SANTA CLARA COUNTY

ADULT CAREGIVER STUDY

Advancing a Person- and Family-Centered Caregiving Support System

JUNE 2023 | LIFECOURSE STRATEGIES

TABLE OF CONTENTS

EXECUTIVE SUMMARY I

INTRODUCTION 1

SANTA CLARA COUNTY ADULT CAREGIVER STUDY: PROJECT DESIGN 6

WHO ARE SANTA CLARA COUNTY CAREGIVERS? 9

SANTA CLARA COUNTY CAREGIVING SUPPORT SYSTEM LANDSCAPE 12

LISTENING TO CAREGIVERS AND EXPERTS 21

CAREGIVER POLICIES AND INITIATIVES 30

CAREGIVER BEST PRACTICE PROGRAMS 33

CONCLUSION: THE WAY FORWARD 37

APPENDIX A: STUDY RECOMMENDATION NOTES 39

APPENDIX B: COMMON REPORT ABBREVIATIONS AND TERMS 42

APPENDIX C: SANTA CLARA COUNTY COMMUNITY-BASED ORGANIZATIONS 44

APPENDIX D: SANTA CLARA COUNTY LICENSED HOME CARE ORGANIZATIONS 49

APPENDIX E: STUDY INTERVIEWEES 50

APPENDIX F: STUDY WORKGROUP MEMBERS 52

REFERENCES 53

ACKNOWLEDGEMENTS 55

Executive Summary

The experience of providing care for a loved one varies from person to person. It can be meaningful, isolating, expensive, burdensome, fulfilling, overwhelming, stressful, and exhausting. Caregivers may experience some of these emotional and physical responses simultaneously, and their responses can and often do change—sometimes day to day, sometimes over time. But what many of the 38 million family caregivers in the U.S. have in common is that they step into their caregiving role feeling unprepared and unsure of where to go for information, help, and support.[1]

Caregiving has attracted significant attention in recent years. The 2022 *National Strategy to Support Family Caregivers* and the April 2023 *Presidential Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers* outline a robust federal strategy to provide more comprehensive and coordinated care and support for family caregivers.[2,3]

California, too, is addressing the caregiving issue. In addition to supporting these recent federal initiatives, the California Department of Aging (CDA) is leading implementation of the 2021 California Master Plan for Aging (MPA), "a ten-year blueprint for building a California for all ages." Goal four of the MPA's five bold goals is "Caregiving that Works."[4] Caregiving program changes are also happening at the county level in the Golden State. Concurrent with CDA's efforts to address caregiving, counties across the state are evaluating and developing plans to respond to the rapidly escalating need for accessible, affordable, and culturally responsive caregiving services.

In May 2022, as part of the Age-Friendly Three-Year Action Plan, the Santa Clara County Board of Supervisors authorized the Santa Clara County (SCC) Adult Caregiver Study to identify and address the demand for, availability and accessibility of, and gaps in caregiving services and supports in SCC through actionable recommendations, before county resources are overwhelmed. The study conducted an analysis of caregiving in SCC with a primary focus on family caregivers—because of their numbers and needs—and a secondary focus on direct care workers, an essential caregiver workforce.

Study Activities and Definitions

Key study activities included the following:

- Analysis of SCC family caregiver data.
- Surveys of organizations serving family caregivers and direct care workers.
- Interviews with caregiver experts—individuals with extensive experience working with or on behalf of family caregivers and direct care workers.
- Focus groups with family caregivers and direct care workers.
- Review of relevant caregiver legislation.
- Research on caregiver best practices.

Family caregivers of adults with care needs are from all adult age groups: young (Generation Z and millennials), middle-aged, and older. They are spouses, adult children, siblings, parents, friends, neighbors, and families of choice. Some live with their care recipient; some live in a different state.

Not surprisingly, family caregivers represent all socioeconomic classes, races, ethnicities, and genders. They provide a range of supports, including help with activities of daily living (ADLs)—eating, bathing, dressing, toileting—and instrumental activities of daily living (IADLs)—shopping, preparing meals, paying bills, and cleaning. They may also provide skilled care, such as managing medications and medical equipment. SCC has approximately 177,000 family caregivers.[1]

Direct care workers are individuals who are paid to assist older and disabled adults. The most common categories of direct care workers are personal care aides, home health aides, and certified nursing assistants. Like family caregivers, direct care workers assist with ADLs, IADLs, and sometimes skilled care.

Direct care workers are an essential part of the caregiver equation. They provide critical services to older adults and persons with disabilities. SCC has approximately 40,000 direct care workers providing personal care aide services.[5] Just over 30,000 are In-Home Supportive Services (IHSS) providers, most of whom are family members.[6,7] [Ÿ] The remaining direct care workers are personal care aides for home care organizations and other community organizations, and private personal care aides.

Key Study Findings

SCC *family caregivers* say they need:

- An accessible, responsive, streamlined information and referral system that can assist family caregivers no matter where they are in their caregiver journey.
- Respite care, in and out-of-home, that is affordable and accessible.
- More support groups and counseling.
- Improved transportation for care recipients.
- Education and trainings on various caregiving issues, including managing care recipient needs and behaviors, legal and financial issues, and medical/nursing tasks (e.g., organizing and administering medications, performing wound care, and managing medical equipment), which so many family caregivers provide.

[Ÿ] IHSS program provides in-home assistance to eligible aged, blind, and disabled individuals as an alternative to out-of-home care and enables recipients to remain safely in their own homes.

SCC *direct care workers* say they need:

- A living wage.
- Stable and steady work hours.
- Training and career advancement.
- Safe working conditions.
- Job oversight and support.
- Affordable housing and other supports (e.g., childcare and transportation stipends).

A prominent study finding is that SCC's caregiving support system, a component of the long-term care service system (which includes medical and non-medical care for persons unable to live independently), is underdeveloped. Ten Adult Day programs (ADPs)—a non-medical model of care for adults and persons with disabilities—and seven Adult Day Health Care (ADHC) centers—a medical model of care for older persons and adults with chronic medical, cognitive, or mental health conditions—serve the entire county. A small collection of community-based organizations in SCC provides additional caregiver services and supports, but their collective capacity is insufficient to meet current and future caregiver needs. Moreover, few of any of these types of caregiver programs and services are available in the eastern and southern parts of the county.

When SCC's current caregiver service landscape is juxtaposed with key demographic and health care projections, the gap between resources and needs widens. First, the number of adults aged 65 and older in SCC is projected to make up to 20 percent of SCC's population by 2030 and 25 percent by 2060.[8] Second, the number of individuals aged 55 and older with Alzheimer's disease and related dementias (ADRD) is also expected to increase from 45,924 in 2025 to 82,336 in 2040.[9,10]

These population projections underscore that the number of family caregivers and direct

care workers needed to attend to older adults and adults with ADRD in the county will have to increase. SCC has a tremendous opportunity to strengthen and expand its caregiving support system to meet the needs of both groups, now and in the future. Not addressing the moment poses risks. Failing to provide financial and service supports to family caregivers and direct care workers is likely to result in major human and economic costs for the county.

To shore up and expand SCC's caregiver services, SCC Social Services Agency Seniors' Agenda, in partnership with representatives of relevant groups (supporters, advocates, unions, experts, family caregivers, direct care workers) should evaluate the study recommendations below. The partnership should then fold approved recommendations into a multipronged five-year plan to advance a person- and family-centered caregiving support system for SCC.[ø] To be effective, some selected recommendations may require others to be acted upon simultaneously.

Implement system changes

- Enhance an existing information and referral system to create a "no wrong door" model that meets the needs of caregivers wherever they are in their caregiving journey.*
- Evaluate the opportunity to develop a countywide direct care worker registry for care recipients, family caregivers, and others.
- Identify opportunities to provide more support and oversight to IHSS providers. Request that health care systems and providers recognize, engage, and support family caregivers in their caregiving role and participate in county caregiving initiatives.

[ø] In this report, **county** refers to all residents, organizations, and entities in SCC, and **County** refers to SCC government.
[*] No Wrong Door means every door in the system should be the right door with a range of services accessible to everyone from multiple points of entry.

Promote caregiver awareness, education, and training

- Launch a countywide caregiver education campaign that will help residents recognize themselves as caregivers and seek information and support.
- Use existing information and partnership communication channels to notify family caregivers, IHSS providers, and other direct care workers about caregiver education and training opportunities.
- Increase public awareness about the importance of participating in the California Health Interview Survey (CHIS) and Behavioral Risk Factor Surveillance Survey (BRFSS).

Increase the availability and affordability of caregiver services and supports

- Develop a long-term plan to increase the number and affordability of respite care services in- and out-of-the-home.
- Evaluate the viability of creative program ideas and partnerships to solve SCC's long-term care needs–including caregiver challenges and needs.
- Form a coalition of long-term care stakeholders (community organizations, advocates, health care systems and payers, etc.) to explore developing new sources of caregiver funds.

Invest in the direct care workforce

- Through cross-sector collaboration, increase wages for direct care workers.
- Research the viability of creating and implementing an IHSS direct care worker career ladder.

Promote paid family leave benefits

- Develop a campaign to increase knowledge about paid family leave benefits for all employees and employers in the county, including employees of Santa Clara County.

Introduction

Adults living with a serious health condition or disability are living longer than ever before. And many want to remain in their homes and communities for as long as possible. Major factors contributing to these developments include new medical advancements, technology, and the contributions of caregivers—family caregivers primarily, but also direct care workers. Caregivers provide fundamental support that enables people with a serious medical condition or disability to age in place and live as independently as possible.

Ubiquity of Family Caregiving

Family caregivers of adults with care needs are members of every community. While some of these individuals may not think of themselves as a "caregiver" or define the care and support that they provide as "caregiving," they are part of a large and growing group of people providing millions of hours of unpaid care to their loved ones every year in the U.S.

Family caregivers assist with functional everyday tasks that include activities of daily living (ADLs)—eating, bathing, dressing, toileting—and instrumental activities of daily living (IADLs)—shopping, preparing meals, paying bills, and cleaning. Many also perform complex medical and nursing tasks, such as managing wound care, medications, and feeding tubes, and operating medical equipment from Hoyer Lifts to glucose meters.

Approximately 38 million adults provide unpaid care to an adult with functional limitations in the U.S.[1] The 2020 National Alliance for Caregiving report, *Caregiving in the U.S.,* underscores several reasons for this number: aging baby boomers, direct care workforce shortages, a preference for home- and community-based support over institutional care, and greater self-awareness among family members that they are in fact caregivers.[11]

With so many people currently caring for an older adult or adult with a serious illness or disability, the experience of family caregiving can be appropriately referred to as ubiquitous. Rosalyn Carter's 2011 statement that "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers" aptly characterizes caregiving as a family life-cycle stage for millions of Americans.

People enter the caregiving role in different ways. Some become caregivers overnight; others slowly find themselves providing more and more care for a loved one over time. The latter experience is common for individuals caring for persons living with a progressive dementia, as well as those caring for individuals with complex or serious health conditions and limited functional abilities.

Regardless of the process of becoming a family caregiver, most people step into their caregiving role feeling unprepared. Many are unaware of the scope of their care recipient's care needs, what they need to provide safe care, or how they will provide it. Added to this, caregivers typically do not know how long their caregiver journey will be or what personal adaptations they will need to make along the way, physically, emotionally, and financially. Furthermore, few receive information, training, and support when they need it most, at the start of caregiving.

Instead, most family caregivers gather information about their care recipient's health condition and where and how to address health, social service, legal, and financial needs through hands-on learning. This process is especially difficult for individuals juggling multiple responsibilities (e.g., complex care, work, school, children, personal needs).

Family caregiving can be a deeply rich and meaningful experience, but it can be stressful. Caregivers consistently report experiencing depressive symptoms, burden, loneliness, isolation, and emotional stress related to caregiving.[11,12] They also report the negative effects of caregiving on their physical health. In 2019, the Centers for Disease Control (CDC) identified caregiving as a public health issue.[13] Another major stressor for caregivers is the financial costs of providing care. From care recipient medical expenses to housing and home modifications to out-of-pocket costs and disruptions in employment (e.g., job loss, reduced work hours), the economic impact of caregiving is significant for many caregivers.[14]

> *"Even the adult daycare centers, when they look at income, I don't think they're looking at the cost of living for care recipients or the out-of-pocket costs that family members who care for them pay. I am paying a lot and am worried about my retirement."*
>
> – Family caregiver

Recognizing the omnipresence of family caregiving is just the beginning of the task at hand for municipalities and communities across the country. More can and needs to be done, especially for caregivers who are low-income and experience service barriers related to their race, ethnicity, and primary language.

Direct Care Workers: Essential Caregivers

America's caregiver equation includes another critical variable: paid caregivers. This group, generally referred to as direct care workers, is paid to assist older and disabled adults with ADLs, IADLs, and other needs. The three occupational categories for this workforce are: 1) home care workers, which includes personal care aides (PCAs), home health aides (HHAs), and some nursing assistants (referred to in some states as certified nursing assistants, or CNAs); 2) residential care aides, which includes PCAs, HHAs, and nursing assistants who work in group homes, assisted living communities, and other residential care settings; and 3) nursing assistants in skilled nursing homes.[15]

Direct care workers can be employed by individuals (care recipients, family members, or conservators) and organizations (community centers, home care organizations, and assisted living and skilled nursing facilities). Most direct care workers are women; approximately half are immigrants, and many come from historically marginalized and underserved communities.[15,16] Not unlike family caregivers, direct care workers face a number of profound challenges, chief among them that caring for older adults and people with disabilities is hard work, physically and emotionally, with myriad health and safety risks to the caregiver.

Adding to these challenges, direct care worker wages are low, and most workers have limited access to benefits, training, career advancement opportunities, and affordable housing. Together, these factors have contributed to a shrinking direct care workforce, just as the needs for these workers has grown.

Advocacy and Activism: California's Response to Caregiving

Legislation and Plans

California was an early adopter of legislation supporting family caregivers. In 1984, the state authorized the development and funding of a statewide system of Caregiver Resource Centers (CRCs) through *The Comprehensive Act for Families and Caregivers of Brain-Impaired Adults* [Chapter 1658, Statutes of 1984]. California has 11 CRCs throughout the state 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 and Parkinson's disease; cerebrovascular diseases; traumatic brain injury; and other serious illnesses. CRCs provide a wide range of free and low-cost services to California caregivers, from information and caregiver assessments to family consultation and respite. All CRCs use CareNav™, an online application, as both a caregiver-facing information portal and repository for longitudinal caregiver data.

As the most populous state in the country, California is guided by several caregiving blueprints. The most seminal of these is the 2018 report, *Picking Up the Pace of Change in California: A Report From the California Task Force on Family Caregiving*.[17] Seven policy recommendations outlined in the report were submitted to the California State Legislature. Together they detail key actions needed to support the health and financial well-being of California family caregivers, such as increasing caregiver access to information and education, providing more affordable and accessible services, and implementing standardized caregiver assessments across the state.

Building on the Task Force report, goal four of California's 2021 *Master Plan for Aging (MPA),*[4] "Caregiving that Works," includes three core strategies: family and friends caregiving support, direct care job creation, and virtual care expansion. The goal also includes a target of creating one million caregiving jobs by 2030.

Caregivers are an important focus of CalAIM (California Advancing and Innovating Medi-Cal), a multiyear plan (2022-2027) to transform California's Medi-Cal program.[18] Medi-Cal is the state's public health insurance program (California's Medicaid program), which provides health care services for low-income individuals. Since older adults represent the fastest-growing age cohort receiving care through California's safety-net provider system (which includes the array of Medi-Cal providers delivering a broad range of health care services to medically underserved and uninsured populations), assessing and responding to the needs of caregivers is essential to supporting the health of Medi-Cal beneficiaries with serious illness and disability.[19]

CalAIM is administered by Medi-Cal managed care health plans. The initiative contains several programs that engage caregivers, including Enhanced Care Management, which requires contracted providers to include caregivers in members' person-centered care plans and provide education to them to support the objectives described in the plan of care, and Community Supports, which offers short-term respite services to caregivers of eligible Medi-Cal members.[20]

Programs and Initiatives

California's commitment to innovative and responsive health care transformation led the state to create the groundbreaking IHSS program in 1974, the largest personal care program in the U.S. IHSS services include housecleaning, meal preparation, laundry, grocery shopping, personal care services, accompaniment to medical appointments, and protective supervision for the mentally impaired. Services can be provided by a parent, a spouse, or a caregiver—referred to as an "IHSS provider." IHSS providers may provide certain paramedical services (e.g., administration of medications, puncturing the skin), with appropriate training, if "ordered by a licensed health care professional lawfully authorized to do so, which a person could provide for themselves, but for their functional limitations."[21]

California has been monitoring the direct care worker issue for many years with the goal of developing policies to address recruitment, training, and retention challenges. In 2021, there were an estimated 811,670 direct care workers in the state, encompassing PCAs (which include the state's 550,000 IHSS providers), HHAs, and CNAs.[16,22,23] ž To increase these numbers, California recently invested over $964 million in a series of programs and initiatives to support direct care workers. Examples include IHSS Career Pathways, which provides training opportunities to enhance IHSS providers skills, and California GROWs (CalGrows), a CDA Direct Care Workforce Initiative, which incentivizes, supports, and funds career pathways for the home and community-based services (HCBS) workforce (non-IHSS).[24]

State programs and initiatives for family caregivers and direct care workers have made an impact. Still, work remains to meet the needs of both caregiver groups at the state and county level.

SCC's Caregiver Imperative

Santa Clara County is abundantly diverse in its geography and population. It is also a county committed to addressing emerging social needs and challenges, including the cost of living, housing and homelessness, and a rapidly aging population. In 2021, the total population in SCC was 1,805,508, and adults aged 65 and older comprised 14.5 percent of the adult population—1,489,581—which includes adults aged 18 and older. This percentage is expected to increase to 20 percent in 2030. [8,25]

Today, approximately 177,000 family caregivers are caring for an adult in SCC.[1] The number of direct care workers providing paid caregiver services and supports to adults in the county is estimated at 40,000 (based on US Bureau of Labor Statistics and IHSS data).[5] This includes 30,214 IHSS providers.[6] With the last of the baby boom generation retiring in 2030, SCC will have even greater numbers of older and disabled adults and caregivers—family caregivers and direct care workers—in need of services. Addressing the caregiving issue now is imperative to meeting SCC's current and future caregiving needs.

ž The exact number of direct care workers in California is difficult to calculate. Some workers are independent providers and not included in formal counts; others have multiple jobs in various categories and could be counted more than once.

Santa Clara County Adult Caregiver Study: Project Design

As a multiracial, multiethnic, multicultural, and multilingual county, SCC is committed to ensuring health and social equity for all residents. To meet its commitment to older adults and caregivers—family caregivers and direct care workers—today and tomorrow, the SCC Board of Supervisors authorized the SCC Adult Caregiver Study.

Primary Framing Objectives

- Identify who needs caregiving in the county, the types of caregiving needed, who is currently providing care—formally and informally—and the gaps and barriers to accessing needed support.
- Map the landscape of available caregiver services.
- Identify caregiver policies and best-practices for SCC to promote or adopt.
- Develop actionable recommendations to address the needs for and gaps in caregiver services and supports in SCC.

Methodology

The study used a mixed-methods approach of collecting and analyzing primary quantitative and qualitative data to meet the study objectives. It also analyzed secondary caregiver data from the following sources:

- California Health Interview Survey data (CHIS) for SCC (2019 and 2020). CHIS is a critical source of data on Californians.
- CareNav™ data for SCC (FY2021 and FY2022). CareNav™ is the online data system used by California's 11 CRCs to collect caregiver and care recipient data. It is also an online platform for caregivers to receive specialized information and communicate with CRC staff. Family Caregiver Alliance (FCA) serves as the Bay Area CRC for six counties, including SCC.
- Sourcewise caregiver survey data (2019)—part of the Santa Clara County Area Plan on Aging (2020-2024). Sourcewise is the designated Area Agency on Aging for SCC, providing services and supports to older adults, persons with disabilities, and caregivers.

Data used for the secondary caregiver data analysis came from 127 unduplicated SCC caregivers served by FCA who completed CareNav™ assessments in two fiscal years (FY2021 and FY2022) and 161 SCC residents who reported "currently providing care for a family member or friend aged 18 years and older" in CHIS in 2019 and 2020, combined. Selected variables and figures for the analysis mirror those used by the University of California Davis Family Caregiving Institute in their evaluation of the statewide CRC system.[26]

Key findings from the Sourcewise caregiver survey data (2019) were not part of CHIS-CareNav™ caregiver data analysis but are presented in the report to highlight information not included in this analysis. The Sourcewise caregiver data are from an online survey sent to 1,525 SCC residents identified as caregivers in 2019; 181 caregivers completed the survey.[Ω]

[Ω] SCC caregivers who received the survey were identified by Sourcewise, Family Caregiver Alliance, Avenidas, and the Alzheimer's Association.

An accompanying data chartbook to the SCC study, *Santa Clara County Adult Caregiver Study Data Chartbook,* includes tables of the caregiver and organizational survey data collected and analyzed for this study. It also includes CHIS California (statewide) caregiver data (2019 and 2020), for additional reference.

Organization Survey Data*

- Survey of organizations providing services and/or supports to family caregivers.
- Survey of organizations providing services and/or supports to direct care workers.

Key Informant Interviews and Caregiver Focus Groups (methodology details below)

- Interviews with caregiving experts.
- Focus groups with family caregivers and direct care workers.

Caregiver Policy/Legislation

- Review of caregiver policy, laws, and pending legislation relevant to SCC.
- Interviews with California caregiver policy experts.

Caregiver Best-Practices Environmental Scan

- Environmental scan of caregiver best-practices.

Interview and Focus Group Methodology: Four focus groups–two with family caregivers and two with direct care workers–were conducted. Participants were selected from online applications to represent the diversity of SCC with respect to race, ethnicity, primary language, gender, relationship to care recipient, and residential zip code. Each focus group was held for 90 minutes. Two were in person, and two were hosted on Zoom (a video conferencing software program). One of the Zoom focus groups was held with Vietnamese-speaking direct care workers; two professional interpreters provided translation. All participants gave verbal informed consent, and each participant received a $30 gift card for their participation.

The caregiving expert interviews and focus groups were video recorded, with participant consent, and transcribed. Transcripts were analyzed by multiple reviewers and coded using an online qualitative analysis platform. Analysis of words (word repetitions, key words in context) and constant comparative analysis (comparing themes) were used to identify emergent themes and reach consensus on final themes.

Limitations: The study has several important limitations, which may restrict the generalizability of the study findings. Due to time and project constraints, the study conducted only four caregiver focus groups. While focus group participants contributed salient information about the caregiver experience in SCC, future studies should expand the number of caregiver focus groups and include more caregivers representing underserved communities. Additionally, efforts should be made to include caregivers who lack access to the online application process, which was used to enroll focus group participants for this study. Last, the small number of SCC caregivers in both the CHIS - SCC (161) and FCA - SCC (127) datasets represents another limitation.

* Some survey questions had a "check all that apply" response option, so corresponding percentages do not add up to 100 percent.

Note: Although elder abuse is not a focus of the study, it is a critical issue that merits attention. In FY2021, the Santa Clara County APS program conducted in-person case investigations and provided services to 10,025 active abuse cases throughout the county.[27,28] The National Council on Aging reports that abusers are both women and men. In almost 60% of elder abuse and neglect incidents, the perpetrator is a family member. Two-thirds of perpetrators are adult children or spouses.[28,29]

Knowing about elder abuse and self-neglect, what they are and are not, and encouraging reporting of abuse to local adult protective services (APS) programs or to the long-term care ombudsman, if the older adult or person with disability resides in a long-term care facility, is a shared societal responsibility. SCC representatives and partners must continue to discuss and address elder abuse in the context of all services and supports for older adults, dependent adults, and caregivers.

> *"Not all caregivers have good intent. A lot of abuse, neglect, and exploitation happens by family members."*
>
> – Caregiver expert

Who Are Santa Clara County Caregivers?

Family caregivers are often described as the backbone of every community's long-term care system. They are. Most long-term care is provided at home by unpaid family members, many of whom serve as a bulwark against placing care recipients in a nursing home or other facility.

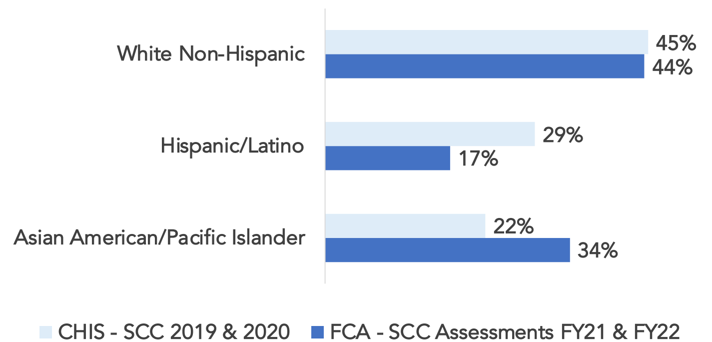
In 2021, close to a fifth of all adults (aged 18 and older) in SCC provided unpaid care to adults. It is equally important to look at the component parts of this aggregate number. Caregiver sociodemographic, health, and other characteristics provide valuable information about who is providing care, what their caregiving needs are, and whether they have access to services and supports that enable them to continue safely in their caregiving role.

Vital Role of SCC Family Caregivers

An analysis of sociodemographic characteristics of SCC family caregivers, from the CareNav™ and CHIS datasets, reveals that most family caregivers are women, an adult child of the care recipient, 45 – 64 years of age, and married. White non-Hispanic caregivers are the largest racial/ethnic group, followed by Asian American/Pacific Islanders in the CareNav™ data (34 percent) and Hispanic/Latino in the CHIS data (29 percent). See Figure 1.

Most caregivers report "some college" or being a "college graduate." Over half live with the care recipient. Although the impact of caregiving on caregiver employment (outside of caregiving responsibilities) is frequently cited as significant in caregiving research, the majority of caregivers in both datasets report no change in employment status associated with their caregiving.[11] A small percentage of CHIS and CareNav™ caregivers report earning income below the poverty level.

Figure 1. Caregiver Race/Ethnicity*



*Other racial identities beyond the three in this chart are not reported due to the small CHIS and CareNav™ datasets.

Alzheimer's disease and related dementias (ADRD), stroke, and diabetes are the top reported medical conditions for care recipients. When caregivers were asked how many hours per week they provide care, most CareNav™ caregivers report providing 40 or more hours, while most CHIS caregivers report 10 hours or less. This discrepancy may be associated with the fact that as caregiver clients of FCA, CareNav™ caregivers have greater awareness about their caregiving role. By contrast, CHIS caregivers are participants in a statewide health survey and may not view their caregiving role or needs similarly.

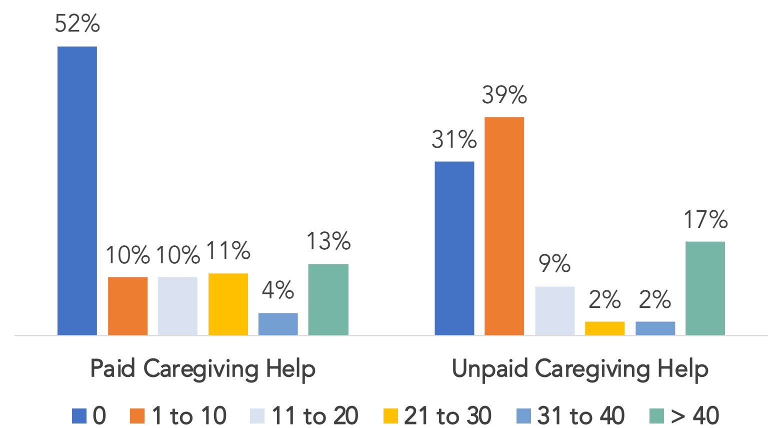
How caregivers rate their health status and how lonely they feel, provide important insights into the personal impact of the caregiving role on caregivers. A vast majority of caregivers report their overall health as "fair," "good," or "very good." In response to the UCLA 3-Item Loneliness Scale, half of caregivers report feeling lonely "some of the time" or "often."[30]

FCA Family Caregivers

FCA is a state and national leader in family caregiver assessment, education, training, and policy. With over 40 years of experience serving family caregivers, FCA collects a range of caregiver and care recipient data through the CRC standardized caregiver intake and uniform caregiver assessment–reported in CareNav™. The following is additional nuanced information about the caregiver experience in SCC from FCA caregivers.

- **Over half** provide care for either two to five or more than five years.
- **83 percent** provide the highest level of caregiver intensity (formula source: AARP, Level of Care Index).[31]
- **79 percent** perform medical/nursing tasks (administering medications, managing tube feedings, providing catheter and colostomy care).
- **Over 90 percent** perform IADL tasks; more than half assist with ADLs.
- **Most report** receiving zero to less than 10 hours a week of paid or unpaid help (Figure 2).
- **36 percent** reported moderate symptoms of depression, and **31 percent** reported either moderately severe or severe symptoms over the past two weeks (instrument source: Patient Health Questionnaire-PHQ-9).[32]
- **58 percent** experience high [caregiver] strain (instrument source: Zarit Burden Interview).[33]

Figure 2. Hours Per Week of Caregiving Help



Sourcewise Data: Caregiver Priorities

In the Sourcewise caregiver survey, caregivers were asked about their needs and priorities.

- **56 percent** reported that in-home assistance is the top service missing for older adults.
- **73 percent** identified respite (short-term break) as the most important unmet need for caregivers.
- **64 percent** said family, friends, colleagues, or word of mouth are the primary source of caregiver information.
- **62 percent** said their primary source for caregiver information is a medical or health professional.
- **Top caregiver priorities are:**
  - Information on caring for a loved one
  - Counseling or help managing care
  - Information on managing difficult behaviors

Direct Care Workers: A Crucial Workforce

Family caregivers, alone, cannot meet the care needs of older adults and persons with disabilities in SCC. **Direct care workers** are an essential part of the caregiver service system.

Despite overlapping responsibilities, each category of direct care worker (PCAs, HHAs, and CNAs) has a distinct structure with specific training, supervision, and oversight requirements. The job category most central to this study, however, is that of PCAs. This group predominantly comprises employees of home care and community organizations (e.g., adult day programs) or individual consumers.

IHSS providers are the largest group of PCAs in California and SCC. Hired and managed by IHSS recipients, IHSS providers provide care that is primarily custodial (i.e., not requiring skilled medical care). As previously noted (see section, *Advocacy and Activism: California's Response to Caregiving*), IHSS providers may be allowed to provide paramedical services, with appropriate training, if ordered by a licensed health care professional.[34] Demographically, direct care workers in California are predominantly women, immigrants, and people of color.

In SCC and communities around the country, the field of direct care work is under stress.[16,35] Low hourly wages (most below a living wage); limited full-time work opportunities and access to benefits; and the absence of wraparound support services to attend trainings (e.g., childcare and transportation stipends), restrict direct care workers' ability to pursue career advancement opportunities and meet their costs of living. Other factors impact the stability and growth of this workforce, including unstable work schedules, physically and emotionally demanding work, and higher risks for work-related injuries and health issues.

Demographics for SCC IHSS providers (2022):[6,7]

- 72 percent of the county's 30,214 IHSS (2022) providers are female, and 28 percent are male.
- 75 percent care for a relative (most are adult children).
- 44 percent are aged 50 to 64, and 39 percent are 18 to 49 years old.
- English is the most common language spoken by providers (46 percent), followed by Vietnamese (22 percent), Spanish (9 percent), and Chinese (9 percent).

Family Caregivers and Direct Care Workers: Both Matter

Most family caregivers and direct care workers in SCC are women between the ages of 45 and 64, who speak English—while Vietnamese, Spanish, and Mandarin are the primary language for many IHSS providers. Both groups provide critically needed personal care assistance for older adults and persons with disabilities, and both need more support. Of note, an increasing number of family caregivers need and depend on direct care workers.

Responding to the needs of family caregivers and direct care workers is essential to building a strong and sustainable caregiving support system in SCC. Family caregivers, who are providing intense care for longer periods than in the past and who cannot afford respite care, want access to a streamlined information system, respite care, and counseling. Direct care workers want education, training, career advancement, benefits, and a livable wage.

Santa Clara County Caregiving Support System Landscape

Home- and community-based services (HCBS) are the structural foundation of every community. They provide a vital network of medical, health, and social services, and other supports, that enable older adults and people with disabilities and their caregivers to live and thrive in community. Each HCBS system is different. Most HCBS providers are nonprofit. Some offer a robust balance of adult day services, senior centers, and home health care; others, especially those in less populated areas, offer fewer and, often, more limited services.

Ascertaining the availability of HCBS in SCC is a precursor to identifying caregiver service gaps and opportunities to close them. To understand the services and supports available to family caregivers and direct care workers in SCC, as well as demographics about each population, the study developed two surveys with questions addressing these issues: one for organizations serving and supporting family caregivers and one for organizations working with or on behalf of direct care workers. Representatives from these organizations are referred to as "caregiver experts" in this report.

Sixty-four HCBS organizations providing caregiving support in SCC were identified and received an online survey link. Thirty-five completed the survey, representing adult day programs and adult day health care centers, health and wellness programs, voluntary health organizations (i.e., Alzheimer's Association), county programs, Medi-Cal managed care health plans, senior centers, VA caregiver programs, and advocacy organizations.

The second study survey was sent to 34 organizations working with or providing support to direct care workers: Thirteen organizations completed the survey, representing home care organizations, IHSS SCC, Public Authority by Sourcewise, and an HCBS organization providing advocacy, training, skill development, and services to people with disabilities.

The *Santa Clara County Adult Caregiver Study Data Chartbook* presents both surveys in full, aggregate data responses for items in each survey, and the names of the organizations that completed the surveys. The sections that follow present highlights from the two surveys.

Serving and Supporting Family Caregivers

Top services provided to family caregivers are case management/family consultation—care navigation, information and assistance/ specialized information, and caregiver education and training. Almost half (15) of respondent organizations provide caregiver support groups. See Table 1.

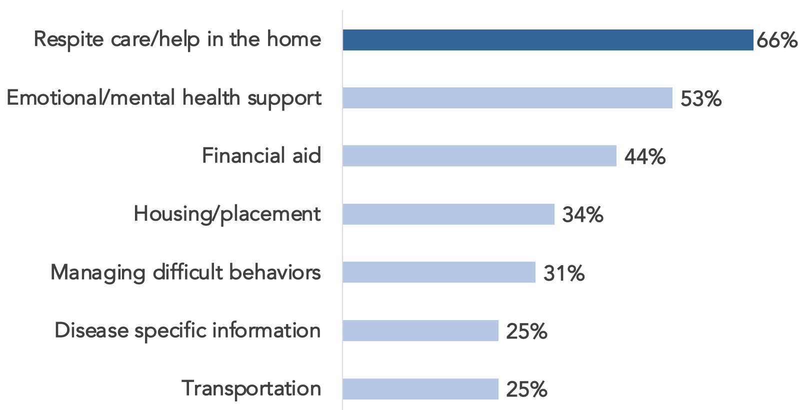
Table 1. Caregiver Core Services

Caregiver Core Services (n=34 Organizations)		
	#	%
Case Management/Family Consultation--Care Navigation	23	64%
Information & Assistance/ Specialized Information	20	56%
Caregiver Education & Training	17	47%
Caregiver Support Groups	15	42%
Dementia Care Education/Training	11	31%
Advance Care Planning	10	28%
Durable Medical Equipment	10	28%
Respite Care: Out-Of-Home	10	28%
Action Plan	8	22%
Transportation	8	22%

The majority of organizations reported using a combination of in-person, internet, and telephone service delivery methods (although most in-person services were not available during the COVID-19 crisis). Slightly more than three-quarters (76 percent) of family caregivers receiving services and support are women, 40 percent are White, 19 percent are Asian, 17 percent are Latinx, and 14 percent are African American/Black.

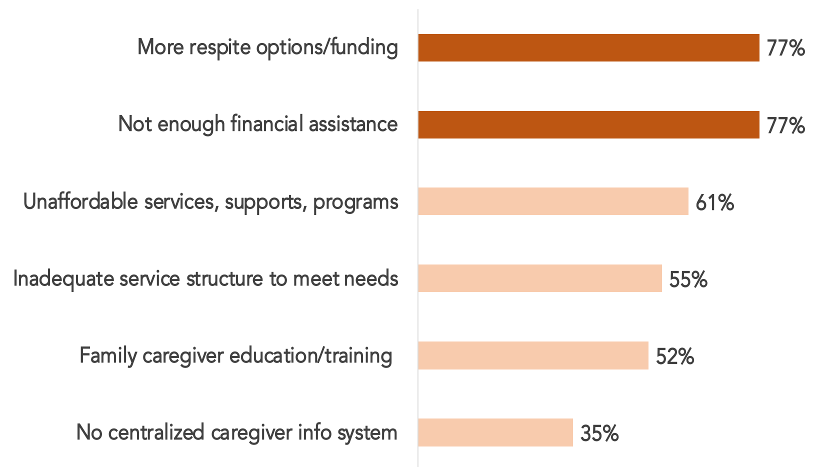
Over 50 percent of caregivers report a household income of less than $59,000 a year, and 28 percent have income between $60,000 and $99,000. English is the most common language spoken among caregivers (72 percent), followed by Spanish (10 percent), and Mandarin (5 percent). Most organizations provide services to family caregivers who are IHSS providers.

Figure 3. Family Caregiver Needs



Major family caregiver needs are for respite care/help in the home, emotional/mental health support, and financial aid (Figure 3). Respite care and financial support were also reported as the top gaps in caregiver services (Figure 4). The most common health condition for care recipients is dementia (69 percent), followed by frailty/advanced age (58 percent), multiple conditions (50 percent), and mobility issues (38 percent). Regarding the types of support organizations provide to care recipients, over half (56 percent) provide emotional support and 30 percent provide adult day care.

Figure 4. Gaps in Services/Supports



Several other survey items provided additional insight into the network of organizations providing services and supports to family caregivers. All respondents reported providing services Monday through Friday, 84 percent do not charge for caregiving services, less than half receive grants to provide caregiver services, and over half report partnering with adult day programs, adult day health care centers, Community-Based Adult Services (CBAS) programs, and senior centers.[Š]

Over 80 percent provide services in Spanish, 54 percent in Mandarin, 38 percent in Cantonese, and 35 percent in Vietnamese. The chief reason caregivers stop requesting support from an organization is the death of the care recipient.

[Š] CBAS centers are licensed ADHCs for older adults and adults with certain disabilities; CBAS is a Medi-Cal Managed Care benefit for eligible Medi-Cal beneficiaries.

To gather more nuanced information about organizations providing family caregiver services and supports in SCC, respondents identified resources and supports that are missing or in limited supply that, if available, would improve their ability to serve family caregivers.

What resources or supports–including those that are missing or that there are not enough of–would improve your ability to serve family caregivers?

A Central Information System	Addressing the High Cost of Living
"We need a single coordinated information/ referral and intake system that can manage a large volume of inquiries to provide caregivers with general information about caregiving and locally available resources. The system should also be able to screen and refer caregivers to specific organizations."	"Many family caregivers leave their jobs to care for their family members. Some are able to receive payment for caregiving through IHSS, but the hourly rate is insufficient for the high cost of living in this county."

A Reframing of Family Caregiving	A Registry of Direct Care Workers
"Redefine family caregiving away from a narrow, crisis-driven definition (e.g., caring for very sick/elderly) and towards a holistic human definition (e.g., caring for those around us is something we do all the time)."	"We need a registry listing reliable, vetted, skilled, and affordable home care providers that are not just IHSS providers."

Building the Workforce	Funds and Affordable Housing
"We need more trained physicians, nurses, nurse practitioners, trained professional caregivers/ CNAs, more financial planners with experience in neurological diseases."	"The county needs more funding for respite care along with lower-cost respite options and more shared housing options."

SCC Caregiver Service Point Maps

The caregiver service point maps on the following pages detail the location of HCBS that provide direct services and supports to family caregivers (i.e., services provided directly to the family caregiver) in SCC by supervisorial district. They include the following types of organizations.

- Adult Day Programs
- Adult Day Health Care Centers
- Community-Based Organizations
- Senior Centers

Appendix B lists organizations in each of the above categories. Community-based organizations that provide direct services and supports to caregivers in SCC but do not have a physical address in the county are marked with an asterisk in the list and grouped in San Jose, the county seat, in the point maps.

Despite variability across senior centers in the level of direct services that they offer family caregivers, all SCC senior centers were included in the point maps because they are an important service linchpin for older adults and caregivers in the county.

Community-based organizations that provide important, albeit indirect, services and supports to SCC family caregivers (i.e., services that benefit family caregivers but are not provided directly to them) are not included in the point maps but are listed separately in Appendix B.

What the Maps Tells Us

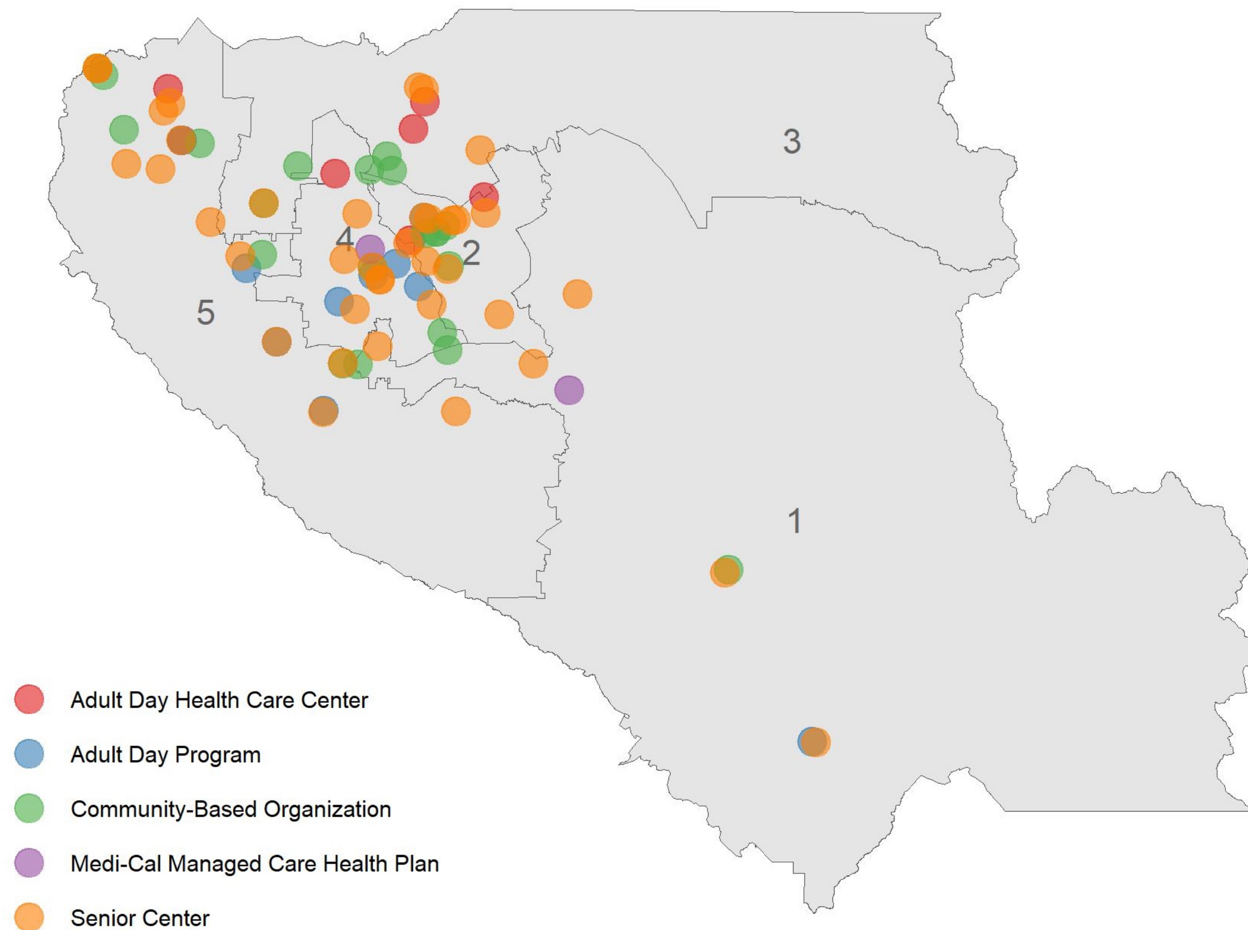
The total number of HCBS in SCC is modest, given the nearly 1.5 million adults aged 18 and older living in the county. Most services are clustered around cities and dense population centers in Supervisorial Districts 2 and 4. By contrast, the southern, eastern, and western parts of the county, which are the lower population density areas comprising Supervisorial Districts 1, 3, and 5, have very few HCBS. Residents in these districts typically must travel elsewhere for services.

Several organizations are in the process of developing new adult day services in the county; two are scheduled for the southern and eastern parts of the county:

- On Lok PACE is planning to open a PACE program in South San Jose.
- Live Oak Adult Day Services is planning to open an ADP on the eastern side of SCC.
- WelbeHealth is planning to open a PACE program in San Jose (Hamilton Avenue and Meridian Avenue).

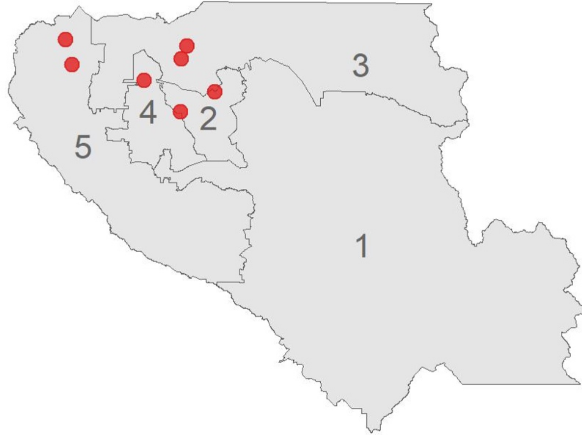
Notwithstanding a modest population decrease during the COVID-19 pandemic, SCC's population has been growing steadily over the past decade. This trend, coupled with aging demographic and dementia projections, underscore the need for more HCBS strategically located throughout the county, so residents in both low and high population density areas can access them.

Point Map: Location of SCC Family Caregiver Services and Supports by Supervisorial District

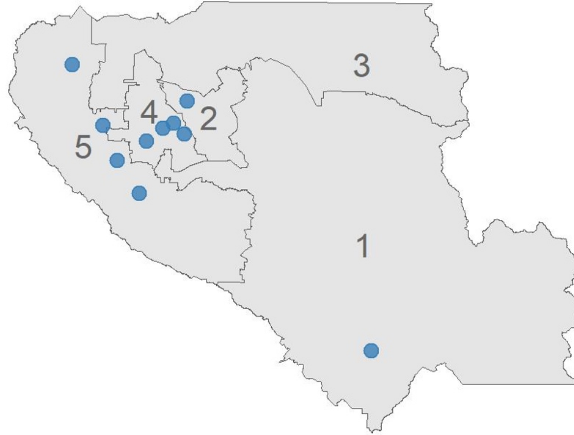


Family Caregiver Services and Supports by Type Point Maps

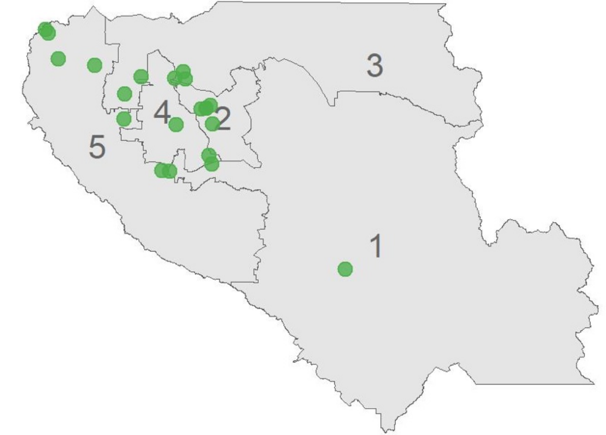
Adult Day Health Care Centers



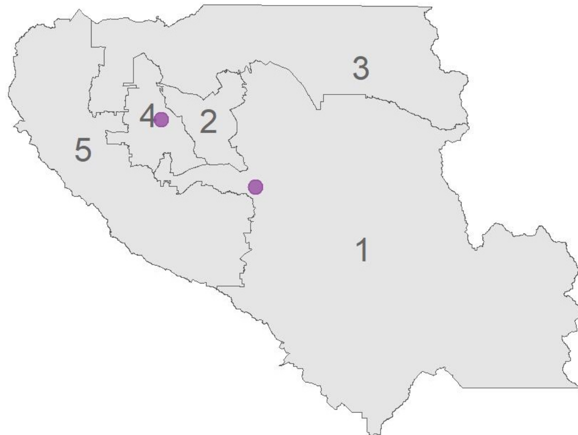
Adult Day Programs



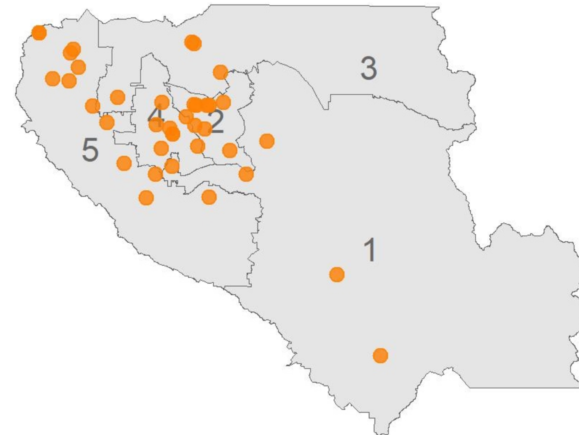
Community-Based Organizations



Medi-Cal Managed Care Health Plans



Senior Centers



Employing and Supporting Direct Care Workers

Thirty-four organizations working with or on behalf of the direct care workforce in SCC received a survey. Thirteen organizations completed it. Only respondents employing direct care workers reported on their operations (e.g., hours, pay, and fees), while all respondents provided information about the direct care workers they serve, their services, and the service needs and gaps for the direct care workforce.

Organizations Employing Direct Care Workers

The majority of organizations responding to operations questions reported being a home care organization (HCO) employing direct care workers as "paid caregivers." Most are franchises. The majority (83 percent) operate their business seven days a week and all offer hourly services.

All respondents provide companionship, home helper services, and personal care services. The majority offer dementia care services (92 percent), respite (92 percent), and modified medical care service support (75 percent). Most pay direct care workers $19 – $22/hour (85 percent) and charge customers (i.e., older adults, persons with disabilities, family caregivers, and persons recovering from illnesses) $40 – $44/hour (67 percent). See Figures 5 and 6.

Benefits to direct care workers are decided by the HCO. If HCOs do offer them, many require their direct care workers to reach a specified threshold of work hours (e.g., average number of hours per week, average number of months per year), before they are eligible to receive them.

Figure 5. Hourly Rate – Direct Care Workers

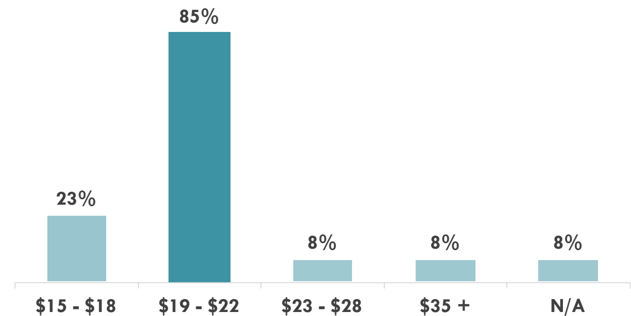
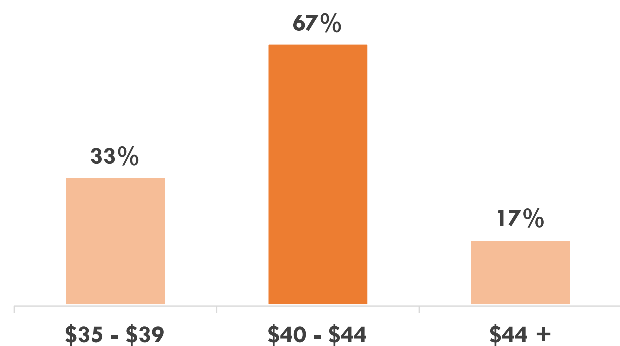


Figure 6. Hourly Rate – Customers



To recruit direct care workers, organizations rely primarily on their own recruitment outreach efforts and employees who refer other caregivers. To engage clients, organizations advertise via flyers and brochures (85 percent), social media (85 percent), and at health fairs (62 percent).

Eighty-four percent of direct care workers are women; 54 percent are 18 – 44 years old, and 26 percent are in the age group 45 – 54. Half speak English in the home (56 percent), 23 percent speak Spanish, and 19 percent speak Tagalog.

Public Authority Services by Sourcewise

The IHSS program is a central component of SCC's long-term care system. Because of the unique structure of the IHSS program, the Sourcewise survey was not included in the direct care worker organization survey analysis. Sourcewise manages the program. Their survey responses are included in the *Santa Clara County Adult Caregiver Study Data Chartbook.*

Sourcewise manages SCC Public Authority Services and 30,214 IHSS providers. In this role, Sourcewise is responsible for the following:

- Creating and maintaining a provider registry.
- Acting as the employer of record for collective bargaining.
- Maintaining benefits administration for qualified independent IHSS providers.
- Providing access to training for IHSS recipients and providers of IHSS.
- Providing enrollment processes and assistance for all new IHSS providers.

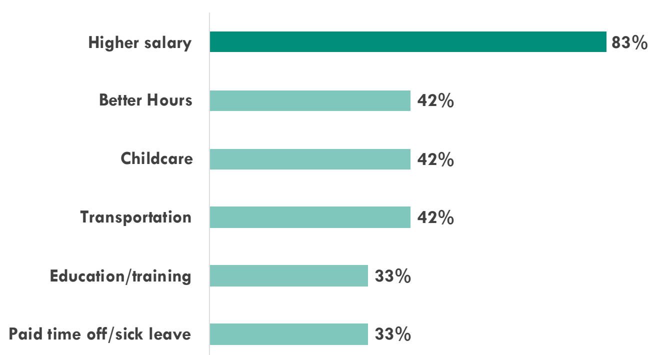
IHSS consumers are considered the employer of their IHSS provider.

Organizations Employing and Supporting Direct Care Workers

All organizations responding to the survey answered questions about the direct care workers they serve. Most organizations (92 percent) provide caregiver education and training, 83 percent offer employment. Many offer languages other than English to customers: five organizations offer Spanish; and one organization offers all languages–through the use of a language line.

Prominent service gaps for this workforce include services to address inflation/cost of living (92 percent), housing costs (75 percent), low salary (75 percent), and transportation (67 percent). The biggest need for this population is a higher salary (Figure 7).

Figure 7. Direct Care Worker Needs



A Caregiving Support System in Need of Attention

SCC needs a more robust caregiving support system. The family caregiver organization survey data and point map confirm that the current system is inadequate to meet the needs of SCC's 177,000 family caregivers. Family caregiver service gaps to address include the need for financial assistance; affordable services and programs, especially in and out-of-home respite care; and a centralized information system.

Findings from the direct care worker organization survey highlight several priority service gaps to address for this workforce as well. They include assistance with wages and living expenses, housing, and transportation. Separately, organization staff reported needing help recruiting direct care workers.

Strengthening and expanding the caregiving support system now will benefit current and future family caregivers and direct care workers. This urgency is underscored by the projected growth of older adults and persons with ADRD in SCC. By 2060, the county will see a 203 percent increase in residents aged 60 and older.[36] Equally important, the number of individuals aged 55 and older living with ADRD in SCC is expected to increase from 45,924 in 2025 to 82,336 in 2040, a 78% increase.[9,10]

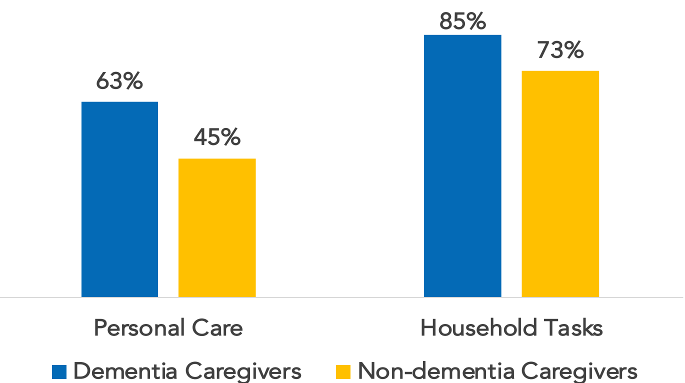
Compared to caregivers of persons without dementia, ADRD caregivers are more likely to provide intensive and extensive ADL and IADL assistance for their care recipient and manage difficult emotional, mental health, and behavioral problems. This group of caregivers is also at greater risk for negative health and economic outcomes, including caregiver burden, strain, depression, poor physical health, and financial hardship, than non-ADRD caregivers.[37-41]

The California Behavioral Risk Factor Surveillance System (BRFSS) survey underscores several of these risk factor associations for ADRD caregivers.[42] BRFSS is an on-going telephone survey of randomly selected adults, which collects information on a wide variety of health-related behaviors. The Alzheimer's Association analyzed 2021 BRFSS caregiver data and highlighted the following key findings regarding California dementia caregivers:[43]

- More than 1 in 5 caregivers (22 percent) provide care to an individual with Alzheimer's disease or other form of dementia.
- 24 percent are also caring for a child.
- Most (43 percent) are a child or child-in-law, 24 percent are another relative, 19 percent are a non-relative, and 15 percent are a spouse or partner.
- Age is nearly evenly distributed among the following age groups: aged 55 and under (36 percent), aged 56-64 (34 percent), and aged 65 and older (30 percent).
- About 1 in 5 dementia caregivers is "in frequent poor mental health."

In addition, more dementia caregivers spend 20 or more hours per week providing care than non-dementia caregivers (37 percent versus 24 percent) and care for the person with ADRD for two years or longer (58 percent versus 45 percent). Dementia caregivers additionally provide more ADL and IADL assistance than non-dementia caregivers (Figure 8).

Figure 8. Type of Assistance Provided



These critical survey findings shine an important light on a subpopulation of caregivers and direct care workers. To reduce the stress associated with caring for people with ADRD and improve caregiver coping skills, self-efficacy, and health, dementia caregivers need access to affordable, evidence-informed services, programs, interventions, and support.[44]

Listening to Caregivers and Experts

Caregiving experts, family caregivers, and direct care workers provided their insights, perspectives and lived experiences through interviews conducted for this study. Their stories and suggestions are invaluable to understanding the lives and needs of caregivers and how the county might design and implement a more responsive caregiving support system.

Twenty-six caregiving experts working with or on behalf of family caregivers and direct care workers participated in study key informant interviews. They responded to questions about SCC's current caregiving support system addressing the issues of access, affordability, gaps, and needs. Interviewees represented a diverse group of organizations, from public agencies and community-based organizations to advocacy groups and a local labor union.

Four focus groups, two with family caregivers and two with direct care workers, were also conducted, with participants discussing topics similar to those discussed in the caregiving expert interviews (e.g., caregiver needs and experiences; access, availability, and gaps of caregiver services).

In this section, caregiving expert interviewees are referred to as "interviewees." Focus group participants are referred to as "family caregivers," and "direct care workers."

Insights from SCC Caregiver Experts

The information provided by caregiving experts reflects their deep caregiving knowledge, expertise, and commitment to improving SCC's caregiving support system. Emerging themes capturing what they shared follow.

SCC's Caregiver Landscape is Underdeveloped

SCC has a dedicated group of organizations providing critical support to family caregivers and direct care workers. Representatives from these organizations participated in the study interviews. They openly shared their experiences with and insights into the needs of the two caregiver groups, including what services and supports are available and what is missing.

Organizations providing services to family caregivers reported offering a range of services: resource information, support groups, and respite care. Several offer education and training; one offers specialized caregiver intake and assessment. Organizations working with or on behalf of direct care workers provide employment, training, support, and advocacy.

Leading SCC caregiver organizations

- Alzheimer's Association
- Asian Americans for Community Involvement (AACI)
- Avenidas
- Family Caregiver Alliance
- Hearts and Minds
- Home Care Organizations
- IHSS/Public Authority
- Jewish Family Services Silicon Valley
- Live Oak
- On Lok-PACE
- Sourcewise
- VA
- Working Partnerships USA
- Yu Ai Kai

All the organizations supporting family caregivers are mission-driven, with a strong commitment to supporting family caregivers and care recipients; however, interviewees emphasized that the current system is

structurally underdeveloped. There are not enough affordable and accessible programs and services to meet caregiver service needs and demands. Moreover, most family caregivers in the county do not know what services are available or how to access them. Interviewees cited the absence of a centralized information system for caregivers, with comprehensive information about caregiver resources and how to navigate them, as a missing key component of SCC's caregiver service system.

Interviewees additionally reported that with so few organizations providing family caregiver services and supports, there should be more intentional and dedicated collaboration between organizations to close service gaps.

> *"In the county, most organizations [serving family caregivers] are looking for the same thing. We're all trying to collaborate. We all want to serve more people. I think where we end up with barriers is when we end up with a whole lot of people that are just sending flyers back and forth to each other. We don't always take that step of moving outward together and collaborating. I think that's the big stumbling block."*
>
> – Caregiving expert

Caregivers Face Multiple System-Level Challenges

SCC faces a multitude of challenges that impact family caregivers and direct care workers across public and non-profit systems. Besides a modestly constructed long-term care system (which includes the caregiving support system), several interviewees characterized the system as too individual-centered, and not enough family- centered. While not all people with caregiving needs have family members helping them, the majority do. Interviewees highlighted that because most care recipient programs and services are designed and operated without family member input, caregiver services are not as family friendly as they should be.

Experts also find that health care providers and systems are so patient-centered that family caregivers sometimes feel excluded. This experience occurs frequently for family caregivers when their loved ones are being discharged from the hospital or attending outpatient doctor appointments.

Interviewees emphasized that another important system level challenge for SCC, as well as other California counties, is the unaffordability of most long-term care services for low- to middle-income care recipients. Individuals with incomes ranging from above the Federal Poverty Level (FPL) to middle-income (defined as two-thirds to double the U.S. median household income) have little or no financial cushion to pay out of pocket for long-term care services, such as adult day services programs. At the same time, they are ineligible for public programs, which limits their respite and support options.

> *"The bottom line is every level of government, whether it's county, state, or federal, needs to look at the cost of respite care to families and how it is going to be subsidized. Because we're not adult day health—we're adult day care—our program is not covered by Medi-Cal. While we keep our price as low as we can, subsidizing respite care would be a huge benefit to a lot of families."*
>
> – Caregiving expert

Additional county level system challenges for family caregivers include insufficient and poorly managed transportation services; a lack of understanding by employers about caregiver responsibilities; limited early diagnosis, treatment, and support for individuals with ADRD in diverse communities, including the LGBTQ and Black communities; and the dearth of mental health supports for family caregivers experiencing stress and depression.

Caregiving experts identified several county level system challenges for direct care workers. They noted that elimination of the asset limit for all Medi-Cal programs for seniors and disabled persons scheduled for January 1, 2024, will increase the number of individuals eligible for long-term care services covered by Medi-Cal. Interviewees expressed concern that county systems currently managing the IHSS and Public Authority programs are understaffed, and once the higher asset limit goes into effect, both programs will be overwhelmed.

In addition, direct care workers receive low wages, limited benefits (although IHSS providers are eligible for medical, dental, and vision benefits), unstable work schedules and hours, and challenges accessing training. Interviewees reported that there are training options for the direct care workforce, some with available incentives and tuition reimbursements, but that direct care workers may not be aware of them. Low enrollment may also be linked to childcare and transportation needs or scheduling conflicts.

One system level issue that affected both family caregivers and direct care workers was the COVID-19 pandemic, which shone a light on the limited and fragile network of caregiver services, especially for under-resourced and marginalized communities. The pandemic revealed and exacerbated longstanding systemic health, economic, and social inequities, as well as health disparities for care recipients and caregivers of color. The crisis also led to program closures and reduced service hours, which increased family caregivers' feelings of loneliness and social isolation and decreased the ability of many direct care workers to work.

> *"In the Black community, women are not only more likely to be caregivers, but they still have an added risk of a breast cancer diagnosis that has to be navigated."*
>
> – Caregiving expert

Major Family Caregiver Challenges Mirror Major Family Caregiver Service Gaps

Key family caregiver challenges cited by caregiving experts include SCC's lagging long-term care service system; respite care options being out of reach for many low-to middle-income residents; the lack of a single, coordinated information system; and the absence of a meaningful partnership connection between health care providers and caregivers.

The digital divide experienced by many family caregivers, an issue shaped by race, education, and poverty, is another significant gap which creates inequality around access to caregiving services and supports. It refers to the growing gap between those who have access to modern information and communication technology (internet, computers, smart phones, tablets) and those who do not. During the COVID-19 pandemic, the digital divide became a chasm. In-person programs and supports shifted to online platforms, leaving many caregivers without access to technology and deprived of the services, supports, and connections they needed.

"One of the specific areas that I see as a gap is that caregivers don't know what resources are available to them and where to go, and who to go to, to learn about the disease that caused them to step into the role of caregiving. Accessing this information now means the caregiver must work through this labyrinth of trying to figure out 'where do I go, who do I call, what do I do?'"

– Caregiving expert

Another notable gap is the lack of services and supports to diagnose and treat the signs and symptoms of ADRD, especially in communities of color. One interviewee defined the absence of needed services in some areas of the county as "*neurodiverse deserts*." If a resident lives in one of these deserts, they are less likely to have access to a specialist who can officially diagnose them and to receive appropriate and timely interventions and treatments.

Related to the health care provider-caregiver challenge, interviewees underscored that many health care providers do not take the time to listen to caregivers to understand their experiences caring for care recipients. Nor do they assess caregiver needs and risks or discuss community resources that could help caregivers manage their caregiving responsibilities and stress. Caregivers are the eyes and ears of health care providers in the home: they can monitor care recipient needs, changes in cognition and brain health, and risk factors for ADRD (e.g., high blood pressure). Limited engagement of family caregivers by health care providers diminishes caregivers' ability to partner with providers for the best possible outcomes for care recipients.

Care recipients and their caregivers—both family caregivers and direct care workers—want to be seen, engaged, and respected by health care and other service providers for the care they provide and the important role they play.

"I go to doctor's appointments and the hospital with some of my older adult clients, and medical staff don't know about Adult Protective Services or have a list of community resources to give our clients or their caregivers."

– Caregiving expert

Caregiving Experts' Recommendations to Strengthen and Expand SCC's Caregiving Support System

- **Leverage existing caregiver assets and accelerators to improve the caregiving support system.** Community-based organizations and County departments should take advantage of their longstanding partnerships and committee structures (Seniors' Agenda, Long-Term Care Integration Committee, Aging Services Collaborative, Caregivers Count Conference) to build stronger alliances and collaborations to ensure accessible, equitable, affordable services and supports for caregivers throughout SCC.

  In addition, caregiving experts and advocates should consider promoting a local countywide campaign to educate residents about caregiving and where to find information, classes (online and in-person), and resources.

- **Intentionally reach out to, engage, and respond to the needs of caregivers representing underserved and diverse communities.** As Dr. Kimberly Curseen, a leader in advancing health equity interventions to improve care for Black patients makes clear, "People with limited resources [and access] cannot always afford to choose what they want; they have to choose what they can have or what is given. Addressing [caregiving] goals before addressing the need is not productive."[45,46]

  Formative work is being done in SCC to understand and address the needs of caregivers and care recipients in marginalized communities. Working with organizations leading this work should be a countywide priority, to ensure that representatives of diverse communities are part of the decision-making process, which determines what programs are needed, where they should be located, how they will be funded, and who will operate them.

  "LGBTQ older adults have some misgivings about seeking help because of fear of discrimination or rejection–that they're not going to be welcomed. What could be done is having service providers make a concerted effort to make LGBTQ caregivers and older adults in general feel that they're part of that community."

  – Caregiving expert

- **Increase support for IHSS providers, promote career opportunities for direct care workers, and establish an effective direct care worker registry.** Numerous interviewees suggested that SCC increase IHSS and Public Authority staff to provide more support and oversight of IHSS beneficiaries and providers. They also recommended the County actively promote state initiatives sponsoring training and career advancement opportunities to direct care workers (i.e., IHSS Career Pathways, California GROWs–CDA Direct Care Workforce Initiative).

  "When I think about care services provided by the County IHSS Public Authority Program, the biggest thing needed is oversight. And that's something the County [Public Authority] has a difficult time doing. There needs to be an accountable person in charge of overseeing IHSS workers to ensure that they are delivering what they are supposed to."

  – Caregiving expert

Interviewees also recommended creating and operating a countywide direct care worker registry with profiles of workers, such as training qualifications, experience, skills, availability, and contact information, that people needing care can access (e.g., family members, direct care workers seeking employment, and others). See IHSS Connect, a registry model for home care workers.

- **Educate health care systems administrators and providers about the importance of family caregivers and collecting relevant caregiver data.** Interviewees suggested that health care payers (e.g., from Medi-Cal managed care plans and commercial health insurance plans), require health care providers working with older and disabled adults to use a standardized caregiver assessment form. Collected assessment data should be used to improve the quality and number of services.

  They also recommended hospitals follow California's Caregiver Advise, Record, Enable (CARE) Act.[47] The act requires hospitals to do three things: ask patients if they have a family caregiver (and document accordingly), contact that person if the patient is to be discharged or transferred, and teach the family caregiver how to provide the care the patient will need after discharge. Interviewees proposed that outpatient providers and systems follow the intent of CARE and collect and document similar caregiver information.

- **Adequately invest in and fund innovative long-term solutions to SCC's caregiver crisis.** Interviewees recommended SCC and partners commit to investing in creative long-term solutions to the caregiver crisis.

  Considering limited state and federal funds and program structures for long-term care services and supports, interviewees recommended SCC consider financing a skill-based career ladder for IHSS providers. Each tier would have an hourly wage increase associated with a set of training, skill, and competency requirements.

  Another proffered solution is for the County and its partners to consider building and operating county long-term care health facilities, with a living wage structure and career advancement opportunities for staff.

  Independent of specific solutions chosen, interviewees highlighted that strengthening the county's long-term care service system will require new partnerships and innovations.

"The broad problem is that there's this huge part of the economy that's providing vital services essential to the workings of much of the rest of the economy, but we're under-investing in the people who do this work. This is ubiquitous across the caregiving field. So, we have to try and find ways to move the dial on this. It's rarely a case where you have to convince people that the work is important or that people are not being paid or supported enough. The challenge is the financing because of the numbers that are going to be needed to fund these kinds of support and the cost."

– Caregiving expert

Santa Clara County Caregivers

In the focus group interviews, participants revealed both the uniqueness and common characteristics of caregivers and the caregiving experience. For example, some family caregivers and direct care workers became caregivers "overnight," after their loved one sustained an injury or experienced a serious medical event. Others expanded their caregiver role slowly, over time. Several non-family member IHSS providers entered the profession because the opportunity presented itself and they wanted to help people. Independent of how participants ended up in their caregiving role, what they all had in common was compassion for the care recipient and a desire to be a good caregiver.

Improvements Needed in SCC's Caregiving Support System

Family caregivers and direct care workers were eager to tell their stories. Both groups reported problems identifying and navigating caregiver services. Family caregivers underscored how difficult it is to know where to begin as caregivers—where to go for information, what resources are available to them—and how to finance everything from adult day services to medical appointments to transportation.

> *"In looking around the County website, it would've been nice if there was a list of caregiver education and training classes, support groups, and respite options. That would've been really useful."*
>
> – Family caregiver

Direct care workers expressed frustration that the IHSS program was often opaque, provided little oversight and support, and that they did not receive timely responses from IHSS or Public Authority staff. Many were confused by the County IHSS/Public Authority system. For example, they did not know how to help their IHSS recipient obtain more IHSS hours when needed or how to get payment for hours they had already worked.

On a personal level, many family caregivers expressed a need for more respite services that they could afford and access. One-time only respite grants, along with the cost and eligibility requirements of some adult day services, restricted the ability of family caregivers to use in and out-of-home respite services on an ongoing basis. Several family caregivers also said that adult day services programs and other supports do not take family needs enough into account.

Direct care workers emphasized the challenge of stepping into caregiving roles with vulnerable IHSS recipients without family or other support. As a result, most reported their jobs are much bigger than their IHSS provider job description. As one direct care worker explained, "We do a lot more than our job description—in general, we do whatever it takes to help our client."

> *"Especially when they're having bad days, mental health days, we're also like their counselors; they vent to us. And they call me when they're bored, I answer because I'm thinking she fell, and she talks to me."*
>
> – Direct care worker

The expanded role that many IHSS direct care workers take on makes their job more difficult. It also requires consistently defining boundaries with clients. One direct care worker said her client asked her to dye her hair; another was asked to clean the backyard. Boundary setting, hard work, low wages, and not getting enough hours to earn a living were cited as key factors

that make staying in the direct care workforce challenging.

Intersecting Challenges and Gaps

The limited availability of respite care and caregiver navigation support were identified as both challenges and critical service gaps. In addition, transportation emerged as a joint challenge *and* gap theme. Family caregivers and direct care workers both discussed the extensive time family members and IHSS clients spend traveling to and from appointments on Santa Clara Valley Transportation Authority (VTA) ACCESS paratransit service, as a major hardship that points to a service gap.

Direct care workers also noted that because VTA's paratransit service typically does not include assisting riders in entering and exiting their appointments, they must accompany the consumer on VTA to ensure they get to the appointment. Doing this, they reported, entails using "a lot of [their] authorized IHSS hours," which they would prefer to use for personal care activities, such as shopping, preparing meals, cleaning, and doing laundry.

Family caregivers additionally identified inequities in outreach, engagement, and inclusion of diverse caregivers as a service gap. Although the Black population in SCC is under three percent, some caregivers noted that the needs of Black care recipients and their caregivers are underassessed by health care and social service providers compared to White care recipients and their caregivers. Another family caregiver expressed concern about the ability of Spanish-speaking family caregivers to access caregiver services.

> *"I'm Mexican, but I'm fluent in English. But I'm wondering about all those other people who don't speak English. Where do they go for adult daycare? I have not seen any place [for them], so I'm wondering about them, too."*
>
> – Family caregiver

Training emerged as a gap for both caregiver groups. Several family caregivers reported taking caregiver classes, but many reported not knowing that classes were available or how to access them. In both family caregiver focus groups, participants expressed interest in attending online and in-person trainings, especially classes addressing caregiving and dementia, including how to manage difficult behaviors and how to communicate effectively. Nearly all family caregivers reported receiving information about caregiver support groups from organizations they reached out to; half said they had participated in one or were currently participating in one.

Only a few direct care workers were aware of trainings available to them through Public Authority Services. One IHSS provider said that she knew about trainings, but the time and hours were difficult for her. Another said that she was not aware of trainings and that a previous employer had told her to get Hoyer Lift training—which should be done in-person—from a YouTube video.

Many direct care workers expressed interest in receiving more training. They identified CPR classes and trainings on taking care of someone with Alzheimer's disease as priorities. Half the individuals in this group said they would be very interested in taking education classes and trainings if they were part of a career ladder program or opportunity.

Seizing the Moment to Create Change

Focus group participants were unequivocal. They believe now is the time to transform SCC's caregiving support system to meet the needs of family caregivers and direct care workers. They recommended the following:

- **Create a seamless caregiver navigation system** to assist family caregivers wherever they are in their caregiver journey.
- **Increase direct care worker wages** and provide oversight and support.
- **Provide more counseling and mental health services to family caregivers** to support them at whatever stage they may be in the caregiver lifecycle, including those managing end-of-life care for their care recipient and those grieving the death of a loved one.
- **Increase access to and affordability of respite care services** for low and middle-income caregivers.
- **Educate family caregivers and direct care workers** about the availability and importance of caregiver trainings.
- **Reach out to and engage family caregivers representing communities of color** to ensure their caregiver needs are known and addressed and that they are included as decision-makers in the development of county adult day services programs.

Caregiver Policies and Initiatives

In response to the ubiquity of caregiving and the growing needs of caregivers, local, state, and federal governments are focusing on caregiver policies and initiatives. Two recent national caregiver developments have helped to substantively raise the profile of caregivers.

The first is the 2022 National Strategy to Support Family Caregivers (Strategy), which was 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. It details five key goals to support action by a group of federal agencies to improve support for family caregivers.[2] These actions are intended to inspire complementary partnership efforts at state, community, and organizational levels to increase and strengthen access to responsive caregiving programs.

The Five Goals of the 2022 National Strategy to Support Family Caregiver

- GOAL 1: Achieving greater awareness of and outreach to family caregivers
- GOAL 2: Advancing partnerships and engagement with family caregivers
- GOAL 3: Strengthening services and supports for family caregivers
- GOAL 4: Improving financial and workplace security for family caregivers
- GOAL 5: More data, research, and evidence-based practices to support family caregivers

The second is President Joseph Biden's April 2023 announcement of an Executive Order to be signed 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."[3] Both federal initiatives provide a roadmap to improve services and supports for family caregivers.

CDA is working in partnership with the Administration for Community Living to advance the National Family Caregiver Strategy in California, while implementing the state's MPA goals, including goal #4 "Caregiving that Works."[4] With a multipronged approach to supporting the development of equitable, accessible, and affordable caregiver services and supports throughout California, the state is highlighting the importance of caregivers and caregiving. Goal #4 includes a target of creating one million high-quality caregiving jobs and three core strategies:

- Family & Friends Caregiving Support: Focuses on promoting state paid family leave benefits and assessing participation in these benefits, developing options to include family caregivers in home and community assessments, and, consistent with CalAIM, and expanding respite for family caregivers.
- Good Caregiving Jobs Creation: Promotes online training platforms for direct care workers, including career advancement opportunities and diversification of the pathway for them in home and community-based services by testing and scaling emerging models.
- Virtual Care Expansion: Supports new, innovative technologies and expanded telehealth and personal and home technologies to advance health equity, promote healthy aging, and respond to diverse caregiver needs.

After careful study and examination of the complexity of the caregiver issue by multiple state departments, California is investing in two transformational direct care workforce initiatives.

- Growing a Resilient and Outstanding Workforce in the Home and Community (CalGrows)–CDA's Direct Care Workforce Initiative:[48] The goal of this program is to increase the skills, recruitment, and retention of direct care workers (non-IHSS providers with home-and community-based services) through training and stipends.
- IHSS Career Pathways Program: Managed by the California Department of Social Services (CDSS), this program provides training–with compensation for coursework–to IHSS and Waiver Personal Care Services providers to enhance their skills and improve the quality of care provided. [49]

California is also investing in several other workforce initiatives. They include the following: Direct Support Professional Workforce Training and Development, HCBS Clinical Workforce Program, and Certified Nurse Assistant Workforce Program.

Advocates and legislators are equally active in promoting laws that support family caregivers and direct care workers. An appreciable number of bills addressing both groups is currently under review by the state legislature. The following four highlight the diversity and breadth of caregiver issues in California:

AB-518 Paid Family Leave for Chosen Family (Wicks). Expands eligibility for benefits under the paid family leave program from "leave to care for a seriously ill *child, parent, parent-in-law, grandparent, grandchild, sibling, spouse, or registered domestic partner*" to add "*any other individual related by blood or whose association with the employee is the equivalent of a family relationship*." Fact Sheet

AB-524 Discrimination: Family Caregiver Status (Wicks). Family caregiver status would be added as a protected class under the existing California Fair Employment and Housing Act. Fact Sheet

AB-575 Paid Family Leave (Papan). Removes the requirement that a care provider certify that no other family member could provide care at the same time to qualify for Paid Family Leave (PFL) benefits and removes the provision of PFL that allows employers to require employees to use two weeks of accrued vacation before they can receive PFL benefits. Fact Sheet

SB-525 Minimum Wage: Health Care Workers (Durazo). Raises the minimum wage for health care workers (includes health care workers providing caregiving) to $25/hour. Fact Sheet

California's various caregiver initiatives, coupled with ongoing efforts to address caregiver and direct care worker needs through legislative action, underscore the urgency of addressing caregiving as a priority policy area. Counties and communities across California are now preparing for the significant growth expected in the older adult population, which includes strengthening, expanding, and in some cases, redesigning services and supports for both older adults and caregivers, including family caregivers and direct care workers.

Interviews with four California experts in caregiving policy yielded the following

recommendations for enhancing SCC's caregiving support system:

- **Support** CalAIM, which includes respite and personal care options for eligible Medi-Cal beneficiaries.
- **Work** closely with the SCC Department of Public Health on the county *Healthy Brain Initiative,* which aims to build and raise awareness of brain health and its risk factors and cognitive decline risk reduction. SCC recently received another round of initiative funding, which includes funding for caregiver outreach and engagement.
- **Partner** with the California Department of Public Health on the Behavioral Risk Factor Surveillance System (BRFSS) to ensure that SCC residents providing caregiving to individuals with Alzheimer's disease are represented in the survey, which assesses various caregiver risk factors (burden, physical health, mental health).
- **Educate and encourage** direct care workers to participate in IHSS Pathways and CalGrows trainings.
- **Ensure** the caregiver support system includes behavioral health supports.
- **Promote** Paid Family Leave throughout the County. This benefit is largely unknown and underutilized. Education should be ongoing.
- **Provide** hands-on interactive trainings for family caregivers and direct care workers who are supporting individuals with complex and serious illness.
- **Collaborate** with long-term care stakeholders to organize existing information and referral systems into a single "no-wrong door" system with multiple access points. Or create a new countywide "no-wrong door" system that caregivers can use for information, referrals, etc.

> *"I do see progress promoting the Master Plan for Aging work through policy and caregiving bills. On the local level more counties are pushing for aging/disability task force workgroups. It has made a huge impact."*
>
> – Expert in caregiving policy

Caregiver Best Practice Programs

In response to articulated family caregiver needs, the study conducted a search of caregiver best practice programs. Four models emerged. They highlight opportunities for SCC to improve an existing information and referral system, continue and build on the current SCC adult day program pilot, support expansion of the embedded PACE program—a co-located PACE-housing model—and provide home care subsidies for individuals ineligible for other subsidized home care programs.

Caregiver Referral Program

Program and Location: Ayudando a Quien Ayuda™, Los Angeles County

Overview: 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 the University of Southern California Los Angeles Family Caregiver Support Center (FCSC), AARP, 211 LA, and Visión Y Compromiso, to meet the growing needs of Spanish speaking Latino caregivers.

Population/Access:

- 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™.
- Those interested in the program receive a follow-up call from FCSC staff (facilitated by 211), who assess needs and determine next steps (e.g., develop a care plan, offer caregiver services, and supports).
- Since launching in July 2019, FCSC has completed over 2,424 outreach calls, 891 intakes, and 423 assessments.

Cost/Funding:

- The program is funded by AARP with support funds from FCSC.

Notes and Considerations:

- Ayudando a Quien Ayuda™ provides critical support to a population of caregivers that faces significant obstacles to receiving caregiver services and presents with a higher risk for unmet basic needs (e.g., housing, food).

Insights and Recommendations for Success:

- Due to the higher needs of this community, 211 and FCSC staff dedicate extensive time assisting this group of caregivers to ensure their needs are met.

Reference: Ayudando a Quien Ayuda

Santa Clara Adult Day Services (ADS) Pilot Project

Program and Location: Participating Adult Day Programs, Santa Clara County

Overview: The Adult Day Services Subsidy Pilot Program Feasibility Study Report outlined a subsidy model for SCC ADS. The goal of the model is to increase access for unserved and underserved populations in SCC to the substantial benefits that ADS programs provide to both participants and their caregivers. The report led to the development of the Adult Day Services Subsidy Pilot Program facilitated by a partnership between the Senior Care Commission and the Social

Services Agency (SSA) Department of Aging and Adult Services. Following a competitive process in FY2020, SSA entered into agreements with three local ADS providers: Live Oak Adult Day Services, Saratoga Area Senior Coordinating Council (SASCC), and SarahCare.

Population/Access:

- Aged 65 or older.
- Accepted into an Adult Day Program operated by a contracted provider and listed on the client enrollment list.
- Meet specific income thresholds.
- To date, 82 clients and their caregivers have participated in the program, both virtually and in-person.

Cost/Funding:

- The initial project goal was to provide up to three days of on-site services per week for each participant and transportation costs, to help remove the financial barrier of attendance for individuals. Due to COVID-19, transportation funds were redirected to participant funds.

Notes and Considerations:

- Due to COVID-19, two ADS programs, Live Oak and SASCC, developed virtual programming in late FY 2020, delivered through personal digital devices. Some in-person services resumed in FY 2022, although many individuals still participate in virtual services.
- The change in service delivery resulted in lower than anticipated enrollment.

Insights and Recommendations for Success:

- Preliminary data suggests that participants and caregivers are overwhelmingly satisfied with virtual and in-person services at the three- and 18-month follow-ups and that caregiver stress levels declined over time.
- Although the Board of Supervisors has allocated one-time funding for each year of the pilot, on-going funding through more sustainable channels will be required for the continuation of this program. Potential avenues of funding include health systems, health care providers, and other organizations that may be positively impacted by the success of the program.

Reference: ADS Subsidy Pilot Program Scope of Work and Requirements

Embedded Adult Day Services Model

Program and Location: On Lok PACE, San Francisco, CA

Overview: In 1971, On Lok began one of the country's first adult day health centers and created the prototype for the Program of All-Inclusive Care for the Elderly (PACE), a model of care for older adults offering an alternative to nursing home placement. On Lok also operates senior housing buildings in San Francisco and a senior center with an array of culturally and linguistically diverse services for active seniors.

On Lok PACE is a full-service healthcare program that covers all Medicare and Medi-Cal services, plus added services authorized by the PACE interdisciplinary team. PACE participants are frail seniors, 55 and older, who meet the Medi-Cal nursing home-level of care. PACE participants receive care in PACE centers, their homes, other community settings, and institutions. On Lok PACE is coordinated by an interdisciplinary team comprising primary care providers, nurses,

social workers, rehabilitation therapists, activity therapists, dietitians, home care nurses, caregivers, and drivers, with a focus on prevention, health, and wellness.

Marie-Louise Ansak On Lok House was built in 1980 and features a 54-unit building with Section 8 subsidized apartments. The early vision was to create co-located housing with an adult day health care center, demonstrating how integrating housing and services is key to enabling seniors to continue living in the community. In 2017, On Lok completed a $10 million renovation to upgrade the housing units of Marie-Louise Ansak On Lok House and the co-located On Lok PACE Powell Center.

Population/Access:

- Participants are generally referred to the program by community-based organizations, often by case workers. Referrals additionally come from current participants and the general community. Participants are also reached through marketing and outreach activities.
- Participants must be 55+, live in a zip code that is served by a PACE organization, be nursing home eligible, and able to live independently. Participants undergo an in-depth medical assessment that must be approved by the state before being approved to be in the program.
- Some potential participants hesitate to join the program because PACE participation requires they leave their current medical providers.

Cost/Funding:

- Housing and PACE funds are separate. PACE is funded through Medi-Cal and Medicare. Client housing is funded through various sources, e.g., Supplemental Security Income.

Notes and Considerations:

- The embedded PACE program sees higher utilization among participants than non-embedded PACE, because of its on-site care, attention, monitoring, and services.
- Offering on-site housing is cost-effective. Costs are lowered or eliminated for transportation, delivery of supplies, travel for home care workers, and the delivery of care.
- Challenges of the embedded model include preventing overutilization of healthcare services and setting boundaries with clients.
- Not all residents who live in Marie-Louise Ansak On Lok House are PACE participants and not all On Lok PACE Powell Center participants live in Marie-Louise Ansak On Lok House.

Insights and Recommendations for Success:

- Establish strong attendance and visitor policies and set firm client boundaries.
- Adult day services (ADS) and housing programs interested in the embedded model should know the regulations governing each but should work together to promote care coordination.
- Be clear with participants that the program is for those who can live independently. Participants should also be informed that they may have to move if they lose their independence.

Reference: On Lok PACE

Support At Home (S@H) Program

Program and Location: Institute on Aging, San Francisco, CA

Overview: San Francisco advocates, led by Senior and Disability Action, cited a need to create new subsidized home care opportunities to fill the gap for low- and middle-income individuals ineligible for other subsidized home care programs, such as Medi-Cal's IHSS.

Institute on Aging (IOA), with funding from the City & County of San Francisco through the Department of Disability and Aging Services (DAS), introduced a pilot program during FY2017 to provide financial assistance ("vouchers") to San Francisco adults with disabilities and seniors living in the community to purchase home care—either to use a home care agency or hire an independent provider. IOA was initially awarded a contract for a 2.5-year pilot program. A mixed-methods evaluation led by the University of California, San Francisco (UCSF) showed significant savings to the health care system. Since 2019, DAS has provided ongoing funding to secure S@H as a permanent city program.

Population/Access:

- Adult (aged 18 years or older) residents of San Francisco who require assistance with at least 2 Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs).
- Monthly income cannot exceed 100% of Area Median Income; assets cannot exceed $40,000 (apart from one house and one car).
- Ability to demonstrate financial and functional need for subsidized home care and ineligible for other subsidized home care programs.
- Participate in program requirements/ evaluations and pay home care services copayment.
- Since 2017, S@H has provided 280,000 hours of subsidized care and served 379 individuals.

Cost/Funding:

- The program helped to save $1,700.00 per month per enrollee due to reductions in hospitalizations, emergency department visits, and physician visits. Hospitalization reductions provided a total net savings to the City and County of San Francisco of over $2,300,000.

Notes and Considerations:

- The evaluation team found promising results in enrollee program satisfaction and a reduction in enrollee stress and the average number of falls.
- Friend and family caregiver qualitative findings confirmed the program helped increase their own well-being.

Insights and Recommendations for Success:

- Prioritize program outreach and marketing efforts to adults under 60 with disabilities, non-White communities, and non-English speakers.
- Educate participants about the pros and cons of home care so that they can make informed decisions when choosing providers.
- Promote quality measures and oversight with participating home care agencies.
- Note that individuals without a family or friend caregiver often face difficulties finding an independent provider to hire.

Reference: Institute on Aging

Conclusion: The Way Forward

Analysis of study key findings reveals that closing SCC caregiving service gaps and responding to family caregiver and direct care worker needs–today and tomorrow–will require creativity, collaborative partnerships, planning, and financial resources.

Choosing not to invest in SCC family caregivers and direct care workers is likely to result in significant human and economic costs for the County. More family caregivers will suffer from depression, burnout, and poverty. Fewer individuals will become direct care workers, making an already understaffed workforce unprepared to meet future demand. And hospital and health systems will likely experience overcrowded emergency rooms, avoidable hospital admissions, and a surge in nursing home requests.

The following are suggested next steps and actionable recommendations to solve SCC's caregiving challenges now, before county resources are overwhelmed. It is important to note that some recommendations may require others to be acted upon simultaneously to be effective, e.g., establishing a successful "no wrong door" information and referral system, may necessitate launching concurrent campaigns to educate the public as well as health care providers about caregivers.

Suggested next steps include:

1) SCC Social Services Agency Seniors' Agenda should form a partnership to develop SCC's caregiving support system. The partnership should be comprised of representatives from the following groups: Long-Term Care Integration Committee, Aging Services Collaborative, Caregivers Count Conference, Long-Term Services and Supports Committee, health care (payers and providers), unions, family caregivers, and direct care workers.
2) The partnership should evaluate the Santa Clara County Adult Caregiver Study report recommendations. (**See Appendix A for a more expansive discussion of each proposed recommendation**).
3) Each recommendation should be carefully reviewed for viability and achievability.
4) Selected consensus recommendations should be developed and integrated into a five-year plan to strengthen and expand a person- and family-centered caregiving support system for SCC.

Actionable recommendations from the study are on the following page.

STUDY RECOMMENDATIONS

Implement system changes

- Enhance an existing information and referral system to create a "no wrong door" model that meets the needs of caregivers wherever they are in their caregiving journey.
- Evaluate the opportunity to develop a countywide direct care worker registry for care recipients, family caregivers, and others.
- Identify opportunities to provide more support and oversight to IHSS providers.
- Request that health care systems and providers recognize, engage, and support family caregivers in their caregiving role and participate in county caregiving initiatives.

Promote caregiver awareness, education, and training

- Launch a countywide caregiver education campaign—help residents to recognize themselves as caregivers and seek information and support.
- Use existing information and partnership communication channels to educate family caregivers, IHSS providers, and direct care workers about caregiver education and training opportunities.
- Increase public awareness about the importance of participating in the California Health Interview Survey (CHIS) and Behavioral Risk Factor Surveillance Survey (BRFSS).

Increase the availability and affordability of caregiver services and supports

- Develop a long-term plan to increase the number and affordability of respite care services in- and out-of-the-home.
- Evaluate the viability of creative program ideas and partnerships to solve SCC's long-term care needs-including caregiver challenges and needs.
- Form a coalition of long-term care stakeholders (community organizations, advocates, health care systems and payers, etc.) to explore developing new sources of caregiver funds.

Invest in the direct care workforce

- Through cross-sector collaboration, support wage increases for direct care workers.
- Research the viability of creating and implementing an IHSS direct care worker career ladder.

Promote paid family leave benefits

- Develop a campaign to increase knowledge about paid family leave benefits for all employees and employers in the county, including employees of Santa Clara County.

Appendix A: Study Recommendation Notes

Implement system changes

- **Enhance an existing information and referral system to make it a "no wrong door" model that meets the needs of caregivers wherever they are in their caregiving journey.**
  Notes and Considerations:
  - Review existing information and referral systems in SCC and select the most viable (e.g., 211, Sourcewise Information & Awareness) to make into a "no wrong door" system for caregivers, or establish a SCC Aging and Disability Resource Center enhanced information and referral system [a no wrong door system]; reach out to San Francisco's Department of Disability and Aging Services (DAS) to discuss their current collaboration effort to build and launch a dynamic online resource directory to support easier navigation of aging and disability resources for staff, community-based service providers, and the public.
  - Engage residents representing communities of color and those whose primary language is not English in the system revision process.
  - Provide multiple access points to the system, so residents can find and use it easily.
  - Offer both a consumer-facing portal and call center.

- **Evaluate the opportunity to develop a countywide direct care worker registry for care recipients, family caregivers, and others.**
  Notes and Considerations:
  - The registry would include information about individual workers, who consent to participating, e.g., skills/competencies, training, language(s) spoken, availability, rate.
  - It may include available listings of open direct care worker positions.
  - This requires a plan to identify who would operate, fund, and oversee the registry.

- **Identify opportunities to provide more support and oversight to IHSS providers.**
  Notes and Considerations:
  - Increase staff in the IHSS and Public Authority programs to meet the support needs of IHSS providers and prepare for more IHSS recipients beginning January 2024.

- **Request that health care systems and providers recognize, engage, and support family caregivers in their caregiving role and participate in county caregiving initiatives.**
  Notes and Considerations:
  - Use existing information and communication channels with health care systems and providers to implement this recommendation; ensure that health care representatives (payers and providers) are part of caregiver initiatives, including the partnership to develop a five-year plan to develop a person- and family-centered caregiving support system for SCC.
  - Promote the use of a standardized caregiver assessment by health plans and providers (e.g., CRC uniform caregiver assessment) (*ongoing)*.
  - Promote hospital adherence to the Caregiver Advise, Record, Enable (CARE) Act and encourage a similar practice in the outpatient setting (ongoing).

Promote caregiver awareness, education, and training

- **Launch a countywide caregiver education campaign—help residents to recognize themselves as caregivers and seek information and support.**

  Notes and Considerations:
  - Engage representatives from SCC's diverse communities to be part of the team developing the public awareness campaign.
  - The campaign should 1) educate residents about the availability of the revamped no wrong door information and referral system, 2) include information about elder abuse and how to report it, and 3) encourage non-identifying caregivers to reach out for help.

- **Use existing information and partnership communication channels to educate family caregivers, IHSS providers, and direct care workers about caregiver education and training opportunities.**

  Notes and Considerations:
  - Increase outreach efforts to direct care workers about where to access training opportunities, with incentives, i.e., IHSS Training Pathways, CalGrows (ongoing).
  - Provide on-demand training (*as soon as or whenever required*) based on caregiver—family caregiver and direct care worker—needs.
  - Encourage the development of more in-person education and training classes for both family caregivers and direct care workers (*ongoing*).

- **Increase public awareness about the importance of participating in the California Health Interview Survey (CHIS) and Behavioral Risk Factor Surveillance Survey (BRFSS) surveys.**

  Notes and Considerations:
  - Educate residents about participating in CHIS and BRFSS through various public communications methods (e.g., County website, social media, newsletters).
  - County to request that CHIS add caregiver questions that were removed after the 2020 survey back in, and work with the Alzheimer's Association and others on BRFSS analyses.

Increase the availability and affordability of caregiver services and supports

- **Develop a long-term plan to increase the number and affordability of respite care services in- and out-of-the-home.**

  Notes and Considerations:
  - Support the expansion of adult day services in SCC to increase the number of ADPs (currently 10) and ADHCs (currently 7) over the next 10 years.
  - Ensure that ADP and ADHC programs are available in the eastern and southern parts of the county.
  - Assess the impact of the SCC Adult Day Services (ADS) subsidy pilot; continue and build on the pilot model, offering extended subsidies to ADPs throughout the county to increase access for low- and middle-income residents.
  - Offer more grants and/or subsidies for in-home respite care.
  - Communicate and coordinate with Medi-Cal managed care plans offering respite services to family caregivers of eligible Medi-Cal members.

- **Evaluate the viability of creative program ideas and partnerships to solve SCC's long-term care needs-including caregiver challenges and needs.**

  Notes and Considerations:
  - Leverage learnings from the SCC Adult Day Services (ADS) subsidy pilot program; consider testing other caregiver best practices, IOA Support @ Home program, On Lok PACE housing model, 211 Caregiver Referral Program.
  - Work with Working Partnerships USA and other stakeholders to implement creative solutions to SCC's long-term care challenges.
- **Form a coalition of long-term care stakeholders (community organizations, advocates, health care systems and payers, etc.) to explore developing new sources of caregiver funds.**

  Notes and Considerations:
  - Coalition should identify potential new funding sources, such as ballot measures, sales taxes, etc. (see example of San Francisco's Dignity Fund[50]) to fund respite programs, direct care worker wage levels, mental health services for family caregivers, and improved transportation services for older adults and persons with disabilities in SCC—note: counseling and mental health services should be made available to family caregivers at whatever stage they may be in the caregiver lifecycle, including those managing end-of-life care for their care recipient and those grieving the death of a loved one.

Invest in the direct care workforce

- **Through cross-sector collaboration, support wage increases for direct care workers.**

  Notes and Considerations:
  - County and partners ("partnership") should identify and support local and state strategies (i.e., ordinances, legislative action) to increase direct care worker wages to a livable wage.
  - Partnership should also examine and support direct care worker benefits, such as health insurance, paid time off, and childcare and transportation stipends, which help to recruit and retain workers when combined with a livable wage.
- **Research creating an IHSS direct care worker career ladder.**

  Notes and Considerations:
  - The career ladder would include a series of levels for IHSS workers (entry, mid, senior). Each level would be defined by measurable criteria, e.g., education, trainings, experience, responsibilities, and competencies. Wages would be commensurate with the level.

Promote paid family leave benefits

- **Develop a campaign to increase knowledge about paid family leave benefits for all employees and employers in the county, including employees of Santa Clara County.**

  Notes and Considerations:
  - Create education and community awareness campaign regarding paid family leave benefits, start with employees of Santa Clara County.
  - Endorse proposed legislation that removes access barriers to Paid Family Leave; track and advocate legislation that supports family caregivers and direct care workers.

Appendix B: Common Report Abbreviations and Terms

ADLs	Activities of Daily Living: Daily self-care activities such as bathing, dressing, self-feeding, etc.
Adult Day Health Care (ADHC)*	Centers offer a medical model of care through an outpatient day program for older persons and adults with chronic medical, cognitive, or mental health conditions and/or disabilities who are at risk of needing institutional care.
Adult Day Program (ADP)*	Programs offer a social model of care through a day-time program for adults with a focus on protective supervision by trained aides, structured activities, health monitoring, meals, out-of-home respite, and support for the caregiver.
ADS	Adult Day Services—includes both ADHCs and ADP programs.
APS	Adult Protective Services
ADRD	Alzheimer's disease and related dementias
BRFSS	Behavioral Risk Factor Surveillance System
CalAIM	California Advancing and Innovating Medi-Cal, 2022-2027
CareNav™	California Caregiver Resource Center online caregiver database and caregiver portal.
CBAS*	Community-Based Adult Services: Licensed Adult Day Health Care (ADHC) facilities approved by the state to provide a medical model of care to Medi-Cal beneficiaries (individuals who qualify based on income).
CBOs	Community-Based Organizations
CDA	California Department of Aging
CHIS	California Health Information Survey
CNAs	Certified Nursing Assistants
CRCs	California Caregiver Resource Centers
DAAS	Santa Clara County Department of Aging and Adult Services
FPL	Federal Poverty Level
HCBS	Home and community-based services—includes types of person-centered care delivered in the home and community.

HHAs	Home Health Aides
IADLs	Instrumental Activities of Daily Living—activities that include bill paying, shopping, housekeeping, medication management, food preparation, etc.
IHSS	In-Home Supportive Services—a Medi-Cal program providing those 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.
IHSS Providers	IHSS providers can be provided by a parent, a spouse, or a caregiver. IHSS providers may provide personal care services and/or paramedical services as authorized by the IHSS program.
Low-to-Middle Income	Individuals whose income ranges from 100 percent of the Federal Poverty Level (FPL) to middle-income, defined as two-thirds to double the U.S. median household income.
LTSS	Long-Term Services and Supports: LTSS encompasses the broad range of paid and unpaid medical and personal care assistance that people may need – for several weeks, months, or years – when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.
MPA	California Master Plan for Aging
PCAs	Personal Care Aides
SCC	Santa Clara County

*California Association of Adult Day Services definitions.

Appendix C: Santa Clara County Community-Based Organizations

Santa Clara Adult Day Programs

Adult Day Program (ADP)* centers offer a **non-medical model of care** through a day-time program for elderly and younger adults with a focus on protective supervision by trained aides, structured activities, health monitoring, meals, out-of-home respite, and support for the caregiver.

ADULT DAY PROGRAMS	
ORGANIZATION	**ADDRESS/CONTACT INFORMATION**
Avenidas Rose Kleiner Center	270 Escuela Ave Mountain View, CA 94040 650-289-5499
Hearts and Minds Activity Center	2380 Enborg Ln San Jose, CA 95128 (408) 279-7515
Hope Senior Services	1555 Parkmoor Ave San Jose, CA 95128 408-282-0419
Live Oak Cupertino	20920 McClellan Rd Cupertino, CA 95014 408-973-0905
Live Oak Gilroy	651 W. Sixth Street, Suite 2 Gilroy, CA 95020 408-847-5491
Live Oak Los Gatos	111 Church St Los Gatos, CA 95030 408-354-4782
Live Oak Willow Glen	1147 Minnesota Ave San Jose, CA 95125 408-971-9363
SarahCare of Campbell	450 Marathon Drive Campbell, CA 95008 408-374-2273
Saratoga Adult Care Center	19655 Allendale Ave Saratoga, CA 95070 408-868-1254
Yu-Ai-Kai Senior Services	588 N. 4th St San Jose, CA 95112 408-294-2505

*California Association of Adult Day Services definition.

Santa Clara Adult Day Health Centers

Adult Day Health Centers (ADHC)* offer a **medical model of care** through an outpatient day program for older persons and adults with chronic medical, cognitive, or mental health conditions and/or disabilities that are at risk of needing institutional care.

A coordinated team of licensed professionals, including nurses, social workers and physical, speech and occupational therapists, focus on medical, preventive, and social care to improve health outcomes for high cost / high-risk patients. ADHCs provide activities, personal care, hot meals, nutritional counseling, and transportation to and from the center. Most participants are Medi-Cal beneficiaries.

ADULT DAY HEALTH CENTERS	
ORGANIZATION	**ADDRESS/CONTACT INFORMATION**
Avenidas Rose Kleiner Center	270 Escuela Ave Mountain View, CA 94040 650-289-5499
Golden Castle Adult Day Health Center	3803 E. Bayshore Rd Palo Alto, CA 94303 650-964-1964
Grace Adult Day Health Care	3010 Olcott St Santa Clara, CA 95054 408-727-6280
On Lok PACE San Jose Center	299 Stockton Ave San Jose, CA 95126 408-535-4600 (TTY: 711)
On Lok PACE East San Jose Center	130 N. Jackson Ave San Jose, CA 95116 408-795-3888 (TTY: 711)
Prestige Adult Day Health Care	1765 S. Main St, Ste 101 Milpitas, CA 95035 408-586-9000
Silicon Valley Adult Day Health Care Center	631 S. Milpitas Blvd Milpitas, CA 95035 408-956-8578

*California Association of Adult Day Services definition.

Santa Clara County Community-Based Organizations

COMMUNITY-BASED ORGANIZATIONS		
ORGANIZATION	**INFORMATION**	**PHONE NUMBER**
AARP Family Caregiver Resources	AARP Family Caregiver Resource Center helps caregivers navigate their role. The organization provides a wide range of resources, including educational articles and videos on caregiving related topics, as well as state caregiving resource guides. AARP also operates a family caregiving resource line.	AARP Family Caregiving Resource Line: 877-333-5885 toll-free 888-971-2013 toll-free (En Español)
Asian Americans for Community Involvement (AACI)	AACI Senior Wellness Program promotes healthy, active aging through programs, advocacy, and engagement. Programs are designed to foster health, wellness, independence, and social engagement.	408-975-2339 or 408-975-2730
Alzheimer's Association	Alzheimer's Association provides information on Alzheimer's disease and dementia symptoms, diagnosis, stages, treatment, and care and support resources, including support groups.	408-372-9900
Avenidas	Avenidas helps older adults in the community be as active, engaged, and healthy as possible throughout their lives by providing a wide range of programs, information, and services.	650-289-5400
Bay Area Older Adults	Bay Area Older Adults' mission is to stimulate the hearts, bodies, and minds of older adults through easy access to arts and culture, nature, and new friends. The organization organizes a variety of adventures, or individuals can choose to plan activities on their own with the help of their guide.	408-774-0593
Cancer CAREpoint	Cancer CAREpoint model consists of one-on-one Counseling, Assistance, Resources, and Education. Services are open to all Silicon Valley cancer patients, survivors, families, and caregivers at no cost.	408-402-6611
Catholic Charities of Santa Clara County	Provides services and advocates for individuals and families in need, especially those living in poverty. For seniors and people living with disabilities, the organization offers a Senior Nutrition Program, Ombudsman Program, health insurance counseling, mental health services, social and wellness activities.	408-468-0100
Community Services Agency	Community Services Agency delivers vital social services for residents of Mountain View, Los Altos, and Los Altos Hills, providing critical support services that preserve and promote stability, self-reliance, and dignity. The organization operates a Senior Nutrition Program and a Senior Services Program that offers case management services to deliver in-home assessments, counseling, referrals, and educational seminars.	650-968-0836

COMMUNITY-BASED ORGANIZATIONS		
ORGANIZATION	**INFORMATION**	**PHONE NUMBER**
Family Caregiver Alliance*	FCA works to improve the quality of life for caregivers and the people who receive their care. Services include family caregiver assessment and consultation, information, care planning, education and skills training, wellness programs, respite services, and legal/financial consultation vouchers.	800-445-8106 toll-free 415-434-3388
Institute on Aging*	Institute on Aging (IOA) enhances the quality of life for adults as they age by enabling them to maintain their health, well-being, independence, and participation in the community. IOA operates many programs, including CalAIM Santa Clara, which offers enhanced care management for Santa Clara Family Health Plan members who meet program requirements.	410-750-4111
Jewish Family and Children's Services Seniors at Home	Jewish Family and Children's Services Seniors at Home assists seniors to age with respect and dignity and to live safer, healthier, more independent lives. Offers a variety of programs including home care and care management.	415-449-3700
Jewish Family Services	Older adults and caregivers can receive a comprehensive set of supportive services through the Center for Aging and Caregiver Services which helps keep individuals living in their homes safely with quality and dignity. Services include case management, homecare services, fall prevention, caregiver support, enrichment, counseling and therapy, friendly visitor, and Holocaust survivor services.	408-556-0600
Sacred Heart Community Service	Sacred Heart Community Service's vision is a community united to ensure that every child and adult is free from poverty. The organization provides essential services, like food, clothing, housing and financial assistance, utility assistance, and tax preparation, to help provide stability to individuals in the community.	408-278-2160
Self-Help for the Elderly	Self-Help for the Elderly promotes senior independence, dignity, and self-worth. The organization operates the South Bay Center in Sunnyvale where seniors can connect with staff, participate in events, and access services.	408-733-1883
Silicon Valley Independent Living Center	Silicon Valley Independent Living Center's mission is to empower people with disabilities by providing the advocacy, training, skill development and services which enhance every individual's capability.	408-985-1243

COMMUNITY-BASED ORGANIZATIONS		
ORGANIZATION	**INFORMATION**	**PHONE NUMBER**
Sourcewise	Sourcewise's mission is to provide adults and their caregivers the tools and services needed to effectively navigate their health and life options. As the designated Area Agency on Aging, the nonprofit organization offers a comprehensive network of resources and direct support services.	408-350-3200 (Main Office) 408-762-7362 (South County Office)
Sunnyvale Community Services	Sunnyvale Community Services is an independent, nonprofit emergency assistance agency with a mission to prevent homelessness and hunger in our local community. This organization assists residents in Sunnyvale and the Alviso neighborhood of San Jose.	408-738-4321
The Health Trust	The Health Trust is a nonprofit operating foundation with a mission to build health equity in Silicon Valley. The foundation takes a multifaceted approach to addressing health disparities, acting in three ways: as a funder of grants, provider of direct services, and advocate for systems and policy changes.	408-513-8700
VA Caregiver Support	Caregivers for Veterans can contact their local VA caregiver support coordinator who can assist with learning about caregiver assistance available through the VA, match caregivers with services and benefits, and connect caregivers with local resources and programs.	650-614-8419 (Palo Alto VA) 1-855-260-3274 (VA Caregiver Support Line)
West Valley Community Services	West Valley Community Services provides assistance to low-income and unhoused individuals and families in the West Valley communities of Cupertino, Saratoga, West San Jose, Los Gatos, Monte Sereno, and surrounding mountain regions. The organization offers services in four categories: food, housing, support, and mobile.	408-255-8033

* Listed CBOs that provide direct services and support to caregivers in the county but do not have a physical address in SCC.

The following organizations provide indirect support to caregivers in SCC.

- Atlas of Caregiving
- Breathing Spaces
- Plane Tree Health Library
- Caregiver Counts Conference
- Heart of the Valley, Services for Seniors

Appendix D: Santa Clara County Licensed Home Care Organizations

123 Homecare Services, Inc.	24/7 Healthcare, Inc.	AAA Quality Homecare
Absolute HomeAid	AccentCare of CA - San Jose	AHA Auxilio-HomeAide, LLC
All Care for Elders & Seniors	All Seasons Care Giving Solutions, Inc.	Allegra Home Care, Inc.
Ally Home Care	AmeriCARE Silicon Valley, Inc.	AmiCare Services, Inc.
Arc@Home	A&A Advanced Care, Inc. Dba Nurse Next Door	Bay Home Care Services, LLC
Beulah Home Care, LLC	Bonita Springs Home Care	Boundless Care, Inc.
California Seniors Care	Care Indeed, Inc.	Care On Call In-Home Care
Caring Hand Home Health Services, Inc.	Caring Hands Caregivers, Inc	Caring With Care, LLC
Cloverleaf Care	ComForCare Home Care South Bay	CTR Care Caregiver Services
Custom Senior Care	Dedicated Care Living, Inc.	Dial Care Services, LLC
Dream Companion Home Care Agency, LLC	EssentialCare	Exigency Healthcare Services, LLC
Familiar Surroundings Home Care, LLC	Family Love Homecare	Family Matters In-Home Care, LLC
FirstLight Home Care of Silicon Valley	Fruitful Living, Inc.	Heart and Home Personal Care Services, LLC
Help & Care, LLC	The Helping Hands	Home Helpers of Santa Clara Valley
Home Instead	Homecare California	Homecare California, Inc.
HomeCare Professionals, Inc.	Homewatch CareGivers of West San Jose	Immaculate Hearts Home Care
Infinity Family Home Care, LLC	Interim Healthcare Personal Care & Support Service	JC Shield Home Care, Inc.
Kasama Home Care, LLC	Kindred At Home	Kiwi Associates, Inc., DBA A1care
Little Angels Caregivers	Livhome, Inc. DBA Arosa - Silicon Valley	Loving Hands Home Care Services
Maxim Healthcare Services, Inc.	Motherhealth, LLC	My Friendly Care
NexGen Healthcare Inc. of California	Norcal HC Holdings, LLC	Nurse Next Door San Jose
Nurses And Caregivers	Polaris Home Care, LLC	Polynesian Care Agency
Priority Care of Franthena	ProHealth Care, Inc.	ReachPoint Home Care & Resources, Inc.
Right At Home	Right At Home - Peninsula	Right At Home San Jose
Right At Home West Valley	Royal Plus Home Care, Inc.	Samaria Elderly Care, Inc.
SCC At Home, LLC	Sdx Home Care Operations, LLC DBA Comfort Keepers	Senior Care Connection, Inc.
Senior Helpers San Jose	Shield Home Care, LLC	Silicon Valley Legacy Care, Inc. DBA Carewella
Silver Lining Caregivers, Inc.	Speedcare Connect, LLC	Star Home Care, Inc.
Starlight Caregivers	St. Patrick Home Care Services, Inc.	Sumala Health
Supreme Companions	Sweet Angels Caregiving Services LLC	Synergy Homecare of Campbell/Los Gatos
TheKey of California, LLC (Los Gatos)	TheKey of California, LLC (Palo Alto)	Tri Starr Home Care, LLC
True Home Care Services	Visiting Angels	Visiting Angels Gilroy
Visiting Angels of Silicon Valley	Vista Verde Home Care	We Care Personal Services, Inc.
Wohelo Associates, LLC		

List of licensed home care organizations in Santa Clara County downloaded from the California Dept of Social Services website on April 15, 2023.

Appendix E: Study Interviewees

- **Diane Alumno**, LCSW, Adult Day Health Care Program Coordinator, VA Palo Alto Healthcare System
- **Rebeca Armendariz**, Director of Movement Building, Working Partnerships USA
- **Donna Benton**, PhD, Director, USC Family Caregiver Support Center/LACRC
- **Carmen Brammer**, Chair, Senior Care Commission, Global Majority Consulting, LLC
- **Bob Brownstein**, Strategic Advisor, Working Partnerships USA
- **Eunice Chang**, Senior Wellness Program Manager Asian Americans for Community Involvement (AACI)
- **Susan DeMarois**, Director, California Department of Aging
- **Charlene Elefante**, Senior Manager, Community Engagement, On Lok PACE
- **Edith Gong**, MSOD, Director of Public Authority Services, Sourcewise
- **Sandra Green**, Family Care Specialist, Alzheimer's Association, Northern California and Northern Nevada Chapter
- **Lucy Istomenia**, Senior Care Manager, Holocaust Service Program, Jewish Family Services of Silicon Valley
- **Mansi Kathuria**, MPP, Associate Director of Health and Care Policy, Working Partnerships USA
- **Nancy Keegan**, Program Director, Avenidas Rose Kleiner Center
- **Kathleen Kelly**, MPA, Executive Director, Family Caregiver Alliance
- **Thomas Kingery**, MSW, Program Manager, Avenidas Rainbow Collective
- **Lupe Martinez**, Region 5 Member Strength Director, SEIU Local 2015
- **Emi Nagai**, Case Manager, Yu-Ai Kai Japanese American Community Senior Service
- **Erika Neal**, Community Outreach Specialist, Alzheimer's Association, Northern California and Northern Nevada Chapter

- **Maria Nicolacoudis**, Chief Executive Officer, Hearts & Minds Activity Center
- **Ann Peterson**, Executive Director, Live Oak Adult Day Services
- **Lauren Pizzulli**, LCSW, Acting Program Manager, Caregiver Support Program, VA Palo Alto Healthcare System
- **Terri Possley**, LCSW, Social Services Program Manager III, In-Home Supportive Services
- **Gulraj Shahpuri**, Co-Owner, Right at Home, Palo Alto
- **Vanessa Souza**, LCSW, Senior Manager, Community Engagement, Alzheimer's Association, Northern California and Northern Nevada Chapter
- **Gianna Spina**, Senior Manager, Independent Living Services and Personal Assistance Services, Silicon Valley Independent Living Center
- **Adrianna Stankovich**, MPIA, CPG, Supervising Care Manager, Caregivers Network, Sourcewise
- **Sarah Steenhausen**, Deputy Director Division of Policy, Research, and Equity, California Department of Aging
- **Kenneth Tak**, President, Fidelity Senior Solutions, LLC dba Home Instead
- **Mallory Von Kugelgen**, RN, PHN, Health & Wellness Coordinator, Santa Clara Senior Center
- **Norell Wheeler**, MPH, MBHS, Family Consultant, Family Caregiver Alliance

Caregiver Best Practice Programs: Key Informants

- **Donna Benton**, PhD, Director, USC Family Caregiver Support Center/Los Angeles Caregiver Resource Center
- **Susan Chang**, Senior Management Analyst, Department of Aging and Adult Services, County of Santa Clara Social Services Agency
- **Charlene Elefante**, Senior Manager, Community Engagement, On Lok PACE
- **Rowena Fontanos**, BASW, MNA, Senior Manager of Community Programs, Institute on Aging
- **Helen Huckeleberry**, Marketing Director, On Lok PACE
- **Alison Moritz**, Director of Enrichment Center, Institute on Aging

Appendix F: Study Workgroup Members

- **Bob Brownstein**, Strategic Advisor, Working Partnerships USA
- **Sheri Burns**, OTR, Executive Director, Silicon Valley Independent Living Center (SVILC) and Chair of Aging Services Collaborative
- **Susan Chang**, Senior Management Analyst, Department of Aging and Adult Services, County of Santa Clara Social Services Agency
- **Tita Das**, Case Manager, Silicon Valley Independent Living Center (SVILC)
- **Aneliza del Pinal**, Chief Executive Officer, Sourcewise
- **Charlene Elefante**, Senior Manager Community Engagement, On Lok PACE
- **Susan Frazer**, LCSW, Chief Executive Officer, Jewish Services of Silicon Valley
- **Christina Irving**, LCSW, Client Services Director, Family Caregiver Alliance
- **Kristina Lugo**, LCSW, Vice President, Individual and Family Services, Avenidas
- **Diana Miller**, MA, Seniors' Agenda Project Manager, Department of Aging and Adult Services, County of Santa Clara Social Services Agency
- **Vanessa Souza**, LCSW, Senior Manager, Community Engagement, Alzheimer's Association, Northern California and Northern Nevada Chapter
- **Kenneth Tak**, President, Fidelity Senior Solutions, LLC *dba* Home Instead and Member, Morgan Hill Senior Advisory Board
- **Vaughn Villaverde**, MPH, Director of Advocacy, Asian Americans for Community Involvement (AACI)
- **Mallory Von Kugelgen**, RN, PHN, Health & Wellness Coordinator, Santa Clara Senior Center
- **Mary Ann Warren**, Director, Department of Aging and Adult Services, Public Administrator/Guardian/Conservator, County of Santa Clara Social Services Agency

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LifeCourse Strategies, LLC conducted the Santa Clara County Adult Caregiver Study. 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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