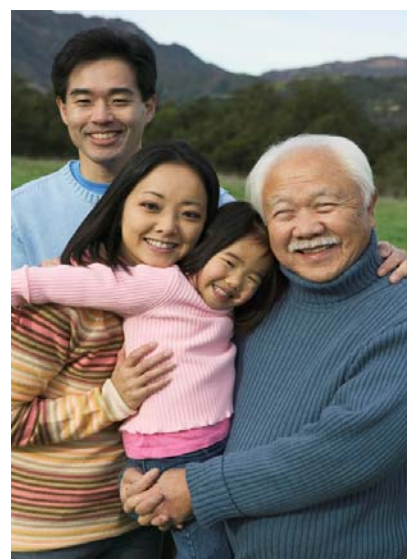
“not able to afford enough food.” Consequently, over 200,000 San Franciscans experience food insecurity, and many are burdened with having to prioritize even their most basic needs, at times forced to choose between satisfying one basic need at the expense of another. For individuals with dementia, poverty forces choices between paying rent, taking prescribed medications, or paying for needed in-home assistance. This struggle is especially prevalent in San Francisco’s communities of color: the income of white San Franciscans is more than twice as high as that of Hispanic/Latino or African American San Franciscans. For five San Francisco neighborhoods the proportion of low-income households is at least 51%: Bayview Hunters Point, Chinatown, South of Market, Tenderloin and Western Addition.



Vulnerability is not limited to those living in poverty. Many middle class individuals who are not eligible for Medi-Cal and are uninsured (or underinsured) with respect to long term care find themselves with fewer resources than do those living in poverty who qualify for Medi-Cal. A common misconception is that middle class San Franciscans are often “house rich and cash poor.” However, only 55% of senior-headed households and 38% of baby boomer-headed households owned their homes at the time of the 2000 Census. These home ownership rates are significantly lower than the national averages, 78% and 70%, respectively.

Diversity & Neighborhoods. One of San Francisco’s greatest attributes is its diversity, but neighborhoods are quite strictly divided along socioeconomic, racial, and cultural lines. San Francisco’s white, minority, and immigrant populations occupy distinct and separate neighborhoods. For six of these neighborhoods (Bayview Hunters Point, Chinatown, Excelsior, Oceanview Merced Ingleside, Portola and Visitacion Valley), the minority percentage is greater than 75%.

Linguistic & Cultural Isolation. Fully 36.8% of San Franciscans were born in another country compared with 26% for the state and 11% for the United States. This percentage is highest among San Francisco’s oldest residents. Only 58.2% of foreign-born residents speak English (CA = 62% and US = 81%) with 22% of San Franciscans speaking an Asian-Pacific Islander language and 10% speaking Spanish. This creates a demographic imperative to ensure that dementia-related outreach, education, services and supports are culturally and linguistically responsive.



Educational Attainment. Educationally, San Francisco has nearly twice the proportion of its population that has achieved a bachelor's degree (45.2%) as compared to national rates (24.4%), but this educational level is not evenly distributed through the community. Some neighborhoods have very high percentages of residents with less than a high school diploma e.g. Chinatown (63.5%), Bayview Hunter's Point (36.6%), Visitacion Valley (41.5%) and Excelsior (33.1%). These communities are also communities with high proportions of Asian, Latino and African American populations. The low level of educational attainment is particularly prominent among these populations and especially prominent in Chinatown and Excelsior among Chinese seniors who were born outside the United States.

Higher levels of education are associated with lower risk of dementia, particularly Alzheimer's. However, once Alzheimer's develops, individuals with higher levels of education tend to decline more rapidly. More highly educated individuals are more likely to be aware of the signs of dementia and the importance of seeking early diagnosis and treatment. Outreach, education, services and supports for individuals with dementia and their caregivers will need to be attentive to the educational levels of the populations being served.

Household Composition. Fewer than one in four seniors in San Francisco (compared to 40% in other cities) have an adult child living within 20 minutes travel-time, a figure likely to worsen in the years to come. San Francisco's population currently has a significantly higher proportion of single person senior-headed households (40%) as compared to the statewide rate (33%). San Francisco's *Strategy for Excellence in Dementia Care* must consider strategies that compensate for: (1) the absence of informal caregivers within close proximity, and (2) isolation of seniors that may result in later identification of the early signs of dementia.

Homelessness. "San Francisco has the worst, most visible expression of homelessness in our country," according to Phillip Mangano, the Director of the Federal Interagency Council on Homelessness. In 2004, San Francisco was estimated to have 3,000 chronically homeless persons. New York City, nine times larger, had just 2,700. A 2006 University of California study showed that the median age of the homeless population in San Francisco and other cities is growing, along with the number of years the homeless have been on the street. The 2009 Homeless Count survey found that 28% of homeless persons were age 51 or older (24% were age 51-60, 4% were 61 and older). Experts believe that around 70% of homeless people abuse drugs or alcohol and 30 to 40% are mentally ill. For those who may also be experiencing the early stages of dementia, there is a risk that service providers and the public will misinterpret behavior and miss the opportunity to offer appropriate services and supports. They may struggle to access services depending on whether their primary diagnosis is dementia or mental illness, and finding housing with supports for the full constellation of challenges they face may prove very difficult.

Caregivers. Informal caregivers supporting family members or friends with dementia represent a final consumer population with respect to support services. While caregiving has its satisfactions, for many, the burden of care is substantial. Caregiving poses physical, emotional, and economic challenges. Traditionally, most caregivers have been the wives or adult daughters of the individual with dementia; 75% of caregivers are women. This imposes a disproportionate level of stress, both emotionally and economically, on a particular segment of the community.



Many caregivers are themselves elderly. Of those caring for someone aged 65 or older, the average age of caregivers is 63 years old with one-third of these in fair to poor health. Compared to other caregivers, those who care for people with severe memory problems are more likely to: experience financial hardship, report health difficulties, experience emotional stress, and suffer from sleep disturbances. The needs of caregivers are often overlooked by the health system. Health providers often fail to provide education and support to caregivers and to assess the caregiver's capacity to provide sustained support to the individual with dementia.

II.C. PROJECTIONS OF POPULATION GROWTH & COSTS OF DEMENTIA CARE

The Expert Panel undertook a number of research activities to achieve a better understanding of the fiscal impact of the crisis in dementia care. This section presents:

1. The panel's baseline analysis of current City funding for seniors with dementia;
2. Projections of the growth of the population of San Francisco residents with Alzheimer's and related dementias in order to provide a sense of scale for the likely future growth in demand for services; and
3. Findings from a comprehensive study and analysis of the total costs of services for individuals with Alzheimer's and other forms of dementia.

The costs of formal care and the value of informal care are projected to increase by 79 percent and 77 percent respectively between 2008 and 2020. Meanwhile, the Expert Panel's analysis of city spending suggests the current General Fund (GF) burden related to seniors with Alzheimer's disease and other dementias is already approximately \$52.3 million. This research suggests that there is a strong fiscal incentive to facilitate early intervention, especially education and support for caregivers, in order to reduce the amount of time individuals spend in higher, more costly levels of care.³

Analysis of Current City Funding for Seniors with Alzheimer's and Related Dementias

Table I, on the next page, presents the total public cost of services for San Francisco's current senior population and an estimate of the proportion of those services devoted to individuals with dementia. For each city program, the table shows: the total budget regardless of participant age; the amount of

³ Mittelman MS; Ferris SH; Shulman E; Steinberg G; Levin B. "A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial [see comments]". *JAMA*. 1996; 276: 1725.

funding coming from San Francisco's General Fund (GF); the approximate amount of GF dollars estimated to be spent on individuals with dementia at different ages based on population size and Alzheimer's prevalence rates; and the total estimated GF cost for individuals with dementia, \$52.3 million.

These estimates suggest that nearly 60% of all GF dollars spent on seniors age 65 and older in San Francisco support individuals with Alzheimer's or related dementias. However, few of these services are delivered to individuals *because they have dementia*. Many are entitlement programs that individuals would receive or be eligible for simply because they are older and living in poverty. If dementia were cured tomorrow, some of these costs would not change. This being the case, these figures provide a baseline context and sense of scale for the city resources currently dedicated to this population.



Table I: Estimated City Support for Seniors Aged 65+ Across City Departments and Programs

A	B	C	D	E	F	G	H	I
Dept	Programs	Total FY 0809 Original Budget	Total FY 0809 Local GF Original Budget	Total of senior (65+) funding Local GF only	\$\$ funding Seniors aged 65-74 with Alz & other dementias (estimate)	\$\$ funding Seniors aged 75-84 with Alz & other dementias (estimate)	\$\$ funding Seniors aged 85 + with Alz & other dementias (estimate)	Total of Estimated Support for Alz & other forms of Dementia
DAAS	In-Home Supportive Services	\$ 120,233,501	\$ 71,400,000	\$ 51,765,000	\$ 411,325	\$ 6,332,982	\$ 7,148,539	\$ 13,892,846
	Adult Protective Services	\$ 4,789,953	\$ 2,394,977	\$ 1,484,885	\$ 13,019	\$ 236,897	\$ 256,321	\$ 506,237
	Office on Aging	\$ 22,730,759	\$ 15,911,531	\$ 13,365,686	\$ 131,839	\$ 1,356,844	\$ 1,922,654	\$ 3,411,337
	Community Living Fund	\$ 4,000,000	\$ 4,000,000	\$ 3,560,000	\$ 33,165	\$ 379,934	\$ 491,622	\$ 904,721
							DAAS Subtotal	\$ 18,715,141
DPH	Community Health - AIDS - Prevention	\$ 55,587,423	\$ 55,587,423	\$ 1,167,336	\$ 31,985	\$ 303,858	\$ 671,685	\$ 1,007,528
	Direct Access to Housing - Leases and Operating subsidies	\$ 14,148,111	\$ 12,729,012	\$ 1,909,352	\$ 52,316	\$ 497,004	\$ 1,098,641	\$ 1,647,962
	Primary Care / Ambulatory Care / Health Centers	\$ 56,366,081	\$ 47,615,807	\$ 4,571,117	\$ 125,249	\$ 1,189,862	\$ 2,630,221	\$ 3,945,331
	Community Behavioral Health Services	\$ 55,581,144	\$ 55,581,144	\$ 4,446,492	\$ 121,834	\$ 1,157,422	\$ 2,558,511	\$ 3,837,767
	Laguna Honda Locked Units ¹	\$ 68,900,000	\$ 20,670,000	\$ 20,670,000				\$ 20,670,000
	SF General Hospital - Inpatient ¹	\$ 4,500,000		\$ 800,000				\$ 800,000
	SF General Hospital - Outpatient ¹	\$ 144,000		\$ 44,000				\$ 44,000
							DPH Subtotal	\$ 31,952,587
DHS	Homeless Program - Ramen Hotel (Seniors Only) ²	\$ 739,750	\$ 739,750	\$ 523,743.00	\$ 7,706	\$ 21,677	\$ 3,616	\$ 32,999
	Single Adult Shelters	\$ 9,723,224	\$ 9,723,224	\$ 414,209.34	\$ 20,656	\$ 2,554	\$ -	\$ 23,209
	Public Assistance / CAAP ³	\$ 50,100,000	\$ 50,100,000	\$ 1,653,300	\$ 770	\$ 5,595	\$ 2,854	\$ 9,219
							DHS Subtotal	\$ 65,427
MUNI	Paratransit Program	\$ 20,000,000	\$ 13,100,000	0	\$ -	\$ -	\$ -	\$ 1,572,000
							Grand Total	\$ 52,305,155

Notes:

1 - These figures are from FY 07/08. Estimates are based on the program population with a primary diagnosis of dementia. Age break-downs were not provided.

2 - Data from March 2008.

3 - Data from May 2009.

Projections for the Growth in the Population of Seniors with Alzheimer's and Other Dementias

The first step toward understanding the projected growth in costs associated with dementia care is to consider the projected growth in the population of individuals with Alzheimer's and other dementias. The aging of the 'baby boomer' generation will vastly increase the number of seniors at high risk of developing dementia.

"Baby boomers" are adults born between 1945 and 1964, making them age 35 to 54 at the time of the 2000 Census. As they age, current projections indicate that San Francisco's baby boomers will cause a significant increase in the senior population that will mirror the national trend. Growth projections from the California Department of Finance estimate that the aging of the baby boomers between 2000 and 2030 will swell the population age 65 to 85 from 13 to 18 percent of the total population in San Francisco. Furthermore, the population of "older old" seniors in San Francisco (age 85+) is projected to nearly *double* by 2030.

The table below shows the projected growth in Alzheimer's related dementias in San Francisco based on known prevalence rates by age group. From the 2000 Census baseline, these figures show a projected 36 percent increase in the population with Alzheimer's related dementia by 2020, and 77 percent increase by 2030, fueled by the tremendous projected growth in the older old cohort. These figures do not include other dementias and cognitive impairment that are unrelated to Alzheimer's.

Age Range	% Pop. w/ Alzheimer's Related Dementia ⁴	Actual 2000 Population ⁵ (Alz Related Dementia Estimate)	Actual 2007 Population ⁶ (Alz Related Dementia Estimate)	Projected 2010 Population ⁷ (Alz Related Dementia Estimate)	Projected 2020 Population ⁸ (Alz Related Dementia Estimate)	Projected 2030 Population ⁹ (Alz Related Dementia Estimate)
65 to 74	2.75%	53,857 (1,481)	52,070 (1,432)	55,762 (1,533)	81,725 (2,247)	88,239 (2,427)
75 to 84	26%	38,181 (9,927)	40,161 (10,442)	39,457 (10,259)	42,017 (10,924)	63,025 (16,387)
85 +	57%	14,503 (8,267)	18,649 (10,630)	20,445 (11,653)	23,865 (13,603)	28,111 (16,023)
Est. Total Population w/Alzheimer's Related Dementia		19,675	22,504	23,445	26,774	34,837

NOTE: The Alzheimer's Association estimates that Alzheimer's accounts for approximately 60% of all dementias. According to Dementia Estimates and Projections, a report by Access Economics, Alzheimer's accounts for 59% of all dementias. For details of this report, see Appendix 1, page 11.

⁴ Alzheimer's Association of Northern California and Northern Nevada.

⁵ 2000 Census Data

⁶ 2007 American Community Survey

⁷ 2007 California Department of Finance Projections

⁸ 2007 California Department of Finance Projections

⁹ 2007 California Department of Finance Projections

Projections for the Growth in All Costs Related to Dementia Care: 2008-2030

To achieve a more complete understanding of the fiscal implications of the dementia care crisis across all funding sources, the Finance Subcommittee reviewed and adapted the results of a comprehensive study and analysis of the total costs of formal care and the value of informal care attributable to Alzheimer's disease for persons living in the community as well as for persons living in institutions in the Bay Area.¹⁰ Data for the study were collected from non-institutionalized and institutionalized Alzheimer's patients, their primary caregivers, and staff of the institutions in which institutionalized patients resided. A broad range of Alzheimer's patients and their caregivers were included in the study, representing the largest primary data collection effort to date using a sample of persons with Alzheimer's disease studied for cost implications. The study excluded costs associated with conditions other than Alzheimer's disease -- primary caregivers determined whether a formal service or an aspect of informal care was required because of the patient's demented condition.

The study estimated economic costs for both formal and informal care, which represent the value of resources used or forgone as a result of the disease.

Formal services refer to those rendered for a price in the traditional medical and social service marketplace, where dollars are explicitly exchanged for services. Formal services are financed primarily by individuals and their families; over 60 percent of the services provided to patients in either care setting were paid out of pocket. Included in formal care costs are expenditures for hospital and nursing home care, physician services, social services, medications, and other items or services used for the care of the person as a direct result of Alzheimer's disease.

Informal services refer to services, care and support rendered outside those markets and for which providers are not reimbursed. As such, the value of informal services does not represent costs actually paid, but rather the value of the services performed. Informal care provided to the patient as a result of Alzheimer's disease was valued using a replacement cost approach by imputing a market value for services performed; if unpaid caregivers were not available, caregiving services would probably be purchased from paid providers, or else people living with dementia in the community would be placed in institutions such as skilled nursing facilities. While caregivers' indirect productivity losses were not estimated in the study, other studies have identified significant indirect productivity losses for both the individual with dementia and the informal caregiver. This suggests that the value of informal care reported here is an underestimate when productivity losses are taken into account. The inclusion of an accounting for the value of informal care is critical as a means for demonstrating the tremendous role that informal caregivers play in supporting individuals with Alzheimer's disease and related dementias. While informal care contributes to the health



¹⁰ Rice, D., Fox, P., Max, W., Webber, P., Lindeman, D., Hauck, W. and E. Segura. "The Economic Burden of Caring for People with Alzheimer's Disease." *Health Affairs* (Summer), Vol. 12, No. 2: 164-176, 1993.

and well-being of individuals with dementia and is often considered to be rewarding for the caregiver, it is important to note here that the burden of providing informal care is significant, and falls disproportionately upon unpaid, female caregivers. It is worth noting that smaller family size, coupled with the increasing labor force participation by those who provide most of the care – women – will result in fewer available informal caregivers in the future, which will lead to more of these imputed costs becoming actual formal care expenditures.

For a more detailed discussion of the methodology of the study, see Appendix IV.

The Finance Subcommittee utilized California Department of Finance demographic projection data to calculate the number of San Francisco adults at ages 55 and older and then projected the number of those adults who would be at each stage of dementia using commonly accepted prevalence data. Table III summarizes these current and projected costs (for 2020 and 2030), broken down by the following categories:

1. Community settings, residential care settings, institutional settings and all settings;
2. Informal care costs, formal care costs and total care costs; and
3. Mild/moderate impairment and severe impairment cost differentials for community-residents with dementia.

To portray the fiscal realities more accurately, Table III (on the next page) includes calculations that account for the large number of San Franciscans living alone without a loved one nearby. These individuals are unlikely to receive significant informal caregiver support, but the subtotal for informal care costs are projected from estimates of the total San Francisco population projected to have dementia, regardless of whether or not they live alone. To avoid over-estimating the imputed cost of informal care by assuming that all individuals with dementia would receive this support, researchers created a “Living Alone Multiplier” (Column B) and subtracted the imputed cost for informal care that had been attributed to these isolated individuals who would likely not receive informal care. While this adjustment results in lower total costs as seen in column J, it should be seen as a shifting of cost from the informal care sector to the formal care sector, a transfer of burden unique to the City of San Francisco as a result of the higher proportion of older adults living alone. It should also be noted that the population size for people with dementia differs from the figures in Table II because Table III uses a methodology to estimate the number of people with all types of dementia, not just those with Alzheimer’s and related dementias.

Table III warrants discussion. In the most optimistic circumstances, the above analysis projects a near catastrophic increase in the cost for care for individuals with dementia. Current formal care costs in all settings are just over \$920 million annually, but they are projected to increase to \$1.65 billion by 2020 and to \$2.8 billion by 2030, even excluding the imputed cost of informal care. While the vast majority of these costs are Medi-Cal reimbursed, the projected increase in costs is still staggering.



**Table III: Projections of Formal Costs of Care and the Value of Informal Care
for People with Dementia in San Francisco 55+ ***

A	B	C	D	E	F	G	H	I	J
					Informal Care		Formal Care		
		# of People			Cost per Person	Subtotal	Cost per Person	Subtotal	TOTAL COST
Community									
2008	Subtotal	18,685	mild-mod impairment	13,080	\$62,916	\$822,925,969	\$23,732	\$310,410,430	\$1,819,328,055
			severe impairment	5,606	\$71,686	\$401,846,310	\$50,689	\$284,145,347	
	SF Living Alone Multiplier	2,169	Average Cost	2,169	\$67,301	-\$145,965,167	\$49,761	\$107,923,532	-\$38,041,636
	Total	20,854				\$1,078,807,111		\$702,479,309	\$1,781,286,420
2020	Subtotal	22,729	mild-mod impairment	15,910	\$91,602	\$1,457,419,452	\$34,553	\$549,742,837	\$3,222,067,550
			severe impairment	6,819	\$104,372	\$711,678,390	\$73,801	\$503,226,871	
	SF Living Alone Multiplier	2,638	Average Cost	2,638	-\$97,987	-\$258,507,427	\$72,449	\$191,134,649	-\$67,372,778
	Total	25,367				\$1,910,590,415		\$1,244,104,359	\$3,154,694,774
2030	Subtotal	28,527	mild-mod impairment	19,969	\$125,274	\$2,501,631,333	\$47,254	\$943,623,710	\$5,530,616,652
			severe impairment	8,558	\$142,737	\$1,221,581,719	\$100,930	\$863,779,890	
	SF Living Alone Multiplier	3,311	Average Cost	3,311	-\$134,006	-\$443,722,827	\$99,081	\$328,079,194	-\$115,643,633
	Total	31,839				\$3,279,490,226		\$2,135,482,797	\$5,414,973,023
RCFE									
	2008	1,954			\$10,918	\$21,328,897	\$47,092	\$91,998,931	\$113,327,828
	2020	2,632			\$15,896	\$41,835,768	\$68,564	\$180,452,456	\$222,288,290
	2030	3,303			\$21,739	\$71,802,930	\$93,767	\$309,711,422	\$381,514,467
Institutional									
	2008	1,082			\$10,918	\$11,815,394	\$119,424	\$129,242,894	\$141,058,287
	2020	1,329			\$15,896	\$21,118,040	\$173,875	\$231,000,060	\$252,118,100
	2030	1,667			\$21,739	\$36,248,355	\$237,790	\$396,503,287	\$432,751,642
All Settings									
	2008	23,890				\$1,111,951,401		\$923,721,134	\$2,035,672,535
	2020	29,328				\$1,973,544,222		\$1,655,556,875	\$3,629,101,098
	2030	36,809				\$3,387,541,511		\$2,841,697,506	\$6,229,239,018

*Adjusted for SF Medical and General Annual Inflation.

RCFE = Residential Care Facility for the Elderly

The primary drivers of costs in these projections are as follows:

1. **Increases in the total number of people with dementia.**
2. **Increases in the level of cognitive impairment while in community settings.** While living in the community, informal care represents the vast majority of the cost of care (this is an imputed cost since family members are not reimbursed for their care). Note that for individuals living in the community, the cost for formal care increases from just under \$24,000 per individual while at the mild-moderate level of impairment and rises to just over \$50,000 as the individual reaches severe impairment (Column H).
3. **Transitions from community to institutional settings.** As a person moves from the community to living in a Residential Care Facility for the Elderly (RCFE), the cost of formal care rises to over \$47,000 and then to almost \$120,000 upon a move to a nursing home or hospital.
4. **General inflation and high costs of formal care in San Francisco.** Costs of formal care (Columns H and I) are projected to increase from \$923 million in 2008 to \$1.655 billion in 2020, by over \$700 million. They increase another \$1.2 billion from 2020 to 2030, reaching a total of formal costs of over \$2.8 billion. This is a projected increase of over 200 percent, compared to the 54 percent increase in the projected population of people with dementia.

This suggests that the most effective efforts to keep increasing costs in check will be those focused on delaying or preventing transitions from the community to institutional settings, as that is the factor that is most sensitive to local initiatives. Since institutional care costs are roughly \$70,000 more per year than community or RCFE care for individuals with severe impairment, this translates into almost \$6,000 per individual per month. Since in 2008 we estimate approximately 1,063 individuals will be institutionalized with dementia, for each month we delay institutionalization for that population San Francisco could save approximately \$6.4 million ($\$6,000/\text{mo} \times 1,063$) in formal care costs.¹¹ Delaying institutionalization by six months could save almost \$38 million. The success of this strategy will hinge upon ensuring that there is adequate availability of quality support for the individual and caregivers in the community, as the burden of support will shift to them.

Cost is not the only incentive for maintaining individuals in the community. The cost projections in Table III above assume that there are sufficient institutional beds available and preserved for people with dementia. However, San Francisco is losing these beds at an alarming rate. Due to inadequate reimbursement for long term care, nursing homes have been closing. No new nursing home facilities have opened in San Francisco in over 25 years. Laguna Honda Hospital (LHH), the city's long term care facility, has reduced the number of its skilled beds from 1065 to 780 in anticipation of its move to the new LHH facility in 2010. Of the total of 780 beds, three floors of 60 residents each (or 180 beds) will be used for Alzheimer's and dementia care. Thus, by the time the baby boomer bubble bursts onto the scene, the number of long term care beds will be insufficient to meet the demand. So, while projected cost savings are an important incentive for supporting caregivers and facilitating individuals remaining in the community as long as possible, a far greater incentive is that by 2020 there will not be enough institutional beds available to house the projected numbers of people who will need these beds.

¹¹ Estimates of saving vary depending on whether diverted individuals reside at RCFEs or not.

III. IMPROVING THE SERVICE NETWORK

While researchers continue to work on a cure for dementia, or find ways to mediate or eliminate the worst symptoms, it is up to policy makers, administrators and practitioners to use the resources and knowledge available to preserve the quality of life of those with dementia, and to minimize the suffering and burden that dementia imposes on those afflicted and on caregivers. Research suggests that this approach is also fiscally sound as it often limits or delays the use of more costly services.

This section of the report begins by outlining what the Expert Panel discovered in its review of the literature and exploration of evidence-based research and promising practices. (For a more complete literature review, please see Appendix I.) It then provides a summary of the overarching assets and challenges for San Francisco's service delivery network as it faces the crisis in dementia care. Finally, this section describes the key challenges for specific San Francisco service areas, as identified by the work of the Expert Panel.

III.A. LITERATURE REVIEW

From the start, the Expert Panel was committed to using research to inform the recommendations in its *Strategy for Excellence in Dementia Care*. To support that intent, the research team prepared a comprehensive review of the literature that captured: (1) the structures, principles and concepts that have been proven effective in caring for individuals with dementia; and (2) the specific programs, treatments, and models that are achieving their intended beneficial impacts. The Best Practice Summary that is found in Part Two of this *Strategy*, as Attachment I, was developed from an evaluation of over 160 documents, many of which were identified by the Expert Panel. A priority was given to documents published in 2003 or later. Research was reviewed from England, Scotland, Sweden, Australia, New Zealand, Korea, Canada, and the United States. The review included an examination of evidence-based approaches related to:

- Each component of care for those with cognitive impairments, e.g. diagnosis, pharmacological treatment, caregiver support, including education and prevention;
- How other public health and social welfare challenges have been addressed through the implementation of a 'system of care' approach that integrates and coordinates services and supports; and
- Dementia-focused capitated systems such as those in Canada, Australia, England and Scotland, as well as locally developed closed systems like On Lok's PACE model.

Key Findings

Among the key findings identified in this literature review:

- Early identification of cognitive impairment can result in better planning among patient, caregiver and primary care physician;
- A range of pharmacological treatments, and home and community-based services, can slow the advance of cognitive impairment and significantly delay entry into institutional care;

-
- While there is increasing evidence that side effects of pharmacological interventions, particularly anti-psychotics, can complicate their effective use, an increasing amount is being learned about non-pharmacological treatments, which can slow the advance of cognitive impairment and address many co-morbid behavioral, and even physical health symptoms;
 - Caregiver education and support can reduce stress on the caregiver, reduce morbidity for the caregiver, increase capacity to support the individual with cognitive impairment, reduce patient accidents and co-morbidity, and delay entry into institutional care;
 - Environmental modifications (lights, signs, clear directions, alarms, and improvements that prevent falls or help with wandering) in the home and assisted living facilities, skilled nursing facilities and hospitals can reduce symptoms and slow the advance of cognitive impairment;
 - Coordination of care between various agencies, programs, and systems can reduce stress for caregivers, facilitate transitions and discharges, reduce the impact of co-morbidity, and improve a range of outcomes for the patient with cognitive impairment and caregivers;



- Much is known about the effective treatment of dementia and related conditions. Routinely published guidelines describe protocols, interventions, and treatments that can slow the progression of dementia, better support caregivers, improve quality of life, and delay entry into higher levels of care. But these practices are inconsistently implemented. There is a critical need to develop consistent mechanisms for sharing the knowledge and practices found in these guidelines. Target audiences include primary care doctors, assisted living staff, adult day care center providers, family caregivers and others involved in the care and support of individuals with dementia and other cognitive impairments; and
- Within a service delivery network that effectively implements all of the above, a mutually reinforcing impact could be achieved that would significantly delay entry into skilled nursing and hospital care. This would shorten the length of time spent in these institutions, reduce stress and co-morbidity on caregivers, improve the quality of life of both the person with cognitive impairment and caregiver, and reduce public expenditures on institutional care.

The recommendations section of this *Strategy* makes frequent references to promising and evidence-based practices and literature findings. A complete summary of the literature review conducted can be found in Appendix I.

III.B. SAN FRANCISCO'S ASSETS AND CHALLENGES

The assets and challenges for San Francisco to improve and expand dementia care services that are summarized below reflect: (1) the key-informant interviews; (2) input obtained from all Expert Panel and Subcommittee meetings; (3) topics focused upon in research, data, and local, national and international reports; and most importantly, (4) the extensive knowledge and experience of the Expert Panel members themselves.

A variety of assets exist upon which to build the *Strategy for Excellence in Dementia Care*:

A long-standing commitment to addressing the needs of the under-served. San Francisco has a deep commitment to social justice and meeting the needs of its most vulnerable residents. No finer example can be found than the City's response to the HIV/AIDS epidemic. Even more germane to this plan is *Healthy San Francisco*, San Francisco's commitment to universal health care for residents under 65. But beyond these examples, San Francisco has historically pioneered policies that have addressed the needs of the under-served, protecting the rights of new immigrants, advancing the rights of the gay and lesbian community, and creating safety nets for its children. This ethos of commitment to doing whatever is necessary to help those in need is a solid foundation for this plan.

Strong leadership from the Office of the Mayor, the Department of Aging and Adult Services, and significant influence in the national political arena. Mayor Gavin Newsom has been a strong promoter of health care reform and advancing initiatives to support the under-served, with several of the initiatives mentioned above being developed under his leadership. Anne Hinton, DAAS Executive Director, has been a steadfast supporter of all efforts to improve dementia care services in order to provide assistance for people with dementia and for their caregivers. In Washington, San Francisco has its interests well represented by House Speaker Nancy Pelosi and two seasoned and influential California Senators, Dianne Feinstein and Barbara Boxer.

Models of Excellence and Research Expertise. San Francisco is fortunate to be the home of one of the most highly regarded research institutes in the nation, the University of California at San Francisco (UCSF). Neurologists and other specialists from UCSF are in the forefront of dementia research. The San Francisco Bay Area is also home to the nationally prominent Family Caregiver Alliance and the Alzheimer's Association of Northern California and Northern Nevada, two of the most important advocacy and service providers in relation to Alzheimer's and related dementias. Finally, San Francisco is home to a vital service provider community, offering some programs recognized nationally as models or best practices, such as On Lok's PACE (Program of All Inclusive Care for the Elderly) program and the assisted living facilities and services provided by Age Song.

Multiple points of access to care. San Francisco has an extensive array of public and non-profit primary care health centers and community clinics. These health centers and clinics are located throughout the City, providing accessible, high quality, culturally responsive primary medical care. There is an equally strong network of adult day health care and social day care centers, as well as Alzheimer's day care resource centers, which serve as access points for dementia services. San Francisco also has a wide range of community-based service providers, many of which are able to help link clients to various services they might need. Finally, there is the DAAS Integrated Intake Unit, which is the centralized access point in San Francisco for a range of information, referral and assistance services, as well as the enrollment point for: (1) In-Home Supportive Services, (2) Adult Protective Services, (3) Home Delivered Meals, and (4) the Community Living Fund.

A history of collaboration. San Francisco is accustomed to working through highly collaborative processes that seek ways to integrate resources, develop common goals, and advance excellence in practice. Partnerships between and among the public and private sector are the rule, not the exception. For example, DAAS, under the leadership of Executive Director Anne Hinton, has been on the forefront of advancing collaborative strategies for better meeting the needs for long term services and support for older adults and adults with disabilities through the implementation of the *Living with Dignity Strategic Plan* and the work of the Long-Term Care Coordinating Council.

A number of challenges need to be confronted to achieve the Strategy for Excellence in Dementia Care:

A common theme identified through key informant interviews, and the review of the literature, is: the greatest challenge historically has been the failure to develop a way to ensure that at every stage of dementia, in every component of care, we employ what is known to be the best practice. While guidelines exist, and the research points specifically to effective interventions and practices, too often these guidelines are not implemented. Opportunities are missed to slow the progression of the disease, avoid a preventable and debilitating co-morbid condition, or provide caregivers the respite and support they need. This is true in San Francisco and across the country.

Silos (separate organizational structures). Although San Francisco has multiple points of access to services, it is often a challenge to navigate the existing service network, including the variety of housing and residential services. To a significant degree, services function in silos that are more organization- or program-focused than person-focused. Caregivers commented and Expert Panel members affirmed that caregivers are often confused as to where they can get services and information, and that transitions between programs, and across systems, are often difficult. These silos are made more insulated by the absence of a common digital medical record that allows service providers throughout the city to more easily share information and coordinate care.

Inconsistent practice. Standards and guidelines have been developed by a number of sources, including an excellent set of guidelines for care developed by the Alzheimer's Association.¹² These summarize the most appropriate services, assessments, supports, educational information, and residential and home-based care options for every stage of the disease. However, as mentioned under Key Findings, the research review identified many studies indicating that adherence to standards and guidelines is inconsistent in relation to almost every aspect of dementia care. On the local level, Expert Panel members commented that inconsistent care is commonplace in relation to screening, assessment and diagnosis, referral to community-based care, and pharmacological interventions. Inconsistent implementation of guidelines can have significant negative impacts, greatly increasing costs and creating unnecessary human suffering as will be described in more detail in Section II.

Absence of coordinated or integrated care or care management functions. While access to primary care and adult day care was identified as a strength upon which to build, once individuals access care, they face a dizzying range of choices and the need to navigate multiple services and systems with different eligibility criteria, understand coverage limitations, and arrange multiple appointments and services. For people with dementia who have no informal support, the task will quickly become impossible. For those with involved loved ones, their burden will quickly become immense.

¹² California Guideline for Alzheimer's Disease Management, 2008, See Appendix VI.

State and federal regulatory and financing barriers. Medicare and Medi-Cal financing regulations make it difficult to deliver comprehensive care in a manner consistent with best practice. Numerous examples will be cited below, but to cite just two: Medicare does not cover ongoing dementia care, only acute and post acute care, and Medi-Cal does not sufficiently cover community-based care, so many people with dementia get placed in institutional settings prematurely.

General absence of understanding of the needs of individuals with early memory loss. The absence of understanding of early memory loss conditions extends through virtually every aspect of San Francisco life. Most generally, there is a lack of awareness of the symptoms and signs of mild cognitive impairment and the tremendous benefit of early detection and treatment. Among professions that most commonly might interact with individuals with mild cognitive impairment and early stage dementia and identify a problem, there is also lack of knowledge of the signs or of how one would most appropriately connect the individual with services, supports or an assessment. The research describes that even health professionals fail to identify dementia when treating other conditions even in the face of clear indication of confusion, forgetfulness or other symptoms.

Stigma and discrimination. Stigma, ignorance, fear and denial all conspire to prevent individuals with mild cognitive impairment and early stage dementia from accessing early treatment that can delay disease progression. Insurance coverage policies that can exclude individuals with a diagnosis of dementia from eligibility for coverage contribute to individuals delaying being assessed. Stigma and fear of how others will view a person with a cognitive impairment or dementia diagnosis causes many individuals to resist being assessed. Together these factors block many individuals from accessing treatment that could postpone the advance of the disease and prevent important treatment planning while individuals are still cognitively capable of making informed choices for themselves.

Informal care relies upon the availability of largely uncompensated care provided by loved ones. While living in the community, people with dementia require increasing levels of support that in the early stages could be limited to periodic check-ins and monitoring by phone. However, as the disease progresses, daily support from informal caregivers, and eventually around the clock support,



are necessary to ensure safety, adhere to medication regimens, maintain a healthy diet, prevent wandering, and provide help with daily routines and functions. Additionally, informal caregivers must manage finances, negotiate health services and medical appointments, and also care for their own needs. Too often it this last item that gets most neglected. It is estimated that for each year of providing care for a loved one with dementia the informal caregiver's life expectancy is reduced by one year. Research indicates that 75 % of informal caregivers are women. From a social justice perspective, this can be viewed as another

example of gender inequity with largely unpaid female caregivers subsidizing the health care system.

The absence of loved ones nearby will necessitate the provision of paid in-home support or premature institutionalization, either of which would impose significant additional costs for caring for individuals with dementia. From a health planning perspective, the reliance on

informal caregivers poses a significant challenge in San Francisco, as the demographics summarized earlier project that approximately 40% of seniors do not have a family member living within a 20 minute drive of the City. The Finance Subcommittee developed a cost projection model to estimate the value of informal care provided by loved ones. Using this model, it projected that in 2008 the annual cost of informal care and support for San Franciscans living with individuals with dementia exceeded \$1.1 billion (see Section II.C. of this report for the details of this analysis).

III.C. EXISTING SERVICES AND SUPPORTS: KEY CHALLENGES

The Services & Systems Subcommittee developed a comprehensive inventory of the current array of services and supports for people with dementia at each phase of the disease (see Appendix II). It identified all programs in the service areas listed below, categorizing each program by populations served (mild, moderate, or advanced) and by fee structure (entitlement, means-tested, or fee for service). The chart [on the next page] depicts this array of services and supports, which can be accessed by people with cognitive impairment and dementia, and their caregivers.

Nearly all service categories have at least one program serving people at all three stages of dementia (mild, moderate, advanced), with only a few exceptions: Mental Health services and In Home Supportive Services are not available for people with advanced dementia; respite care is not available for those with mild dementia; and nursing care and hospitals are not available for those with mild or moderate dementia.

San Francisco has myriad individual programs and facilities that provide excellent care to individuals with dementia and their caregivers. However, the network is not without its limitations. For example, there is no component of service with the capacity required to fully address the future demand as projected in Section II.C of this report.

The next page provides a visual depiction of dementia care services now in place in San Francisco. The table that follows provides a summary of the key challenges associated with specific service areas, as identified by the Expert Panel, key informant interviews, and a review of local reports.¹³ The recommendations for the *Strategy for Excellence in Dementia Care* respond to many of the challenges highlighted here. Key challenges associated with education and prevention are also included in the table, but a more comprehensive set of findings, recommendations, and curriculum proposals are located in Appendix III.

The extensive array of dementia care and caregiver services and supports has been listed in the following service categories:

- Adult Day Centers
- Advocacy and Protection
- Care Management
- Caregiver Services and Supports
- Diagnostic Assessment
- Education
- Information and Referral
- In Home Supportive Services
- Legal Services
- Mental Health Services
- Money Management
- Multipurpose Senior Centers
- Nursing Care and Hospitals
- Ongoing Medical Treatment
- Public Policy
- Research and Development
- Residential Care
- Respite Care
- Other Services

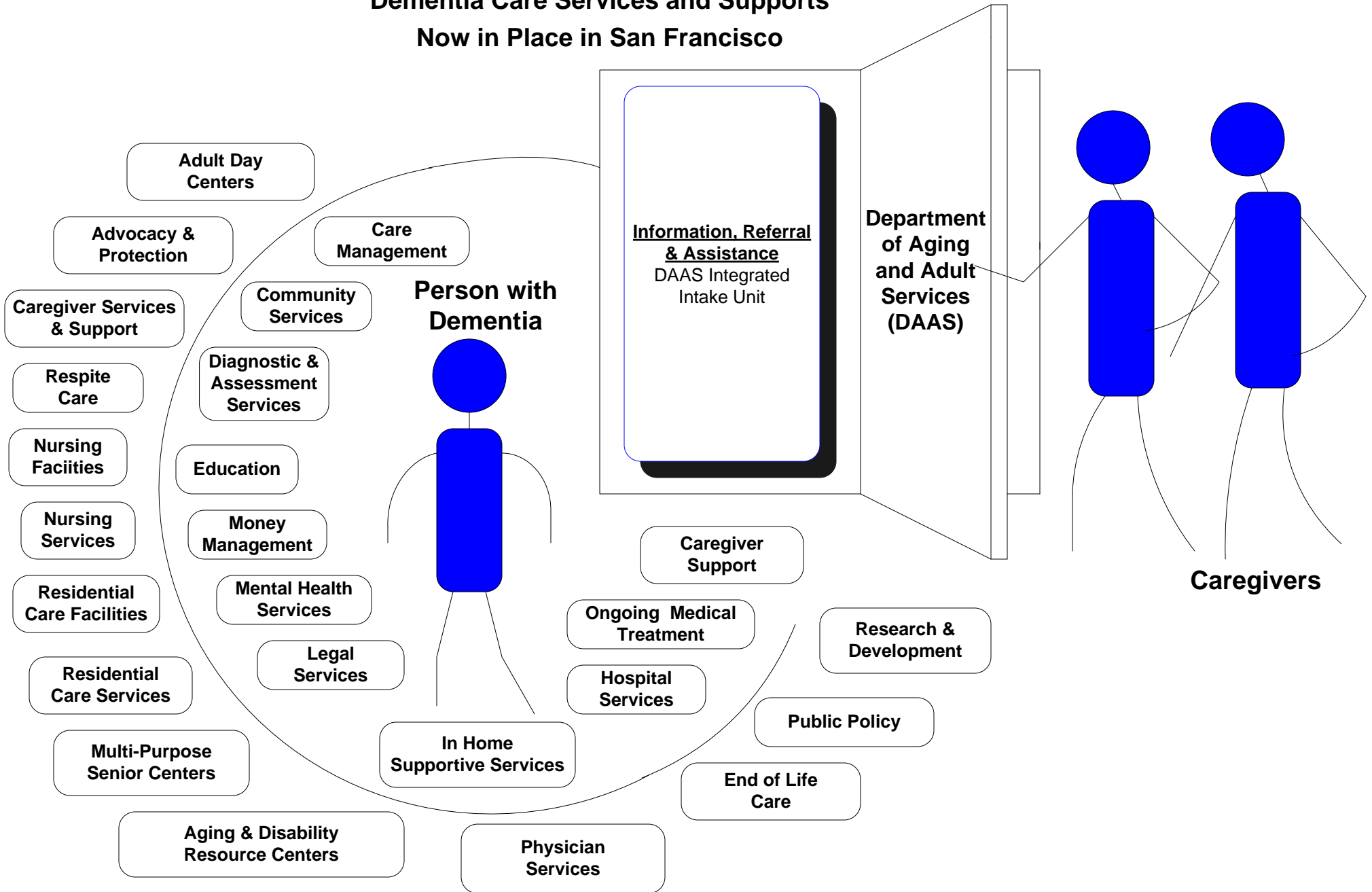
¹³ Service areas are only included in the table below when a variety of key challenges specific to that area were identified.

SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE

WHAT WE HAVE:

Dementia Care Services and Supports

Now in Place in San Francisco



Service Area	Key Challenges
Adult Day Centers (Social Day Programs, Adult Day Health Care Services and Programs, and Alzheimer’s Day Care Resource Centers)	<ul style="list-style-type: none"> ▪ Funding is limited, and heavily dependent on state and local budgets. Social Day Programs are not Medi-Cal funded, and Medi-Cal reimbursements do not cover the entire cost of Adult Day Health Care services. ▪ Staffing ratios vary depending on funding sources, ranging from 1:5 to 1:35. ▪ Communication with primary care physicians for shared treatment plans can be challenging. ▪ Waiting lists are between three months and one year long. Access issues exist for: (1) <i>individuals with traumatic brain injury, co-morbid psychiatric conditions, and aggressive behavior</i>, (2) <i>middle-income individuals</i> who are ineligible for Medi-Cal but cannot afford to pay out of pocket; and (3) <i>younger adults with disabilities</i> who delay seeking services because they feel out of place at programs that serve mostly seniors. ▪ Informal settings such as adult day centers, are not always appropriate for the needs of individuals at all stages of dementia, especially advanced dementia.
Care Management	<ul style="list-style-type: none"> ▪ An overall shortage of care managers forces crisis workers to step in (e.g., Adult Protective Services and the Long Term Care Ombudsman), often without reimbursement. ▪ Professionals and the public often don’t know that services are available, so even those with resources are not necessarily connected to services. Those living alone are even less likely to seek services as their disease progresses. ▪ Communication challenges include: <ul style="list-style-type: none"> ○ A lack of cross-agency communication mechanisms often leaves confusion about which agency is taking the lead in coordinating services. ○ Providers lack mechanisms for information-sharing (e.g., dementia-specific roundtables); many would benefit from an electronic clearinghouse with service listings and resources on current best practices. ○ Communication between providers is hindered by a lack of comprehensive integrated electronic client records and lack of knowledge about HIPAA (Health Information Portability and Accountability Act) and other privacy regulations.
Caregiver Services and Supports	<ul style="list-style-type: none"> ▪ Caregivers do not receive information about available supports at the time of diagnosis, leaving them isolated and without support. ▪ Many caregivers are uneducated about the value of seeking support; they feel guilty about asking for professional help. ▪ There is a shortage of providers with linguistic capacity and culturally-specific caregiver training. ▪ Caregiver assessment is not a universal practice.

<p>Diagnostic Assessment</p>	<ul style="list-style-type: none"> ▪ San Francisco has no system of clinical standards, guidelines, or universal assessments and diagnostic tools. ▪ Wait lists for diagnostic assessments are long, and those without caregiver advocate can miss out. ▪ There is a shortage of resources for follow-up visits. ▪ There is a shortage of psychiatric services for diagnosing co-occurring and pre-morbid psychiatric disorders. ▪ Cultural and linguistic barriers impede the effective administration of diagnostic assessment: validated assessment tools may not be useful for all language and ethnic groups; geriatric psychologists do not usually speak languages other than English; Medi-Cal does not pay for interpreters; and caregivers do not always provide objective and accurate language interpretation. ▪ Medi-Cal reimbursements for diagnosis are too low, and there are no reimbursements for computer-based testing tools.
<p>Education and Prevention</p>	<ul style="list-style-type: none"> ▪ Primary care physicians, first responders, housing providers, and other providers need training to make services “dementia friendly” and to ensure that they can identify people with cognitive impairment and refer to appropriate services. ▪ There is no clear set of standards upon which provider training should be based. ▪ There are cost and logistical challenges in releasing parts of the workforce from work shifts or requiring staff to give up free time to attend training during off-work hours. ▪ Caregivers often receive either too little information or referrals at the time of diagnosis or so much that they become overwhelmed. ▪ San Francisco has no unified and coordinated approach to community-wide education. Such an approach would need to counter stigma, be culturally competent for ethnic and Lesbian, Gay, Bisexual, and Transgender (LGBT) communities, be responsive to different levels of health literacy, and be available in a variety of formats to maximize accessibility.
<p>Information and Referral</p>	<ul style="list-style-type: none"> ▪ Call lines are short staffed and cannot respond to all inquiries, and it is difficult to recruit clinically-trained people to phone jobs. ▪ Lack of communication between Information & Referral providers results in conflicting information and/or duplication of services. ▪ Follow-up is inconsistent.

In Home Supportive Services (IHSS)	<ul style="list-style-type: none"> ▪ There are few affordable services for people with limited budgets who do not qualify for In Home Supportive Services. ▪ Family members sometimes resist turning care over to someone else, either due to a sense of duty or fear of bringing a stranger into the home. ▪ IHSS providers lack training in identifying signs and symptoms of dementia.
Nursing Care and Hospitals	<ul style="list-style-type: none"> ▪ There is a shortage of skilled nursing facilities (SNFs), particularly those with specialized Alzheimer’s units that accept Medi-Cal. ▪ No new SNF facility has been built in San Francisco in the last 25 years, and decreasing Medi-Cal reimbursements make it difficult to do so. ▪ Few beds are available for those who do not qualify for Med-Cal but cannot afford to pay out-of-pocket. ▪ Families face stigma when placing loved ones in SNFs. ▪ Sub-populations with co-occurring conditions are often underserved in SNFs (e.g., individuals needing psychiatric services; those with traumatic brain injury). ▪ No facilities target the LGBT community, and language and ethnic groups are not fully served. ▪ Staff faces challenges in helping individuals and families articulate goals of care, particularly related to end-of-life care. There is a critical need for support in advance directive planning, especially as it related to the tendency of hospitals to push for life-extending interventions that do not contribute to quality of life. ▪ Determining whether someone with dementia is eligible for hospice care is challenging.
Ongoing Medical Treatment	<ul style="list-style-type: none"> ▪ Barriers to accessing community clinics and/or specialty providers exist for: (1) <i>at-risk populations</i> such as those who are homeless, or who have conditions such as HIV/AIDS, substance abuse, and mental illness; (2) <i>middle income people</i> without Medi-Cal or private insurance; (3) <i>people without family advocates</i>; and (4) <i>minority communities</i> whose cultural traditions make them less likely to seek treatment. ▪ Services are organized based on the stages of Alzheimer’s and related dementias, with few methods or procedures in place to assist in transitioning patients as they progress. ▪ Low Medi-Cal reimbursements and little research funding creates a disincentive to provide dementia treatment and study geriatric medicine, leading to shortages of specialists. ▪ Specialists and primary care providers often do not address co-occurring dementia when treating other geriatric conditions, sometimes due to a lack of up-to-date information or training. ▪ People with dementia have a hard time accessing dental, vision, and hearing care.

Residential Care	<ul style="list-style-type: none">▪ Low and middle-income individuals cannot access services when Residential Care Facilities for the Elderly (RCFEs) do not accept Medi-Cal or Medicare.▪ Few RCFEs are dementia-friendly or dementia-capable, and even fewer can handle residents with severe behavioral challenges and/or violent behavior associated with dementia.▪ Family members require emotional support during transitions to residential care.▪ Lack of cultural sensitivity can result in cultural isolation for residents.▪ Communication between residential care providers and hospitals is weak.
------------------	--

IV. RECOMMENDATIONS FOR EXCELLENCE: IN THE SHORT TERM AND IN THE FUTURE

When the Expert Panel set out to develop recommendations to improve care for people with cognitive impairment, and their caregivers, it recognized the scope of the response must go beyond addressing the dementia-related needs for services. People with cognitive impairment - or dementia - are also subject to a range of physical and behavioral conditions requiring access to primary, behavioral and specialty care. Accordingly, the Expert Panel decided to develop a more integrated *Strategy* that addresses: (1) the behavioral, housing, social, primary care, and specialty care needs of each person in need of care; and (2) the services and supports required by informal caregivers, who provide the majority of care while a person is living in the community. Also, the Expert Panel understood the *Strategy* needed to include recommendations for improvements that could be achieved in the near future while providing longer-term recommendations for more substantial, far-reaching reforms that could require years of work to achieve.

The following objectives and recommendations achieve this balance. They are intended to address the growing crisis in dementia care in stages, from early memory loss, to the progression to mild, moderate, and advanced dementia. However, if San Francisco could: (1) help people learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment; (3) offer training and support for caregivers and service providers; and (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, the need for more intensive and costly services could be delayed. The progression of the disease cannot be halted at present. Accordingly, San Francisco should provide comprehensive, compassionate care for people and their care partners at each stage of the disease. Until there is a cure or treatment for cognitive decline, achieving these objectives and implementing these recommendations will allow us to: (1) support caregivers; and (2) better manage each individual's complex medical conditions along with their dementia in a way that will improve quality of life.

OBJECTIVES

The objectives are:

1. Improve capacity to meet the needs of the whole person by delivering integrated care.
2. Improve public and professional awareness and understanding of dementia.
3. Develop an informed and effective workforce for people with dementia.
4. Expand capacity to deliver high-quality early diagnosis and intervention for all.
5. Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and their caregivers.
6. Create expanded and easy access to care, support and advice following diagnosis.
7. Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.
8. Improve the quality of hospital and nursing home care for people with dementia.

-
9. Expand and improve the quality of community-based care for people with dementia.
 10. Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.
 11. Improve access to end of life care for people with dementia.
 12. Advocate for effective state and national support for implementation of this *Strategy*, as well as other improvements for people with Alzheimer’s and related dementias, and their caregivers.
 13. Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.
 14. Facilitate and support an Oversight Committee responsible for implementing this *Strategy* and advocating for the improvement of prevention, education, services and supports related to dementia.

OBJECTIVE 1: Improve capacity to meet the needs of the whole person by delivering integrated care.

To effectively address the whole person requires integrated care that spans disciplines, systems, and treatment sites, and eliminates silos or barriers to care. Integrated care strategies are becoming increasingly important to address the needs of the whole person through the seamless provision of health and social care.¹⁴ The effective treatment of cognitive impairment requires a broad array of services delivered by professionals, paraprofessionals, and informal caregivers, in the home, in the community, and in health care and assisted living settings. This care involves medical, mental health, housing and financial systems support.¹⁵ The effort to improve the effectiveness of this multi-faceted network has led to “investigation of whole system approaches to improve the manner in which sectors, institutions, providers and services work in tandem as a long-term care enterprise.”¹⁶

Locally, efforts are being made to integrate services across silos (separate organizational structures) through increased collaboration, shared planning, and shared budgeting. The first seven of the recommendations in San Francisco’s *Strategy* (Recommendations 1.1-3.4) focus upon improving the capacity of the existing network and creating conditions that would foster more collaboration and service delivery informed by best practices, thereby facilitating the network’s ability to address the full scope of needs of people with dementia.

RECOMMENDATION 1-1. Dementia care should be integrated into San Francisco’s existing long term care service delivery network for older adults and adults with disabilities, which emphasizes ongoing chronic care management. This will enable the needs of the whole person to be considered and addressed.

¹⁴ Kodner, D.L., *Whole system approaches to health and social care partnerships for the frail elderly: an exploration of North American models and lesson*, Health and Social Care in the Community, 14(5), 384-400, 2006.

¹⁵ Feder, J., Komisar H. & Niefeld M. *Long-Term Care in the United States: An Overview*. Health Policy 19, 40-56. 2000.

¹⁶ Kodner, D.L., *The quest for integrated systems of care for frail older people*, Aging Clinical and Experimental Research, 14(4), 307-313.

People with Alzheimer’s and related dementias often have other chronic illnesses and conditions. Integrating expanded and improved dementia care services into the long term care service delivery network will enable issues of co-morbidity to be addressed. It has been shown that the treatment of co-morbid medical conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, arthritis, and diminution of vision and hearing can improve functionality and cognition in persons with Alzheimer’s disease.¹⁷ Also, effective management of behavioral conditions associated with dementia is essential, as more often than not it is the inability to manage behavioral conditions that leads to placement in assisted living or nursing home care. Accordingly, integration would mean ensuring that all community-based long term care services as well as community clinics, health centers and nursing homes all are able to serve people with dementia.

RECOMMENDATION 1-2. All agencies and programs delivering services in the long-term care service delivery network as well as first responders and urgent care clinical settings should become dementia capable. This will require education, training, and support for service providers and families. Agencies and programs serving people with dementia will need to consider the stigma related to dementia, the concerns of existing clients, and the dignity of new clients experiencing cognitive impairment or dementia.

More older adults with cognitive impairment or dementia will be served by community-based programs such as senior centers, adult day health care centers, social day programs, congregate meal programs, specialized group programs, and residential care facilities. To enable these programs and services to address the needs of older adults with cognitive impairment or dementia, and to respond to them with dignity and respect, training to become dementia capable will be necessary. The *Dementia Care Excellence Oversight Committee* should convene a workgroup charged with identifying and prioritizing training needs and methods of delivery. Additional funding will be required for training.

Service providers in the long term care service delivery network should be educated and trained to address the full range of health, medical, social, and spiritual needs of people with Alzheimer’s and related dementias, as well as the needs of their caregiver (family and other informal support). Such education and training should be based on the work of the Education & Prevention Subcommittee, which are summarized in Recommendation 2-1, and provided in detail in Appendix III.

OBJECTIVE 2: Improve public and professional awareness and understanding of dementia.
--

In order to create a more dementia-friendly community, public and professional awareness and understanding of dementia must be improved and the stigma associated with it addressed. This public education campaign would be aimed at increasing awareness among all San Francisco residents thereby increasing understanding of the importance of seeking screening and assessments; increasing the capacity of individuals to identify signs of dementia and understand how to help individuals suspected of having dementia to access screening assessment and services; and to generally increase the level of acceptance of individuals with dementia throughout the city. In short, a public awareness campaign should contribute significantly to creating a ‘memory loss friendly’ community in which those with dementia and their caregivers can thrive.

¹⁷ Wall, A. *Including Persons with Alzheimer Disease in Research on Comorbid Conditions*, from IRB: Ethics & Human Research, February, 2009.

RECOMMENDATION 2-1. Public education should be expanded and enriched and should target those experiencing memory loss and those newly diagnosed with Alzheimer’s and related dementias, and their caregivers, as well as service providers, care managers, and health care professionals. Funding should be sought and obtained to enable the provision of this expanded public education.

Public education about memory loss services and resources should be expanded. This should also address the stigma connected to Alzheimer’s and related dementias. Community-based education centers, which may include neighborhood public libraries, should offer periodic presentations about memory-loss issues and serve to build better understanding of dementia, greater compassion, and an increased ability to identify people who may have mild cognitive impairment (MCI).

Nine key content areas were identified by the Education and Prevention Subcommittee that should be part of a comprehensive education and prevention effort. Following are these content areas with the corresponding recommendations.

Education and Prevention: Content Areas & Recommendations:

- Risk Reduction: Promote cognitive health and create a culture of “brain fitness” through mental stimulation, social engagement, physical exercise, and diet.
- Early Identification of Alzheimer’s and Related Dementias: Educate people about the signs of dementia, how they differ from normal aging, and when and where to seek a diagnosis.
- What To Expect as the Disease Progresses: Offer diagnosed individuals, caregivers, and health care providers information about what to expect throughout the course of Alzheimer’s and related disorders, which will help with future planning.
- Services and Resources: Ensure that caregivers are aware of and have access to community resources, training and support.
- Caregiver Wellness and Support: Help caregivers understand the stresses inherent in caring for a person with dementia and provide resources for self-care.
- Disease Management for Mild, Moderate, & Advanced Dementia, Including End-of-Life Issues: Effective management of early to moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity, and delay entrance into institutional care. Informed medical management of late stage and end-of-life co-morbidities will decrease unnecessary treatment and ease the burden and suffering of the person with dementia and caregiver at the end of life.
- Advanced Care Planning: Advance care planning can help foster greater patient and caregiver understanding of the patient’s medical condition, promote more patient-centered care, and ensure that a person’s preferences are honored at the end of life.
- Ethical Issues: Create an ethics review committee/group to consult on difficult ethical situations involving persons with dementia.
- Emergency Preparedness and Safety: Promote awareness of steps to take to prepare for an emergency and to address common dangerous behaviors prevalent in persons with dementia so as to avoid catastrophic outcomes.

Public education should be viewed expansively and could include feature films, works of art, and other expressions of gifts, talents, strengths and creativity of people with Early Memory Loss (EML). This low-cost strategy is designed to build more memory loss friendly, elder compassionate communities. A variety of community-based EML educational programs should be implemented throughout the city. These programs can serve as a point of entry to supportive services for people with EML and their caregivers.

Services for people with EML, MCI, and early stage dementia are in short supply. Also, people with EML/MCI often miss opportunities for referrals to services that delay the advance of their condition and/or prevent or treat co-morbid conditions. In addition, educational presentations are one avenue for raising the awareness of individuals who come into contact with people with dementia, who could perhaps better facilitate identification and ultimately improve timely access to treatment. Another component of the educational campaign could target individuals who frequently are in a position to identify people with dementia who have not accessed services. Postal workers, paramedics, police, fire, and transportation staff should be educated about the warning signs, behaviors and needs of people with EML/MCI, increasing their ability to better serve these people and to help them access the network of services and supports available.

Public education and training could also target persons with EML/MCI; people with Alzheimer's and related dementias; family caregivers, other family members, interested friends and neighbors; professional paid caregivers – including home care workers, assisted living staff, nursing home staff; physicians, health care providers and allied professions; Adult Protective Services staff; nutrition programs and meal site staff, first responders; and other community-based service providers.

See Appendix III for a comprehensive presentation of the Education and Prevention Subcommittee recommendations for the nine key content areas for education and prevention activities throughout San Francisco. This appendix includes proposed curricula, the types of media to effectively promote the recommended educational efforts, and target populations.

OBJECTIVE 3: Develop an informed and effective workforce for people with dementia.

The health and social services workforce involved in the care of people with dementia must be well trained so workers have the skills and knowledge of best practices to provide the best quality of care in the roles and settings where they work. To ensure an informed and effective workforce, basic training and continuous professional and vocational development in dementia is essential.

Existing research demonstrates that cost savings in the care of people with Alzheimer's are potentially large. Data show that interventions leading to improvements in memory and physical functioning or delaying the rate of decline could lead to cost savings for both formal and informal care.¹⁸ But knowledge of these interventions and how to make referrals to them is not common. Even primary care doctors working with patients over 75 years of age with cognitive impairments rarely refer them for anything other than pharmacological interventions. In one chart review of 240 managed care patients, researchers found so few references for non-pharmacological care that they

¹⁸ Leon J, Cheng C, Neumann P. Alzheimer's disease care: Costs and potential savings. *Health Affairs*. 1998, 17:206-16.

chose not even to report on this data.¹⁹ Failures to refer people with dementia for community treatment and support are missed opportunities. If properly referred, people with dementia and their caregivers could access effective treatments and supports thereby improving the quality of their life, reducing the burden on the caregiver and reducing public expenditures. Expert Panel members confirmed these missed opportunities are also commonplace in San Francisco. Primary care doctors have an immense challenge in being current on guidelines in many areas. Referral for community care is inconsistent, and even identifying the correct pharmacological treatment is not guaranteed.

Recommendations under Objective 3 are designed to: (1) increase the knowledge of current standards and guidelines as well as the effectiveness of service providers; and (2) ensure closer alignment between common practices and known best practices and treatment guidelines.

RECOMMENDATION 3-1. The most current guidelines and standards for dementia treatment and care should be identified and compiled for dissemination to professionals on a regular basis.

Providing health and social service professionals, including community-based service providers and care managers, with the most current dementia care guidelines and standards that inform their care practices for appropriate screening, diagnosis, treatment, disease management, and late stage care, will help to improve the dignity and quality of care, and help to reduce stigmas.

Recommendation 14-1 calls for the creation of a *Dementia Care Excellence Oversight Committee* that will oversee and monitor implementation of this *Strategy*. Some of its most important functions must be to: (1) ensure that guidelines are compiled, maintained, and kept current; (2) see that they are broadly disseminated; and (3) work with program administrators to foster adherence to these guidelines. At first, adherence to guidelines and standards may need to be voluntary, perhaps encouraged through some form of recognition or awards for agencies that implement them effectively. Over time, some standards could be incorporated into city contracts for services provided, thereby institutionalizing practices recommended in guidelines. However, there would need to be safeguards to ensure that mandated practices are current and represent the best understanding of effective practice.

The intent of this recommendation is not to develop new guidelines and standards, but to work with existing resources already identified in our research, and to assemble a set of guidelines and standards that can be distributed throughout the service network. However, even assembling a set of guidelines and standards will be no easy task. Appendix VIII includes a list of initial questions for guiding this process and detailed references for model guidelines and standards that can be used.

RECOMMENDATION 3-2. Training for professionals, including community-based service providers and care managers, should be expanded to facilitate the use of the most current guidelines and standards for dementia care. As part of this recommendation, DAAS should seek and obtain funding to enable the provision of this expanded training.

If professionals, including community-based service providers and care managers, are to meet current dementia care guidelines and standards, expanded training will be needed to boost the capacity and capability of staff working at all levels of care. Training and information should be

¹⁹ Boise, L., Neal, M. B., & Kaye, J. (2004). Dementia assessment in primary care: Results from a study in three managed care systems. *Journals of Gerontology, 59A*, 621-626.

provided to nurses, caregivers (paid and unpaid), care managers, primary care physicians, and Adult Protective Services. Also, expanded training should be provided for staff at assisted living facilities and nursing homes. Funding will be needed for this expanded training.

This training could either consist of or be reinforced by a reader-friendly monthly e-memo about recommended standards of practice, guidelines and community resources as well as standards for training of all personnel serving older adults with chronic conditions including Alzheimer's and related dementias. The monthly e-memo should be disseminated to all service providers and caregivers listed above.

RECOMMENDATION 3-3. Targeted training for primary care physicians, hospitalists, and the medical staff of primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente should be expanded related to medication prescriptions, diagnosis, end-of-life care, and managing difficult behaviors and critical crisis care issues.

Training designed specifically for physicians, hospitalists, and other medical staff is needed to ensure medical conditions are properly diagnosed, medications are correctly used, and over-treatment is not employed to extend life against the wishes of the patient and/or caregiver. Consistent knowledge of the effective use of pharmacological and non-pharmacological interventions must be part of the training.

Expert Panel members also spoke often of poor diagnoses, mistaken pharmacological prescriptions, and unnecessary life-extending procedures that could be avoided with greater and broader understanding of best practices.

Recommendations 3-1, 3-2, and 3-3 are not without significant institutional and practical challenges. Expert Panel members noted:

- It is difficult to mandate training for staff as this requires: (1) releasing staff from shifts and replacing them with other staff; or (2) scheduling training for odd duty hours and paying staff to participate. Even then, in many cases, mandating participation under these conditions could be difficult.
- While the concept of email updates on guidelines and standards makes sense for most staff, there are a plethora of such email updates and simply reviewing them is a challenge, let alone ensuring that the relevant information is at hand when needed.
- The ever-evolving nature of our understanding not just of dementia, but of its interplay with other conditions both behavioral and physical, make it challenging to ensure that guidelines are current and that those for whom the guidelines apply are using the most current recommended practices. Advances in technology may make it possible in the future to make such guidelines immediately available through Blackberries or other hand-held devices, enabling physicians to quickly search for the most current recommended interventions.

RECOMMENDATION 3-4. An electronic medical record (using a "patient dashboard") should be researched and developed for the use of health and social service staff which will: (1) enable cross-system information sharing; and (2) improve service coordination.

For services to be coordinated effectively, service providers must have access to a patient medical record across sites and systems within San Francisco's service delivery network. This record must capture current information from the standardized assessment (above), subsequent service use, and changes in medical, health and social conditions as the patient advances.

OBJECTIVE 4: Expand capacity to deliver high-quality early diagnosis and intervention for all.

People with dementia should have access to a pathway of care that delivers: a rapid and competent assessment; and an accurate diagnosis, sensitively communicated to the person with dementia and their caregivers. Diagnosis should be followed as needed with referral for treatment, care and support. There is abundant research supporting the benefit of early identification for people with cognitive impairment, but research on systems and strategies for early identification was difficult to find. It is estimated that only between one-third to one-half of people with cognitive impairment ever receive a formal diagnosis²⁰. Often, cognitive impairment is not diagnosed until a person is admitted for an acute physical illness, but even then a cognitive impairment diagnosis and referral may be missed as health professionals focus upon the immediate medical crisis.²¹

Early identification of cognitive impairment allows for care management to be initiated with the potential for reducing costs associated with pneumonia, chronic skin ulcers, infection, depression, behavioral disturbances, hip fracture, malnutrition, dehydration, intestinal obstruction, lacerations, sprains, hypothermia and burns.²² Early identification also reduces costs for hospitalization, delays nursing home placement, and permits advance planning.²³ Finally, fiscal projections related to early identification and early introduction of treatments suggest that an average delay of onset of one year could reduce the number of people with cognitive impairment nationally by 210,000 patients, creating an annual projected savings of \$10 billion²⁴.

San Francisco has an extraordinary level of expertise when it comes to diagnosis of dementia. Unfortunately, this expertise is hamstrung by a number of factors outlined under Challenges in Section III.B and addressed with the following recommendations.

RECOMMENDATION 4-1. Diagnosis of mild cognitive impairment (MCI) should be encouraged and facilitated with clearly established diagnostic criteria.

Every person who now has Alzheimer's or a related dementia at one time had MCI. With proper diagnostic criteria already established, and with specialized medical care, a meaningful MCI diagnosis can be made and should be evaluated regularly. These individuals, while not yet demented, still require care and support. Importantly, MCI represents a window of opportunity to evaluate for and treat reversible causes of cognitive impairment before an individual develops dementia.

²⁰ Philip I, *A Recipe for Care—Not a Single Ingredient*, Department of Health, 2007.

²¹ Holmes, J., *Research School of Medicine*, University of Leeds (1999)

²² Alzheimer's Association website: www.alz.org. February 12, 2002.

²³ Shelton, P. Schraeder C, Dworak, D, Fraser C, Sager MA. Caregiver's utilization of health services: results from the Medicare Alzheimer's Disease Demonstration, Illinois site. *American Journal of Geriatric Society*. 2001; 49: 1600-1605.

²⁴ Brookmeyer, R., S. Gray, and C. Kawas. (1998). "Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset." *American Journal of Public Health*, 88(9): 1337-1342.

There is emerging consensus that, as we gain understanding of this disease, we will be identifying and treating people much earlier in disease progression. Most new treatments will be more effective if evaluation is done very early and identified at MCI or earlier, possibly before significant symptoms are evident, and when the individual can most benefit at the highest level of functioning. People with MCI are in a transitional medical state and may very well benefit from support and services offered to people with early stage dementia.



RECOMMENDATION 4-2. A standardized screening tool for chronic conditions and illnesses, which encompasses cognitive function, mood, activities of daily living, and caregiver or family observations, should be selected or developed. This should be used by health care professionals (primary care physicians, physician assistants, nurses, nurse practitioners, social workers and clinics) and psychologists, to assess the need for a comprehensive evaluation for adults with memory complaints or cognitive change, possibly including referral to a specialist for thorough diagnosis.

A standardized screening tool should relate to a number of chronic conditions and illnesses. If it is not workable to develop a comprehensive tool, efforts should be made to incorporate dementia categories into other screening tools. If the use of either screening tool demonstrates the need for a more comprehensive evaluation, and a more thorough diagnosis, it must be effectively and precisely done. This screening tool should also be made available for use to psychologists.

Screening should be done in part to avoid stigmatized and inappropriate responses to people based on unfounded assumptions. Stigmas associated with this disease must be avoided when no diagnosis has been made, but assumptions about that person impact actions for care.

RECOMMENDATION 4-3. A range of clinical geriatric fellowships should be developed at UCSF for physicians, nurses, and social workers training in geriatric practice, with fellows committing to a number of years working in community health services (primary care health centers and clinics operated by the Department of Public Health and the San Francisco Community Clinic Consortium), performing assessments, and managing the care of people with Alzheimer's and related dementias.

The beneficial impact of the use of a screening tool will be mitigated if an appointment for an assessment is difficult to obtain. There is an inadequate number of centers of excellence for diagnosis and management of dementia in San Francisco. At present, long wait lists await a person

seeking an assessment. UCSF can become a strengthened center of excellence with additional funding to support clinical dementia care and to train fellows to provide diagnosis, treatment and management. Such a workforce development initiative would benefit from the passage of Senator Boxer's workforce development legislation that would provide loan forgiveness as incentives. These and other financial incentives should be made available to recruit culturally diverse fellows that mirror the City's demographics.

UCSF dementia care fellowships should be offered for the following: geriatrician medical specialty, geriatric psychiatrist, behavioral neurologist, geriatric nurse practitioner and geriatric social work. Geriatric fellowships could also be developed at San Francisco State University for geriatric case/care managers and at San Francisco Community College for geriatric registered nurses. The development of these fellowships will require grant support as well as lobbying at each institution.

Such fellowships, paired with the fiscal policy recommendation (below), would increase the supply of qualified geriatricians and dementia experts available to diagnose and manage the care of the growing number of people destined to develop dementia.

RECOMMENDATION 4-4. Barriers and financial disincentives in medical care should be removed that deter physicians from providing geriatric assessments, diagnoses, and ongoing care by increasing reimbursement rates for these services.

It will be necessary to remove financial disincentives for doctors to become geriatricians. At present, reimbursement is insufficient so, even with loan forgiveness and fellowship incentives, doctors are not likely to enter the geriatric field. Reimbursement for geriatric assessments and ongoing care are lower than reimbursements for delivery of other services, creating a disincentive to enter geriatric medicine and an ongoing financial loss for programs offering geriatric care.

Changes in reimbursement rates, fellowships and recruitment efforts to expand the number of geriatricians practicing in San Francisco, and effective utilization of a standardized screening tool, would certainly expand access to high quality early diagnoses. However, if program admission policies and financial disincentives await people receiving an MCI or dementia diagnosis, this will inhibit people from seeking an assessment.

Advocacy must be undertaken to remove barriers and financial disincentives that deter doctors from becoming geriatricians and providing needed geriatric assessments, diagnoses, and ongoing care.

RECOMMENDATION 4-5. Barriers and financial disincentives should be removed that limit access to services that are based on a single diagnosis.

Improving access to services for people with dementia will help to reduce discrimination and will encourage service providers to become more dementia friendly and capable. This is necessary because people with multiple chronic care issues, one of which is dementia, may also need other services such as mental health services, adult day services, or assisted living.

Policies need to be promoted that will increase access to these services based on: (1) an individual's capacity to thrive in that service or setting; and (2) an individual's not being excluded solely on the basis of a dementia diagnosis. Clinicians in "medical homes" (public clinics and health centers) should be encouraged to screen for a mental health diagnosis such as depression and other affective

disorders as well as to screen for dementia. Having a mental health condition as the primary diagnosis could increase access to mental health services whereas having a dementia as the primary diagnosis could exclude people from eligibility for mental health services. City departments could also include anti-discrimination language in city-funded programs.

Advocacy must be undertaken to remove barriers and financial disincentives that limit access to services based on a single diagnosis.

OBJECTIVE 5: Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and for their caregivers.

People with dementia and their caregivers should be provided with good-quality information on this illness and on services available, at diagnosis and throughout the disease stages.

RECOMMENDATION 5-1. To enable easy access to quality information, people with cognitive impairment and dementia as well as their caregivers will benefit from the professionally staffed “central door” of San Francisco’s “no wrong door” approach.

The DAAS Integrated Intake Unit is already in place to assist people seeking information about home and community-based services in the network. This Unit is the “central door” to access services. It coordinates Information and Referral to the following services: Home-Delivered Meals, Adult Protective Services, In-Home Supportive Services, and the Community Living Fund. Through this Unit, people seeking services and caregivers have access to comprehensive information about available resources without needing to make multiple calls to a variety of programs. The DAAS Integrated Intake Unit staff will be trained about the range of memory loss and dementia care services and supports available, and about the most appropriate locations where services can be obtained. The advantage of an Intake Unit staffed with experienced and well-trained, professionals is that it will be adept at not just responding to the specific request of the individual or caregiver, but to understand the possible constellation of other needs that may underlie the request for a specific service and be able to suggest other services the caller may not have known about.

In the “no wrong door” approach, all service providers should be able to link clients who have dementia with other services. Accordingly, in addition to the “central door”, there should be multiple additional contact locations that will be able to provide information and linkage to appropriate services, including memory loss, mild cognitive impairment (MCI), and dementia care and support. All service providers will be trained to be sensitive to the needs of people with cognitive impairment. San Francisco is a diverse city and people access services in different ways. With training and education recommended in this



Strategy, still more service providers serving different racial, ethnic, and cultural communities will become familiar with early stages of cognitive impairment and aware of the most appropriate referral

locations where services can be obtained. Part of the training that these agencies will receive will be information about how to utilize the DAAS Integrated Intake Unit.

OBJECTIVE 6: Create expanded and easy access to care, support and advice following diagnosis.

Advice and Support. A dementia adviser should be available to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and for their caregivers. Also, groups should be available to provide ongoing peer support that can provide practical and emotional assistance, as well as help to reduce isolation.

Care Coordination. Significant international research indicates that care coordination or care management is a cost-effective intervention that can delay institutionalization and improve the quality of life for both the patient and the caregiver. Primary care physicians often do not make referrals for community-based care due to lack of sufficient information about resources.²⁵ There is also research that indicates that embedding care managers into primary care settings can ease the burden on the physician and ensure better use of community resources²⁶. Most current US dementia research focuses on pharmacological intervention or a basic search for a cure, and less on precisely how coordination of service delivery is best implemented.²⁷ Nonetheless, there is a significant body of research indicating that different models for embedding care managers, or a team approach to service delivery, can have significant positive impacts upon the individual and caregiver, and there is some evidence that such a model can also reduce public expenditures. See Appendix I, Section 4.C. Care Coordination, on pages 23 to 28, in the Evidence Based Practice Summary, for more information about this issue. Over a half dozen models of coordinated care are reviewed.

Three recommendations related to this objective follow. Their implementation would help increase the degree to which people with dementia and their caregivers experience the network of services as coordinated around their needs rather than organized around institutional needs.

RECOMMENDATION 6-1. A team approach to dementia care and service delivery should be piloted, employing care managers with dementia expertise operating as the “single-point-of-contact” for people with dementia using primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente. This will result in a better informed and coordinated delivery of services.

A team approach would require that care managers with dementia expertise be affiliated with or co-located in clinics where people with dementia receive primary care. Clinic patients and their social and health information would be shared among agencies responsible for the delivery of services

²⁵ Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care Primary care physicians' perspectives. *Journal of General Internal Medicine*, 22, 1487-1492.

²⁶ Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., et al. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *JAMA*, 295, 2148-2157.

²⁷ Bullock, R., Iliffe, S. and Passmore, P., *Can We Afford Not to have Integrated Dementia Services?*, *Age and Ageing*, June 11, 2007.

(confidentiality safeguards honored). Standards of care would be developed for care managers, possibly based upon the standards developed by the National Association of Geriatric Care Managers. Care managers would be the “single point of contact” for patients and caregivers and would be responsible for facilitating access to community resources and serve as a patient caregiver advocate.

Implementing a “single point of contact” method would result in each person with dementia and their caregiver being assigned to a care coordinator. This professional would be responsible for supporting the person and caregiver as they move through the stages of the disease. Immediately after diagnosis, the care manager would meet with the person and caregiver to begin treatment planning and to provide the caregiver with resources and information. In some models, this individual also consults with the primary care physician and other medical/behavioral professionals to ensure that treatment referrals are consistent with current guidelines. The care coordinator becomes the team’s resident expert in services and support for dementia care. Members of the Expert Panel noted that to embed care coordinators in every primary care clinic would not be practical in the current fiscal crisis. However, it would be feasible to pilot this team approach in one or more clinics in a collaborative effort between the Department of Aging and Adult Services and the Department of Public Health (DPH). This team approach is consistent with the DPH concept of a primary care “medical home” for each person covered by Medi-Cal.

RECOMMENDATION 6-2. Structured peer or volunteer support and learning networks should be developed for people with dementia and their caregivers, especially in early and mid stages. The establishment and maintenance of such networks will provide direct informal support delivered by trained volunteers. These networks can also provide practical and emotional support, reduce social isolation, and promote self-care.

While people with dementia are living in the community, it is usually the case that family members provide almost 75% of services and supports. But, as noted earlier, as many as 40% of San Francisco’s baby boomers have no family member living within 20 minutes of the City. For this reason, it is important that San Francisco explore models for providing informal care that do not rely upon family members.

This effort to create peer support and learning networks focusing on dementia could expand on other innovative programs to provide what older adults and adults with disabilities of all ages require to thrive. Three existing local models each rely on the development of a network of volunteers who provide a range of services and supports. These models include: (1) the *Community Living Campaign*, which is helping older adults and persons with disabilities of all ages through the formation of personal and social support networks; (2) *San Francisco Village*, which is a membership program that provides the social, service, and support benefits of a retirement community without having to give up one’s independence and own home or apartment; and (3) *openhouse*, which through community organizing, is fostering the development of intentional lesbian, gay, bisexual and transgender senior communities throughout San Francisco so that members can support one another as they age.

Expert Panel members pointed out that, while there is a need for an alternative to family caregiver support, individuals with dementia may require far greater levels and kinds of support than the populations served in the above models. Any replication or expansion of existing local models would require significant study and probably modifications.

OBJECTIVE 7: Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.

Family caregivers are the most important resource for people with dementia. Active work is needed to ensure that services and supports are available for them. Caregivers have a right to an assessment of their needs. They can best be supported if a comprehensive assessment is used to identify the supports they require to perform the vital role they play in the care of the person with dementia.

RECOMMENDATION 7-1. Immediately upon a diagnosis of dementia being made, a practice should be established where doctors and their staff refer caregivers as well as family members to supports, such as education, counseling, caregiver assessment, and services.

Service referrals should be provided once a person is diagnosed with cognitive impairment or dementia, so caregivers can have immediate access to ongoing resources. The California Guideline for Alzheimer's Disease Management calls for a referral to the Alzheimer's Association and the Caregiver Resource Center in the community to provide assistance to families with resources and supports. In addition to immediate referral to services, following up with the diagnosed person and caregiver is important to ensure that community services and pharmacological treatments are accessed. These resources should include: a comprehensive assessment of their needs as caregivers; structured counseling and education programs and a range of educational materials; and a follow-up call shortly after the diagnosis is received, when additional service referrals can be made.



According to caregiver interviews and Expert Panel comments, people given a diagnosis of dementia are currently told to come back to see the physician in a year. Resources and referrals are rarely provided to them or their caregivers at the time of diagnosis. As noted earlier, immediately after a diagnosis a window exists to involve the individual in treatment planning, to educate and support the caregiver, and to access pharmacological and community treatments that can significantly impact the trajectory of the disease. For all these reasons,

a concerted effort should be made to ensure that support and information are provided to caregivers and that a comprehensive voluntary caregiver assessment is offered and encouraged.

RECOMMENDATION 7-2. Additional respite care services should be developed for people with Alzheimer's and related dementias. Increased respite care should be part of the supports (that include education, counseling, assessment, and services) for caregivers and family members. Funding should be sought for additional respite care.

Respite care is defined as in-home respite and overnight respite. Adult day services and other community-based services such as homemaker can also provide respite. Homemaker can be provided overnight. Surveys of families have indicated that it is considered most desirable for someone to come into the home to provide respite, as this is less disruptive for the individual with dementia.

There are not enough respite care services and resources to meet the needs of San Franciscans and funding available for respite is limited. In the absence of sufficient respite support, loved ones caring for the person with dementia are more likely to develop their own physical health and behavioral health conditions and become unable to sustain sufficient care support to maintain the loved one in the community.

OBJECTIVE 8: Improve the quality of hospital and nursing home care for people with dementia.

Throughout this *Strategy* are recommendations to reduce or delay the use of hospital or nursing home care. This should not be understood to infer that hospitals and nursing homes are not valuable services, but that they should be preserved for the most appropriate use. According to interviews with stakeholders and Expert Panel member comments, too often hospitals and nursing homes become the easiest placement option when available community services and supports are not assembled to enable the person to remain in the community. However, there are times when a hospital or nursing home is the only safe, secure and appropriate placement for a person with dementia. In these instances, it is vital that a consistent high quality of care be provided.

Improving the quality of hospital and nursing home care for people with dementia should be done by defining improved dementia care practices and quality of care standards, establishing care pathways, and identifying dementia care leadership

RECOMMENDATION 8-1. A meeting of acute care hospitals should be convened to review all existing care plans for patients with any type of dementia, identify best practices for the care of hospitalized adults with dementia, and implement best practices to improve their care.

This recommendation is based on the innovative work being done by the Acute Care for Elders (ACE) Unit at San Francisco General Hospital. Lessons derived from this recommended meeting could be used as a basis for training staff in other hospitals in best practice dementia care. If such a meeting were convened annually, it would be a natural venue for providing an update on new guidelines for high quality hospital care. The confidentiality of client records should be maintained.

RECOMMENDATION 8-2. Nursing home placement should not only be for the purpose of safety and containment of dementia related behaviors, but also for person-centered care with an array of services that address all of the needs of the person and not solely the diagnosis of dementia.

Nursing homes can be the most appropriate setting, and the safest and wisest choice, for some adults with advanced dementia, and for their caregivers. Many persons with late stage dementia may require 24-hour skilled nursing care. This is due to the progression of the disease and the often associated diminished impulse control leading to aggressive behavior, the lack of insight and subsequent refusal to accept care with bowel and bladder hygiene or assistance in walking, eating and bathing. Also, older adults often have coexisting medical conditions that require continued professional care.

Successful placement in a nursing home should not be viewed as a matter of an available bed, but of a qualitative placement as envisioned in the recommendations above. There should be consistent assignment of caregivers, with dementia-related training, and with an enriched activity program that would mitigate against a sole reliance on medications for behavior control. Nursing homes should contain dementia friendly environments, with green space, and areas for mobility, if appropriate. In San Francisco, Laguna Honda Hospital and the Jewish Home are best-practice providers of skilled nursing care, including advanced dementia care.

Standards for nursing home quality should be met as defined in the Alzheimer’s Association’s, “Recommendations for Assisted Living and Nursing Homes” and in the Federal Nursing Home Regulations. Training for staff in these quality standards should be provided.

OBJECTIVE 9: Expand and improve the quality of community-based care for people with dementia.

RECOMMENDATION 9-1. An expanded range of community-based services should be developed for people in the early stages of cognitive impairment or Alzheimer’s and related dementias, based upon evidence-based practice and emerging research.

To expand the range of community-based services, there should be therapeutic interventions including creative expression, intergenerational programs, and pet therapy, to be made explicit in the appropriate services and settings, and in the appropriate manner. The beneficial impact of such therapeutic interventions is demonstrated in research. Also, additional grocery and meal delivery services, transportation services, money management, and legal and financial planning services are needed for people with Alzheimer’s and related dementias, and their caregivers. These services will assist people to remain living in the community and help to relieve stress on caregivers.

Research also shows that cost savings in Alzheimer’s care are potentially large. Data show interventions that lead to improvements in memory and physical functioning or that delay the rate of decline could lead to cost savings for both formal and informal care.²⁸ But research into many community-based interventions is still emerging and there are few that have been rigorously evaluated. Many are more accurately characterized as promising practices. The Oversight Committee for this *Strategy* should serve as a clearinghouse that reviews recent research and recommends specific practices found to be particularly effective.

Some supportive services do not require research to verify their efficacy. A range of in-home supports such as meal delivery, as well transportation and legal and financial planning clearly are needed. While they do not necessarily delaying progression of the condition, they are essential to the quality of life and for the effective planning for dementia’s advance.

RECOMMENDATION 9-2. The full range of adult day services (Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers), appropriate for people at different stages of the disease, should be expanded and improved. Day care programs and staff should be informed, trained, and capable of addressing the needs of individuals with cognitive impairment or Alzheimer’s and related dementias and their caregivers.

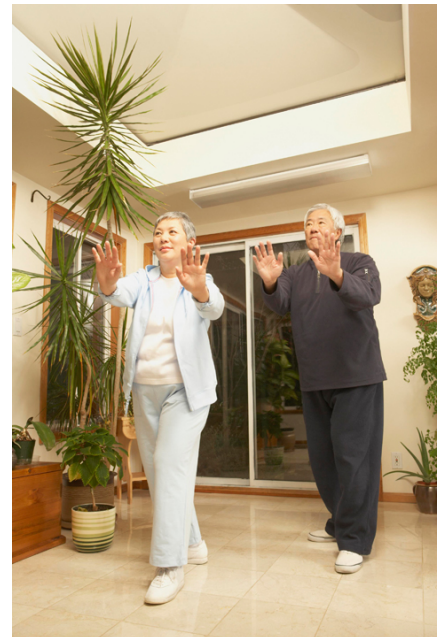
²⁸ Leon J, Cheng C, Neumann P. Alzheimer’s disease care: Costs and potential savings. *Health Affairs*. 1998, 17:206-16.

Given the increasing structure, consistency, support, and personal assistance required by a person with cognitive impairment, and the increased burden placed upon caregivers to provide the vast majority of this support, adult day care provides one of the best settings for the mid-stage individual living in the community. As compared with non-users of adult day care, caregivers of individuals with cognitive impairment using adult day care experience have been shown to have:

- Fewer difficult-to-manage behaviors and less time spent managing symptoms;²⁹
- Fewer hours managing memory difficulties and less burden, strain, and worry;³⁰
- Fewer recreational restrictions and conflicts between care giving and other responsibilities;³¹
- A better relationship with the patient;³² and
- Lower levels of depression, anger and perceived overload.³³

To achieve maximum caregiver benefits, people with cognitive impairment should attend adult day services at least twice a week for an extended period of at least three months. Particularly when initiated early, sustained use of adult day care generates benefits for the participant, delaying nursing home placement³⁴ and attenuating the cognitive decline associated with institutionalization.³⁵

Adult day care services play a critical role in delaying the advance of dementia, supporting the needs of the caregiver, and delaying nursing home placement. For this reason, preserving all existing adult day care resources is essential. This will help to meet the growing demand from the baby boomer population. Also, expanding that base is going to be crucial: a much larger number of affordable, accessible adult day care services (Adult Day Health Care, Social Day Care, and Alzheimer's Day Care Resource Centers) should be available. All levels and forms of day care should have the ability to be sensitive to and respond to individuals with Alzheimer's and related dementias.



²⁹ Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M-A. P., Townsend, A., & Greene, R. (2003a). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18, 55-62.

³⁰ Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M-A. P., Townsend, A., & Greene, R. (2003b). Respite for dementia caregivers: The effects of adult day service use on caregiving hours and care demands. *International Psychogeriatrics*, 15, 37-58.

³¹ Schacke, C., & Zank, S. R. (2006). Measuring the effectiveness of adult day care as a facility to support family caregivers of dementia patients. *Journal of Applied Gerontology*, 25, 65-81.

³² Dziegielewski, S. F., & Ricks, J. L. (2000). Adult day programs for elderly who are mentally impaired and the measurement of caregiver satisfaction. *Activities, Adaptation & Aging*, 24, 51-64.

³³ Zarit, S. H., Stephens, M. A., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: effects of adult day care use. *Journals of Gerontology*, 53B, S267-S277.

³⁴ Ibid

³⁵ Wilson, R. S., McCann, J. J., Li, Y., Aggarwal, N. T., Gilley, D. W., & Evans, D. A. (2007). Nursing home placement, day care use, and cognitive decline in Alzheimer's Disease. *American Journal of Psychiatry*, 164, 910-915.

Following are some specific recommendations for the preservation and expansion of adult day services in San Francisco:

- a. The Adult Day Health Care (ADHC) facility at Laguna Honda Hospital closed in February 2009. The license is not being used and: (1) could be used by the Department of Public Health (DPH); or (2) made available to another organization to develop an ADHC center.

NOTE: A license is not transferable, but an ADHC business can be sold. A new owner would need to do a “Change in Ownership”.
- b. The fee to maintain this license should be paid by DPH annually until the license is used for another ADHC program.

NOTE: The ADHC license was suspended by LHH effective March 20, 2009. The license can be placed in suspension for one year. LHH initially paid the license renewal fees through November 15, 2009. LHH then renewed the ADHC license again in October 2009 for another year - until March 19, 2010.
- c. A new ADHC or exiting ADHC(s) should consider a relationship with a Federally Qualified Health Center, which could result in additional funding for operations.
- d. Additional Adult Day Programs (Social Day) should be developed. This program works well with people who have dementia. It is private pay and not covered by Medi-Cal.
- e. The number of Alzheimer’s Day Care Resource Centers (ADCRCs) should be increased. ADCRCs benefit caregivers, families, and neighborhoods, and help people to remain in the community. ADCRC is a designation that demonstrates expertise in dementia care. This is a specialty at ADHCs or Social Day Care Programs. Funding for the support of ADCRC status may need to be obtained from sources other than the State of California.

It is important to be aware that adult day health care programs are now under a state moratorium. However, social day programs are not. ADCRCs must be licensed as either a social day program or an ADHC. See Section VI, page 92, for the impact of the State budget on each of these programs.

RECOMMENDATION 9-3. Services and supports should be developed for people with cognitive impairment or Alzheimer’s and related dementias who have no family, or who do not have family members living in close proximity to San Francisco.

San Francisco has a high percentage of older adults who live alone, many with no family. Also, given evidence that in San Francisco up to 40% of people with cognitive impairment will not have a family member within twenty minute drive of San Francisco, care and support predicated upon daily involvement from family members will be unresponsive to a significant proportion of our population.

A pilot project should be established to develop support options to address the needs of both the “un-befriended” population with no family involved as well as those elderly with family in the region, but not close enough to provide daily support. A workgroup will be needed to explore the development of this pilot project and other strategies such as those suggested in Recommendation 6-2 on page 59. People with cognitive impairment, or Alzheimer’s and related dementias, who have no other available daily support, should be red-flagged for care management. Without it they will almost certainly require premature institutionalization.

RECOMMENDATION 9-4. A crisis intervention and assessment setting should be developed for the placement of people with cognitive impairment or Alzheimer’s and related dementias who are no longer safe in their own environments and/or who have behavioral issues.



Input from the Expert Panel, supported by findings in research, points to behavioral crises as being a major cause for placement of people with dementia in nursing homes and hospitals. Some of these placements may be premature and could be avoided with the implementation of this recommendation. The crisis intervention and assessment setting would be a place where people with dementia could be assessed for: physical, cognitive and other impairments; for wandering and agitation; or for other challenging behavioral issues that need 24-hour care. This setting could also provide assessment for other appropriate care settings.

RECOMMENDATION 9-5. Advocacy for changes in the mental health system should be undertaken at the local and state level to eliminate the carve-out of mental health services for people with a primary diagnosis of dementia. San Francisco’s mental health system and medical/health care system should be encouraged to collaborate more effectively in serving clients with both dementia and mental illness, or those with Alzheimer’s who develop mental health related conditions.

People with a primary diagnosis of dementia cannot now be served by the mental health system. Dementia is a medical diagnosis, not a mental health diagnosis. At the present time, there must be a specific primary mental health diagnosis for a person to be served in the mental health system.

RECOMMENDATION 9-6. A plan should be developed to provide and fund services, particularly respite care, for people with Alzheimer’s and related dementias who are above Medi-Cal eligibility. The needs of these individuals, who are often unable to get the services they require, should be addressed.

People living just above the poverty line can be hit hard by dementia because they are not able to qualify for Medi-Cal, yet they can’t afford to pay for services out of pocket. Further, many of these individuals are either uninsured or under-insured. Existing models to serve this population include: the Community Living Fund (CLF) and a program through Community Behavioral Health Services that pays for “patch” services – e.g., paying board and care to avoid paying for hospitalization.

Given the high cost of living in San Francisco and the high cost of dementia supports, a number of approaches might be advanced to address the needs of this population:

- Expand eligibility for CLF from 300% to 400% of poverty.
- Consider the use of the ‘patch’ model for programs like adult day care, in-home supportive services, and other forms of respite;
- Develop the use of a sliding scale for services for people above Medi-Cal eligibility;

-
- Provide education and information about dementia related guidelines to all professionals and service providers not just those who serve low-income patients;
 - Advocate for federal support for long term assisted living, adult day health care, and in home supportive services.

OBJECTIVE 10: Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.

The quality of care for people with dementia can be improved in residential care homes by the use of exemplary practices and/or by the development of explicit leadership for dementia within the care homes. Improving dementia care practices and quality of care, establishing care pathways, and identifying dementia care leadership should be part of this effort. Training should be provided for the staff of care homes in following these care practices and quality of care standards.

Also, given the diminishing supply of nursing home beds and the increased demand for care in residential homes resulting from the advance of baby boomers, the role of residential care facilities in delaying entrance or avoiding nursing homes is an essential component of San Francisco's *Strategy*.

It should be noted that residential care is not always synonymous with assisted living. The term residential care implies a licensed residential facility, while assisted living can mean a broad range of residential options including: (1) licensed residential care facilities; (2) residential care homes, which may or may not be licensed depending on how they are organized; (3) board and care homes, which are licensed; and (4) unlicensed residential settings where room and board is provided by the housing operator and care and supervision are provided by one or more other organizations.

Research shows that barriers exist to effective use of assisted living. An excellent study conducted by Hyde, Perez, and Forester, *Dementia and Assisted Living*³⁶ highlights many of the challenges people with cognitive impairment face in entering and maintaining residence in assisted living facilities. Golant (2004) concluded that assisted living facilities were more likely to accept frail older persons when these people had less serious cognitive impairment and when they did not require ongoing supervision (e.g., did not wander; or did not have memory, judgment, or behavioral problems). He also indicated that less than 50% of the assisted living facilities would accept older persons if they had moderate to severe dementia.

Hyde's study cites Hawes and colleagues (2003) who found that fewer than 45% of assisted living providers would retain a resident with severe dementia. Ball and associates (2004), in their study using qualitative methods in five assisted living facilities, found that that given the wish to serve the most frail residents and have an assisted living facility be their last home, there were many issues that had to be contended with, including impaired residents being ostracized and being moved to special dementia units. When care needs are very high, residents can experience neglect that calls into question their quality of life as they age in place.

Hyde concludes by noting that assisted living was developed specifically to be responsive to residents' own definition of quality. The challenge will be to design assisted living facilities that respects that mission and honors the dignity of those whom assisted living seeks to serve; to find

³⁶ Hyde, J., Perez, R., and Forester, B., *Dementia and Assisted Living*, *The Gerontologist*, 47:51-67 (2007).

meaningful and appropriate ways to ask questions of people with dementia; and to measure, with reasonable reliability and validity, their responses to care and treatments. Fortunately, the Research Summary provided in Appendix I, Section 4.K. Assisted Living Facilities & Residential Care Facilities for the Elderly, contains a full discussion of this research and models. See pages 48 to 52.

RECOMMENDATION 10-1. A range of residential care settings should be developed for people who require both residential and nursing care services.

There is a trend across the country and in San Francisco to reduce the number of skilled nursing beds that have provided custodial care for older adults, including people with Alzheimer’s disease and related dementias. The intent is to move people to other types of care. Residential care facilities are needed that can provide custodial care with 24-hour coverage. Step-down affordable residential care options will need to be developed throughout the city. However, without obtaining Medi-Cal waivers to provide funding for these new residential options, the burden on local financial support is increased. See Recommendations 12-3 and 12-5 for a full discussion of this funding issue.

A range of residential care settings should be developed for people who require both residential and nursing care services. This would include a range of affordable residential care options responsive to different stages of dementia and different behavioral conditions.

To fully implement this recommendation will require working with the State Department of Social Services (DSS), Community Care Licensing, to explore existing licensing categories and consider developing new licensing categories. Examples of existing residential care settings follow, each of which could be modified for dementia care:

- Residential Care Facilities for the Chronically Ill developed to address the needs of people with HIV/AIDS, which have a medical/nursing component.
- Adult Residential Facilities for Persons with Special Needs developed to address the needs of persons with developmental disabilities.
- The Green House model, which can be developed as a licensed residential care facility or as a licensed skilled nursing facility. This model provides smaller units that are residential in feeling, with more personalized care planning and greater autonomy for elders. Green Houses provide an environment in which residents receive nursing support and clinical care without this becoming the focus of their existence.
- Board and Care Homes, which are a smaller version of Residential Care Facilities for the Elderly.
- A local promising practice: DPH provides a patch to Residential Care Facilities For The Elderly and Adult Residential Care Facilities to cover the cost of housing and services for clients in the mental health system. The patch is above the SSI rate and is negotiated based on types of services provided.

Potential locations for residential care settings:

- San Francisco should explore using one or more of these examples to develop affordable residential care settings on the Laguna Honda Hospital (LHH) campus. LHH could employ an inter-disciplinary social-health model of care based on community reintegration and choice, which could provide rehabilitation, chronic care, dementia care, and end of life care. Having some step-down residential alternatives on the LHH campus for people who require custodial

care, including those with Alzheimer’s and related dementias, who do not require 24 hour skilled nursing care, would provide a greatly needed and hopefully less costly resource.

- San Francisco should also explore using one or more of these examples to develop affordable residential care settings in under-served neighborhoods – specifically in Bayview Hunters Point. In particular, the Green House model should be explored and possibly developed so residential care settings would be available for people who require custodial care, including those with dementia, who want to remain living in the community.

DSS Community Care Licensing needs to have an explicit statement about dementia care services in its licensing categories and activities, which are tracked and monitored in its licensed facilities. If nursing services are not currently allowed by some residential care facility rules and regulations, these may need to be changed similar to the Residential Care Facilities for the Chronically Ill (RCFCI) regulations. Also, a mechanism to provide for nursing services will need to be established. One possibility is a contract with a home health agency. In regard to funding, every effort should be made to retain Medi-Cal funds for the services and support provided in these residential settings.

RECOMMENDATION 10-2. Residential care settings should be designed and operated not only to ensure individual safety and contain dementia-related behaviors, but also to offer person-centered care with an array of services that address the whole person.

Residential care settings will increasingly serve people with moderately severe dementia (mid-stage) or advanced cognitive decline (late-stage). Many of these people may require 24-hour skilled nursing care and/or 24-hour skilled personal care. While placement in a residential care facility can forestall nursing home placement, providing person-centered care and responding to the needs of people with mid-to late-stage dementia requires clarity about the capacity of each provider to address specific conditions related to these stages of dementia. To ensure the highest quality of care, the *Oversight Committee* should ensure the dissemination of standards for quality in residential care settings and encourage residential care facilities to meet them. To start, the recommendations for quality of care in facilities, found in the Alzheimer’s Association’s, “Recommendations for Assisted Living and Nursing Homes” should be used. Training for staff in these quality standards should be provided.

Ideally, a plan for dementia services in residential care settings should address quality issues to include: appropriate staffing levels and ratios per resident; more than required training in dementia; person-centered activities; and allowances for self-determination. At present, there are no low income or affordable residential care facilities that have a dementia focus in San Francisco.

OBJECTIVE 11: Improve access to end of life care for people with dementia.

People with dementia and their caregivers should have easy access to end of life care including hospice care. However, the requirement of a six-month terminal prognosis creates a major barrier to accessing these services. The uncertainty related to the final stage of dementia often results in people not being able to access hospice care at all. Loved ones are sometimes pressured to extend life with the use of feeding tubes and other extraordinary interventions while people with dementia are under hospital care.

RECOMMENDATION 11-1. Advocacy should be undertaken for changes in local, state and national policies to enable individuals with late stage Alzheimer's and related dementias to be able to more easily access hospice care. This will require establishing diagnostic criteria that are more in line with the progression of late stage dementia, allowing for the extension of time limits, and ensuring palliative care is available to people with dementia.

Hospice care is recommended for provision throughout Laguna Honda Hospital (LHH). Hospice care and the Medicare Hospice Benefit should be available to all terminally ill LHH patients, including those with Alzheimer's and related dementias, whether or not they reside in the Hospice Unit. Dementia patients receive care throughout LHH and are not currently admitted to that Unit.

NOTE: Hospice, a Medicare benefit and model of care that provides a constellation of support services at the end of life, is available in homes, skilled nursing facilities, and assisted living facilities (ALFs). Hospice care can be provided in ALFs as long as there is non-ambulatory status established for each ALF in which it is provided. The ALF must also apply for a waiver. It is up to the facility whether it can manage the care level and many do allow it if a bed is available.

The criteria for hospice care is so narrow that many people with dementia don't fit until they have approximately 3 to 5 days to live. Doctors are reluctant to give a 6-month terminal diagnosis for someone with dementia because physically they may live much longer and this is difficult to determine without a more predictable additional diagnosis (i.e., cancer). Recognizing that Alzheimer's and related dementias are a terminal condition with a less certain timeline to end of life, a change in hospice admission policies should be considered at the local, state, and national levels.

<p>OBJECTIVE 12: Advocate for effective state and national support for the implementation of this <i>Strategy</i>.</p>

As noted elsewhere, some of the recommendations in this *Strategy* can be implemented largely with local efforts and not require state or national reforms. However, many recommendations require policy or funding reforms, waivers or legislation. It will fall to the *Dementia Care Excellence Oversight Committee* to organize an ongoing advocacy role to implement these recommendations.

RECOMMENDATION 12-1. Education and advocacy for universal coverage for long-term supports and services should be undertaken so that this is part of national health care reform. Work to assure that Medicare and Medicaid regulations are coordinated to allow for the best possible patient care.

Following are specific areas where education and advocacy will be needed:

- Development of a comprehensive long term care benefit as part of a national health care benefit. Respite care, adult day health care, in home supportive services, and community-based long term care services should be included in this benefit.
- Changes in Medi-Cal that effect reimbursement levels for diagnosis, care management, assisted living, in-home supports and other vital services.
- Expansion of the scope of Medicare funding to include long term care. For example, changes should be sought in Medicare that would allow people in Medicare-funded assisted living programs to also attend Medicare-funded adult day care services – especially nursing, PT, OT, and speech therapy.

RECOMMENDATION 12-2. The City should advocate for legislation that would require the State Department of Health Care Services (DHCS) and State Department of Social Services (DSS) to develop expertise in dementia care.

Existing state licensing regulations do not adequately address the needs of people with dementia. State agencies such as DHCS and DSS dealing with facilities and services that will serve those with cognitive impairment need to have dementia care expertise to develop new licensing categories. To address this issue, the State DHCS and DSS should develop this expertise. Also, the State DSS Office of Community Care Licensing should hire a nurse who could facilitate the development of new or altered licensing categories for the range of affordable residential care options that will be serving people with Alzheimer's and related dementias. These people will require custodial long term care, including both residential care and nursing care services.

RECOMMENDATION 12-3. The City should explore federal waivers for assisted living programs that will enable San Francisco to retain Medi-Cal funds for these services and manage them locally.

There are two waiver options that San Francisco could pursue to achieve this recommendation. The first is for the City to seek involvement in the California Assisted Living Waiver, which has been renewed. The second involves using the Home and Community-Based Services Waiver (based on AB 2968) being designed specifically for San Francisco. This waiver would provide for services covered by Medi-Cal in the affordable residential care facilities. Each of these options would retain Medi-Cal funds in San Francisco for community-based services in assisted living programs, including services for Alzheimer's and related dementias.

RECOMMENDATION 12-4. An enhanced nursing home diversion services project should be considered. This project would be developed in collaboration with the California Department of Aging, funded by a grant from the federal Administration on Aging.

The enhanced nursing home diversion services project is an initiative of the Administration on Aging in cooperation with State Units on Aging and Area Agencies on Aging. It seeks to alleviate fiscal pressure on Medicaid and Medicare. The services would target individuals at the same level of clinical need as Medicaid waiver eligibility, but who have assets in excess of Medicaid financial eligibility, not to exceed an average of \$25,000. The target for this project would be older adults and adults with disabilities, including people with Alzheimer's and related dementias.

RECOMMENDATION 12-5. The feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including those with Alzheimer's and related dementias, should be explored.

Such a demonstration project could create an actual system of chronic care for older adults with functional and cognitive impairments. It would retain Medi-Cal funds in San Francisco for community-based long-term services and supports, including services for Alzheimer's and related dementias. Examples of similar programs include: (1) Multi-Purpose Senior Services Program (MSSP), which San Francisco already has in place, operated by the Institute on Aging (IOA); and (2) the Program of All Inclusive Care for the Elderly (PACE), operated by On Lok and the IOA. This demonstration project would need to be more inclusive than the PACE program, however, and not limited to serving people who are eligible for or at risk of nursing home placement. It could be a

chronic care management model like PACE, but without the PACE program’s age and income restrictions.

This managed chronic care demonstration project could complement “Healthy San Francisco”, a city program that makes health care services accessible and affordable for uninsured residents under 65. Possibly, some of the PACE requirements and services could be unbundled so that they could be accessible to people within this system. For more details on the creation of a managed chronic care demonstration project, see Appendix IX.

OBJECTIVE 13: Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.

People with memory loss, and Alzheimer’s and related dementias, are subject to stigma and discrimination in the community that arise largely out of ignorance and misunderstanding. This objective and the following recommendation seek ways to call San Francisco residents and their institutions to eliminate stigma and discrimination and replace it with compassion and understanding

RECOMMENDATION 13-1. Efforts should be undertaken to make San Francisco more accommodating of people experiencing forgetfulness and cognitive impairment. These efforts should be connected to the local, national, and international movements toward creating age and disability friendly communities.

The efforts toward creating age and disability friendly communities will benefit people with memory loss and their caregivers. Partnerships should be sought with the San Francisco Public Library, the Planning Department, and the Department of Parks and Recreation.

The vision for age and disability friendly communities in San Francisco goes beyond providing what dementia services people need. It responds to a broader, more fundamental issue: what people require for a good life. This is especially true for people with early to mid-stage dementias, and may include: (1) the formation of personal and social support networks that promote the contributions of people with dementia, with the goal of strengthening our neighborhoods and communities; and (2) the creation of age- and disability-friendly communities that offer accessible and affordable housing, improved public safety, improved access to parks and recreation, and opportunities to be meaningfully engaged in the community.

Achieving this broader vision speaks to the larger issue of helping people with dementia and their caregivers not just to endure, but to thrive. Achieving this vision requires delivery of the highest quality services and supports, but it goes beyond that. It requires creating a community that has empathy and compassion and demonstrates these values in every nuance of daily life:



-
- Where the mailman understands the person in a home or apartment is demented and that s/he will knock on the door, say hello, and pay attention to any signs of decline.
 - Where the single room occupancy hotel manager works cooperatively with a care manager and a resident with dementia to explore options for retaining housing and ensuring safety; and
 - Where a librarian recognizes a person with memory challenges whose symptoms are worsening and makes a call to the DAAS Integrated Intake Unit to see what help and support may be available.

Each of these examples illustrates how a more compassionate community could contribute to a greater quality of life for people whose cognitive capacities are diminishing. Advocacy and public education will provide San Francisco yet another opportunity to extend its long history of caring compassionately for those in vulnerable circumstances. Making San Francisco friendlier to people increasingly experiencing forgetfulness should be tied in to the national movement toward creating age and disability friendly communities.



OBJECTIVE 14: Facilitate and support an Oversight Committee responsible for implementing this *Strategy*, and advocating for improvement of prevention, education and services related to dementia.

RECOMMENDATION 14-1. A Dementia Care Excellence Oversight Committee should be established for: (1) overseeing the implementation of this Strategy and its recommendations; (2) monitoring the progress of workgroups, (3) monitoring the participation of partners; (4) undertaking advocacy efforts to influence state and national legislation; (4) overseeing the exploration and initiation of pilot projects and demonstration projects; (5) identifying guidelines and standards of care for all components of the network of services for individuals with dementia; and (6) fostering adherence to these standards by all appropriate service providers.

A standing *Dementia Care Excellence Oversight Committee* should be created that will be responsible for overseeing the implementation of this *Strategy* and its recommendations. It could also be the forum for considering emerging research and recommending changes to standards, approaches and strategies. It should provide updates periodically to the Long Term Care Coordinating Council. The Oversight Committee should have staffing from the Department of Aging and Adult Services and hold quarterly meetings. New workgroups, with staff support for each, will be required to ensure implementation of specific recommendations.

V. ACTION PLAN AND NEXT STEPS:

San Francisco's response to the growing crisis in dementia care should be comparable to the City's comprehensive and effective response to the AIDS epidemic back in the 1980s. To be successful, the implementation of this *Strategy for Excellence in Dementia Care* will require a unified, proactive, long term response. This effort should not be the responsibility of any single city department. Should this be the case, implementation will falter or fail. Instead, this effort will require the involvement of many city departments, non-profit agencies, social service agencies, health care providers, residential care and institutional care providers, and advocacy groups. Success will also require that ongoing staffing for the seven recommended workgroups is provided by several different city departments.

Leadership required to advance this Strategy

Visible leadership will be required to make this *Strategy* a reality. The overarching leadership and direction for its implementation across city departments should come from the Mayor's Office. A *Dementia Care Excellence Oversight Committee*, whose members should be appointed by the Mayor, will oversee all implementation activities. The Department of Aging and Adult Services will take part of the leadership role. However, other city departments, agencies, and organizations will need to be actively involved and commit resources, staffing, advocacy, and time to this effort.

Other city departments, agencies, and organizations recommended for participation and leadership include: the Department of Public Health, University of California at San Francisco (UCSF), the Alzheimer's Association of Northern California and Northern Nevada, Family Caregiver Alliance, Institute on Aging, San Francisco Medical Society, Sutter Health, Catholic HealthCare West, Brown & Toland Physicians Medical Group, Hill Physicians Medical Group, On Lok Lifeways, Kaiser Permanente's national office in Oakland, and the Long-Term Care Coordinating Council. Expert consultation on specific issues will be required from members of the Expert Panel periodically for a limited time. For example, they may need to provide access to the UCSF Department of Medicine.

Recommended workgroups required to implement this Strategy

1. Training And Education
2. Guidelines And Standards
3. Additional Services And Settings
4. Medical Resources
5. Shared Electronic Medical Records System
6. Waivers, Pilot Projects, And Demonstration Projects
7. Advocacy

THE ACTION PLAN BEGINS ON THE FOLLOWING PAGE

NOTE:

RECOMMENDATIONS ARE NOT REPEATED COMPLETELY IN THIS ACTION PLAN. INSTEAD, THEY ARE ABBREVIATED ON THE FOLLOWING SUMMARY AND DETAILED CHARTS, AND IN THE ACCOMPANYING NARRATIVE. THE NUMBERS OF EACH RECOMMENDATION CORRESPOND TO EACH FULLY STATED RECOMMENDATION FOUND IN SECTION IV. PLEASE REFER BACK TO THE PREVIOUS SECTION FOR THE SPECIFIC WORDING OF EACH FULLY STATED RECOMMENDATION TO OBTAIN ANY CLARIFICATION REQUIRED.

Action Plan - Summary

Planning and Implementation Responsibilities

PHASE ONE – PLANNING (November and December 2009)		
Recommendation		Leadership Responsibility
14-1	Establish an ongoing <i>Dementia Care Excellence Oversight Committee</i> to oversee implementation of this <i>Strategy</i> and recommendations.	Alzheimer's/Dementia Expert Panel Planning Committee
PHASE ONE – IMPLEMENTATION (2010 to 2011)		
Recommendation		Leadership Responsibility
1-1	Integrate dementia care into San Francisco's long-term care service delivery network.	Dementia Care Excellence Oversight Committee
1-2	Train all agencies and programs to become dementia capable.	Training and Education Workgroup
2-1	Improve public awareness and understanding of dementia.	Training and Education Workgroup
3-1	Identify and promote current guidelines and standards to service providers and other professionals.	Guidelines and Standards Workgroup
3-2	Train service providers and other professionals to implement current standards and guidelines.	Training and Education Workgroup
3-3	Train and educate primary care physicians, hospitalists, primary care center staff and health clinic staff.	Training and Education Workgroup
4-1	Facilitate diagnosis of mild cognitive impairment with established diagnostic criteria.	Medical Resources Workgroup
5-1	Train DAAS Integrated Intake Unit staff to be experts in dementia resources and services.	Training and Education Workgroup
PHASE TWO – IMPLEMENTATION (2012 to 2015)		
Recommendation		Leadership Responsibility
3-4	Research and develop a medical record system enabling cross system information sharing.	Shared Electronic Medical Records System Workgroup
4-2	Develop screening tool for chronic illness that includes issues related to dementia.	Medical Resources Workgroup
4-3	Create clinical geriatric fellowships at UCSF for physicians and other medical professionals.	Medical Resources Workgroup
6-1	Establish team approach to dementia care using care managers in health centers and clinics. This may be a pilot project.	Waivers, Pilot Projects and Demonstration Projects Workgroup
6-2	Create structured peer support and learning networks for people with mild cognitive impairment and caregivers	Additional Services and Settings Workgroup
7-1	Immediately upon diagnosis, doctors and staff should refer caregivers to supports such as education, counseling, caregiver assessment, and services.	Medical Resources Workgroup
7-2	Create additional respite care services for people with dementia as support for caregivers.	Additional Services and Settings Workgroup
8-1	Convene a meeting of acute care hospitals to review existing plans for dementia care and identify best practices.	Medical Resources Workgroup

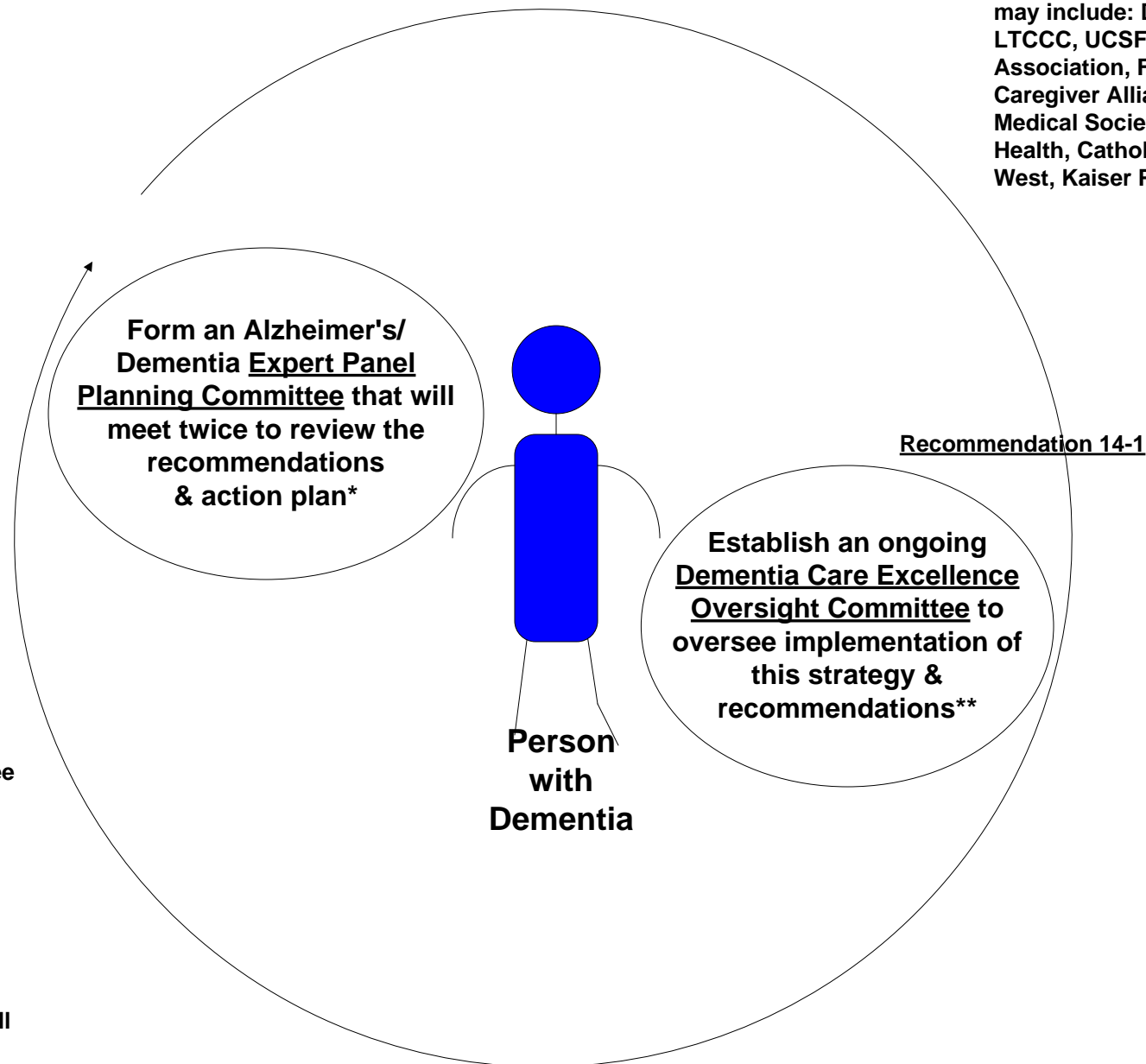
8-2	Ensure nursing home quality standards are met to provide person-centered care and an array of dementia care services.	Dementia Care Excellence Oversight Committee
9-1	Develop an expanded range of community-based services based on best practices.	Additional Services and Settings Workgroup
9-2	Expand and enhance range of adult day services and train staff to address cognitive impairment at all stages of the disease.	Additional Services and Settings Workgroup
9-3	Develop dementia services and supports for people who have no family or none close.	Additional Services and Settings Workgroup
9-5	Advocate for changes in mental health system to end carve-out from mental health services.	Advocacy Workgroup
9-6	Develop a plan to provide dementia services for people above Medi-Cal eligibility.	Additional Services and Settings Workgroup
10-1	Develop a range of residential care settings for people who need residential and nursing services.	Additional Services and Settings Workgroup
10-2	Ensure residential care quality standards are met to provide person-centered care and an array of dementia care services in residential care facilities.	Dementia Care Excellence Oversight Committee
4-4	Advocate to remove barriers for doctors to provide geriatric assessments, diagnoses and care by increasing reimbursement.	Advocacy Workgroup
4-5	Advocate to remove barriers for people that limit access to services based solely on diagnosis.	Advocacy Workgroup
11-1	Advocate to change policies so that people with late stage dementia can easily access hospice care.	Advocacy Workgroup
12-1	Advocate for universal coverage for long-term services and supports as part of national health care reform.	Advocacy Workgroup
12-2	Advocate for legislation for the California Department of Health Care Services and the California Department of Social Services to develop dementia expertise.	Advocacy Workgroup
12-3	Explore participation in the Assisted Living Waiver or the Home and Community-Based Services Waiver being designed for San Francisco in order to retain Medi-Cal funds.	Waivers, Pilot Projects and Demonstration Projects Workgroup
12-4	Consider developing an enhanced nursing home diversion services project.	Waivers, Pilot Projects and Demonstration Projects Workgroup
13-1	Undertake efforts to make San Francisco friendlier to people experiencing forgetfulness and memory loss.	Additional Services and Settings Workgroup
PHASE THREE – IMPLEMENTATION (2016 to 2020)		
Recommendation		Leadership Responsibility
9-4	Develop a crisis intervention and assessment setting for people with dementia who are not safe in their own environments or who have behavioral issues.	Additional Services and Settings Workgroup
12-5	Explore the feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including people with dementia, to retain Medi-Cal Funds.	Waivers, Pilot Projects and Demonstration Projects Workgroup

SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE

ACTION PLAN: PHASE ONE - PLANNING

Recommendations that can be implemented in
FIRST TWO MONTHS (November and December 2009)

****This oversight committee may include leadership from the public sector and the private sector. Membership may include: DAAS, DPH, LTCCC, UCSF, Alzheimer's Association, Family Caregiver Alliance, SF Medical Society, Sutter Health, Catholic Healthcare West, Kaiser Permanente**



***This Planning Committee will consist of the Co-Chairs of the Expert Panel (Kathy Kelly and Jay Luxenberg), the four Subcommittee chairs (Ruth Gay, Patrick Fox, Cynthia Kauffman, Elizabeth Edgerly), and DAAS (Anne Hinton & Bill Haskell).**

ACTION PLAN
PHASE ONE – PLANNING
TWO MONTHS (November - December 2009)

PHASE ONE – PLANNING will cover two months devoted to organizing a *Dementia Care Excellence Oversight Committee*. During this period, an Alzheimer’s/Dementia Expert Panel Planning Committee will oversee implementation of recommendation 14-1.

RECOMMENDATION 14-1. Establish an ongoing Dementia Care Excellence Oversight Committee to oversee implementation of this Strategy and recommendations.

The Planning Committee will meet twice to: (1) review and complete the action plan; (2) participate in organizing the *Dementia Care Excellence Oversight Committee*; and (3) plan for the transfer of responsibilities to it for the implementation of this *Strategy*. The Planning Committee will include:

- The two co-chairs from the Expert Panel: Kathy Kelly and Jay Luxenberg;
- The four chairs of the subcommittees: Ruth Gay, Patrick Fox, Cindy Kauffman, and Elizabeth Edgerly; and
- The Department of Aging and Adult Services: Anne Hinton and Bill Haskell.

Leadership Responsibility: Alzheimer’s/Dementia Expert Panel Planning Committee

Proposed Key Partners: The members of the *Dementia Care Excellence Oversight Committee* should be appointed by the Mayor. Co-chairs should be identified. Representatives from the following public and private sector agencies and organizations, among others, should be considered for membership:

- Department of Aging and Adult Services;
- Department of Public Health;
- University of California at San Francisco;
- Alzheimer’s Association of Northern California and Northern Nevada;
- Family Caregiver Alliance;
- San Francisco Medical Society;
- Institute on Aging;
- Sutter Health;
- Catholic Healthcare West;
- Brown & Toland Physicians Medical Group;
- Hill Physicians Medical Group;
- Kaiser Permanente;
- On Lok Lifeways;
- Long-Term Care Coordinating Council; and
- The Mayor’s Office

Recommended Workgroups:

1. Training And Education	5. Shared Electronic Medical Records System
2. Guidelines And Standards	6. Waivers, Pilot Projects, & Demonstration Projects
3. Additional Services And Settings	7. Advocacy
4. Medical Resources	

Each workgroup will require the designation of a chair or co-chairs, and the identification of staff support.

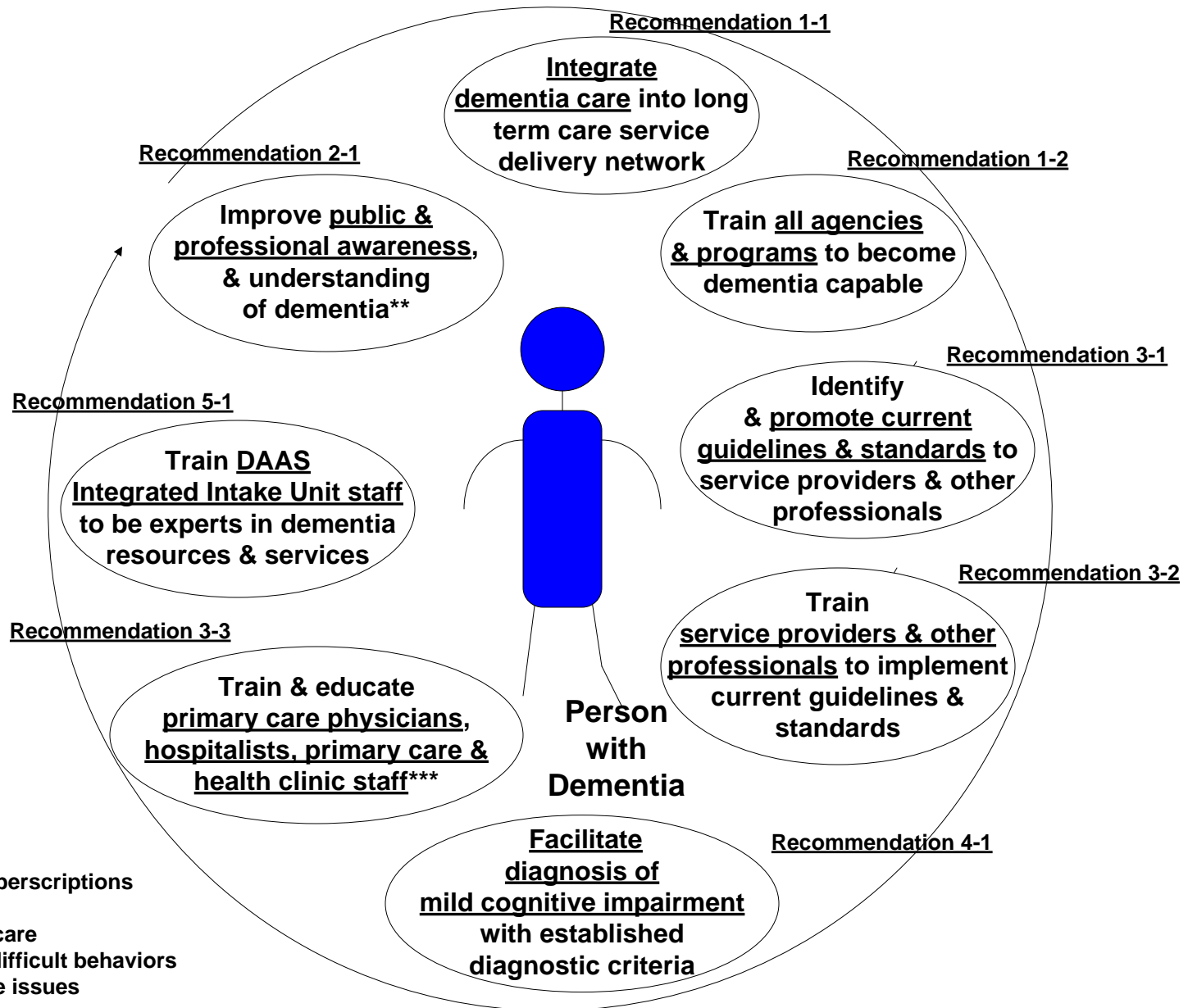
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE

ACTION PLAN: PHASE ONE - IMPLEMENTATION

Recommendations that can be implemented in
ONE TO TWO YEARS (2010-2011)

****Public Education on:**

1. Risk Reduction
2. Services & Resources
3. Early Identification
4. What to expect as the disease progresses
5. Disease management - mild, moderate, severe
6. Advanced Care Planning
7. Ethical Issues
8. Caregiver wellness & support
9. Emergency preparedness & safety



*****Training in:**

1. Medication prescriptions
2. Diagnosis
3. End of life care
4. Managing difficult behaviors
5. Critical care issues

ACTION PLAN

PHASE ONE – IMPLEMENTATION

ONE TO TWO YEARS (2010-2011)

PHASE ONE – IMPLEMENTATION will focus on implementing eight recommendations that do not require either a significant infusion of funding or major reforms. These recommendations focus on public education and targeted training to improve the capacity to implement best practices by implementing recommendations 1-1, 1-2, 2-1, 3-1, 3-2, 3-3, 4-1, and 5-1.

RECOMMENDATION 1-1. Integrate dementia care into San Francisco’s long term care service delivery network.

Leadership Responsibility: Dementia Care Excellence Oversight Committee

Proposed Key Partners: Department of Aging and Adult Services (DAAS), Department of Public Health (DPH), Family Caregiver Alliance, Alzheimer’s Association, Community-based service providers including senior centers, adult day care centers, social day centers, and institutional service providers, assisted living facilities, board and care facilities, Police Department, Fire Department

NOTE: This is a fundamental recommendation for the Expert Panel and will be achieved through the accomplishment of most or all of the other recommendations that follow.

RECOMMENDATION 1-2. Train all agencies and programs to become dementia capable.

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, urgent care providers, first responders, emergency room staff.

RECOMMENDATION 2-1. Improve public awareness and understanding of dementia.

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, San Francisco Public Library, Community based service providers including community centers, senior centers, adult day care centers, social day centers, primary care clinics, Mayor’s Office, Police Department, Fire Department

RECOMMENDATION 3-1. Identify and promote current guidelines and standards to service providers and other professionals.

Leadership Responsibility: Guidelines and Standards Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, representation from state agencies, and local service provider groups.

RECOMMENDATION 3-2. Train service providers and other professionals to implement current standards and guidelines.

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: Alzheimer’s Association, Family Caregiver Alliance, Institute on Aging, representation from state agencies and from local service provider groups.

RECOMMENDATION 3-3. Train and educate primary care physicians, hospitalists, primary care center staff and health clinic staff

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: DPH, UCSF, Alzheimer’s Association, San Francisco Community Clinic Consortium, Laguna Honda Hospital, Kaiser Permanente, Catholic Healthcare West

RECOMMENDATION 4-1. Facilitate diagnosis of mild cognitive impairment with established diagnostic criteria.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DPH, UCSF, Institute on Aging, Alzheimer’s Association, San Francisco Community Clinic Consortium, and major San Francisco hospitals, e.g. Kaiser Permanente, Catholic Healthcare West, Sutter Health Care.

RECOMMENDATION 5-1. Train DAAS Integrated Intake Unit staff to be experts in dementia resources and services.

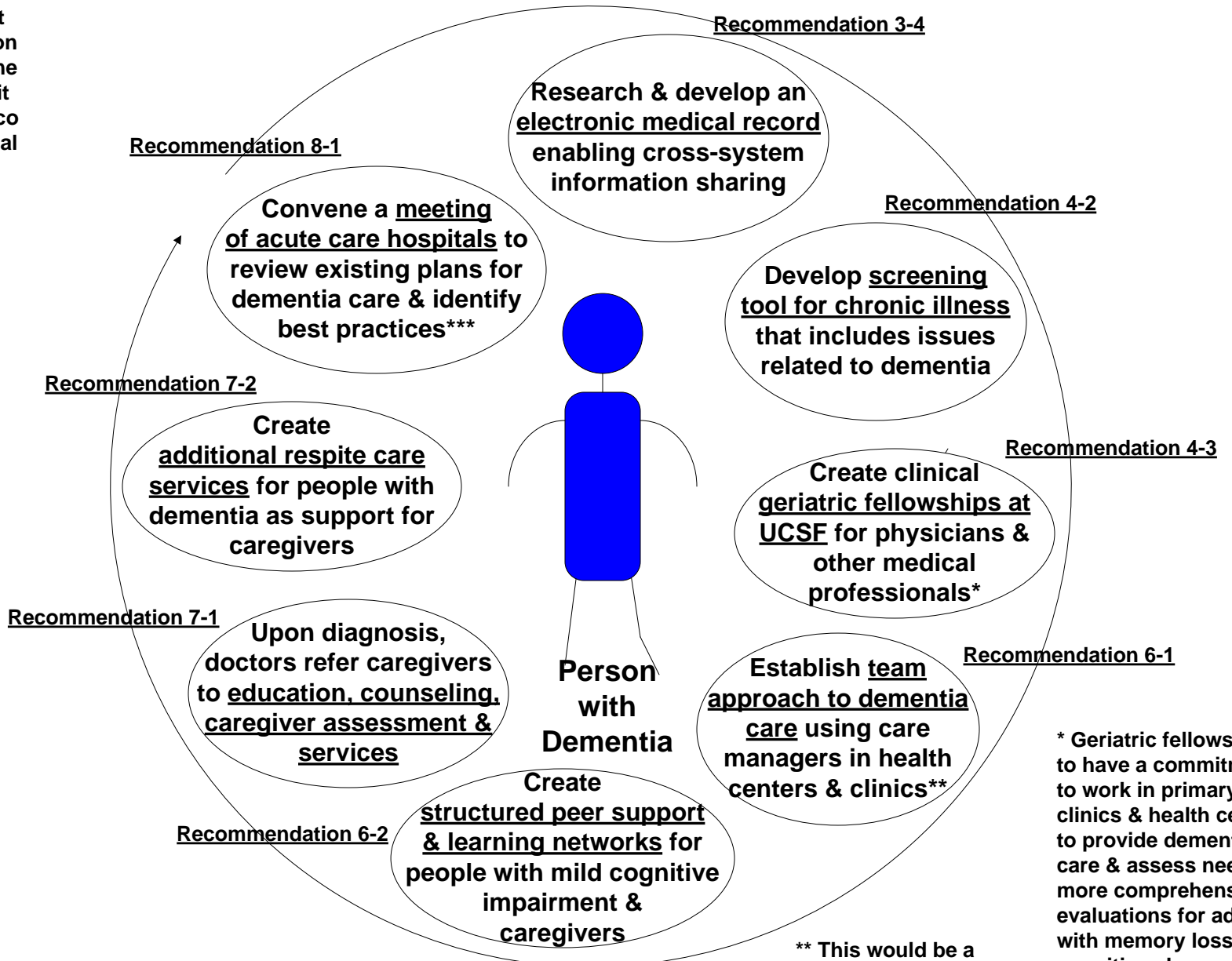
Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: Alzheimer’s Association

SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE **ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 1 of 3)**

Recommendations that can be implemented in
THREE TO SIX YEARS (2012-2015)

*** This summit could expand on work being done by the ACE Unit at San Francisco General Hospital



* Geriatric fellowships to have a commitment to work in primary care clinics & health centers to provide dementia care & assess need for more comprehensive evaluations for adults with memory loss or cognitive change

** This would be a pilot project between DAAS & DPH

ACTION PLAN
PHASE TWO – IMPLEMENTATION (FOR CHART 1 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-1 IMPLEMENTATION focuses upon building the network’s infrastructure and capacity to deliver integrated services. To achieve this purpose, the Oversight Committee will advance Recommendations 3-4, 4-2, 4-3, 6-1, 6-2, 7-1, 7-2, and 8-1.

Recommendation 3-4. Research and develop a medical record system enabling cross system information sharing.

Leadership Responsibility: Shared Electronic Medical Records System Workgroup

Proposed Key Partners: DAAS, DPH, UCSF, City and County of San Francisco, and information technology partners such as Google or Microsoft, San Francisco Community Clinic Consortium, Kaiser Permanente, Catholic Healthcare West, Sutter Health, Institute on Aging, Kindred Nursing and Rehabilitation Centers, and various local service providers, San Mateo County’s medical records

RECOMMENDATION 4-2. Develop screening tool for chronic illness that includes issues related to dementia.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DAAS, DPH, UCSF, Institute on Aging, Kaiser Permanente, Catholic Healthcare West, Sutter Health, San Francisco Medical Society, San Francisco Community Clinic Consortium

RECOMMENDATION 4-3. Create clinical geriatric fellowships at UCSF for physicians and other medical professionals.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DAAS, UCSF, Institute on Aging

RECOMMENDATION 6-1. Establish team approach to dementia care using care managers in health centers and clinics. This may be a pilot project.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente, San Francisco General Hospital

RECOMMENDATION 6-2. Create structured peer support and learning networks for people with mild cognitive impairment and caregivers.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, Community Living Campaign, San Francisco Village, openhouse

RECOMMENDATION 7-1. Immediately upon diagnosis, doctors and their staff should refer caregivers to supports such as education, counseling, caregiver assessment, and services

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: Kaiser Permanente, Hill Physicians Medical Group, Brown & Toland Physicians Medical Group, Family Caregiver Alliance, Alzheimer’s Association, On Lok, and Institute on Aging.

RECOMMENDATION 7-2. Create additional respite care services for people with dementia as support for caregivers.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, adult day care and adult day health care providers, & in-home supportive services programs.

RECOMMENDATION 8-1. Convene a meeting of acute care hospitals to review existing plans for dementia care and identify best practices.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DAAS, DPH, San Francisco General Hospital ACE Unit, local hospitals, especially emergency rooms and urgent care settings ,UCSF, Institute on Aging.

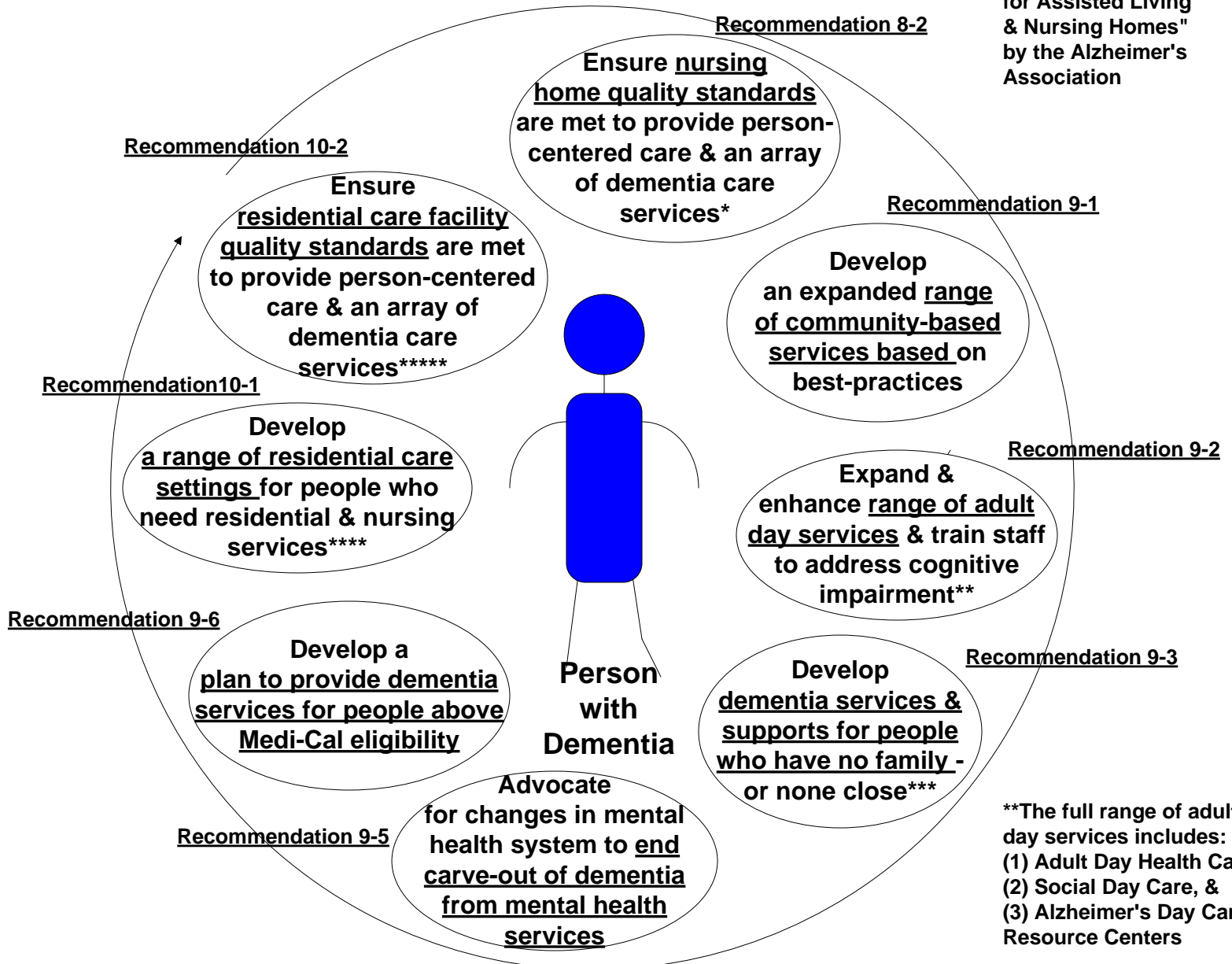
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE

ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 2 of 3)

Recommendations that can be implemented in
THREE TO SIX YEARS (2012-2015)

* Standards of quality should be met as defined in "Recommendations for Assisted Living & Nursing Homes" by the Alzheimer's Association

***** Standards of quality should be met as defined in "Recommendations for Assisted Living & Nursing Homes" by the Alzheimer's Association



**** This will require working with the California Department of Social Services' Office of Community Care Licensing to explore existing licensing categories and consider new licensing categories.

**The full range of adult day services includes:
(1) Adult Day Health Care,
(2) Social Day Care, &
(3) Alzheimer's Day Care Resource Centers

***This will be developed as a pilot project

ACTION PLAN
PHASE TWO – IMPLEMENTATION (FOR CHART 2 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-2 IMPLEMENTATION continues work developing and implementing standards and advancing a pilot demonstration project while expanding the range of services available to individuals with dementia and their caregivers. Phase II-2 would focus on implementation of Recommendations 8-2, 9-1, 9-2, 9-3, 9-5, 9-6, 10-1, and 10-2.

RECOMMENDATION 8-2. Ensure nursing home quality standards are met to provide person-centered care and an array of dementia care services.

Leadership Responsibility: Dementia Care Excellence Oversight Committee

Proposed Key Partners: Long Term Care Ombudsman, Laguna Honda Hospital, Alzheimer’s Association, & other nursing home providers, California Association of Nursing Home Reform

RECOMMENDATION 9-1. Develop an expanded range of community-based services based on best practices.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community based-service providers, including adult day health care, social day care, & Alzheimer’s Day Care Resource Centers, On Lok Lifeways.

RECOMMENDATION 9-2. Expand and enhance range of adult day services and train staff to address cognitive impairment at all stages of the disease.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community based service providers, including Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers, & San Francisco Adult Day Services Network.

RECOMMENDATION 9-3. Develop dementia services and supports for people who have no family or none close.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, In Home Supportive Services Registry Board, & New Leaf Services and other community-based agencies that provide services or other forms of home-based support (e.g. meals, transportation).

RECOMMENDATION 9-5. Advocate for changes in mental health system to end carve-out from mental health services.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH Community Behavioral Health Services, Alzheimer's Association, Family Caregiver Alliance, San Francisco Mental Health Association, & mental health providers.

RECOMMENDATION 9-6. Develop a plan to provide dementia services for people above Medi-Cal eligibility.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Controller's Office, Alzheimer's Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community-based service providers, including adult day health care, social day care, and Alzheimer's Day Care Resource Centers.

RECOMMENDATION 10-1. Develop a range of residential care settings for people who need residential and nursing services.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, San Francisco Planning Department, San Francisco Redevelopment Agency, Mayor's Office of Housing, California Department of Social Services, Laguna Honda Hospital, Long Term Care Coordinating Council.

RECOMMENDATION 10-2. Ensure residential care quality standards are met to provide person-centered care and an array of dementia care services in residential care facilities.

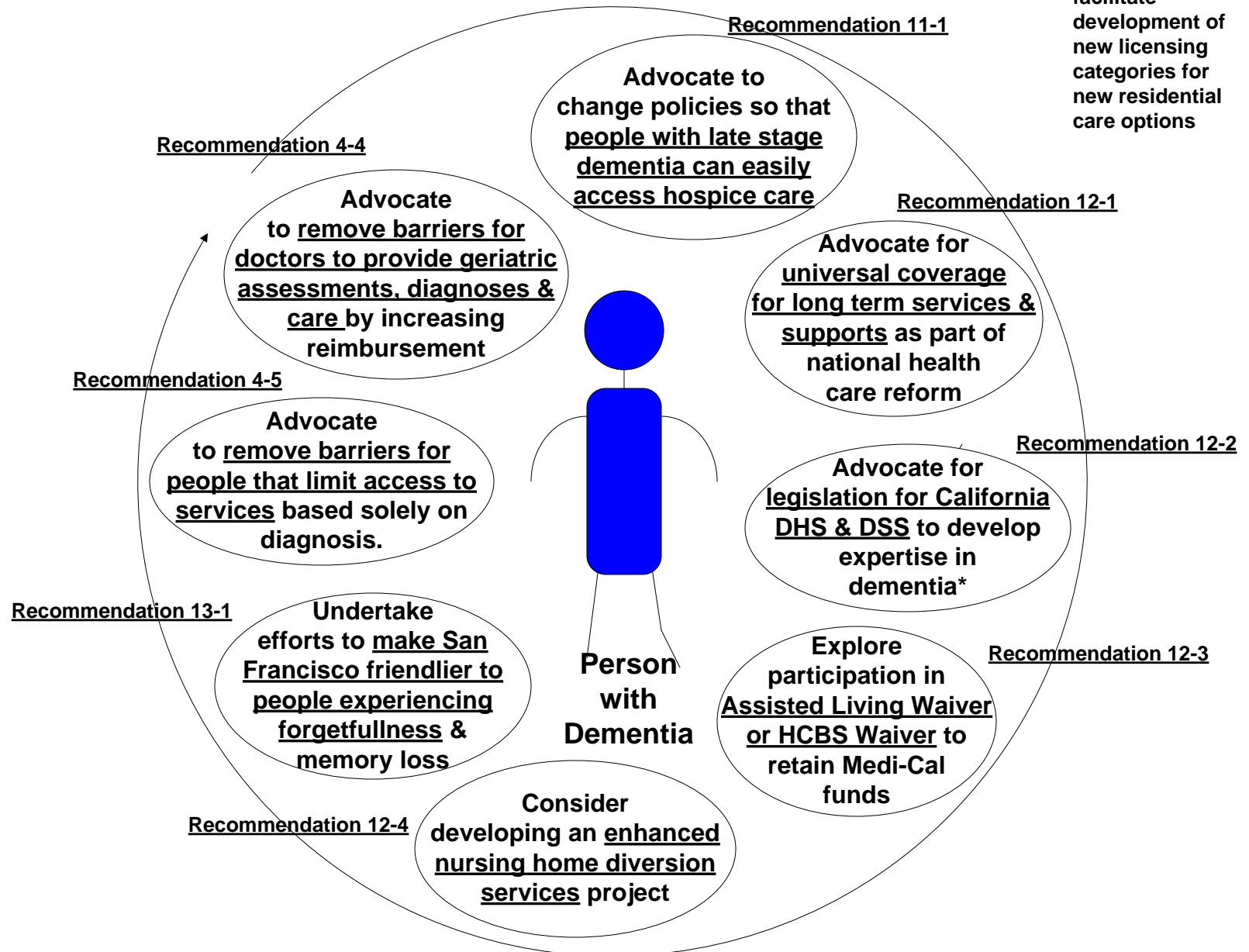
Leadership Responsibility: Dementia Care Excellence Oversight Committee

Proposed Key Partners: DAAS, Alzheimer's Association, Family Caregiver Alliance, UCSF, Institute on Aging, Laguna Honda Hospital, Long Term Care Ombudsman, California Alliance of Residential Care Providers, California Assisted Living Association, and residential care facilities, California Association of Nursing Home Reform.

SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE **ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 3 OF 3)**

Recommendations that can be implemented in
THREE TO SIX YEARS (2012-2015)

*The State DSS, Office of Community Care Licensing, should hire a nurse to facilitate development of new licensing categories for new residential care options



ACTION PLAN
PHASE TWO – IMPLEMENTATION (FOR CHART 3 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-3 IMPLEMENTATION addresses recommendations 4-4, 4-5, 11-1, 12-1, 12-2, 12-3, 12-4, 13-1. Most of these recommendations focus on either advocacy to remove fiscal and/or programmatic barriers to access to services and supports, an improved, more accepting community culture for people with memory issues, and to demonstrate new approaches to services that require waivers or other regulatory changes.

RECOMMENDATION 4-4. Advocate to remove barriers for doctors to provide geriatric assessments, diagnoses and care by increasing reimbursement.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, UCSF, Institute on Aging, physician groups, & local hospitals

RECOMMENDATION 4-5. Advocate to remove barriers for people that limit access to services based solely on diagnosis.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Community Behavioral Health Services, Alzheimer’s Association

RECOMMENDATION 11-1. Advocate to change policies so that people with late stage dementia can easily access hospice care.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, local hospitals, other nursing homes, hospice programs

RECOMMENDATION 12-1. Advocate for universal coverage for long term services and supports as part of national health care reform.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: Alzheimer’s Association of Northern California and Northern Nevada, Family Caregiver Alliance

RECOMMENDATION 12-2. Advocate for legislation for the California Department of Health Services (DHS) and the California Department of Social Services (DSS) to develop dementia expertise.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, Mayor's Office, DPH, Alzheimer's Association, Family Caregiver Alliance

RECOMMENDATION 12-3. Explore participation in the Assisted Living Waiver or the Home and Community Based Services (HCBS) Waiver being designed for San Francisco in order to retain Medi-Cal funds.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: DPH, Long-Term Care Coordinating Council, & assisted living providers

RECOMMENDATION 12-4. Consider developing an enhanced nursing home diversion services project.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: DAAS, DPH, Institute on Aging, State Department of Aging, Laguna Honda, Alzheimer's Association, Family Caregiver Alliance, On Lok Lifeways

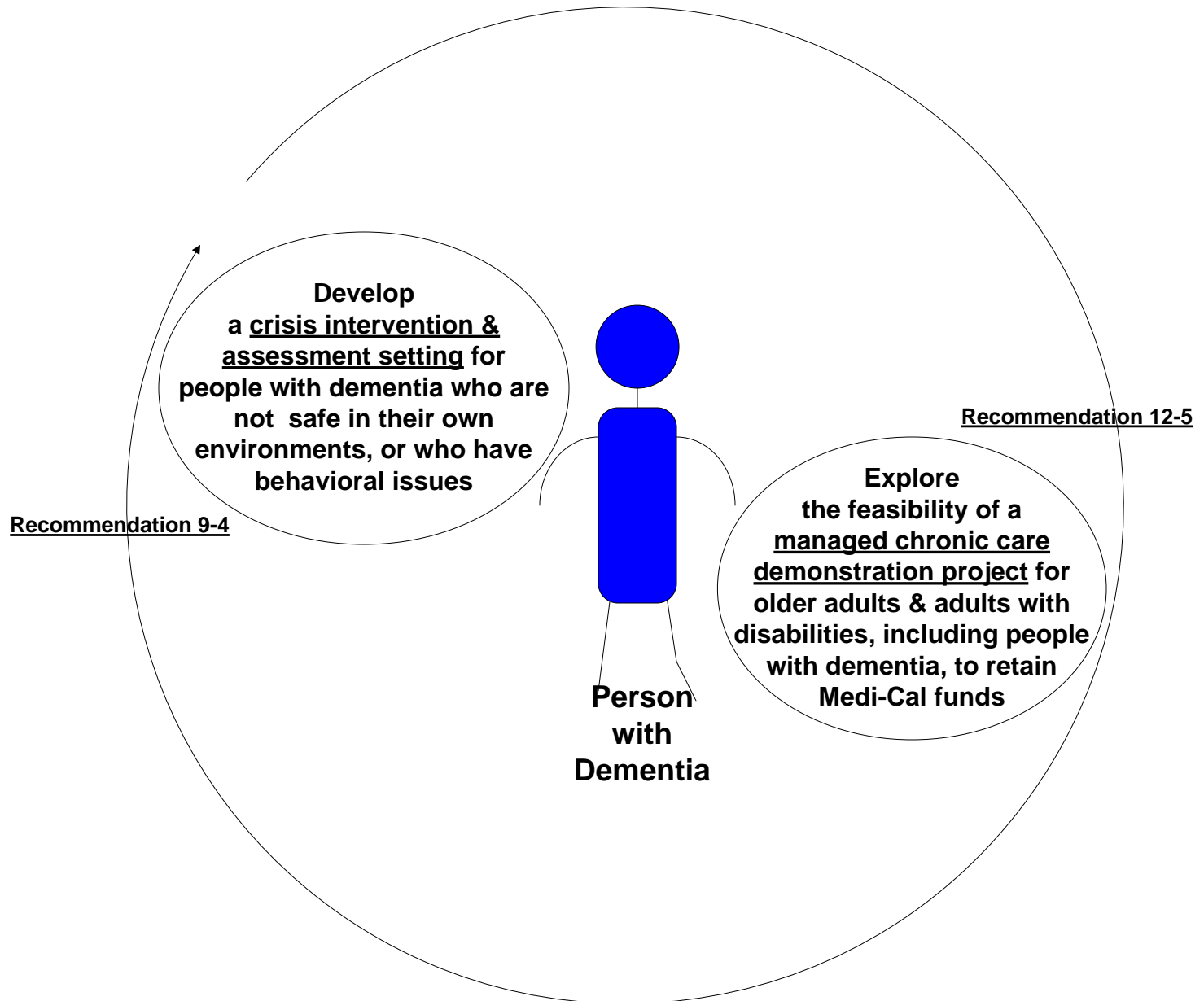
RECOMMENDATION 13-1. Undertake efforts to make San Francisco friendlier to people experiencing forgetfulness and memory loss.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer's Association, Family Caregiver Alliance, community-based agencies, San Francisco Public Library, San Francisco Community Clinic Consortium, Board of Supervisors, Mayor's Office, San Francisco Planning Department.

SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE **ACTION PLAN: PHASE THREE – IMPLEMENTATION**

Recommendations that can be implemented in
SEVEN YEARS TO 11 YEARS (2016-2020)



ACTION PLAN
PHASE THREE – IMPLEMENTATION
SEVEN To 11 YEARS (2016-2020)

PHASE THREE – IMPLEMENTATION covers the period from 2016-2020 and focuses upon implementation of two recommendations: Recommendation 9-4 and Recommendation 12-5, both of which involve developing new approaches to the delivery of services that will require waivers and or changes in regulations.

RECOMMENDATION 9-4. Develop a crisis intervention and assessment setting for people with dementia who are not safe in their own environments, or who have behavioral issues.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, Family Caregiver Alliance, Police Department, Adult Protective Services Forensic Center

RECOMMENDATION 12-5. Explore the feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including people with dementia, to retain Medi-Cal funds.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects. Workgroup

Proposed Key Partners: DAAS, DPH, Long Term Care Coordinating Council, UCSF, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, Family Caregiver Alliance, & local community-based service providers, On Lok

VI. IMPACT OF 2009-10 STATE BUDGET ON SAN FRANCISCO'S EXPERT PANEL RECOMMENDATIONS: DECEMBER 15, 2009

The impact on services under-funded or eliminated during the State's severe economic downturn cannot be understated. The State of California, in particular, has struggled with budget shortages of a magnitude that could not have been predicted. In the face of balancing a budget that required deep cuts in education and services, the impact on families dealing with Alzheimer's disease and related dementias are particularly cruel. In California, the final budget included \$4 billion in health and human service program cuts. The actual impact is closer to \$6-8 billion when the loss of federal matching funds is accounted for.

- It is a myth that the federal stimulus money will enable the health and social service infrastructure to continue, as asserted by the Governor.
- The administration is looking to private organizations to mitigate the funding gaps.
- The Governor's predicted mid-year budget cuts, slated for release January 2010 are expected to potentially further reduce or even eliminate the remaining fragile services that have already been slashed to the bare edge of service delivery. This will require active and capable advocacy efforts to preserve and protect these remaining fractured programs for the future.

Implementation of budget cuts for people with Alzheimer's disease and related dementias are ongoing, but some key and severe budget shortfalls are in the following programs:

- Caregiver Resource Centers (CRC) were cut 70% throughout California. In San Francisco, the loss of state caregiver support funding may impact the Bay Area Caregiver Resource Center significantly. Staff reductions, a halt in respite funding, and reductions in services are in process at this time.
- Alzheimer's Day Care Resource Center funding (ADCRC) was eliminated, with the State encouraging the Area Agencies on Aging (AAA) to consider using Older Americans Act money to fund these specialized Alzheimer's Day Care programs. An interesting challenge is that the Adult Day programs that received this special funding stream, will still be required to operate to their licensing requirements. Many ADCRCs have indicated they want to continue to operate under the name because of the business identify they have in their local communities, but are scrambling to consider how to fund their quality of adult day care.
- California Alzheimer's Disease Centers (CADCs) were cut by 50%. The California Department of Public Health has reduced each Center's grant from \$526,500 to \$281,800 but is also continuing to fund the Evaluation and Data Center at UCSF at \$282,000. Most of the CADCs also have other sources of funding, such as for research. Each Center will be impacted in different ways, and all will continue to operate with varying impact on delivery. Most hard hit in this program are these Centers' outreach to diverse communities, testing and diagnostic abilities for people with cultural and language needs other than English.
- The diminished In-Home Supportive Services (IHSS) budget will reduce or eliminate services to individuals with the lowest need. The criteria that was included in the budget language was intended to guide development of a plan of care, not to deny services. It is

estimated 36,179 recipients statewide will be dropped, and of great concern are those individuals who are in the moderate stages of Alzheimer's who may need supervision and ongoing minimal support to dress, eat and manage their daily lives, but will no longer meet criteria for such services. These changes were due to go into effect September 1, 2009 but the State has delayed implementation because the details are still being worked out.

Several legal actions are currently underway, which may impact to some degree on the budget reductions

- The federal district court in Oakland has issued an injunction to halt the implementation of the three-day cap in Adult Day Health Care (ADHC) services.
- The federal district court in San Francisco on August 20th turned down a request for a temporary injunction of the elimination of nine Medi-Cal optional benefits for adults, including dental, podiatry, optical, incontinence creams and washes. The benefits were eliminated July 1, 2009. A state court previously denied the request.
- The February budget reduced In-Home Supportive Services (IHSS) wages from \$12.10/hour to \$10.10/hour. A lawsuit was filed in US District Court and the wage cut was halted in June. The State has appealed.
- An injunction is currently in place to protect those currently receiving IHSS services from being cut due to changes in eligibility criteria.

In any case, the well considered and staged recommendations of the San Francisco Expert Panel cannot roll out without considering these daunting budget implications. In the face of these difficult times and fear of even more impact, it may be that **the Alzheimer's/Dementia Expert Panel recommendations provide an opportunity for the City and County of San Francisco to build an infrastructure from the scaffolding of these fallen or damaged structures into a city that is Alzheimer's and dementia "capable". Several considerations provide opportunity:**

- Early diagnosis and identification is a theme throughout this document. However, the Panel's PHASE ONE recommendations focus primarily on creating a "dementia friendly" community through increased public awareness, education and training, and professional education and training for all service providers as well as identification and promotion of standards and guidelines. This effort should include looking at ways to build a network of services that implements these recommendations, even as they promote awareness of and best practices with an Alzheimer's/dementia population.
- While we cannot predict whether the severe budget impact will continue for many years, the PHASE TWO recommendations – which would begin implementation in years 3-6 – have a focus on advocating for universal coverage for people living in the community as part of Health Care Reform, advocating for building dementia expertise, and especially removing barriers that limit access to services. Moving in this direction will appropriately help position the City and County of San Francisco to further develop the structure and integrated network of private and public services.
- It is impossible to ignore the impact of the current and ongoing budget cuts on Alzheimer's/dementia care programs and services. The PHASE THREE recommendations will take into account the changes of previous years and will need to move forward based on where the service delivery is at that point.

The implementation of the Expert Panel recommendations must essentially consider how to weave the current and remaining texture of service delivery into the hopes and dreams that are present in the Panels' short term, middle and long term recommendations for the future of San Francisco, so that we can realize *San Francisco's Strategy for Excellence in Dementia Care*.

VII. CONCLUSION

Conclusion

There is no cure for dementia on the immediate horizon. A wave of baby boomers is approaching the age where Alzheimer's and related dementias will begin to emerge. There will be a crisis in dementia care and San Francisco must respond. The Alzheimer's/Dementia Expert Panel spent months deliberating on research, local data, and input from caregivers and other stakeholders. The recommendations provided in this report are the product of that focused and intensive work. San Francisco must act with urgency, move forward to implement these recommendations, and realize our vision of care for people with dementia so that they can live in dignity and thrive.

