LOS ANGELES CAREGIVER LANDSCAPE ANALYSIS

CREATING A MORE INCLUSIVE AND RESPONSIVE SERVICE SYSTEM FOR LOS ANGELES FAMILY CAREGIVERS

AUGUST 2022

Acknowledgements

We would like to thank the many individuals who generously shared their time, expertise, and passion for improving the lives of family caregivers in Los Angeles County for this analysis. Their valuable insights, experiences, and recommendations broadened the lens of what is needed to provide comprehensive, culturally relevant, services and supports to family caregivers.

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LifeCourse Strategies conducted the Los Angeles Caregiver Landscape Analysis. LifeCourse Strategies is a health care consulting firm specializing in project management, community-based research, gap analyses, and strategic planning for health and social service organizations serving vulnerable and underserved communities. www.lifecourse-strategies.com

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EXECUTIVE SUMMARY

Family caregivers are spouses, partners, families of choice, adult children, siblings, neighbors, and friends. They are diverse with respect to age, racial and ethnic background, the condition of their care recipient, and caregiving arrangement, but surprisingly cohesive with respect to needs. Most want **accessible and affordable respite care in- and outside-the-home**, **education and training**, and **support**. These needs are greater for family caregivers providing care to persons from diverse and underserved communities and those with Alzheimer's disease and related dementias (ADRD).

> ***"Every step of the way caring for my wife for the last 10 years, I have had to fight, fight, fight to get social security and support. This [Alzheimer' disease] happened to my wife before her 56th birthday. She worked all her life. I'm a fighter but that is gone. All the fight is out of me now."***
>
> ***– Caregiver***

To support the development of a countywide ADRD strategic plan that addresses policy, systems, and environmental changes, in 2021, the Los Angeles Department of Public Health helped to launch the three-year Los Angeles County Building Our Largest Dementia Infrastructure for Alzheimer's Act Initiative (LA BOLD). The University of Southern California Family Caregiver Support Center (USC FCSC) assumed oversight of the Los Angeles Caregiver Landscape Analysis, a critical part of the initiative. The goal of the analysis is to identify, understand, and respond to the diverse needs of family caregivers in Los Angeles County (LAC) with a set of actionable recommendations.

To meet this project goal, LifeCourse Strategies, the health care consulting firm selected to perform the Los Angeles Caregiver Landscape Analysis, conducted the following:

> ***"A lot of individuals do not identify as caregivers because they are family members taking care of their families. As a Cuban Latina, you don't associate the job of a caregiver with caring for your parent, because it's almost kind of like a cultural given that you do that. I'm my mother's daughter. That's my job."***
>
> ***– Caregiver/service provider***

- Review of secondary caregiver data from the California Health Interview Survey-LAC and the California Caregiver Resource Center System CareNav™-FCSC.
- Survey of community-based organizations to assess the range of available caregiver services and corresponding gaps.
- Semi-structured interviews with leading LAC caregiver stakeholders.
- Focus groups with Los Angeles family caregivers.
- Environmental scan of caregiver best practice models that could be used or expanded in Los Angeles.

Key Analysis Recommendations^

Recommendation #1	Leverage existing infrastructure to strengthen and build family caregiver services and supports.

- **Form a single countywide collaborative comprised of leading caregiver stakeholders, including organizations representing Los Angeles's ethnically diverse communities.**
    - Explore opportunities to streamline the current array of information and assistance programs serving Los Angeles family caregivers into a coordinated system with multiple access points.
    - Build on existing caregiver best-practices in LAC: Ayudando a Quien Ayuda™ program and Alzheimer's Los Angeles Dementia Care Network El Portal Project[€] to address the needs of historically marginalized and underserved communities.
    - Launch a countywide caregiver education and marketing plan targeting family caregivers who don't self-identify as caregivers—help them to recognize themselves as caregivers and to reach out for information and support.
- **Partner with senior centers, libraries, and community parks to increase caregiver access to caregiver information, services, and supports in their communities.**

Recommendation #2	Promote health care payer, provider, and system recognition of and support for family caregivers.

- **Advocate for health insurance plans (public and private) assessing and providing benefits to caregivers of individuals with serious illness, including ADRD.**
    - Promote the use of a standardized caregiver assessment by health plans and providers.
- **Encourage health care providers to develop partnerships with family caregivers.**
- **Partner with community organizations and allied health professionals in the community to better support family caregivers.**
- **Promote hospital adherence to the Caregiver Advise, Record, Enable (CARE) Act and make "family caregivers" a searchable field in electronic medical records (EMR).**

Recommendation #3	Increase respite services for caregivers.

- **Increase access to in- and out-of-home respite care.**
    - Increase the number of in-and out-of-home respite services and grants for low and middle-income caregivers.
    - Address common barriers to accessing out-of-home respite, specifically adult day services (ADS).

^Note: It is recommended that the Los Angeles Department of Public Health in partnership with key caregiver stakeholders identify the lead(s) to implement each of these recommendations.

[€] Alzheimer's Los Angeles was the lead entity in the development of El Portal and subsequent Dementia Care Networks model serving Latino, African American, and Asian American communities in Los Angeles County and beyond.

BACKGROUND

The long-predicted longevity revolution has arrived. In the last half of the 20th century, leaders in sociology and health care began documenting dramatic aging trend lines in the United States and other countries. In addition to writing about data portending increased life expectancy, the group wrote about the potential impact this demographic shift would have on society.[1,2] Dire prognostications ranged from increased ageism, intergenerational conflict, and an economy turned upside down, to large numbers of older adults living in poverty. Sanguine predictions highlighted medical breakthroughs with the potential to significantly expand life expectancies, and opportunities for seniors to find deeper purpose in life, engage in positive intergenerational collaborations, and "give back" as community volunteers. What was missing from these publications was recognition of the unprecedented change that longer life expectancy would have on family members.

Family caregivers matter

Buoyed by medicine and technology innovations, people are living longer with serious illness and disabilities, including Alzheimer's disease and related dementias (ADRD). As a result, the number of family caregivers in all 50 states has increased. In 2015, family caregivers comprised 16.6% of the adult population in the United States, today it is 19.2%.[3] In 2017, approximately 41 million family caregivers in the United States provided an estimated 34 billion hours of uncompensated care to an adult with functional limitations. The estimated economic value of this care was $470 billion.[4] Several other economic aspects of caregiving to note include the tremendous number of workers who leave the workforce each year to care for loved ones—a dynamic amplified by the COVID-19 pandemic—and the rising amount of out-of-pocket costs caregivers spend each year. The annual average amount caregivers spend is $7,242; however, Hispanic/Latino and Black/African American caregivers experience higher financial strain than White and Asian American caregivers.[5]

DEMENTIA

Dementia is an umbrella term for a group of symptoms that typically include disruptions in cognition that affect individuals' 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.

Caregivers and caregiving arrangements are as diverse as the people who provide care. They are young adults who range from Generation Z and Millennials to middle-agers to older adults. They are spouses, partners, families of choice, adult children, siblings, and friends. They represent every racial and ethnic group and live in communities across the country. Some live with the care recipient, some live in a neighboring region, some live in a different state. Caregivers assist loved ones with a variety of tasks from activities of daily living (ADLs)—eating, bathing, dressing, toileting—to instrumental activities of daily living (IADLs)—shopping, preparing meals, paying bills, cleaning. A growing number of caregivers perform complex medical/nursing tasks, such as administering medications (including injections), wound care, and managing medical equipment.

Given the extent of caregiver duties and responsibilities that many family caregivers have, caregiving is often stressful—emotionally, physically, and financially. Moreover, it is not uncommon for caregivers to report stepping into their caregiver role feeling unprepared and unsure of where to go for information, services, and supports.[4] Dementia caregivers report higher levels of stress and negative effects on their health, employment, income, and financial security than their non-dementia caregiver counterparts. This difference is attributed to the intensity of care they provide, from extensive assistance with ADLs, to managing challenging behaviors, to constant supervision.[6]

Passage of the National Family Caregiver Support Act by Congress in 2000 authorized federal grants to states to help family members care for an older adult at home. The legislation was a bold first step in nationally recognizing and responding to family caregivers. Twenty plus years later, not only are more people providing care today, older adults and people with disabilities prefer to remain in their homes and communities, in lieu of institutions, for as long as possible. These trends and the myriad personal and societal costs of caring for individuals with Alzheimer's and other serious health conditions, signal that a "next" national step to address caregiver needs is required.

California's continuing focus on family caregivers

As the most populous state in the nation, California passed innovative legislation in 1984 authorizing the development and funding of a statewide system of Caregiver Resource Centers (CRCs): Chapter 1658, Statutes of 1984, "The Comprehensive Act for Families and Caregivers of Brain-Impaired Adults." Today, California has 11 CRCs throughout the state committed to serving family caregivers of adults (aged 18 years and older) affected by chronic and debilitating health conditions, including neurodegenerative diseases, such as Alzheimer's disease, Parkinson's disease, Huntington's disease, and multiple sclerosis; cerebrovascular diseases; traumatic brain injury; and other serious illnesses. The CRC system provides a wide range of free and low-cost services to California caregivers, from information and caregiver assessment to family consultation and respite.

In recent years, policies supporting family caregivers have been integrated into several leading strategic roadmaps for California. In 2018, the California Task Force on Caregiving produced the report, *Picking Up the Pace of Change in California*. The report submitted seven policy recommendations to the California Legislature to support the health and financial well-being of family caregivers and equip the state with the tools it needs to increase affordable and accessible services. Several years later, the state addressed family caregivers in the 2021 California Master Plan for Aging. The plan includes a caregiver goal and several supporting strategies.[7]

Acknowledgement of and engagement with family caregivers are also part of the recently implemented CalAIM (California Advancing and Innovating Medi-Cal) care delivery and payment reform initiative.[8] The multi-year initiative designed to improve health equity, quality of care, and well-being for California Medicaid (Medi-Cal) enrollees, includes assessing and responding to caregiver needs. CalAIM's Enhanced Care Management (ECM) program requires contracted providers to include caregivers in ECM members' person-centered care plans, regularly check-in with caregivers; and provide culturally and linguistically appropriate education and care coordination.[9] In CalAIM's Community Supports program, respite services in the form of "short-term services aimed at providing relief to caregivers of those who require occasional or temporary assistance or supervision" is one of 14 preapproved supports. Respite gives caregivers of a loved one with dementia or complex care needs a much-needed break from caregiving responsibilities.

LA BOLD and Los Angeles's diverse family caregivers

Efforts to understand and increase support for family caregivers throughout the state are complemented by county-level assessments of caregiver needs, largely performed by local Area Agencies on Aging (AAAs). Because the number of Californians living with Alzheimer's disease is expected to increase from 660,000 in 2019 to 1.5 million in 2040, every county in the state is facing the pressing need to prepare for this expanding population.[10] Aided by state and federal grants, public and nonprofit organizations are increasingly working together to expand public awareness of dementia and dementia services, so individuals with ADRD and their family caregivers—especially communities of color and women—are supported. Los Angeles is one of these counties.

The Los Angeles County Building Our Largest Dementia Infrastructure for Alzheimer's Act Initiative (LA BOLD) is led by the Division of Chronic Disease and Injury Prevention at the Los Angeles County Department of Public Health (DPH). Launched in 2021, the primary goal of this three-year collaborative-driven initiative is to support the development of a countywide ADRD strategic plan that addresses policy, systems, and environmental changes. Because family caregivers provide critical and essential care for individuals with ADRD, the University of Southern California Los Angeles Family Caregiver Support Center ("FCSC") and Los Angeles Caregiver Resource Center provided oversight for a critical component of LA BOLD: the Los Angeles Caregiver Landscape Analysis. The purpose of this analysis is to identify, understand, and respond to the diverse needs of family caregivers in LAC, many of whom are caring for individuals with ADRD, with a set of actionable recommendations.

Los Angeles caregiver landscape analysis

A combination of primary and secondary research practices was used in this analysis. Key caregiver and care recipient data from the California Health Interview Survey (CHIS) Los Angeles and FCSC CareNav™ System were reviewed. Semi-structured interviews with 12 leading LAC caregiver stakeholders —providers, advocates, policymakers—and two focus groups with family caregivers were conducted to understand the diversity of caregiver needs and opportunities to meet them. To understand the range of available caregiver services and corresponding gaps, an online survey was sent to 43 community-based organizations assisting family caregivers, 20 organizations completed the survey. An environmental scan of caregiver best practices that could be used or expanded in Los Angeles was conducted: four promising models emerged and are profiled. Last, analysis of the major findings from each of these components informed this report's final recommendations.

LOS ANGELES FAMILY CAREGIVER DATA

An estimated 1.6 million adults provided care to individuals aged 18 years or older, in Los Angeles County in 2019-2020, approximately 1 in 5 adults.[11] To gain a deeper understanding of the socio-demographic characteristics and health status of family caregivers in LAC, two data sources were used in this analysis: CareNav™ FCSC and the California Health Interview Survey (CHIS) LAC. CareNav™ is the online data system used by California's 11 Caregiver Resource Centers (CRCs), including FCSC. CareNav™ serves as a repository for caregiver data collected through a standardized intake procedure and a uniform caregiver assessment, as well as an online platform for caregivers to receive specialized information and communicate with CRC staff. Data from 531 unduplicated FCSC caregivers (all of these caregivers reside in LAC) who completed assessments in 2020-2021 were analyzed.

CHIS is the largest state health survey in the nation. Disseminated on a continuous basis through web and phone surveys, CHIS provides a nuanced picture of the health and health care needs of Californians. CHIS is conducted by the UCLA Center for Health Policy Research in collaboration with the California Department of Public Health and the Department of Health Care Services. Among the 21,941 adult respondents who voluntarily participated in the CHIS in 2020, 5,362 reported providing care for a family member or friend aged 18 years or older in the last 12 months. Of these, 1,049 were LAC residents. Data from this subgroup of survey caregiver respondents were analyzed.

Selected variables and figures from the two datasets follow those presented by the UC Davis Family Caregiving Institute in their evaluation of the CRC system.[12] An accompanying data chartbook, *Los Angeles Caregiver Landscape Analysis Data Chartbook,* includes tables of the CareNav™ FCSC ("FCSC") 2020-2021 and 2020 CHIS LAC caregiver data. Reported percentages in figures and tables reflect the percentage of the total number for each variable excluding missing values.

Caregiver population comparisons

Socio-demographic differences among LAC caregivers are captured in the two different datasets: FCSC and CHIS LAC. While most caregivers in both datasets are married women, more FCSC

Figure 1: Caregiver Age

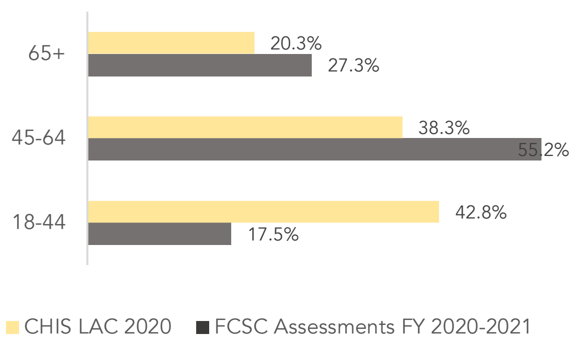
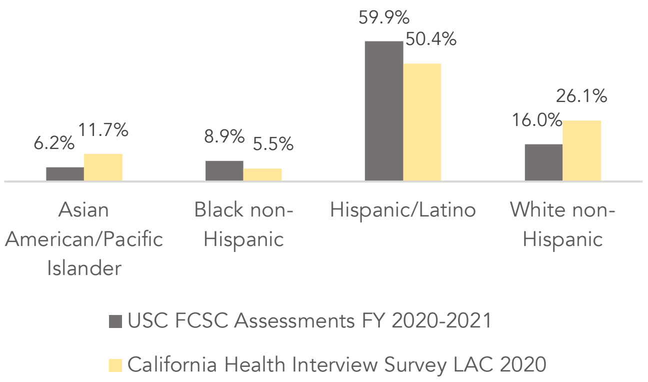


Figure 2: Caregiver Race/Ethnicity



caregivers are in the age group 45-64 than CHIS LAC caregivers (55% vs. 38% CHIS LAC), Figure 1, and a greater percentage of the former are Latino and Black/African American compared to CHIS LAC Caregivers (60% vs. 50% CHIS LAC and 9% vs. 6% CHIS LAC), Figure 2.

More than half of caregivers (55%) served by FCSC reported their employment status as "On Leave, Unemployed, Retired," compared to slightly more than a third of CHIS LAC caregivers (35%). Moreover, 36% of FCSC caregivers reported earnings below the Federal Poverty (FPL) compared to 15% for CHIS LAC caregivers.

Employment Status

More than half of caregivers receiving services from FCSC reported their employment status as "On leave, unemployed, or retired," versus a third of CHIS caregiver respondents.

Living Below Federal Poverty Line

35% of FCSC caregivers report earnings below the Federal Poverty Line (FPL) compared to 15% for CHIS LAC caregivers.

Analysis of caregiving characteristics data for FCSC and CHIS LAC reveal that most LAC caregivers are an adult child; however, 28% of FCSC caregivers are a spouse or partner compared to 13% of CHIS LAC caregivers. Other key differences between FCSC and CHIS LAC caregivers are notable. For hours per week caregiving, most CHIS LAC caregivers reported less than 10 hours per week (57%) while the majority of FCSC caregivers (68%) reported 40 or more hours per week (Figure 3). FCSC data additionally show a higher percentage of care recipients have ADRD, compared to CHIS LAC 39% vs. 22% (Figure 4).

Figure 3: Hours Spent Caregiving Per Week

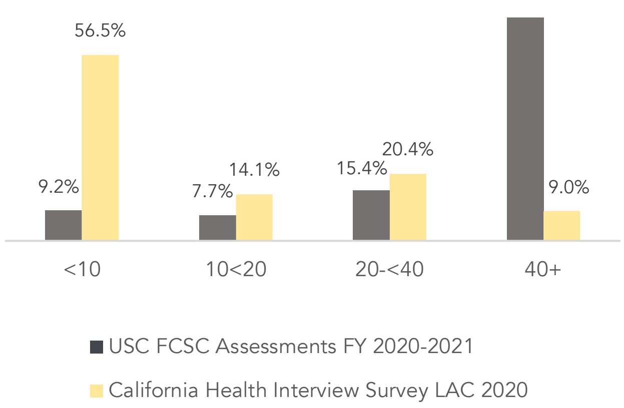


Figure 4: Care Recipient Primary Diagnosis

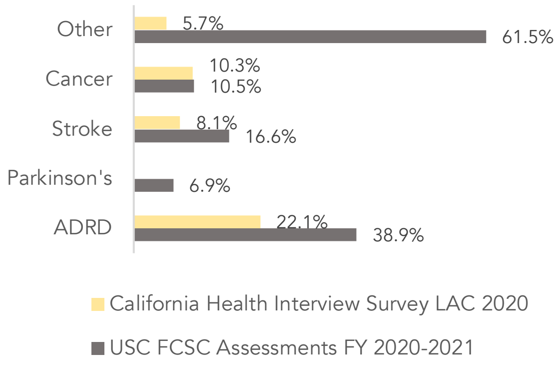


Table 1 compares caregiver health status for the two caregiver populations. It shows scores for caregiver self-rated health and the UCLA Loneliness Scale. Fewer FCSC caregivers reported "very good" health compared with CHIS LAC caregivers (11% vs. 32%). More than a third of FCSC caregivers reported either good (39%) or fair (37%) health. The UCLA 3-Item Loneliness Scale, developed from the Revised UCLA Loneliness Scale, assesses caregivers' subjective feeling of loneliness. It asks survey respondents to indicate how often (hardly ever, some of the time, often) they feel a lack companionship, left out, and isolated from others.[13] Lower scores (3-5) indicate feeling not lonely; higher scores (6-9) indicate feeling lonely. Nearly a quarter of FCSC caregivers, 22%, and 16% of CHIS LAC caregivers reported feeling lonely on the UCLA Loneliness Scale.

FCSC caregiver population

With a focus expressly on family caregivers, the CRCs detailed intake and comprehensive uniform caregiver assessment enable CRCs to understand, track, and respond to the unique needs of the family caregivers they serve. In turn, the CRC CareNav™ expansive and longitudinal caregiver database provides a fuller picture of the experiences and needs of FCSC caregivers (note: caregivers participate in a baseline assessment and six-month reassessment).

Table 1. FCSC and CHIS LAC Caregiver Health Status 2020-2021

	FCSC 2020-2021 (%)	CHIS LAC 2020-2021 (%)
Self-Rated Overall Health	***n* = 519**	***n* = 1,049**
Excellent	3.7	14.8
Very Good	11.4	31.6
Good	39.3	35.8
Fair	36.6	14.2
Poor	9.1	3.6
UCLA Loneliness Scale	***n* = 390**	***n* = 1,049**
3-5 (Not Lonely)	71.0	84.5
6-9 (Lonely)	22.3	15.5

The duration of caregiving for FCSC caregivers is split: 35% provided care for less than two years; 26% provided care for 2-5 years, and 39% provided care for more than 5 years (Figure 5). The intensity and complexity of care provided—measured by an adapted version of the Level of Care Index developed by AARP which calculates a level of intensity based on the number of hours of care provided per week and the number of ADL and IADLs a caregiver performs for the care recipient— revealed that most FCSC caregivers were grouped in level 5 (62%), indicating that they provide the highest level of care for their care recipient.[14] (See Appendix B for the adapted AARP Level of Care Index methodology.)

Figure 5: Caregiving Duration

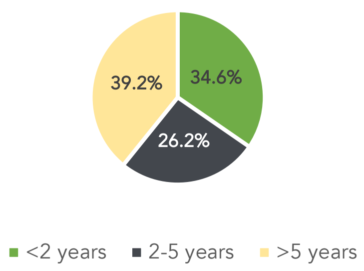
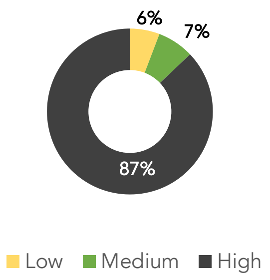
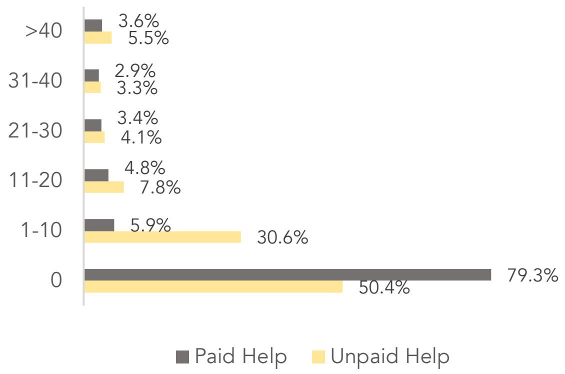


Figure 6: Care Intensity



For Care Intensity, 87% of FCSC caregivers provide the most intense care (Figure 6). This finding has greater import when understood in context: 74% of FCSC caregivers report performing medical/nursing tasks (organizing medications, administering oral medications, administering injections, etc.). Figure 7 shows the percent of hours of help per week care recipients receive both paid and unpaid. Most FCSC caregivers (79%) receive ***no paid*** help and half (50%) receive ***no unpaid*** help with weekly caregiving tasks and responsibilities (Figure 7).

Figure 7: Hours of Help per Week



Most FCSC caregivers help their family members with functional and instrumental activities of daily living: 81% assist their care recipients with bathing/showering, 76% help with dressing/undressing, and 99% help with toileting. In the area of IADLs, 99% of FCSC caregivers help with shopping, 93% with managing money/finances, and 97% with transportation. A majority of FCSC care recipients experience memory problems or memory loss (87%) and cannot be left alone for more than an hour (22%) or at all (41%). Two-thirds of care recipients have an advance health care directive, living will, or power of attorney for health care.

With respect to experiencing symptoms of depression, half of all FCSC caregivers reported minimal to mild symptoms of depression over the past two weeks, measured by the Patient Health Questionnaire-9 (PHQ-9). In response to questions about caregiver stress, measured by the Zarit Burden Interview-4 Item, half of FCSC caregivers reported low caregiver strain, half reported high.

Discussion

The objective of comparing the two datasets, FCSC and CHIS LAC, is to capture the backgrounds and experiences of Los Angeles caregivers. Caregivers participating in both surveys were predominantly women and married. Beyond these shared demographics, there are significant differences between the datasets with respect to other caregiver characteristics. Note: Some difference is not unexpected, as FCSC caregivers are actively seeking caregiver support.

More FCSC caregivers are in the 45-64 age group, Latino and Black/African American, and either retired, unemployed or left their job compared to CHIS LAC caregivers. A greater number of FCSC caregivers report earnings below the FPL and spend significantly more hours per week providing care then their CHIS LAC caregiver counterparts. Last, a higher percentage of FCSC caregivers are caring for persons with ADRD compared to CHIS LAC caregivers.

Analysis of FCSC caregiver data shows that close to two-thirds of caregivers provide care for two years or longer and the majority provide the highest level of care, according to the Level of Care Index. In addition, nearly three-quarters report performing medical/nursing tasks, half experience minimal to mild symptoms of depression, and close to one-fifth receive paid help. While each dataset serves a vital purpose, the FCSC data provide a fuller picture of caregiver characteristics and experiences, highlighting the important role of collecting comprehensive caregiver data.

ORGANIZATION SURVEY KEY FINDINGS

In May 2022, the Los Angeles County Caregiver Gap Analysis Community-Based Organization online survey was sent to 43 organizations. The purpose of the survey was to gather information from a diverse group of community-based organizations providing services and supports to family caregivers in LAC—primarily or secondarily—to understand and assess the range of available caregiver services and corresponding gaps. Organizations represented health care, legal, and caregiver services, as well as senior centers, durable medical equipment providers, and home care agencies. Forty-three organizations received the survey, 20 completed it (Table 2). See Appendix C for the names of the organizations that completed the survey. The analysis data document, the *Los Angeles Caregiver Landscape Analysis Data Chartbook*, presents aggregate responses for each survey item. Survey highlights are presented in this section.

Table 2. Survey Response Rate

Survey Response Rate	
Providers Invited to Complete Survey	43
Survey Respondents	20
Response Rate	**47%**

In 2020-2021, survey respondents reported serving approximately 7,989 family caregivers in LAC. Table 3 shows the top 11 core caregiver services offered by survey respondents. The vast majority, 85%, provide information and assistance (I&A) and specialized information, 65% provide caregiver support groups, 55% offer caregiver education, and half provide case management. Close to half offer family consultation and care and respite financial assistance and grants. More than a third, 35%, work with family caregivers to develop an action plan and provide short-term counseling/counselors, and 30% offer caregiver training and out-of-home respite care.

Table 3. Caregiver Core Services

Caregiver Core Services (n=20 Organizations)		
	#	%
Information & Assistance/Specialized Information	17	**85%**
Caregiver Support Groups	13	**65%**
Caregiver Education	11	**55%**
Case Management	10	**50%**
Family Consultation and Care	9	**45%**
Respite Care Financial Assistance/Grants	9	**45%**
Action Plan	7	**35%**
Short-Term Counseling Counselors	7	**35%**
Other	7	**35%**
Caregiver Training	6	**30%**
Respite Care - Out-of-Home	6	**30%**

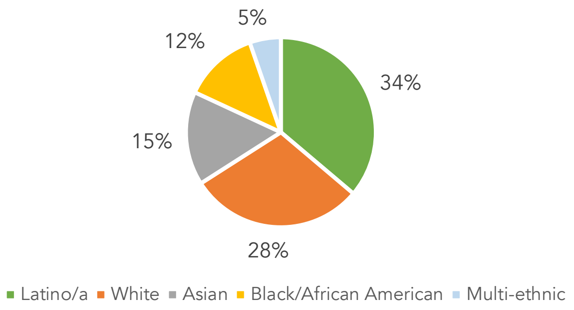


Figure 8: Caregiver Race/Ethnicity

Over half of survey respondents reported providing services to family caregivers in-person and via the Internet; 42% provide services by phone. Approximately three-quarters of these family caregivers are women and a third are Latino, 28% are white, 15% are Asian, 12% are Black/African American, and 5% are multi-ethnic (Figure 8). A third of organizations reported that 50% of the family caregivers whom they serve are In-Home Supportive Services (IHSS) providers, indicating that half of the care recipients directly or indirectly served by the reporting organizations are receiving in-home assistance through the Medi-Cal IHSS program.

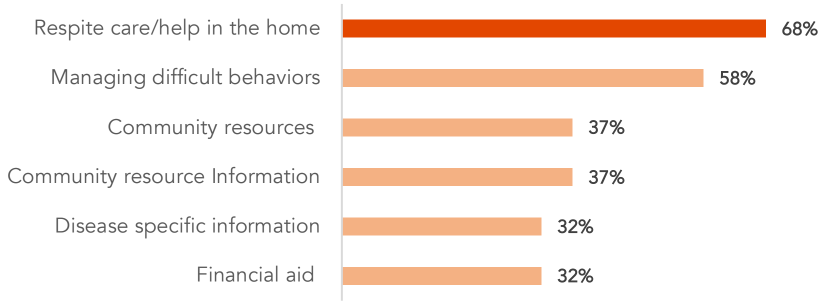


Figure 9: Caregiver Needs

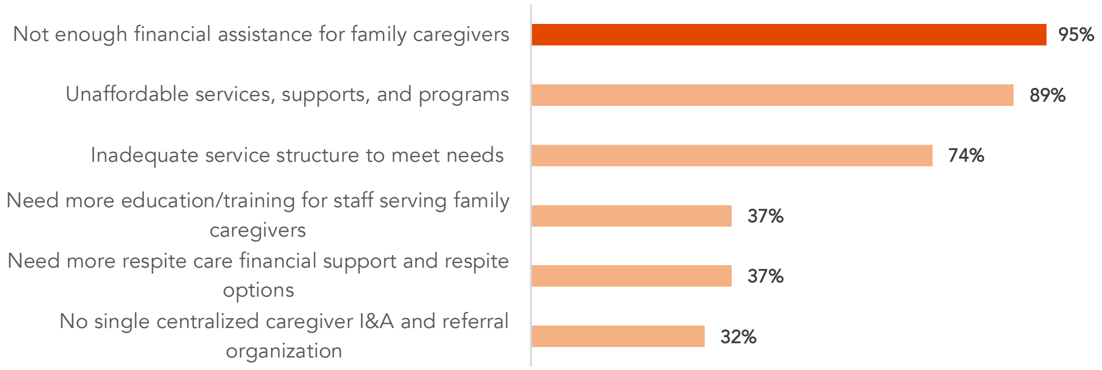


Figure 10: Gaps in Family Caregiver Services/Supports

Results from the organization survey highlight respite and help in the home, managing [care recipient] difficult behaviors, community resource information—and community resources, and financial assistance as leading caregiver needs (Figure 9). The most common gaps in caregiver services and supports are the need for financial assistance; unaffordable services, supports, and programs; and an inadequate service structure to meet need (Figure 10).

The most reported health condition for care recipients is ADRD. Among organizations providing services to care recipients, 11% reported providing adult day health care, adult day care, and caregiver surveys (to assess their needs or the needs/functional status of their care recipient), 28% reported providing other services, and 39% indicated N/A.

At the close of the survey, respondents were asked two open-ended questions. The questions and examples of responses are presented below.

What resources or supports–including those that are missing or not enough of–would improve your ability to serve family caregivers?
Better marketing and more referrals; marketing to hospitals (doctors and nurses), doctor's offices, local press, fellow organizations that serve our community that we can collaborate. *Expanded funding and eligibility criteria.* *Grants for respite care; cost of private caregiving has increased a lot; more support in finding IHSS caregivers for our clients that are on Medi-Cal and IHSS eligible.*

How might your services and supports support LA BOLD's countywide Alzheimer's disease and related dementias (ADRD) strategic plan?
We could serve a record number of people by providing day services, weekly support groups, resources, education etc., with more referrals. We have tons of room to grow in terms of the number of people we serve! *Caregiver support groups, respite activities for loved ones, educational presentations on dementia, self-care, financial planning, end of life planning, assisted living, self-care for the caregiver to avoid burnout, access to community resources and education, one-on-one support, overall tips, strategies, and support for the family caregiver, and connecting them to fellow caregivers who are on the same journey, so they know they are not alone.* *As a state designated California Alzheimer's Disease Center, we will be tasked with helping to carry out the BOLD Act through programming and patient care in our dementia clinic.* *We have a department that focuses on ADRD clients. The main issue is just informing them and the community about the services available to help these clients and their caregivers.*

Discussion

Although the number of organizations responding to the survey was small (20), the categorical and open-ended responses to primary caregiver needs and gaps were unequivocal. Caregivers need more accessible respite, in- and outside-the-home, education and training—especially on how to manage challenging behaviors, and ongoing information and support. Gaps in services were equally clear. Caregivers need more financial assistance, and the county needs more affordable and accessible services with a coordinated service structure that is easier for caregivers to navigate.

KEY INFORMANT INTERVIEWS AND CAREGIVER FOCUS GROUPS

Twelve semi-structured interviews were conducted with Los Angeles experts in family caregiving to understand the diversity of caregiver needs in LAC and how best to close gaps in services for this population (see Appendix D for list of interviewees). Information and themes culled from the interviews were complemented by feedback from family caregivers who participated in a caregiver focus group. This section presents thematic findings from both the interviews and focus groups.

All interviews were video recorded and transcribed. Analysis of words (e.g., word repetitions, key words in context) and constant comparative analysis (comparing themes) were used to identify, organize, and analyze themes from the transcripts. Given the size, geography, and diverse population of LAC, it is important to note that interview findings may not be generalizable to all LAC family caregivers due to the sample size of the interviews and focus groups.

Key Informant Interviews

The goal of the key informant interviews was to complement information about the level and types of family caregiver services and supports currently available in LAC, identified in the organization survey responses. Interviewees were asked to share their perceptions about key gaps in services, supports, training/education, and funding for family caregivers. Respondents were additionally asked to describe solutions to close these gaps.

Three major themes emerged from the analysis: 1) *critical gaps in family caregiver services and supports; 2) major challenges for family caregivers*; and 3) *viable opportunities to close gaps in services*. Subthemes for each major theme are presented.

1. **Critical Gaps in Family Caregiver Services and Supports.** Key gaps in family caregiver services and supports range from the lack of accessible, affordable, culturally responsive caregiver services to limited adoption of a health care provider-caregiver partnership approach to care, to lack of understanding among service providers of the multiplicity of caregiver needs.

> ***"What we desperately need are adult daycare programs. The state restructured them a decade ago and now we have very few programs."***
> ***– Service provider***

- ***Limited Accessibility to Equitable, Quality-driven, Culturally Responsive Caregiver Services and Supports.*** Los Angeles is home to a broad array of health and social service programs. Given the significant number of residents providing care to an adult care recipient in the county, however, the service structure to meet the needs of the estimated 1.6 million adults providing care to individuals aged 18 years or older in LAC is inadequate.[11] There are too few adult day service (ADS) programs, and not enough respite funds to help family caregivers pay for these programs or access the in-home care they need for breaks or to go to work. See Appendix E for an overview of ADS.

Like caregivers across the country, family caregivers in Los Angeles want services that are in their neighborhoods—easily accessible—with staff who understand and respect their cultural background, sexual orientation, need for services in their primary language, and food preferences. Funding and sustaining these programs, however, are difficult. A chief reason: the inflexibility of funding streams. Local, state, and national caregiver funds all have requirements related to infrastructure, metrics, and outcomes. Smaller organizations serving specific ethnic communities are not always able to meet these requirements. To meet their clients' needs, they often pursue subcontracts with larger organizations, which require extensive but non-reimbursable administrative time.

> ***"You want to be fair and equitable and sometimes by trying to be equitable by not showing favoritism, then it's not equitable because then certain people can't access services [i.e., not in their geographic area or are not culturally/linguistically accessible]. It's something that requires conversations, problem solving, and flexibility."***
>
> ***– Service provider***

> ***"In general, the materials that are out there for caregivers are written for the Anglo community. They have to be adapted and nuanced for other communities.***
>
> ***– Clinical provider***

COVID-19 further challenged the county in providing equitable and accessible caregiver services. The pandemic shifted the major thoroughfare of services from in-person programs and interactions to online platforms. The transition left many low-income caregivers without access to electronic devices, the Internet, and needed technology education and training—the "digital divide" writ large.

> ***"During the pandemic, people who had no WIFI and don't use a computer lost. The people who were more sophisticated loved that they had greater access to a lot of our services."***
>
> ***– Service provider***

> ***"Within the LGBT community, what we've looked at research-wise is that generally, folks as they're aging, have less access to resources—including caregiver support—than their straight counterparts."***
>
> ***– Service provider***

> ***"We take care of a unique group of individuals of Mexican heritage in LA County with early-onset Alzheimer's disease—starting in their late 30s and 40s. It is an incredible community that deserves our support."***
>
> ***– Clinical provider***

Other communities too experience barriers to services. Older members of the LGBTQ community are more likely to live alone and less likely to have family of origin support as they age, including children. As a result, it is not uncommon for this group of individuals to rely on chosen family caregivers. When they lose the support of these family members, frequently because the caregiver becomes ill, they may need to rely on paid carers or institutional care. For many LGBTQ seniors the former is prohibitive, and the latter presents safety and acceptance concerns.

Individuals who suffer from early onset Alzheimer's (30s,40s,50s) and their caregivers experience significant disruptions in their lives. Because of the intensity of the disease and the fact that many caregivers in this group are young adults themselves, likely still in the workforce and caring for young children, their unique needs may not be met by most ADRD services. The lack of responsive services for this group of caregivers is exacerbated for families whose primary language is not English.

> ***"Fragmentation is there [health care system]. There is a lack of coordination, the family's often left to navigate on their own, and the payment mechanisms aren't quite there. We also don't see a greater focus on advance care planning, which is good for both the care recipient and caregiver."***
> ***– Caregiver advocate***

- *Inadequate Partnerships Between Health Care Providers and Caregivers.* Health care providers and caregivers each juggle countless complications, demands on their time, and a finite number of hours in the day to do all they have to do. When these worlds intersect, caregivers frequently walk away from encounters with their care recipient's health care provider feeling that they were not heard, seen, or directed to resources and support that could help them in their caregiving role. HIPAA laws and respect for the autonomy of care recipients able to voice their preferences, may contribute to some health care providers hesitancy to engage caregivers apart from the care recipient.

- *Lack of Recognition of the Multiplicity of Caregiver Needs.* The most prominent need identified for caregivers is respite followed by education and training (e.g., how to manage challenging behaviors, caregiver self-care, setting up legal and financial documents, etc.). Attending to these dominant caregiver priorities, health and community service providers can miss the confluence of other fundamental caregiver needs, such as transportation, food access and security, housing, well-being, and maintaining or seeking employment.

> ***"We assess their needs. For example, we ask if they have CalFresh. If they are a senior, we assess if the food issue is related to neglect. We turn a simple, basic need call into something more involved, and then we collaborate."***
> ***– Service provider***
>
> ***"Transportation is a big issue for care recipients and many caregivers."***
> ***– Service provider***

2. **Major Challenges for Family Caregivers.** Key informants identified several paramount challenges for caregivers. They include the economic squeeze that many caregivers

experience, as well as the impact of caregiving on mental health, and the ramifications for caregivers who do not self-identify as caregivers.

- **Economic Squeeze.** A consistently reported challenge for people providing care to others is the economic repercussions of caregiving. From losing employment, to withdrawing from the workforce, to working while managing extraordinary caregiving responsibilities, caregivers feel financial pressure every day. These stressors are compounded by significant out-of-pocket costs for food, medicine, and medical supplies not covered by insurance. A particularly hard-hit community are caregivers whose care recipients have incomes above the limit for public programs that provide support (e.g., Community-Based Adult Services-CBAS, or In-Home Supportive Services- IHSS Program) but below an income level that would allow them to pay privately for ADS or in-home care without risk of falling into poverty.

> ***"There is a huge gap in funding and service needs for caregivers. If you have a caregiver client caring for mom or dad and their Social Security is over the IHSS threshold, they may be able to pay a share of cost or maybe they make a bit too much. For these families, many adult children end up leaving their job to be fulltime caregivers."***
>
> ***– Service provider***

CBAS is a community-based day health program for eligible Medi-Cal beneficiaries that provides services to older persons and adults with chronic medical, cognitive, or mental health conditions and/or disabilities that are at risk of needing institutional care. IHSS provides individuals with limited income who are disabled, blind, or over the age of 65 with in-home care services to help them remain safely at home. Many family members serve as IHSS providers.

- **Mental Health Needs**. Recognizing and responding to the link between caregiving and depression, stress, feelings of burden, and burnout was cited as a predominant challenge for family caregivers, especially for carers of adults with dementia.[15] Interviewees emphasized the lack of accessible, affordable mental health services for caregivers, with clinicians who understand them and the emotional demands of caregiving.

> ***"Caregivers struggle with emotional issues and the pandemic made it worse. We received a lot of calls from caregivers asking for mental health services and supports."***
>
> ***– Service provider***

COVID-19 exacerbated these associations. Pre-pandemic, caregivers who had a break when family members attended adult day programs or received respite care in the home, suddenly found themselves caring for loved ones around-the-clock during the crisis. Unable to receive help from even family members, caregivers assumed the responsibility of providing more care than usual, resulting in increased feelings of loneliness, isolation, and caregiver burden. The effect on care recipients was equally devastating. Without the structural supports of adult day programs and congregate meals, which offer socialization and purposeful activities, many care recipients with dementia experienced an accelerated cognitive decline during the pandemic.

“For some communities, there is no word for “caregiver” and many are reluctant to call themselves caregivers or accept outside help because then, you're not doing your job, then somehow you've failed in doing your job.”
– Service provider

- **Impact of Not Self-Identifying as a Caregiver.** For many communities, especially communities of color, caring for an adult family member is expected. This expectation falls disproportionately on women: wives, daughters, sisters, and sisters-in-laws. An unintended consequence of this practice is that many family members don’t identify themselves as caregivers. Caregivers who don’t think of themselves as caregivers may not ask health care or community-based organizations for help. In parallel fashion, if caregivers don’t self-identify as caregivers, service providers may not see them as needing help.

3. **Viable Opportunities to Close Gaps in Services.** In response to the reality of limited program funds for caregivers, at all levels, and other reported service barriers, several creative opportunities to expand and strengthen caregiving services and supports emerged.

“Let’s get over ourselves. Our work is complementary, not competitive. Share the resources, share the information, and find ways to truly do collaborations.”
– Service provider

“We need to build on our existing infrastructure (e.g., CRCs, ADRCs, Alzheimer's LA, Alzheimer’s Association) and promote and market existing services, so that people know where to find them. Then we need to build more.”
– Service provider

   - **Leverage Existing Infrastructure.** “Don’t reinvent the wheel” a key informant emphatically stated, summarizing a common refrain. To provide the depth and breadth of services required to meet Los Angeles caregiver needs, key informants recommended forming a single caregiver collaborative comprised of a broader and more diverse group of caregiver stakeholders. Instead of creating new systems and programs, or elevating one system or program over another, the collaborative would determine how best to leverage the existing infrastructure and caregiving funds. They also recommended a supplemental goal for the collaborative: launching a public awareness/marketing campaign to educate the public about caregiving and available caregiver resources—with a focus on family caregivers who don’t self-identify as caregivers.

   - **Promote Promising Caregiver Support Models.** Several key informants were directly involved in caregiver service models that have proven effective and responsive to community needs. Ayudando a Quien Ayuda™ (Helping the Helper), a partnership between Los Angeles 211, USC Family Caregiver Support Center, AARP, and Vision Y Compromiso, is a program that helps callers find caregiver support services in their communities. Alzheimer's Los Angeles Dementia Care Network, an interorganizational community-based collaborative model established to provide dementia care services to diverse ethnic communities is another program model with promise (note: the model has been replicated but requires ongoing funding for program sustainability). Both programs are profiled in the next section, Environmental Scan: Caregiver Best Practices.

Additional promising practices for replication or expansion include Los Angeles County L.A. Found, a voluntary program that offers trackable bracelets to at-risk individuals to help caregivers of person with ADRD, and the social care network Find Help, which assists users with finding and directly connecting to needed services.

- **Partner with Health Care Providers Upstream.** Caregivers want to be seen, engaged, and respected for the care they provide and the important role they play. Key informants highlighted opportunities for health care providers to partner more intentionally and creatively with caregivers. System support for this partnership allows caregivers to play a more pivotal role in promoting care recipient brain health, early identification of risk factors for ADRD (e.g., high blood pressure) and advance care planning discussions—the latter for care recipients ***and*** caregivers.

> ***"Our focus is on risk reduction, especially in communities that in the past have not received as much attention. Latino communities and Black communities have vascular risk factors that, if you are able to help people control them, you could actually decrease either the risk for dementia or mixed picture dementia or just even progression to dementia."***
> ***– Policymaker***

Caregiver Focus Groups

Two 90-minute Zoom-based focus groups with caregivers were held to hear directly from caregivers about their needs and current gaps in caregiver services and supports in Los Angeles. Caregivers interested in participating in the focus group were asked to complete an online application. Eight participants were selected for each focus group representing the diversity of LAC with respect to racial and ethnic background, gender, relationship to care recipient, and neighborhood. A modest honorarium was given to participants. The focus groups were recorded and transcribed.

Three major themes emerged from analysis of the highly interactive caregiver focus groups: *greater support needed for caregiver self-care*; *worries about the future; and health care providers must partner with caregivers.* Each theme is presented with supporting information.

"After the diagnosis, you are on your own. You are not given resources but are told to 'take care of yourself.' But no one tells you how to do that."

– Caregiver

1. **Greater Support Needed for Caregiver Self-Care.** Caregivers underscored the need for concrete respite care above all other forms of caregiver self-care support. While education, training, and help with care navigation were cited as important, the stated priority for caregivers was receiving regular breaks from and help with caregiving in the home. Caregivers additionally asked for more affordable adult day programs with flexible eligibility and participation requirements. They want their loved ones to have opportunities to socialize and be part of an external community without concern that they might be sent home, for example, because of a bowel accident.

   Other recommended self-care supports included having the county organize mobile health vans to bring needed specialty services (e.g., dentistry, audiology, primary care), to community locations such as local senior centers or libraries, a 24/7 hotline that caregivers can call in an emergency for advice and support, and more support groups to reduce loneliness and provide caregivers with opportunities to speak to other caregivers who understand.

"Keeping him safe and from being taken advantage of—that is what I worry about."

– Caregiver

"I worry about who will take care of my mom, if something happens to me."

– Caregiver

2. **Worries About the Future.** Chief among the issues that keep caregivers up at night is concern for their loved one should they fall ill, die, or no longer be able to provide care. Caregivers also discussed grave financial concerns. They worry about whether they will have enough money to provide care. Several described the difficulty they had legally accessing care recipient resources to help with the care they provide, including that they were viewed with suspicion. Many focus group participants also shared feeling anxious about the safety of their loved one, with concerns about falls cited as the biggest concern.

"We need to know what to expect and how to navigate the system. Doctors can treat us differently. We can be and are fierce advocates for our loved ones. Maybe we can partner better with health care."

– Caregiver

3. **Health Care Providers Must Partner with Caregivers**. Focus group members were asked about their interactions with health care providers, including 1) whether they were recognized as a caregiver, 2) if they were educated by the provider about the care recipient's health condition and risk factors for ADRD, and 3) if they were asked about their care recipient's advance health directive. Although several caregivers stated that they had open and trusting relationships with their care recipient's health care provider, this was not a uniform experience.

   Most caregivers shared experiences of not being acknowledged or engaged by their care recipient's health care provider. Some stated that the provider would not interact with them out of respect for the autonomy and privacy of the care recipient. While caregivers understood this response, they equally felt that providers should find a way to engage with them, so they can share what they are experiencing vis à vis the care recipient at home. Care recipients often present a higher functioning persona to the doctor than at home: caregivers want to discuss this and what it means with the health care provider and team.

Discussion

The subthemes that emerged under the key informant primary themes—*critical gaps in family caregiver services and supports*, *major challenges for family caregivers*, *viable opportunities to close gaps in services*—presented a detailed and nuanced framework for understanding the experiences, needs, concerns, and aspirations of Los Angeles caregivers. Under the major gaps theme, subthemes highlighted a clarion call for respite care, including accessible and affordable adult day programs and home care, services responsive to the ethnic, racial, language, sexual orientation, and cultural diversity of caregivers, and acknowledgement of overlooked caregiver needs, e.g., transportation, education, and training on managing challenging behaviors.

Challenges for caregivers revealed how the economic sequalae of caring for loved ones financially impacts family caregivers, from the loss or modification of employment (hours, income), to significant out-of-pocket expenses to cover food, medicine, and supplies, to struggles for low- and middle-income caregivers who cannot afford to pay privately for caregiver services but are ineligible for public programs. This theme additionally highlighted the link between caregiving and stress, burden, and symptoms of depression. It also illuminated the impact on caregivers who do not self-identify as caregivers: they may not receive the help and support they deserve.

The third primary theme of potential strategies and opportunities to improve the lives of Los Angeles caregivers highlighted several subthemes. The first, leverage the existing infrastructure of caregiver services and supports. Second, consider expanding and replicating current promising programs to reach more caregivers, i.e., Ayudando a Quien Ayuda™, Alzheimer's Los Angeles Dementia Care Network, and Los Angeles County L.A. Found. Last, promote the importance of health care providers and systems partnering more openly and intentionally with family caregivers.

The focus group themes of *support for caregiver self-care*; *worries about the future*; and *health care providers must partner with caregivers* enhanced the key informant interview themes by providing a granular picture of what caregivers think about, want, need, and hope for. We learned that caregivers often find themselves "on their own" without a lot of information or support—including respite care—after receiving news about their care recipient's diagnosis or condition. Worry about what will happen to the care recipient should something happen to them [the caregiver], was the dominant concern for all focus group caregivers. Last, caregivers underscored that they want to work more collaboratively with their care recipient's health care provider to ensure they are providing the best care possible to their care recipient while getting the support they need.

ENVIRONMENTAL SCAN: CAREGIVER BEST PRACTICES

Following a state and national search to identify caregiver best practice programs with a ***whole-person approach,*** in sync with LA BOLD's commitment to identifying opportunities to engage, educate, and support family caregivers caring for loved ones with ADRD, four promising caregiver best-practice models emerged. The models reflected several strategies and action items in the report, "Supporting Caregivers: A Healthy Brain Initiative Issue Map."[16] Two programs, the California Caregiver Resource Center (CRC) System-FCSC and Alzheimer's Los Angeles, currently serve family caregivers in LAC. Two out of state examples are the Minnesota Family Caregiver Services Elderly Waiver Program and the Florida Statewide Medicaid Managed Care Long-Term Care Supplemental Assessment. Each model is profiled in this section.

Since family caregivers are typically the catalyst for care recipients to express and document their treatment preferences, efforts were made, as part of the environmental scan, to identify effective advance care planning (ACP) programs engaging family caregivers. Because most individuals with ADRD reach a time when they can no longer express their care wishes, helping them communicate their treatment choices and preferences early in the disease process is important. It ensures their choices will be respected when they are no longer able to speak for themselves.

WHOLE PERSON APPROACH

Whole-person care is the patient-centered optimal use of diverse healthcare resources to deliver the physical, behavioral, emotional, and social services required to improve care coordination, well-being, and health outcomes while respecting patients' treatment choices.

ADVANCE CARE PLANNING (ACP)

A process of communication that often occurs over time. ACP conversations are typically between the patient, the family or health care proxy, and health care staff. They center on prospectively identifying a surrogate, clarifying treatment preferences and values, and developing individualized goals of care should a person become unable to speak for him or herself in the event of an accident or serious illness.

While no best practice model addressing caregivers and ACP emerged, the research did reveal several opportunities for health care and community organizations to educate care recipients and their caregivers about ACP. The process begins with reframing the value of ACP as a longitudinal communication process rather than a series of steps leading to completion of an advance health care directive (AHCD) document. Engaging patients and family members in discussing health care and treatment preferences "helps people understand and share their personal values and goals, and helps surrogates (often family caregivers) prepare for in-the-moment decision making."[17] To support this approach, health care organizations and community organizations are encouraged to:

1. Thread ACP conversations into routine health care for all adults beginning at age 18.
2. Recognize and support the role of family caregivers in ACP—as advocates for care recipients but also as adults themselves who would benefit from ACP discussions.
3. Promote ACP tools, websites, and practices that are culturally and linguistically respectful of diverse family caregivers, e.g., Prepare for Your Care. (The PREPARE website helps patients and their loved ones prepare for medical decision-making in five steps. Website and materials are available in English and Spanish.)

California Caregiver Resource Center System

Overview. The California Caregiver Resource Center (CRC) System is a network of 11 non-profit centers throughout California that provide support to family caregivers of individuals with an adult-onset cognitive impairment, including ADRD, Parkinson's disease, stroke, traumatic brain injury, Huntington's disease, multiple sclerosis, etc. Many centers additionally support family caregivers of adults aged 60 and older with chronic debilitating health conditions. Each year the California CRC System serves over 18,000 family caregivers.

Core Services. A range of CRC services are offered to family caregivers: information and referral, a standardized intake procedure, a uniform caregiver assessment, individualized family consultation and care navigation in partnership with the caregiver client, a variety of caregiver trainings and educational classes, support groups, and vouchered services (including respite, legal/financial consultation, and short-term individual counseling). Services are available in-person, by phone or video, as well as through the CRC online client record system, CareNav™, which has a consumer-facing portal.

Primary Funding. The California CRC System is funded by the California Department of Aging (CDA). Individual CRCs also receive funding at the local level from the Older Americans Act Title III-E (Family Caregiver Support Program) and Title III-B (Supportive Services Program), donations, private foundations, and grants.

Collaboration/Partnership. CRCs collaborate with a broad group of partners. Key partners include CDA, local Area Agencies on Aging (AAAs), Adult Day Health Centers (ADHCs), Adult Day Programs (ADPs), Community Based Adult Services (CBAS), Aging and Disability Resource Centers (ADRCs), health systems, and disease specific community organizations.

Featured Caregiver Best-Practice Innovations

- **Ayudando a Quien Ayuda™: A FCSC, AARP, 211, Vision Y Compromiso Collaboration**

  Ayudando a Quien Ayuda™ (Helping the Helper) is a Los Angeles County caregiver referral program that engages underserved, low-income Latino family caregivers and connects them with comprehensive services in their community. The program was created through a collaboration between FCSC, AARP, 211 LA, and Vision Y Compromiso, to meet the growing needs of Spanish speaking Latino caregivers. Latino callers who reach out to 211 for information and support are screened to determine if they are a caregiver, and if so, if they are eligible for Ayudando a Quien Ayuda™. Caregivers interested in the program receive a follow-up call from FCSC staff (facilitated by 211), who assess their needs and determine next steps (e.g., develop a care plan, offer caregiver services, and supports). Since the program launched in July 2019, FCSC has completed 2,424 outreach calls, 891 intakes, and 423 assessments. Ayudando a Quien Ayuda™ provides critical support to a population of caregivers that face significant obstacles to caregiver services, and report higher risk of unmet basic needs (e.g., housing, food). As a result, 211 and FCSC staff dedicate extensive time to assisting this group of caregivers to ensure their needs are met.

- *Kaiser Permanente Northern California + Redwood CRC*

The collaboration between a dedicated geriatrician at Kaiser Permanente (KP) Northern California, Santa Rosa (Sonoma County) and the director and senior clinical staff at Redwood CRC based in Santa Rosa, was years in the making. The partnership stemmed from an awareness that family caregivers of individuals diagnosed with dementia needed more support than what was provided by the health care system alone. The partnership addressed an outstanding need: to connect family caregivers with support as early as possible in the community once a patient is diagnosed with ADRD. This program gives family caregivers information and services they need at the outset of their caregiver journey.

> ***"I can take care of the patient, but I need the caregiver to be involved. Together we can make sure the care recipient has what they need and the caregiver too."***
>
> ***– Wynnelena Canio, MD, AGSF, Kaiser Permanente Northern California***

As part of this protocol, when a KP patient receives a diagnosis of dementia, the family caregiver is offered the opportunity to enroll in the Dementia Care Program, which includes the following supports: a resource handbook entitled, "Caring for a Person with Dementia;" access to a series of caregiver educational trainings, including Caregiver 101; and a referral to Redwood CRC for individualized services and support. A key feature of the partnership is that KP staff and Redwood CRC staff work collaboratively to address caregiver needs (note: caregivers sign a consent form prior to enrolling in the Dementia Care Program).

Although the original partnership was with KP Northern California in Santa Rosa, the partnership has expanded. It is now operational in KP geriatric centers in other areas of Sonoma County, as well as Marin County. Based on the program's success, the partners are working toward a broader KP-CRC system partnership in other parts of California. Not only has the partnership provided critically needed assistance to caregivers suddenly confronted with having to navigate the health care system and their unique caregiver challenges, but it has also embraced caregivers as essential members of the care recipient's health care team. The program highlights a promising health care system-community organization partnership approach to providing family-centered dementia care.

Alzheimer's Los Angeles

Overview. Alzheimer's Los Angeles has been delivering innovative programs, services, and support to families affected by Alzheimer's disease and dementia in the Los Angeles area for over 40 years.

Core Services. Alzheimer's Los Angeles provides a range of free services to individuals with ADRD, their families, and the community, from a Helpline and Resource Directory to support groups to individual care counseling with dementia specialists to information and workshops. Alzheimer's Los Angeles also offers low-cost dementia training and education to health care professionals. Due to COVID, programs and services are currently available online and by phone.

Primary Funding. Primary funding streams for Alzheimer's Los Angeles are government grants and contributions from individuals, corporations, and private foundations.

Collaboration/Partnership. Alzheimer's Los Angeles works in partnership with a host of diverse organizations. Leading partners are the Administration for Community Living (ACL), CDA, City of Los Angeles Department of Aging, Riverside County Office on Aging, County of Los Angeles Department of Public Health, FCSC, and Kaiser Permanente Woodland Hills Medical Center. Alzheimer's Los Angeles additionally supports Alzheimer's research and advocacy. For example, the organization participated in a pilot project testing an advocacy model supporting dementia-capable systems change in California managed care health plans. The study recommended that health plans develop a caregiver protocol (i.e., assessment tool) to assess the stress and needs of caregivers.[22]

Featured Caregiver Best-Practice Innovation

- Dementia Care Networks

  Alzheimer's Los Angeles launched the first Dementia Care Network, "El Portal" Project, in 1992 to increase ADRD services to the Latino community including day care programs, support groups, elder law clinics, and care consultation services. The Network model aims to create dementia services in underserved communities through "community empowerment via partnerships with local public and private entities, a mutual exchange of knowledge regarding dementia and culture, an emphasis on human resource development, and the development of culturally competent responses to patient and caregiver needs."

  Over the past several decades, Alzheimer's Los Angeles created Dementia Care Networks in other underserved communities, addressing the needs of Black, Chinese, Vietnamese, Korean, Japanese, and Filipino families. Not all the networks have been sustained over the years, leading the organization to highlight the importance of securing adequate multi-year funding to ensure community network sustainability. Note: Alzheimer's Los Angeles created a replication manual for other organizations to learn how to implement Dementia Care Networks in their own communities.

Minnesota Family Caregiver Support – Elderly Waiver Program

Overview. The Minnesota Department of Human Services offers family caregiver services through the Elderly Waiver (EW) program, which provides home and community-based services to seniors who qualify for Minnesota's Medicaid program, *Medical Assistance*, and who require nursing home level care. The program's definition of a family caregiver is someone who "is not paid or employed by, or a volunteer through an organization that cares for the person who receives services." Family caregivers can include relatives or non-relatives (e.g., neighbors or friends). See the Minnesota Department of Human Services website for more information on family caregiver services.[18-20]

Core Services. The EW program provides services to seniors and their families who wish to remain at home. It includes an assessment, education, and coaching for family caregivers, as well as training in evidence-based interventions to support caregivers living with a friend or family member with dementia. Services are individualized to meet the needs of the family caregiver. Despite the comprehensiveness of the EW program, enrolling caregivers in the program has been a challenge. Program staff are collaborating with other programs to develop trainings for lead agencies and providers to promote awareness of EW family caregiver services throughout the state.[18]

Florida Statewide Medicaid Managed Care Long-Term Care (LTC) Supplemental Assessment

Overview. The Statewide Medicaid Managed Care Long-Term Care (LTC) program requires managed care programs (MCPs) to offer a variety of home and community-based services (HCBS) to enrollees who require a nursing facility level of care, but who wish to reside in the community. For an individual to receive LTC services, a 701-B Comprehensive Assessment and LTC Supplemental Assessment, which includes an evaluation of family caregiver (or natural supports) needs, are required.[21] While no standard, uniform LTC Supplemental Assessment form exists, each contracted MCP LTC plan must include the above required elements and be approved by the Agency for Health Care Administration. After completion of the assessment, enrollees receive a summary of services that have been authorized for their individualized plan of care.

Core Services. The LTC Supplemental Assessment must include two main components: 1) how long an enrollee can stay home alone safely and 2) how able family caregivers are to assist with enrollee needs. Regarding the latter, family caregiver availability and willingness to participate in the enrollee's care is assessed, along with caregiver stress, well-being, and other non-caregiving responsibilities. Based on the plan of care for the enrollee, family caregivers may be eligible for supportive services, including information on behavioral management, caregiver training, and respite care.

CONCLUSION

Analysis of the Los Angeles Caregiver Landscape Analysis data findings and caregiver best-practice models revealed three prominent recommendations* to improve the lives of diverse family caregivers in LAC: leverage existing infrastructure to strengthen and build family caregiver services and supports; promote health care provider-caregiver partnerships; and address the significant need for more caregiver respite services given the population of Los Angeles.

LAC can make great strides in meeting the needs of its diverse and growing population of family caregivers, especially those caring for loved ones with ADRD. But it will require leadership, advocacy, partnership, and a shared vision by a more inclusive group of caregiver stakeholders.

Recommendation #1	Leverage existing infrastructure to strengthen and build family caregiver services and supports.

- **Form a single countywide collaborative comprised of leading caregiver stakeholders, including organizations representing Los Angeles's ethnically diverse communities.** Consistent with the core principles of the California Master Plan for Aging, the collaborative aim is to bring existing caregiver councils, task forces, and advisory groups together into one coordinated body to plan a seamless no wrong door entry system for LAC residents seeking caregiver information, services, and supports. Plan will identify opportunities to build on existing infrastructure to provide culturally responsive caregiver services, and fund and support more equitable and accessible services for LAC caregivers:
    - **Explore opportunities to streamline the current array of information and assistance programs serving Los Angeles family caregivers into a coordinated system with multiple access points.** The collaborative should review information and assistance programs including FCSC, 211, Alzheimer's Los Angeles, Los Angeles Workforce Development Aging & Community Services, Aging Disability Resource Centers, and the City of Los Angeles Department of Aging to identify a coordinated system with multiple entry avenues to better serve family caregivers.
    - **Build on existing caregiver best-practices in LAC—Ayudando a Quien Ayuda™ program and Alzheimer's Los Angeles Dementia Care Network El Portal Project—to address the needs of historically marginalized and underserved communities.** Evaluate opportunities for funding, expansion, and replication of these programs to increase Black/African American, Hispanic/Latinx, Asian American and LGBT communities' access to these needed caregiver services and supports.
    - **Launch a countywide caregiver education and marketing plan targeting family caregivers who don't self-identify as caregivers—help them to recognize themselves as caregivers and to reach out for information and support.** The overarching goal of the campaign will be to educate the public about caregiving, caregivers, and available caregiver services.
- **Partner with senior centers, libraries, and community parks to increase caregiver access to caregiver information, services, and supports in their communities.** Work with city and county services and programs (Information & Assistance, LA Found), and caregiver organizations (FCSC and Alzheimer's Los Angeles) to bring services to where people live—in the community. Consider deploying mobile vans used for food distribution or health education fairs for this effort.

Recommendation #2	Promote health care payer, provider, and system recognition of and support for family caregivers.

- **Advocate for health insurance plans (public and private) assessing and providing benefits to caregivers of individuals with serious illness, including ADRD**. Recognizing and responding to the needs of family caregivers with information, support, and respite services, helps caregivers care for their care recipient and reduces avoidable health care crises and hospital admissions.
- **Promote the use of a standardized caregiver assessment.** Health care plans and providers should assess caregiver needs using a comprehensive caregiver assessment. The CRC caregiver assessment, in combination with a standardized intake tool, collects caregiver sociodemographic, health, caregiving, and outcomes data, which help CRCs match caregiver needs with services.
- **Encourage health care providers to develop partnerships with family caregivers**. As valuable health care provider allies, family caregivers can ensure that care recipients receive the best care possible at home while being recognized and supported for their important caregiving role.
- **Partner with community organizations and allied health professionals in the community to better support family caregivers.** The Kaiser Permanente Northern California + Redwood CRC program partnership represents an innovative model with replication potential for Los Angeles. Health care organizations should additionally explore opportunities to train and partner with community health workers (CHWs)/promoturas to provide caregiver information, education, and ACP discussions.
- **Promote hospital adherence to the Caregiver Advise, Record, Enable (CARE) Act and make "family caregivers" a searchable field in electronic medical records (EMR).** CARE requires hospitals to provide hospitalized patients (especially those with cognitive impairment) with an opportunity to identify a family caregiver (the individual's name and contact information are recorded in the EMR). The hospital is required to notify the family caregiver as soon as possible when the family member will be discharged or transferred– and consult with him or her about the discharge plan.

Recommendation #3	Increase respite services for caregivers.

- **Increase access to in- and out-of-home respite care.** With over 166,000 Los Angeles adults aged 65 and older living with Alzheimer's disease ***alone***, the county has an inadequate supply of ADS to serve the number of persons with ADRD, as well as other complex conditions, and their caregivers in the county.[23] To address this urgent issue, LAC should pursue all options to do the following:
    - **Increase the number of in-and out-of-home respite services and respite grants for low and middle-income caregivers**. LAC must increase the number of in- and out-of-home respite programs and grants, especially for low and middle-income residents. LAC should evaluate current respite funding streams in LA (local, state, national) and critical stakeholders, including health plans, to identify creative funding opportunities, e.g., pooled funding.
- **Address common barriers to accessing out-of-home respite, specifically adult day services (ADS).** The most common ADS barriers are affordability, transportation, and lack of awareness among caregivers and the public about the existence of services. Removing these barriers may involve finding new funding streams and partners (e.g., health plans, Program of All-Inclusive Care for the Elderly—PACE programs), testing pilot programs, and launching a caregiver public awareness campaign.

*Note: It is recommended that the Los Angeles Department of Public Health in partnership with key caregiver stakeholders identify the lead(s) to implement each of these recommendations.

APPENDICES

APPENDIX A. Glossary of Terms/Commonly Used Acronyms

ADHC	Adult Day Health Care medical-model of Adult Day Services (ADS) through which a community-based licensed health-facility offers frail elderly persons or adults with disabilities, at risk for institutional placement, a full range of skilled health care and psychosocial services provided by a multidisciplinary team.
ADLs	Activities of Daily Living: Daily self-care activities such as bathing, dressing, self-feeding, etc.
ADP	Adult Day Program—they represent the social model of Adult Day Services (ADS).
ADRD	Alzheimer's Disease and Related Dementias
ADS	Adult Day Services represents a system of professionally delivered, integrated, home- and community-based, therapeutic, social, and health-related services provided to individuals to sustain living within the community.
CareNav™	CareNav™ is a California Caregiver Resource Center (CRC) caregiver data repository and online platform for caregivers served by CRCs.
CHIS	California Health Interview Survey
CHIS LA	California Health Interview Survey Los Angeles
CHWs	Community Health Workers
CRC	Caregiver Resource Center
DPH	Los Angeles County Department of Public Health
IADLs	Instrumental Activities of Daily Living: Activities that include bill paying, shopping, housekeeping, medication management, food preparation, etc.
LA BOLD	Los Angeles County Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD) Initiative
FCSC	University of Southern California Family Caregiver Support Center
PHQ-9	Patient Health Questionnaire-9
Promotoras	Lay Hispanic community health care educators
ZBI-4-Item	Zarit Burden Interview (4-Item)
CalAIM	California Advancing and Innovating Medi-Cal—a multi-year plan to transform California's Medi-Cal program to improve outcomes for the millions of Californians covered by Medi-Cal, including those with the most complex needs.

APPENDIX B. Caregiver Level of Care/Care Intensity

The Level of Care/Care Intensity Score calculated for FCSC caregivers is modeled on an index used by the UC Davis Family Caregiving Institute, which is modeled on the Level of Care/Care Intensity scale developed by AARP.[24] It uses two CareNav™ measures: the number of weekly hours of reported caregiving with points assigned for the number of hours of care, and the types of care provided (six ADLs: transferring, dressing, using the toilet, bathing/showering, incontinence, eating, and seven IADLs: managing finances, shopping, household chores, preparing meals, transportation, taking medications, using telephone from the 15-item FCSC ADL/IADL table are used for the index), with points assigned for the number of ADLs and IADLs performed.

Hours of Care	Points Assigned
	1 point
11-<20	2 points
20-<40	3 points
>40	4 points

ADL and IADL Totals	Points Assigned
0 ADLs; 1 IADL	1 point
0 ADLs; 2+IADLs	2 points
1 ADL; + any number of IADLs	3 points
2+ ADLs + plus any number of IADLs	4 points

The level of care/intensity of care score is calculated based on total scores for both types of care provided and weekly caregiving hours.[25]

Scoring for Caregiver Level of Care/Care Intensity

Total Points (Weekly caregiving hours + types of care provided)	Level of Care	Care Intensity
2-3 points 4 points	Level 1 Level 2	Low Intensity
5 points	Level 3	Medium Intensity
6-7 points 8 points	Level 4 Level 5	High Intensity

APPENDIX C: Organization Survey Respondents

- Alzheimer's Los Angeles
- American All Care Services
- Assisted Living Locators
- Beach Cities Health District
- Bet Tzedek Legal Services
- Carson Adult Day Health Care Center
- Cedars Sinai Medical Center
- Connections - Care Home Consultants
- USC Family Caregiver Support Center
- Heritage Clinic & CAPS Pasadena
- Human Services Association
- Leeza's Care Connection
- Little Tokyo Service Center
- Mary S. Easton Center for Alzheimer's Disease Research at UCLA
- Mobility & Durable Medical Equipment Association
- National MS Society
- ONEgeneration
- Pacific Clinics
- St Barnabas
- Well Spouse Association

APPENDIX D: Landscape and Best Practices Key Informants

Key Informants

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

Ellen Eidem, MS, Director, Office of Women's Health, Los Angeles County Department of Public Health, and **Viviana Criado**, MPA, Project Manager, Los Angeles Alliance for Community Health and Aging (LAACHA) Office of Women's Health, Los Angeles County Department of Public Health

Tony Kuo, MD, MSHS, Steering Group Member, Healthy Brain LA Coalition and Director, Division of Chronic Disease and Injury Prevention, Los Angeles County Department of Public Health

Amy M. Phillips, Director of Program Administration, Little Tokyo Service Center

Maribel Marin, MCP, Executive Director, 211 LA County

Monica Moore, MSG, Community Health Program Manager, Mary S. Easton Center for Alzheimer's Disease Research at UCLA

Michael Murray, Director, Business Integration, AARP California

Sang-Mi Oh, Senior Vice President and Executive Director American Heart Association LA Chapter

Kiera Pollock, MSW, Director of Senior Services, Los Angeles LGBT Center

Lorenza C. Sánchez, Assistant Director, Aging & Adult Services, Los Angeles County Workforce Development Aging & Community Services

Diane Ty, Director, Alliance to Improve Dementia Care and Director, Center for the Future of Aging Milken Institute

Freddi Segal-Gidan PhD, Associate Professor of Clinical Neurology, USC Keck School of Medicine

Best Practices Interviewees

Judy Thomas, Executive Director, and **Kris Wallach**, Chief Operating Officer, Coalition for Compassionate Care of California

Wynnelena C. Canio, MD, AGSF, Geriatrician (Internal Medicine) and Psychiatrist, Clinical Lead for the Kaiser Permanente Northern California Dementia Care Program and Chief of Kaiser Permanente San Rafael Geriatric Medicine and
Nancy Powers Stone, Director, Redwood Caregiver Resource Center in Santa Rosa, Californiaf

Jennifer Stevens, Human Services Program Consultant, Minnesota Department of Human Services (DHS) and **Catherine Engstrom**, Family Caregiving Supports Developer, Family Caregiving Supports Developer, Minnesota Board on Aging/Department of Human Services

Paula James, AHCA Administrator, Florida Agency for Health Care Administration

APPENDIX E: Adult Day Services Overview

An essential component of the long-term care system—a continuum of home, community-based, and institutional services and supports that help to address the medical and non-medical needs of people with limitations—is Adult Day Services (ADS). This valued community-based resource enables older adults and individuals with disabilities to age in place and their caregivers to continue providing care and stay in the workforce. Three licensed ADS models operate in California:

Adult Day Program (ADP). ADPs are the social model of ADS (i.e., non-medical) provided in a licensed community-based facility. ADPs provide care to persons 18 years of age or older in need of personal services, supervision, or assistance essential for sustaining the activities of daily living or for the protection of these individuals on less than a 24-hour basis. At a minimum, ADPs provide an individual plan of care, activity programs, dietary services, assistance with medication management, meals/snacks, personal care, supervision, and support. ADPs additionally provide critical services to caregivers including 1) respite, 2) the ability to enter or remain in the work force, and 3) information and referrals to other public/private safety-net programs and services that enable participants to continue living in their home and community for as long as medically possible.

Most ADPs receive support funds from a variety of sources (e.g., local government contracts, the Older Americans Act, donors) and charge a flat rate to participants or offer a sliding scale. Some ADPs may offer scholarships or waive a portion or all fees for participants with limited to no income.

Adult Day Health Care (ADHC). ADHCs are the medical-model of ADS through which a community-based licensed health-facility offers frail elderly persons or adults with disabilities, at risk for institutional placement, a full range of skilled health care and psychosocial services provided by a multidisciplinary team. Activities include health services, therapeutic activities, and social services. ADHC participation requires a physician referral and must include all the services of an ADP plus transportation, medication administration, social services, skilled nursing, physician services, mental health services, occupational therapy, physical therapy, and speech therapy. ADHCs provide caregivers respite and support, and the opportunity to enter or stay in the workforce.

In 2012, California transitioned ADHC funding for Medi-Cal beneficiaries from a Medicaid optional state plan benefit to a managed care benefit, known as "Community-Based Adult Services" (CBAS). ADHC participants not covered under CBAS pay privately, often on a sliding scale.

Alzheimer's Day Care Resource Center (ADCRC). ADCRC is a specialized program that addresses the psychosocial, mental, functional, and cognitive needs of individuals with dementia. ADCRCs provide a range of services to assist each participant to function at her or his highest level, while providing caregiver support and respite. Like ADPs, ADCRCs receive funds from various sources and either charge a flat rate or offer a sliding scale to participants. Many also offer scholarships to participants with limited ability to pay.

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