

● March 2024



California's Hidden Dementia Care Asset: Social Workers

Promoting a Family and Dementia Care
Consultant Role for Social Workers
and Community Professionals



**A CALGROWS
PROJECT**



Acknowledgments

Special thanks go to the many experts in dementia care, caregiving, and dementia care specialist training who generously shared their insights, experiences, ideas, and recommendations for this report. Their contributions were instrumental in shaping the final project recommendation, which proposes the development of a new role for social workers and community professionals to address the complex needs of individuals with dementia and their caregivers.

About CalGrows

CalGrows is a California Department of Aging program designed to strengthen and expand a diverse caregiving workforce in California. CalGrows offers information, training, and other support services to paid and unpaid caregivers of older adults and people with disabilities.

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Report Abbreviations

ACL	Administration for Community Living	CRCs	California Caregiver Resource Centers
ADRC	Aging Disability Resource Center/Connection	D-SNPs	Dual Eligible Special Needs Plans in California
ADI-SSS	Alzheimer’s Disease Initiative-Specialized Supportive Services	DCS	Dementia Care Specialist
ADPI	Alzheimer’s Disease Program Initiative	FCA	Family Caregiver Alliance
ADRD	Alzheimer’s Disease and Related Dementias	FDCC	Family and Dementia Care Consultant
ADSSP	Alzheimer’s Disease Supportive Services	GWEP	Geriatric Workforce Enhancement Program
AoA	Administration on Aging	HCBS	Home and community-based services
APS	Adult Protective Services	HRSA	Health Resources and Services Administration
BOLD	Building Our Largest Dementia Infrastructure	IHI	Institute for Health Improvement
CaAIM	California Advancing and Innovating Medi-Cal	LTSS	Long-Term Services and Supports
CaISWEC	California Social Work Education Center	MPA	California Master Plan for Aging
CBOs	Community-Based Organizations	NADRC	National Alzheimer’s Disease Resource Center
CDA	California Department of Aging	NAPA	National Alzheimer’s Project Act
CDC	Centers for Disease Control and Prevention	NIA	National Institute on Aging
CDPH	California Department of Public Health	NIH	National Institutes for Health
CDSS	California Department of Social Services	PLWD	Persons Living with Dementia
CHWs	Community Health Workers	UCSF	University of California, San Francisco
CMS	Centers for Medicare & Medicaid	WHO	World Health Organization

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Executive Summary

Three trends are converging in the United States: first, Alzheimer’s disease and related dementias (ADRD) are on the rise and expected to continue increasing over the next several decades—currently, 6.7 million Americans are living with ADRD; second, more Americans than ever (38 million) are family caregivers providing unpaid care to an aging or disabled adult (family caregivers are spouses, partners, families of choice, adult children, siblings, neighbors, friends); and third, the size of the dementia care workforce, consisting of healthcare and social service workers, is insufficient to meet current and future demand.^{1,2} Guided by demographic and population health data, federal agencies have invested in and implemented initiatives to address these trends for decades.

Building on these initiatives, states and healthcare organizations have developed dementia care programs to serve persons living with dementia (PLWD) and their caregivers. To ensure program staff serving these populations have the core dementia skills and competencies they need, many programs provide training in dementia and family caregiving. Completing this training, often with additional education and experience, can lead to the title of dementia care specialist (DCS). Across dementia care models, however, this title can refer to doctors, nurses, social workers, community health workers, and care navigators. With the increasing number of PLWD, all these members of the dementia care workforce are needed. There is also an opportunity for social workers and community professionals with advanced skills in the complexity of ADRD and caregiving to play a more significant role in this workforce.

Family Caregiver Alliance (FCA) and RUSH University Medical Center’s Center for Excellence in Aging and its Center for Health and Social Care Integration (RUSH) partnered on a CalGrows DCS project to strengthen California’s dementia care workforce. The project goal was to understand opportunities to leverage community professionals better—focusing on social workers—to improve outcomes for PLWD and their caregivers. Core project activities included conducting a national literature review and environmental scan of federal and California ADRD and caregiving policy and initiatives, as well as innovative dementia care programs, models, and training. Twenty experts in ADRD, caregiving, and DCS training were interviewed. Additionally, a roundtable of California thought leaders was convened to gain insights into the need for, as well as the barriers and facilitators to, creating a program for training and certifying social workers and community professionals in family and dementia care. Three framing questions guided the project.





- ▶ ***What roles, training programs, and certificates are available for professionals, nationally and in California, working with dementia patients, families, and family caregivers?***
- ▶ ***Is there a need to elevate social workers' and community professionals' competencies and skills to work with these populations in California?***
- ▶ ***Are there key partners in California that could support the development of this specialized workforce role for social workers and community professionals?***

Key findings from the environmental scan confirmed 1) there is an imperative and momentum to focus on people with ADRD and those caring for them in their homes and the community; 2) best-practice dementia care programs use a variety of on-the-ground approaches to implementation; 3) dementia training should be specific to the role, incorporate opportunities for application, and be supported by ongoing quality assurance and support efforts, and 4) there is a possible family caregiver DCS role for social workers and other community professionals working with PLWD and their caregivers in California.

Analysis and discussion of these findings with experts and roundtable participants yielded three project recommendations:

- 1. Addressing the three converging trends will require zooming out from just a health and social service framing of the challenge to a bigger-picture perspective** that includes multiple sectors and creative, solution-driven thinking.
- 2. California would benefit from having social workers and other community professionals with specialized training in dementia and family dynamics**—*Family and Dementia Care Consultants* (FDCCs)—to work with PLWD and family caregivers. They bring advanced skills in assessment, engagement, intervention, evaluation, advocacy, evidence-based practice, care coordination, and community resources.
- 3. Creating and sustaining an FDCC role for California social workers and community professionals will require a standardized training curriculum**, ideally with certification, and multiple pathways for eligible groups to access the training.

FDCC eligible groups include students pursuing graduate or undergraduate degrees in social work (Master or Bachelor of Social Work, MSW or BSW) or related fields, individuals with an MSW or graduate degree in a related field, or a BSW or other undergraduate degree and relevant work experience. A recommended next step is for the California Department of Aging (CDA) to review the viability of developing and sponsoring a pilot FDCC training and certification program and identify potential partners, e.g., California Department of Social Services (CDSS), California Social Work Education Center (CalSWEC), California Caregiver Resource Centers (CRCs), Aging Disability Resource Connections (ADRCs), and community organizations. The following personas show various training pathways to becoming an FDCC.

	 Stefan	 Madison	 Amaya	 Louisa
Education	Second year student in MSW program	Undergraduate (Junior)	Has master’s degree in public health (MPH)	Has a Bachelor of Arts (BA) in humanities
Training Pathway	School of Social Work offers FDCC training/certification	Undergraduate program in aging offers FDCC training/certification	Community program offering FDCC training/certification	Community program offering FDCC training/certification

In health and social services, the complexity of need dictates the response. Using social workers and community professionals as FDCCs can help California meet its dementia care workforce challenge.

Introduction

Several critical trends have intersected for the past several decades, each with far-reaching health implications for communities nationwide. The first is the dramatic increase in the number of persons diagnosed and living with Alzheimer’s disease and related dementias (ADRD); the second is the mushrooming number of Americans who provide unpaid care to loved ones with ADRD; and the third is a dementia care workforce unable to meet demand. The latter includes professionals and paraprofessionals providing care and support to persons with dementia (PLWD) and family caregivers. The convergence of these trends is becoming a public health concern and a growing priority focus for local, state, and federal government agencies.

Dementia

Dementia is an umbrella term for a group of symptoms that typically include disruptions in cognition that affect an individual’s memory, language, problem-solving, and ability to perform every day functional tasks. Many dementias, like Alzheimer’s disease—the most common cause of dementia—are a progressive degenerative brain disease.

A staggering nearly seven million Americans are living with ADRD.¹ For each individual represented by this number, a diagnosis of dementia involves a profound loss in nearly every aspect of the person’s life—cognition, physical and functional ability, intimate and social relationships, income, and finances. Equally important, because increasing age is one of the most significant risk factors for developing ADRD, and the number of Americans age 65 and older is expected to increase from 58 million in 2021 to 88 million in 2040, many more Americans will be living with ADRD in the coming decades.^{3,4}

Once a diagnosis of ADRD is made, many PLWD and their family caregivers find themselves overwhelmed. Family caregivers commonly report not knowing where to turn for information, services, and support. Most lack the emotional support to process the diagnosis and determine what to do next. As a result, many caregivers adopt a “learn it as you go” approach. As their loved one moves through the different stages of ADRD, they respond in kind, shifting care responses, routines, resources, and emotions to meet the moment’s needs, often putting their own physical health and emotional needs aside.

Family caregivers are not a monolithic group. They are spouses, partners, adult children, siblings, parents, friends, families of choice, and neighbors who step into an unpaid caregiving role. Moreover, they are members of every adult generation from the Greatest Generation to Generation Z. They speak many languages and represent every racial, ethnic, and socio-economic group in America. Some live with or near the care recipient; some live in other states. And there are different types of caregivers. Some provide physical assistance, while others may offer financial support. Because PLWD are living longer than in the past, caregiving today is often a protracted experience, made more complicated if the PLWD have comorbid conditions (heart failure, diabetes). Significant numbers of caregivers perform

complex medical nursing tasks, such as administering medications (including injections), performing wound care, and managing medical equipment.

The adage that “caregiving is stressful” is especially applicable to dementia caregivers. ADRD caregivers report higher levels of stress and adverse effects on their health, employment, income, and financial security than their non-dementia caregiver counterparts.⁵ Compared to caregivers of persons without dementia, ADRD caregivers are more likely to provide intensive and extensive assistance with activities of daily living (ADLs)—eating, bathing, dressing, toileting—and instrumental activities of daily living (IADLs)—shopping, preparing meals, paying bills, attending doctor’s appointments, cleaning, and managing complex emotional, mental health, and behavioral problems. They are also at much greater risk for negative health and economic outcomes, including caregiver burden, strain, depression, poor physical health, and financial hardship than non-ADRD caregivers.⁶⁻¹¹

As the incidence and prevalence rates of ADRD increase, government agencies at all levels are examining the adequacy, capacity, and readiness of the dementia care workforce.¹² The size of this workforce has been decreasing both before and after the outbreak of the COVID-19 pandemic. Today, it is inadequate to meet current and future needs.

As the most populous state in the nation with a rapidly growing older adult population, California is facing a severe shortage of dementia-trained workers.¹³ This CalGrows project explored the converging ADRD, family caregiver, and dementia care workforce shortage trends, nationally and in California, and evaluated the need and opportunity for California to support a specialized family and dementia care role and training program for social workers and community professionals. The report presents key findings and recommendations for addressing the complexity of issues and needs faced by PLWD and caregivers and highlights the role highly trained social workers and community professionals can play in bridging a significant part of the dementia care workforce gap.

Dementia Care Workforce
includes a range of professional and paraprofessional workers, e.g., primary care physicians and medical specialists (geriatricians, neurologists, palliative care physicians, psychiatrists), nurses, psychologists, social workers, community health workers, care navigators, and the direct care workforce, including personal care aides, home health aides and nursing assistants.



The aging of our population is a megatrend, and there is a huge gap in caregiving services and supports, especially in dementia caregiving.

- Diane Ty, MBA, MA, Managing Director, Milken Institute Future of Aging

Federal and California Responses to Converging Trends

For years, federal agencies and key partners have been addressing the rapid growth in the numbers of Americans living with dementia, those serving as unpaid family caregivers, and the looming shortage of workers to address the needs of both groups. California was one of the first states to address these emerging trends. Examples of significant policies and initiatives in these areas, federally and in California, provide a big-picture view of these efforts and context for developing a possible social work role for California's dementia care workforce.



National Efforts to Address ADRD, Family Caregiving, and the Dementia Workforce

ADRD is a public health issue. In 1984, the National Institute on Aging (NIA), one of the 27 Institutes and Centers of the National Institutes of Health (NIH) and the primary federal agency supporting and conducting Alzheimer's research, funded the establishment of Alzheimer's Disease Centers.¹⁴ Located at medical institutions nationwide, the centers were charged with researching Alzheimer's disease prevention and treatment while improving care and diagnosis. NIA's emphasis on translational research contributed to the development of federal and state ADRD initiatives. Section 398 of the Public Health Services Act (1990) created the Alzheimer's Disease Demonstration Grants to States in 1992.¹⁵ The program, later renamed the Alzheimer's Disease Supportive Services Program (ADSSP), is overseen by the Administration on Aging (AoA) and the Administration for Community Living (ACL). ADSSP supports developing and expanding dementia capability in states to ensure that PLWD and caregivers access sustainable, integrated long-term services and supports.

AoA and ACL also oversee the Alzheimer's Disease Program Initiative (ADPI), which provides grants to states and community-based organizations to improve or develop their dementia systems capability, and the Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS). This program is designed to fill gaps in dementia-capable long-term services and supports at state and community levels for PLWD, those at high risk of developing ADRD, and their caregivers. Each of these initiatives is profiled in the National Alzheimer's and Dementia Resource Center (NADRC), which provides technical assistance to AoA/ACL and its grantees and serves as a repository of dementia program information and resources for the public.¹⁵

In 2011, the National Alzheimer's Project Act (NAPA) was signed into law.¹⁶ This vanguard legislation led to the development of the first National Plan to Address Alzheimer's Disease in 2012. Guided by an Advisory Council on Alzheimer's Research, Care, and Services and

convened by the Secretary of the U.S. Department of Health and Human Services, the plan established six goals to meet the current and future needs of people living with ADRD.¹⁷ Major progress in coordination, collaboration, and innovation on Alzheimer’s disease was reported on the 10th anniversary of the national plan (May 2022).

The Alzheimer's Association and the Centers for Disease Control and Prevention (CDC) created the first national Healthy Brain Initiative in 2007. The most recent iteration of the initiative was launched in 2018. The initiative offers federal funds to states to support state and local public health partnerships to create more coordinated, aligned, and equity-focused systems of care for those at risk for or living with ADRD.¹⁸ Partnerships select action steps from the initiative Road Map. Activities include addressing the cognitive health of people living in the community with a focus on populations with high ADRD burden, eliminating health disparities, supporting family caregivers, and ensuring a competent workforce, the latter by “strengthening the knowledge, skills, and abilities of health care professionals who deliver care and services to people with ADRD and their family caregivers.”¹⁸

Table 1. Federal ADRD Policies and Initiatives

Date	Policy/Initiative	Focus
1984	Alzheimer's Disease Centers	National Institute on Aging (NIA) established the centers.
1992	National Alzheimer's Disease Resource Center (NADRC) supports the Alzheimer's Disease Supportive Services Program (ADSSP); Alzheimer's Disease Program Initiative (ADPI); and Alzheimer's Disease Initiative- Specialized Supportive Services (ADI-SSS). Formerly called the Alzheimer's Disease Demonstration Grants to States.	Administered by AoA/ACL. NADRC provides technical assistance and program information to non-grantees. ADSSP supports the development and expansion of dementia capability in states; ADPI provides grants to states and community-based organizations to develop and expand the availability of dementia-capable supports and services; ADI-SSS fill gaps in dementia-capable long-term services and supports at state and community levels.
2011-2012	National Alzheimer's Project Act (NAPA) , National Plan to Address Alzheimer's Disease	Overseen by Advisory Council on Alzheimer's Research, Care, and Services and Office of the Assistant Secretary for Planning and Evaluation to create a national plan to overcome Alzheimer's disease.
2018	Healthy Brain Initiative	Overseen by the Centers for Disease Control and Prevention (CDC) to support state and local public health partnerships to collect data, increase awareness of brain health, address high ADRD communities.
2018	Building Our Largest Dementia Infrastructure (BOLD) for Alzheimer's Act	Overseen by CDC to create a uniform national public health infrastructure.
2023	Guiding an Improved Dementia Experience (GUIDE) Model	Center for Medicare and Medicaid Innovation (CMMI) will test an alternative payment model for supportive care for community-dwelling Medicare fee-for-service beneficiaries with ADRD and their unpaid caregivers.

Complementing the Healthy Brain Initiative, the Building Our Largest Dementia Infrastructure (BOLD) for Alzheimer’s Act was passed into law in 2018.¹⁹ BOLD creates a uniform national public health infrastructure to promote early ADRD detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and support for dementia caregivers. The legislation, directed by the CDC, funds public health departments to carry out specific activities. It also established three Alzheimer’s and Related Dementias Public Health Centers

of Excellence (each Center specializes in one topic-specific area: Early Detection, Alzheimer's Disease Risk Reduction, and Dementia Caregiving). The Centers disseminate research findings and evidence-informed best practices.

Most recently, in July 2023, the Center for Medicare and Medicaid Innovation (CMMI), part of the Centers for Medicare & Medicaid Services (CMS), announced an alternative payment model for supportive care for PLWD and their unpaid caregivers. The Guiding an Improved Dementia Experience (GUIDE) Model provides care and support to patient-partner dyads.²⁰ GUIDE will test whether a comprehensive package of standardized services and supports delivered by an interdisciplinary team with dementia proficiency and coordinated by trained care navigators can improve quality of life for people living with dementia, enabling them to remain in their homes and communities while reducing strain on their unpaid caregivers. Caregivers will have access to an annual respite benefit, a 24/7 support line, and education, training, and other supports. GUIDE is designed for eligible community-dwelling Medicare fee-for-service beneficiaries, including beneficiaries dually eligible for Medicare and Medicaid. The model launches on July 1, 2024, and will run for eight years.

Caregiving is also a public health issue due to its impact on caregiver well-being and the large number of Americans providing care. The Older Americans Act Amendments of 2000 (Public Law 106-501) was the first significant legislation addressing family caregiving. The law established the National Family Caregiver Support Program (NFCSP), Title III Part E.²¹ NFCSP services include caregiver information, assistance in gaining access to services, counseling and training support, temporary respite, and limited supplemental services to complement the care provided by caregivers.

Complementing NFCSP was the establishment of the Aging Disability Resource Center Program (ADRC) in 2003.²² ADRCs provide more coordinated long-term services and supports (LTSS) information systems for older adults, family members, and others. To address challenges with the ADRC program, namely that streamlining LTSS access for all populations and payers requires engagement and involvement from multiple agencies and organizations at the state and local level, the model laid the foundation for the No Wrong Door (NWD) System Initiative in 2012.²³ Today, state NWD systems are built on partnerships and follow a set of core elements that promote efficient, cost-effective, consumer-driven LTSS systems.

In 2022, the National Strategy to Support Family Caregivers (Strategy), developed jointly by the advisory councils created by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act—with input from the public, presented five key goals to support action by a group of federal agencies to improve support for family caregivers.²⁴ The actions are a clarion call to states, communities, and organizations to form partnerships, within and outside their traditional networks, and align with the Strategy to increase and strengthen access to culturally competent caregiving programs.

Building on the Strategy, in April 2023, President Joseph Biden signed an Executive Order (EO) on Increasing Access to High-Quality Care and Supporting Caregivers that includes “50

directives to nearly every cabinet-level agency to expand access to affordable, high-quality care, and provide support for care workers and family caregivers.”²⁵ The GUIDE model represents a key deliverable from this EO. Together, these federal caregiver initiatives and initiatives addressing ADRD have raised the profile of family caregivers.

Table 2. Federal Caregiving Policies and Initiatives

Date	Policy/Initiative	Focus
2000	National Family Caregiver Support Program Older Americans Act Amendments of 2000 (Public Law 106-501), Title III Part E, (NFCSP)	Overseen by ACL. Provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible.
2003	Aging Disability Resource Center Program (ADRC)	ADRC work is supported by AoA, ACL, Centers for Medicare & Medicaid (CMS) and the Veterans Administration (VA). ADRCs serve as single points of entry into the long-term services and supports (LTSS) system for older adults, people with disabilities, caregivers, veterans and families. ADRCs are an important part of the No Wrong Door (NWD) system model.
2022	National Strategy to Support Family Caregivers (Strategy)	Created by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act and supported by ACL. The Strategy identifies more than 350 actions the federal government will take, and more than 150 states, local governments, and organizations can take, to support family caregivers.
2023	Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers	President Biden signed the Executive Order (EO) in April 2023 to ensure care workers and family caregivers receive the resources they need. Building on the Strategy, the EO includes more than 50 directives to federal agencies to expand access to affordable, high-quality care, and provide support for care workers and family caregivers.

The trends in ADRD and caregiving have brought significant changes to each respective field through research, policies, and programs. They have also brought **dementia care workforce shortages** to light, which directly impact PLWD, their family caregivers, and the healthcare and community service systems they rely on. Expanding the number of professionals (health care, social service, behavioral health providers) and paraprofessionals (direct care workers) in this workforce has been and continues to be a focus of national and state efforts. While professional schools (medical, nursing, social work) have not consistently or uniformly focused on preparing a workforce that can work with older adults, many states and local municipalities have been addressing the shortage of professionals and paraprofessionals in elder care for years due to their growing aging populations.

The World Health Organization (WHO) analyzed worldwide aging population projections in the early aughts.²⁶ They found that the supply of geriatric-certified physicians, nurse practitioners, and nurses to provide appropriate, safe, and effective care to older adults was limited. This led them to identify the components of “age-friendly health care.”²⁷ The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) further developed this paradigm to create Age-Friendly Health Systems and the 4 Ms framework. Participating healthcare systems and providers are trained in the framework and the core concepts that

4 Ms Framework: Age-Friendly Health System

- ▶ **What Matters:** Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.
- ▶ **Medication:** If medications are necessary, use age-friendly medications that do not interfere with What Matters, Mentation or Mobility.
- ▶ **Mentation:** Prevent, identify, treat, and manage depression, dementia, and delirium across settings of care.
- ▶ **Mobility:** Ensure that older adults move safely every day to maintain function and do What Matters.

every older adult 1) gets the best care possible guided by an essential set of evidence-based practices, 2) experiences no healthcare-related harms, and 3) is satisfied with the health care they receive consistent with *What Matters* to the older adult and their family.²⁸

Most of the federal ADRD initiatives recognize and support developing a dementia-capable workforce. To leverage these efforts, the Health Resources and Services Administration (HRSA), established the Geriatric Workforce Enhancement Program (GWEP). Each GWEP focuses on developing collaborations

between academia, primary care delivery sites and systems, and community organizations to educate and train health care and supportive care workers to care for older adults.²⁹ A core objective of GWEPs is providing dementia training to direct care workers, healthcare providers, health professions students, residents, fellows and faculty, and individuals, patients, families, and caregivers.

Many national, state, and local organizations have similarly taken a lead role in addressing the workforce issues related to dementia care. Eldercare Workforce Alliance, a national organization comprised of 35 national organizations, proposes and advocates for practical solutions and policies to strengthen the elder care workforce to improve the quality of care for older adults.³⁰ Universities, state health departments, and voluntary health organizations have also developed training programs for staff implementing dementia care programs to ensure they have the core competencies and skills needed. Examples include Care Ecosystem (University of California, San Francisco [UCSF]); Wisconsin's Dementia Care Specialist Program; MIND at Home (Johns Hopkins University); and the Alzheimer's Association *essentiALZ*[®] – Alzheimer's Association Training and Certification Program.

One discipline often overlooked in workforce initiatives focusing on dementia care is social workers. With honed skills in psychosocial assessment, mental and behavioral health, a deep understanding of complex interactions between people and their environments (the *ecological perspective*), and a commitment to improving quality of life for individuals and communities, social workers can play a more critical role in the care of PLWD and caregivers.³¹ Because of social worker supply and demand concerns, it makes sense to focus on enhancing and strengthening their role in the dementia care workforce now. The U.S. Bureau of Labor Statistics has predicted a shortage of approximately 74,000 social workers each year for the next ten years, and while the HRSA Health Workforce Simulation Model found that the supply of social workers trained at the master's degree level or higher will meet demand by 2030, the administration acknowledged that the increase in demand may

be significantly higher than the report's projections due to data limitations, the evolving role of social work, and growing requests for social workers across different service systems^{32, 33}

Table 3. National Initiatives Impacting the Dementia Care Workforce

Date	Policy/Initiative	Focus
2000-2018	Age-Friendly Health Care Age-Friendly Health Systems	WHO identified components of age friendly health care; the John A. Hartford Foundation and the Institute for Health Improvement (IHI) built on this foundation to create the framework for age-friendly health systems.
2015	Geriatric Workforce Enhancement Program (GWEP)	Overseen by HRSA, GWEPs educate and train the health care and supportive care workforces to care for older adults by collaborating with community partners.
2008	Eldercare Workforce Alliance	The Alliance brings together national organizations to build a caring and competent workforce to work with older adults and family caregivers; the Alliance supports policies that invest in and build a workforce trained in geriatric principles.

California: Out in Front

California has long been out in front of ADRD, family caregiving, and elder care workforce issues. In 1984, the California Department of Public Health (CDPH) launched a network of ten California Alzheimer’s Disease Centers. The centers provide culturally and linguistically appropriate dementia care and support to patients living with dementia and their families, conduct ADRD research, and train health care professionals.³⁴ CDPH is currently administering the CDC Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia Road Map, and the state is participating in the CDC BOLD to Public Health Programs to Address Alzheimer’s Disease and Related Dementias initiative. BOLD grantees implement community-based ADRD activities in their communities in alignment with their strategic plan and Road Map actions.¹⁹

Starting in 2012, California followed a course to address the urgency of ADRD outlined by California’s State Plan for Alzheimer’s Disease: An Action Plan for 2011-2021. Actions included ensuring access for PLWD to high-quality, coordinated care, and establishing a comprehensive approach to support family caregivers.³⁵ In 2020, the Governor’s Task Force on Alzheimer’s Disease Prevention, Preparedness, and the Path Forward developed follow-up recommendations on how California “can prevent and prepare for the growing number of Alzheimer’s cases and forge a path forward for families” in the plan, Our Path Forward.³⁶

It is important to note the Path Forward recommendations were developed in collaboration with the 2021 California Master Plan for Aging, “a blueprint for aging across the lifespan.”³⁷ The Master Plan outlines five statewide goals for California, one of which, Goal 2, *Reimagining programs and services for older adults*, includes the core strategy, *Dementia in Focus*. The strategy contains six initiatives that advance a more coordinated and collaborative approach to dementia and brain health awareness for the state. Dementia Care Aware (DCA), a statewide program providing free online training, tools, and support to primary care

providers on administering cognitive health assessments, is a component of Goal 2 of the Master Plan. DCA was launched in April 2023, a partnership between the California Department of Health Care Services (DHCS) and UCSF.³⁸

California has several significant statewide systems supporting older adults, people with disabilities, and family caregivers. The Adult Day Services network includes Adult Day Programs, a non-medical day program for adults who need socialization, assistance with personal care, and supervision; and Adult Day Health Care (ADHC) centers, which offer a medical model of care in an outpatient day program to frail older adults and younger adults with chronic disabling medical, cognitive, or mental health conditions at risk of needing institutional care. The Caregiver Resource Center (CRC) system, founded in 1984, established 11 CRCs to serve family caregivers of adults affected by chronic and debilitating health conditions, including neurodegenerative diseases. CRCs provide free and low-cost services, from caregiver assessments to family consultation and respite care. CDA oversees the CRCs.

Family caregivers mattered in the 1980s, and they still matter today. To increase services and support to this constantly expanding population, the California Task Force on Caregiving submitted seven recommendations to the Legislature in their 2018 report, *"Picking Up the Pace of Change in California."*³⁹ The report focused on the state's nearly seven million family caregivers and contributed to the development of goal four of the California Master Plan for Aging, "Caregiving that Works." The goal includes three core strategies: family and friends caregiving support, direct care job creation, and virtual care expansion. It additionally includes the target of creating one million caregiving jobs by 2030.

A more recent statewide system that positively impacts the lives of persons with dementia and caregivers is the California Advancing and Innovating Medi-Cal (CalAIM) initiative (2022-2027). Medi-Cal is the state's public health insurance program, which provides health care services for low-income individuals. CalAIM is a multiyear plan designed to transform California's Medi-Cal program.¹⁸ The initiative includes several programs that provide eligible PLWD and their caregivers with services. Enhanced Care Management offers comprehensive care management, and Community Supports offers support services to address health-related social needs. CalAIM additionally ensures that vulnerable members with complex health needs receive coordinated, supportive care aligned with their preferences.⁴⁰

Like other states, California is addressing the workforce issue for older adults and persons with disabilities. California's Health and Human Services Agency (HHS) Workforce for a Healthy California is an interagency investment in expanding and diversifying California's health and human services workforce.⁴¹ The state is equally investing in workforce initiatives like CalGrows to tackle the challenges of recruitment, training, and retention of the paid and unpaid caregiver workforce. Notwithstanding these critical initiatives, there is a dearth of skilled social workers and community professionals to work with PLWD and caregivers to provide advanced practice services (e.g., complex care coordination, assessment, triage). Filling this gap will require innovative education, training solutions, and collaboration.

Dementia Care: Policy, Programs, Training

To identify strategies to utilize community professionals, particularly social workers, more effectively to enhance outcomes for individuals living with dementia and their caregivers, RUSH conducted a comprehensive environmental scan and analysis of the current dementia care landscape. They conducted a thorough literature review following industry research standards to define the research question, methodology, and search terms and identified 45 articles that were relevant to key search topics, i.e., “dementia,” “social worker,” “train,” and “dementia care specialist.” A complementary search of the gray literature and prominent websites such as HRSA, the National Association of Social Workers, and the Council on Social Work Education was also conducted.

The collected information was sorted into three categories: **system efforts and policies** to improve outcomes among PLWD and their caregivers through government policies and system change efforts; **dementia models and programs** that focus on professional and peer roles, training and certification requirements, intervention settings, program impact, and stakeholder perspectives on facilitators and barriers; and **dementia education training programs** currently offered to professionals and paraprofessionals.

Four key findings emerged from the analysis of the collected information.

1. There is an increasing imperative and momentum to focus on people with ADRD and those caring for them in their homes and the community.

The previously highlighted national and California policies and programs addressing Alzheimer's disease and dementia caregiving with increased stakeholder recognition of these issues (examples below) underscore the imperative to address ADRD and caregiving.

Table 4. National and California Stakeholder Recognition of ADRD and Dementia Caregiving

- ▶ [Multisector Plan for Aging \(MPA\)](#) - references blueprints (10+ years) for states outlining plans to create more coordinated and streamlined healthcare, housing, transportation, and support systems to support older adults' ability to live as independently as possible in the setting of their choice. MPAs additionally address issues related to social engagement, healthy living, and social determinants of health.
- ▶ Dementia Communities and other local/state planning
 - [Dementia Capable States and Communities: Lessons Learned from Administration on Aging Grantees](#)
 - [San Francisco's Strategy For Excellence In Dementia Care](#) - first city-level effort
 - [California State Plan for Alzheimer's Disease: Action Plan from 2011-2021](#)
- ▶ [Alliance to Improve Dementia Care](#) and report, [Guiding the Care Journey: Building Dementia Workforce and System Capacity through Care Navigation](#)
- ▶ Philanthropic foundations investing in addressing caregiving issues:
 - Grantmakers in Aging: [Family Caregiving Funders Community](#)
 - [The John A Hartford Foundation](#) - including alignment with Age-Friendly Health Systems
 - [Retirement Research Foundation for Aging](#)

2. Best practice dementia care models and innovative programs use a variety of on-the-ground approaches to implementation and training.

Table 5. Best Practice Dementia Care Programs: Diversity of Approaches

Issues	Key Findings	Supporting Information, Resources, Citations
Staff	▶ Staff have diverse backgrounds	▶ Titles/education requirements vary: RN, social worker (Master of Social Work, Bachelor of Social Work), bachelor's degree, high school graduate
Intervention Focus	▶ Intervention foci vary from program to program: some are narrow in scope, and some are broader	<p>▶ Examples of different intervention foci:</p> <p>▶ Case management activities</p> <ul style="list-style-type: none"> ○ Schiller, C., Gruenzig, M., Heinrich, S., et al. (2022). Case management for people with dementia living at home and their informal caregivers: A scoping review. <i>Health & Social Care in the Community</i>, 30(4), 1233-1253. <p>▶ Dementia-specific navigation</p> <ul style="list-style-type: none"> ○ Anthonisen, G., Luke, A., MacNeill, L., et al. (2023). Patient navigation programs for people with dementia, their caregivers, and members of the care team: a scoping review. <i>JBI Evidence Synthesis</i>, 21(2), 281-325. <p>▶ Behavior management</p> <ul style="list-style-type: none"> ○ Walaszek, A., Schroeder, M., Albrecht, T., et al. (2021). Effectively training dementia care specialists and other dementia professionals on using the DICE Approach™ with caregivers to improve the management of behavioral and psychological symptoms of dementia. <i>Alzheimer's & Dementia</i>, 17. <p>▶ Caregiver stress reduction</p> <ul style="list-style-type: none"> ○ Lee, J. A., Ju, E., Zhang, J., et al. (2022). Culturally and linguistically appropriate home visit intervention for underserved dementia family caregivers: Preliminary results from a randomized controlled trial. <i>Alzheimer's & Dementia</i>, 18: S8. <p>▶ Preventive services (awareness, screening for dementia)</p> <ul style="list-style-type: none"> ○ Alam, R. B., Ashrafi, S. A., Pionke, J. J., et al. (2021). Role of community health workers in addressing dementia: a scoping review and global perspective. <i>Journal of Applied Gerontology</i>, 40(12), 1881-1892.
Setting	▶ Interventions are based out of different settings and have different payer sources	<p>▶ ADRCs</p> <ul style="list-style-type: none"> ○ Felten, K., & Marschall, K. (2018). P3-501: Wisconsin's Dementia Care Specialist Program: Pilot To Program and Beyond. <i>Alzheimer's & Dementia</i>, 14(7S_Part_24), P1314-P1314. <p>▶ Hospices</p> <ul style="list-style-type: none"> ○ Jones, T. M., & Brody, A. A. (2021). Adaptation and piloting for hospice social workers of Aliviado Dementia Care, a Dementia Symptom Management Program. <i>American Journal of Hospice and Palliative Medicine</i>®, 38(5), 452-458. <p>▶ Healthcare and community-based organization partnerships</p> <ul style="list-style-type: none"> ○ Garcia, G., Gosselin, K., & McCarthy, L. (2017). Dementia Care Coordination Program. <i>Alzheimer's & Dementia</i>, 13(7S_Part_9), P490 <p>▶ Health system</p> <ul style="list-style-type: none"> ○ Meyer, H. (2022). In New Orleans, Navigating Dementia With A Guide: <i>Health Affairs</i>. Jun;41(6):782-786. <p>▶ Payers</p> <ul style="list-style-type: none"> ○ Flatt, J. D., Hollister, B., & Chapman, S. A. (2018). Dementia care specialist workforce in California: Role, practice, training, and demand. UCSF Health Workforce Research Center on Long-Term Care.

Issues	Key Findings	Supporting Information, Resources, Citations
Facilitators of Successful Dementia Care Programs	▶ Effective dementia care programs use interdisciplinary teams, shared decision-making, and innovative strategies to deliver services and support to PLWDs and caregivers	<ul style="list-style-type: none"> ▶ Intervention key components <ul style="list-style-type: none"> ○ Backhouse, A., Richards, D. A., McCabe, R., et al. (2017). Stakeholder's perspectives on the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. <i>BMC Health Services Research</i>, 17(1), 1-11. ▶ Shared decision-making and decisional capacity <ul style="list-style-type: none"> ○ Molony, S., & Bouma, R. (2013). The care manager role in person-centered care for people with dementia. <i>Generations</i>, 37(3), 79-82. ▶ Strategies used in interdisciplinary care settings <ul style="list-style-type: none"> ○ Davila, H., O'Malley, K. A., Shin, M. H., et al. (2022). Supporting Veterans with dementia to remain in the community: strategies used in 12 Veterans Health Administration programs. <i>Home Health Care Services Quarterly</i>, 41(2), 149-164. ▶ Interdisciplinary dementia care approach <ul style="list-style-type: none"> ○ Harrison, K. L., Boyd, N., & Ritchie, C. S. (2023). Toward Geroneuropalliative Care for Patients with Dementia. <i>New England Journal of Medicine</i>, 389(9), 775-778.
DCS Leads	▶ Across dementia care programs, different staff successfully serve in the role of DCS lead	<ul style="list-style-type: none"> ▶ Care managers/interventionists perspective <ul style="list-style-type: none"> ○ Kellett, K., Robison, J., McAbee-Sevick, H., et al. (2023). Implementing the Care of Persons with Dementia in their Environments (COPE) intervention in community-based programs: Acceptability and perceived benefit from care managers' and interventionists' perspectives. <i>Gerontologist</i>, 63(1), 28-39. ▶ Positive impact of care navigator role in dementia care <ul style="list-style-type: none"> ○ Bernstein, A., Harrison, K. L., Dulaney, S., et al. (2019). The role of care navigators working with people with dementia and their caregivers. <i>Journal of Alzheimer's Disease</i>, 71(1), 45-55
Dementia Care Trainings	▶ Best-practice dementia care trainings are diverse in structure, setting, approach, and targeted learners	<ul style="list-style-type: none"> ▶ Summary data on trainings <ul style="list-style-type: none"> ○ 28 unique trainings included in inventory support individuals serving in a range of clinical and non-clinical roles ○ 1 of 28 intended for bachelor's in health and human services field and 1 for trainees with master's degree in social work or related field; the rest of the trainings are targeted to user's employment, work history ○ 5 of 28 provide continuing education credits for one or more disciplines; some programs include certification of training ○ Variation in training format (e.g., asynchronous modules, live training, shadowing) and whether there is a demonstration of competency
Outcomes	▶ Comprehensive case management and highly trained teams improve outcomes for PLWD and caregivers	<ul style="list-style-type: none"> ▶ Case management <ul style="list-style-type: none"> ○ Review of 13 randomized controlled trials found improvements in patient symptoms and outcomes, healthcare costs, and caregiver outcomes: Reilly, S., Miranda-Castillo, C., Malouf, R., et al. (2015). Case management approaches to home support for people with dementia. <i>Cochrane Database of Systematic Reviews</i>, (1).

The scan showcases effective dementia care practice programs for PLWD and their caregivers, as well as workforce trainings that new initiatives can build on. No matter the specific setting or workforce, however, it is critical that programs address support services PLWD and caregivers may benefit from, provide the training necessary for team members to apply key knowledge and skills, establish processes for identifying clients and sustaining the program, and finally, provide concrete resources to staff to aid them in carrying out their work (e.g., interpreter services).

3. Research suggests dementia care training should be specific to the role, incorporate opportunities for application, and be defined by quality measures.

Table 6. Elements of High-Quality Dementia Care Training Programs

Key Findings	Supporting Information, Resources, Citations
<p>▶ The literature review revealed that there are 10 characteristics of successful dementia training</p>	<p>Effective dementia care training program characteristics:</p> <ol style="list-style-type: none"> 1. Is relevant and realistic to the role, experience, and practice of learners rather than a one-size-fits-all training program 2. Includes active participation 3. Underpins practice-based learning with theoretical or knowledge-based content 4. Ensures experiential and simulation-based learning includes adequate time for debriefing and discussion 5. Is delivered by an experienced trainer/facilitator who can adapt training to the needs of each group 6. Does not involve reading written materials (paper or Web-based) or in-service learning as the sole teaching method 7. Is of a total duration of 8+ hours with individual training sessions of at least 90 minutes 8. Includes active, small, or large group face-to-face learning either alone or in addition to another learning approach 9. Includes learning activities that support the application of training into practice 10. Provides staff with a structured tool, method or practice guideline to underpin care practice, see, Surr, C. A., Gates, C., Irving, D., et al. (2017). Effective dementia education and training for the health and social care workforce: a systematic review of the literature. <i>Review of Educational Research</i>, 87(5), 966-1002.
<p>▶ Effective dementia care training should utilize a diverse approach with hands-on learning opportunities and address key administrative and implementation components related to service delivery.</p>	<p>▶ Center for Health and Social Care Integration (CHaSCI) promotes a person and family-centered social care model that advances practice change to improve quality of care, health, and health equity; training in the model covers core administrative and implementation components as well as the direct service intervention.</p> <p>▶ Newbould, L., Samsi, K., & Wilberforce, M. (2022). Developing effective workforce training to support the long-term care of older adults: A review of reviews. <i>Health & Social Care in the Community</i>, 30(6), 2202-2217. *This publication informed the training program elements profiled in the training inventory</p>
<p>▶ Requiring healthcare and social service staff who have direct contact with clients who may have or be at risk of developing AD/DRD to complete continuing education (CE) units in dementia indicates high-quality training.</p>	<p>▶ Illinois requires dementia CEs for staff with direct access to clients with AD/ADRD</p> <ul style="list-style-type: none"> ○ Illinois Public Act 100-1074 - Alzheimer’s Services Curriculum ○ Overview of Illinois requirements by healthcare setting <p>▶ Illinois has a CE requirement in Alzheimer’s disease and other dementias for social workers who provide health care services to patients 26 years of age and older, see: Illinois Social Workers CE Requirements</p>

4. Analysis of the literature review and landscape analysis key findings suggest a possible family caregiver-dementia care specialist role for social workers and other community professionals working with PLWD and their caregivers in California.

Dementia care programs and services tend to be tailored to the care setting and needs of PLWD and their caregivers. This patchwork approach creates an opportunity to establish a defined community professional role to fill the current gap in the dementia care workforce for social workers and community professionals with advanced skills in assessment, caregiver education, engagement, intervention, evaluation, advocacy, evidence-based practice, care coordination, and community resources. This role ensures that PLWD and their caregivers with complex needs receive the care they need to maintain an optimal quality of life.

Table 7. DCS Role for Social Workers and Community Professionals in California

Key Findings	Supporting Information, Resources, Citations
<p>▶ Align role with existing systems and initiatives in California.</p>	<p>Systems and initiatives that could benefit from social workers and community professionals trained in family caregiving and dementia care include: *</p> <ul style="list-style-type: none"> ▶ California Caregiver Resource Center System (CRC System) ▶ California Advancing and Innovating Medi-Cal (CalAIM) ▶ Dual Eligible Special Needs Plans in California (D-SNPs) D-SNP dementia policy guide states: "If the member has documented dementia care needs, the interdisciplinary care team must include the member's caregiver and a trained dementia care specialist to the extent possible and as consistent with the member's preferences. Dementia care specialists must be trained in understanding ADRD; symptoms and progression; understanding and managing behaviors and communication problems caused by ADRD; caregiver stress and its management; and community resources for enrollees and caregivers." ▶ Aging, Disability, Resource Connection (ADRCs) ▶ Guiding an Improved Dementia Experience (GUIDE) Model (Federal demonstration model with local pilot sites) ▶ California-based dementia care programs include: <ul style="list-style-type: none"> ○ Care Ecosystem (UCSF) ○ Alzheimer's Los Angeles Dementia Capable Health Systems ○ UCLA Alzheimer's and Dementia Care Program
<p>* Plus, other systems and settings including healthcare settings (hospitals, clinics) and community-based organizations serving PLWD and their caregivers</p>	

Summary Recommendations for California

The landscape analysis suggests that California could improve statewide dementia care by training and utilizing social workers and community professionals more fully to address the complex needs of PLWD and their caregivers. As noted, California has various systems and initiatives currently in place where these professionals could be both effective and influential.

Four training programs emerged from the analysis that could be leveraged to build out a role, structure, and training for these professionals (i.e., they provide training and/or allow for replication of their training materials). The following section profiles each of these programs:

- ▶ Care Ecosystem (UCSF)
- ▶ Wisconsin DCS Program and University of Wisconsin Interprofessional Dementia Caregiving Badge partnership (This program may be of additional relevance to California because it is a statewide program overseen by a state department, the Wisconsin Department of Health Services)
- ▶ Johns Hopkins Dementia Care Specialist Certification Program—based on the Johns Hopkins Maximizing Independence at Home (MIND at Home) Program
- ▶ essentiALZ® – Alzheimer's Association Training and Certification

The program profiles include core skills and knowledge areas covered, targeted audience-professional role, prerequisites, service settings, length of training, structure/format, synchronous/asynchronous format, completion requirements, and demonstration competencies. Because of the physical, emotional, and financial challenges of dementia caregiving, which often grow more complicated over time, particular attention was paid to whether the training programs covered the following topics in the curriculum: elder abuse and neglect, cultural competency/humility, complex care, and crisis interventions.

A download of the full inventory of training programs identified through this environmental scan is available at [CalGrows Environmental Scan Training Inventory](#).



Because there are so many different ways that we could train people. I'm not sure that a single curriculum is going to be the answer. But a compendium of existing curricula that we could offer schools and that could lead to accreditation might be a good way to go.

- Debra Cherry, PhD, Executive Vice President, Alzheimer's Los Angeles

Care Ecosystem Training (University of California San Francisco)

Program	Care Ecosystem Training
Developer	University of California San Francisco (UCSF)
Website	Care Ecosystem (UCSF)
Cost	No charge for training materials; see website for attribution requirements
CEUs	None reported
Dementia Care Model	Care Ecosystem helps address the unmet needs of persons with dementia and their caregivers to improve quality of life, prevent unnecessary hospitalizations, and delay admissions to long-term care institutions. Program provides caregiver support, linkages to community resources, advance care planning, medication support, and care coordination by a multidisciplinary team. Includes an accompanying training program.

Training program features:

▶ Skills covered	<ul style="list-style-type: none"> ▶ Strategies to communicate with persons living with dementia ▶ Screening for dementia, behaviors, and care needs ▶ Identifying abuse, neglect, and exploitation ▶ Providing disease education ▶ Participating in an interprofessional care team ▶ Identifying common medication side effects ▶ Therapeutic interventions to support caregiver well-being ▶ Using DICE model (Describe, Investigate, Create a Care Plan, Evaluate) to manage dementia behaviors ▶ De-escalation of intense emotions ▶ Environmental interventions to manage behaviors ▶ Facilitating advance care planning and end-of-life discussions ▶ Supporting caregivers at end-of-life and during bereavement
▶ Knowledge areas covered	<ul style="list-style-type: none"> ▶ Overview of geriatric syndromes (e.g. dementia, delirium, UTI, syncope) ▶ Cultural considerations ▶ Abuse, neglect, and exploitation ▶ Underlying causes of dementia ▶ Forms of dementia and treatments ▶ Medicare, Medicaid, VA Benefits ▶ Dementia medications ▶ Polypharmacy ▶ Common caregiving experience ▶ Dementia behaviors (e.g., agitation, wandering, resistance to care) ▶ Environmental factors influencing behaviors ▶ Capacity and decision making ▶ Advance directives and end-of-life care ▶ Financial and legal considerations
▶ Targeted audience/ Targeted professional role	▶ Individuals and organizations/care team navigators and other professionals working on the Care Ecosystem team
▶ Pre-requisites	▶ None specified
▶ Service setting	▶ Multiple settings (e.g., hospitals, health care clinics, senior center, memory care clinic)
▶ Length of training	▶ 10 modules (40-90 minutes/module)
▶ Structure/format	▶ Didactic modules with knowledge checks; hybrid with shadowing opportunities
▶ Synchronous/asynchronous	▶ Asynchronous
▶ Completion requirements	▶ Receive a score of 90% or above on all quizzes
▶ Demonstration of competencies	▶ None reported

Wisconsin Dementia Care Specialist Program and University of Wisconsin Interprofessional Dementia Caregiving Badge Partnership

Program	Wisconsin DCS Program and University of Wisconsin Interprofessional Dementia Caregiving Badge Partnership *
Developer	Wisconsin Department of Health Services
Website	Wisconsin DCS Program
Cost	Program replication materials publicly available
CEUs	None reported; dementia care specialist (DCS) training is a condition of the DCS job
Dementia Care Model	Wisconsin’s Dementia Care Specialist Program supports people with dementia and their caregivers to ensure the highest quality of life possible while living at home. Program has three pillars: train staff at ADRCs/municipalities to become dementia-capable, help communities become dementia-friendly, provide education and support to people with memory concerns or dementia, and their families, to allow them to live at home safely. Includes an accompanying training program hosted by the State.

Training program features:

▶ Skills covered	▶ How to assess for communication and behavioral changes ▶ How to recognize someone who has dementia ▶ How to interact with someone who has dementia ▶ Identify and implement strategies to create and sustain dementia-friendly communities
▶ Knowledge areas covered	▶ Definition of dementia ▶ Different types of dementia, including mild cognitive impairment ▶ Basic demographic data about dementia and population level information ▶ Disparities in dementia prevalence ▶ General stages of dementia ▶ Brain changes in dementia ▶ Common symptoms of Alzheimer’s disease and related dementias ▶ Needs of caregivers ▶ Needs of a person with dementia ▶ Importance of screening and diagnosis and diagnostic process with a focus on early diagnosis ▶ Normal aging versus dementia ▶ Conditions that mimic dementia ▶ Brain health, dementia risk factors, and prevention ▶ Safety at home or in another environment
▶ Targeted audience/ targeted professional role	▶ Wisconsin Department of Health Services staff serving in the DCS role/ DCS staffing ADRCs
▶ Pre-requisites	▶ BA in health and human services related field; master’s degree preferred
▶ Service setting	▶ Wisconsin ADRCs in each of the state’s 72 counties
▶ Length of training	▶ Unavailable
▶ Structure/format	▶ Virtual and in-person
▶ Synchronous/asynchronous	▶ Unavailable
▶ Completion requirements	▶ Unavailable
▶ Demonstration of competencies	▶ Unavailable

*The Interprofessional Practice Learning (IPL) Dementia Caregiving Badge is a Telehealth Interprofessional Community Placement partnership with the Wisconsin Department of Health Services to educate University of Wisconsin health and social care professional students to learn and work collaboratively with each other and with caregivers of people living with dementia.

Johns Hopkins Dementia Care Specialist Certification Program

Program	Johns Hopkins Dementia Care Specialist Certification Program (based on the Johns Hopkins Maximizing Independence at Home (MIND at Home) *)
Developer	Johns Hopkins University (JHU)
Website	MIND at Home
Cost	Costs unknown; copyright restrictions
CEUs	None reported; dementia care specialist (DCS) training is a condition of the DCS job
Dementia Care Model	MIND at Home is a comprehensive, home-based care coordination intervention for people with ADRD who live in the community and for their family caregivers; program assesses and helps address unmet needs that may be barriers to persons with dementia remaining in their home, while maintaining their health and well-being and that of their caregiver. Includes a training program for staff implementation.

Training program features:

▶ Skills covered	<p>Program has three tiers</p> <ul style="list-style-type: none"> ▶ Tier 1: Diagnosing dementia; assessing home and personal safety ▶ Tier 2: Application of knowledge and skills from previous tiers ▶ Tier 3: Live instructor-led course includes targeted didactic presentations with case-based learning techniques with small group breakouts and large group discussions to apply knowledge from Tier 1 and Tier 2 courses
▶ Knowledge areas covered	<p><u>Tier 1:</u></p> <ul style="list-style-type: none"> ▶ Module 1: Causes, Symptoms, and Risk Factors for Alzheimer’s Disease and Related Dementias ▶ Module 2: Diagnosing Dementia including use of Validated Cognitive Screening Tools ▶ Module 3: Best Practices for Managing Dementia and Associated Behaviors ▶ Module 4: Health Care Needs and Navigating Care Transitions ▶ Module 5: Assessing and Addressing Home and Personal Safety ▶ Module 6: Supporting Caregivers and Connecting to Community Resources <p><u>Tier 2:</u></p> <ul style="list-style-type: none"> ▶ Module 1: Health Disparities in Screening, Diagnosis, and Treatment ▶ Module 2: Strategies for Managing Challenging Behaviors ▶ Module 3: Working with Dementia Caregivers ▶ Module 4: Person-Centered Care Planning <p><u>Tier 3: (Covers abuse, neglect, and crisis intervention)</u></p> <ul style="list-style-type: none"> ▶ Live instructor-led course contingent on completing Tiers 1 and 2 ▶ Cognitive Screening Tools and Skills for Assessing Cognition ▶ Skills Application: Performing MOCA-Blind/Telephone Version and Scoring ▶ Case Discussion: Addressing and Problem-Solving Challenging Behaviors ▶ Skills Application: Cognitive Screening and Behavioral Assessment ▶ Supporting Caregivers ▶ Care Planning in Dementia ▶ Skills Application: Developing Problem Care Plan with SMART Goals ▶ Practical Tips for Common Issues ▶ Skills Application: Developing Initial Care Plan ▶ Skills Application: Revising the Care Plan
▶ Targeted audience/targeted professional role	▶ Case managers, nurses, behavioral health, community health workers, social workers, physicians, allied health professionals
▶ Pre-requisites	▶ None specified
▶ Service setting	▶ Managed care health plans, primary care, and home health care

▶ Length of training	▶ Tier 1 three-hour course with six modules; Tier 2 three-hour course with four modules; Tier 3 eight-hour live instructor-led course
▶ Structure/format	▶ Elearning and in-person includes videos, problem-based scenarios, case studies, knowledge checks activities to apply concepts and knowledge learned
▶ Synchronous/asynchronous	▶ Asynchronous Tier 1; synchronous for Tiers 2 and 3
▶ Completion requirements	▶ Must complete
▶ Demonstration of competencies	▶ Includes pre- and post-knowledge tests

* Upon conclusion of the Tier 1 elearning course, learners will obtain a certificate of completion. Learners who complete Tier 1 will then be able to enroll in the Tier 2 elearning course; learners who complete Tier 2 course can enroll in Tier 3 live instructor-led course. Learners who complete all three tiers will receive certification of training program completion by JHU.



When dementia hits, there are multiple domains of cognition affected. Teaching that to staff serving caregivers is essential. Staff also need to know about the diversity of neurodegenerative diseases; they are not all the same. They need to know how this particular disease impacts this individual’s functioning and the caregiver. If our staff take standardized training and get on-the-ground experience with supervision, they will be in a much better position to assess the caregiver, develop an appropriate care plan, offer tailored education and training, and direct the caregiver back to the care recipient’s medical provider to ask their medical questions with confidence.

- Nancy Powers-Stone, Director, Redwood Caregiver Resource Center

essentiALZ[®] — Alzheimer’s Association Training and Certification

Program essentiALZ[®] — Alzheimer's Association Training and Certification

Developer Alzheimer's Association

Website [essentiALZ[®] — Alzheimer's Association Training and Certification](#)

Cost \$59.99/person; up to 62% off for group purchases

CEUs 3.5 CEUs

Dementia Care Model **essentiALZ training and certification program**, developed with evidence from the Dementia Care Practice Recommendations (practice recommendations developed for professional care providers who work with PLWD and families in long-term and community-based care settings), educates professional care workers on current evidence-based, person-centered practices to care for individuals living with dementia.

Training program features:

▶ Skills covered	▶ Educate PLWD and caregivers on dementia ▶ Creating person-centered care plans ▶ Conducting assessments ▶ Discussing/teaching strategies to adapt activities of daily living ▶ Communicating with PLWD
▶ Knowledge areas covered	▶ Basics of Alzheimer’s and dementia ▶ Person-centered care ▶ Assessment and care planning ▶ ADLs and IADLs ▶ Communication changes and dementia-related behavior ▶ Normal cognitive aging vs. dementia ▶ Components of person-centered care plans and interdisciplinary teams ▶ Assessment tools
▶ Targeted audience/targeted professional role	▶ Individuals/organizations/Social workers, nurses, psychologists
▶ Pre-requisites	▶ None reported
▶ Service setting	▶ Managed care health plans, primary care, and home health care
▶ Length of training	▶ 3 hours (self-paced)
▶ Structure/format	▶ Didactic modules with interactive components/virtual
▶ Synchronous/asynchronous	▶ Asynchronous
▶ Completion requirements	▶ Receive a score of 90% or above on final exam
▶ Demonstration of competencies	▶ Post-knowledge tests

Utilizing Social Workers in the California Dementia Care Workforce

The environmental scan provided a rich historical and present-day frame for understanding national and California-based ADRD, family caregiving, and dementia care workforce policies and programs. It also highlighted high-quality dementia care models, best-practice dementia care training programs, and multiple interpretations of the dementia care specialist role. Although the research did not find training programs specifically designed for social workers, it did underscore opportunities where this hidden workforce, if trained in family and dementia care, could be an asset to existing California service systems and settings.

To assess this possibility more explicitly, the CalGrows project team conducted the following: an internet search of gerontology courses and programs currently offered in California schools of social work; interviews with experts in dementia, caregiving, and dementia care specialist programs around the country; and a roundtable discussion with California thought leaders with expertise in dementia and caregiving, to discuss their feedback on a possible specialized family and dementia care role for social workers and community professionals.

California Schools of Social Work: Aging Curriculum Focus

The internet-based search of gerontology courses and programs offered by California's 26 accredited Master of Social Work (MSW) programs revealed the following (findings should be considered approximations):⁴²

- ▶ Five schools offer or are affiliated with programs that offer a specialization, concentration, certificate, or joint master's degree in gerontology/aging, e.g., *Adulthood and Aging Specialization*, California State University, Long Beach; *Aging and Health Graduate Certificate*, University of Southern California.
- ▶ Eight additional schools offer aging-specific courses, e.g., *Social Work Practice with Older Adults*; *Elder Abuse: Policy & Practice with Older Adults & Their Families*; *Aging: A Multigenerational Perspective—Advanced Social Work Practice*; *Aging, A Multi-Generational Perspective—Policy and Social Work*.
- ▶ Three schools are affiliated with gerontology programs for undergraduates, e.g., *Gerontology Program*, California State University, Fresno; *Applied Gerontology Institute*, California State University, Los Angeles; *Gerontology Interdisciplinary Minor at the University of California*, Los Angeles.



There is an opportunity for clinical social workers as well, as undergrad and graduate students pursuing a Master's or Bachelor of Social Work to have access to specialized family and dementia care training, but we should also look at professionals working in public health or behavioral health as candidates for this training. It will take a multi-faceted team to do this work.

- Norell Wheeler, MPH, MBH, Family Consultant, Family Caregiver Alliance

The California Board of Behavioral Sciences (BBS) requires that MSWs registering to become an Associate Clinical Social Worker must have 10 hours of Aging, Long Term Care, and Elder/Dependent Adult Abuse coursework before gaining experience hours that count toward licensure. Most accredited California schools of social work include these topics in mandatory generalist practice courses. Perhaps as a result, very few offer distinct aging courses, programs, or concentrations. This finding is corroborated by a recent survey of California schools of social work conducted by the California Social Work Education Center (CalSWEC), the country's largest social work workforce development center.⁴³

What the Experts Say

Individual and group interviews with twenty experts in dementia and dementia care models, family caregiving, and workforce training, and a subsequent roundtable discussion with a group of California thought leaders with expertise in these subjects, provided nuanced information about different ways to think about and address the three converging trends, and the opportunity for social workers to assume a more specialized role in California's dementia care workforce. Three recommendations emerged from the discussions and convening.

1. Addressing the converging trends will require zooming out from just a health and social service framing of the challenge to a bigger-picture perspective that includes multiple sectors and creative, solution-driven thinking.

- ▶ Those sectors should include education (K-12, community colleges, colleges, and universities), first responders, law enforcement, legal, workforce development agencies, and others. The national movement of multi-sector plans on aging and California's Master Plan for Aging are examples of opportunities to engage these diverse perspectives.
- ▶ The bigger picture perspective must also include the racially and ethnically diverse communities that make up each sector (including newer immigrant communities, e.g., Afro-Caribbean, East African), and rural communities.

2. California would benefit from social workers and other community professionals with specialized training in dementia and family dynamics to work with PLWD and family caregivers—they bring advanced skills in assessment, engagement, intervention, evaluation, advocacy, evidence-based practice, care coordination, and community resources.

- ▶ The draft name for this role is Family and Dementia Care Consultant (FDCC). The moniker does not compete with Dementia Care Specialist (DCS), which can refer to people with a range of professional backgrounds, e.g., medical providers, social workers, or community health workers. FDCCs would specifically address current gaps in caregiving services that include complex care coordination, care planning, assessment and triage, crisis response, education and training, and community referrals.
- ▶ In settings and programs using interdisciplinary teams, FDCCs may assume additional management responsibilities, e.g., supervising community health workers/care navigators and coordinating and facilitating family meetings.

3. **Creating and sustaining an FDCC role for social workers and community professionals in California will require a standardized training curriculum, ideally with certification, and multiple pathways for eligible groups to access the training.** These groups include students pursuing graduate or undergraduate degrees in social work (MSW or BSW) or related fields and individuals with an MSW or graduate degree in a related field or a BSW or other undergraduate degree and relevant work experience. Because CalSWEC works with California universities, colleges, schools of social work, and other partners to prepare a diverse group of social workers for careers in multiple fields, including aging, they were identified as a critical partner to help develop, implement, and sustain a possible FDCC training program. Potential pathways for the FDCC training in California include:
- ▶ Schools of Social Work
 - ▶ Undergraduate colleges and universities
 - ▶ Community programs (e.g., CRCs, ADRCs, Alzheimer’s Association, Alzheimer’s Los Angeles)

Interviewees and roundtable discussants highlighted two California-based dementia care programs that could further inform the development of the FDCC training.

- ▶ Alzheimer’s Los Angeles has provided advanced-level dementia care specialist (DCS) training for care managers at health plans and healthcare organizations for many years. The DCS Training aims to improve the dementia capacity of the plan or organization by creating specialists with dementia expertise who can advise and guide organization staff, support health plan members and families, and promote evidence-based assessments and best-practice care plans.⁴⁴
- ▶ CalZ Connect is a dementia-capable home and community-based services system pilot for PLWD and their caregivers. The pilot is implemented in three California counties in designated or developing ADRCs that use a no-wrong-door approach. In addition to the ADRCs, project partners include CDA, Partners in Care Foundation, and Alzheimer’s Los Angeles. Care Team Navigators (CTNs) are the primary staff working with PLWD and caregiver dyads. They provide specialized dementia education and assist the dyad with developing a care plan, connecting to community services, and making care transitions. The dementia care model for the pilot is the Care Ecosystem in a community setting.



I think the credentialing piece is obviously very important professionally. But I also think we need to be mindful that this group of individuals [FDCCs] has what I often refer to as a gift of presence—an ability to empathize with people, meet them where they are, and be sensitive to people of color and folks of various backgrounds.

- Cynthia Carter Perrilliat, MPA, Executive Director, AC Care Alliance (ACCA)

Conclusion

California has the potential to invest in and support social workers and other community professionals as critical members of the dementia-capable workforce. The project's environmental scan and interviews with field experts and California thought leaders support this conclusion. A recommended next step is for CDA to review the viability of developing and sponsoring an FDCC training and certification program pilot and identify possible partners to help develop the pilot (e.g., CDSS, CalSWEC, CRCs, and ADRCs). Each of these partners is vital to raising awareness about and bringing more social workers and community professionals into the FDCC role. As such, the pilot should be considered a starting point.

The success of the FDCC training pilot and program will depend on following the best practices recommended in this report and collaborating across various sectors such as public, healthcare, nonprofit, and academia. It will require multiple training pathways and a curriculum emphasizing cultural competency and humility. Finally, to ensure program sustainability, the training must incorporate *as-needed* content and format changes to equip trainees with the necessary skills and competencies to work in an evolving field.

The following table illustrates how individuals eligible for the FDCC training could access various training pathways. The accompanying job description outlines the FDCC role.



	Stefan	Madison	Amaya	Louisa
Education	Second year student in MSW program	Undergraduate (Junior)	Has a Master of Public Health (MPH) degree	Has a Bachelor of Arts (BA) in humanities
Experience	Prior to graduate school, worked in a program for high-risk youth; completed first year field placement hospital-based dementia clinic	Primary caregiver to grandmother with dementia for the past three years	Working as a public health educator in a county public health department or other public agency program (e.g., department of aging, social services)	Working as a program assistant at an adult day program; assists participants and family caregivers with activities, resources, family meetings
Professional Goal	Interested in the field of dementia and family care and pursuing his clinical license	Interested in gaining more skills and competencies in dementia care and family caregiving	Interested in transitioning to a position that works more directly with clients and their caregivers struggling with dementia	Interested in gaining more skills and competencies in dementia care and family caregiving
Preferred Setting for FDCC Role	Hospital, clinic, home health agency as member of an interdisciplinary team	Community program serving older adults and family caregivers (e.g., CRCs, ADRCs, program)	Public health or other public agency program serving older adults and family caregivers	Community programs serving older adults and family caregivers (e.g., CRCs, ADRCs, adult day, Alzheimer's program)
Training Pathway	School of Social Work sponsored FDCC training and certification	Undergraduate program in aging that offers FDCC training and certification	Community program offering FDCC training and certification	Community programs offering FDCC training and certification

Vector Sources: [Venngage](#) and [Vecteezy](#)

Family and Dementia Care Consultant: Job Description

Moniker

Family and Dementia Care Consultant (FDCC)

Role

FDCC works with persons living with dementia (PLWD) and their family caregivers, providing services that may include assessment, triage, complex care coordination, care planning, crisis response, education and training, family meeting facilitation, and community referrals.

Setting

FDCCs would assume a primary role in community-based organizations and health care settings, working with family caregivers and PLWD (examples below).

- ▶ Adult day care services
- ▶ California Aging and Disability Resource Connection (ADRCs)
- ▶ California Caregiver Resource Centers (CRCs)
- ▶ Community-based organizations (CBOs)
- ▶ Dual Eligible Special Needs Plans (D-SNPs)
- ▶ Hospitals, specialty clinics, community health centers
- ▶ Medi-Cal managed care health plans (MCPs)—including Enhanced Care Management, Community Supports
- ▶ County agency/department
- ▶ Residential Care Facilities
- ▶ Skilled Nursing Facilities

Background/Qualifications

Core qualifications to pursue the FDCC role include:

- ▶ A Bachelor of Arts or Science degree is required, preferably in the health or human services-related field; a master's degree in social work or a related field is preferred.
- ▶ Relevant work background.
- ▶ Completed FDCC training (see below).
- ▶ Ability to provide culturally responsive services and supports.

Organizations employing an FDCC are expected to outline additional qualifications, as well as specific job duties and responsibilities unique to the organization and setting.

Training

A comprehensive FDCC training would include in-depth education addressing core areas related to dementia, dementia care, caregiving, and family dynamics. The training may include additional requirements such as live training, shadowing, and case consultation; the curriculum could be modeled on suggested training through Care Ecosystem, MIND at Home, Wisconsin's DCS Program, and essentiALZ® – Alzheimer's Association Training and Certification Program.

- ▶ Training Length/Structure (Online/Virtual)/Certification: TBD
- ▶ Training Partner(s): CDA, CDSS, CalSWEC, CRCs, ADRCs, Others
- ▶ Incentives: TBD (May include stipends or student loan forgiveness).

Expert Interviewees and Roundtable Participants

Expert Interviewees

Natasha Boissier, LCSW, Elder Care Counselor, University Health Services at UC Berkeley

Debra L. Cherry, PhD, Executive Vice President, Alzheimer's Los Angeles; **Jennifer Schlesinger**, MPH, CHES, Vice President, Healthcare Services & Professional Training, Alzheimer's Los Angeles

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Kelly Dearman, Executive Director, San Francisco Department of Disability and Aging Services, San Francisco Human Services Agency

Sarah Dulaney, RN, MS, CNS, Clinical Director, Care Ecosystem Study, Clinical Nurse Specialist, Memory and Aging Center, University of California, San Francisco

Elizabeth Edgerly PhD, Executive Director & Regional Leader at Alzheimer's Association of Northern California and Northern Nevada

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Nancy Powers-Stone, MA, Director, Redwood Caregiver Resource Center

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