

April 1, 2022

Dear San Francisco Family Caregiver Advocate,

San Francisco is an extraordinary place to live. Brimming with diversity, vitality, and natural beauty, 875,000 people call the *City by the Bay* home. As unique as the city is though, it shares more than a few trends in common with cities across America. Chief among them, an aging population. San Francisco adults aged 60 and older are the fastest growing age demographic in the city. By the year 2030, this age group is expected to represent nearly 30% of the total population. Another important statistic San Francisco shares with the rest of the country: approximately 89% of adults (aged 18 years and older) who care for older adults and persons with disabilities in the city are family caregivers (includes family members, friends, neighbors, and “families of choice”). The median age for these caregivers is 49 yrs.

Family caregivers are the front line of defense in caring for the seriously ill in all our communities, and the number of adults providing unpaid care for loved ones is increasing across the country. In 2015, family caregivers comprised 16.6 % of the adult population in the United States, today it is 19.2% (*Caregiving in the U.S., 2020 Report, AARP*). The work family caregivers do is difficult, essential, and contributes significantly to society. Nearly 60 % of all caregivers perform a variety of complex medical/nursing tasks, such as administering medications (including injections), wound care, and managing medical equipment. In 2017, approximately 41 million family caregivers in the United States provided an estimated 34 billion hours of uncompensated care to an adult with functional limitations. The estimated economic value of this care was **\$470 billion** (*Valuing the Invaluable: 2019 Update, AARP*).

Many caregivers report that what distinguishes their caregiver experience from other experiences is that they stepped into the caregiving role feeling unprepared—unaware of the scope of their care recipient’s care needs, what they needed to provide safe care, and how they would provide it. In short, caregivers often assume the responsibility of providing care with little or no training or support. This is of special concern given the numbers of caregivers providing complex care and those who are younger (in their 20s, 30s, 40s), who may be juggling work, children, spouse or partner demands, *and* caregiving.

Given the extent of caregiver duties and responsibilities for many family caregivers, it is important to recognize that caregiving can be both a deeply rich and meaningful experience and emotionally, physically, and financially stressful. The latter is associated with the costs of providing care, from care recipient medical expenses to housing and home modifications, to out-of-pocket costs, job loss, and

reduced work hours. Although family caregiver policies and programs have increased in recent years, the range of supports necessary to fully address caregiver needs requires a broader national and state effort.

California is fortunate to have a statewide system of 11 nonprofit Caregiver Resource Centers (CRCs) committed to serving family caregivers of adults (aged 18 years and older) affected by chronic and debilitating health conditions, including dementia, Alzheimer's disease, cerebrovascular diseases, degenerative diseases such as Parkinson's, Huntington's and multiple sclerosis, or traumatic brain injury. CRCs provide a wide range of free and low-cost services from information and caregiver assessment to family consultation and respite. In 2020, the CRC system implemented CareNav™ to better understand, identify, track, and respond to the unique needs of California's family caregivers. CareNav™ serves as both a repository for caregiver data, collected through a standardized intake procedure and a uniform caregiver assessment, and an accessible, safe online platform for caregivers to receive specialized information and communicate with CRC staff.

Even with the CRC system and a host of community organizations serving family caregivers, as the state with the most adults aged 60 and older in the US, California must **do more** to address current family caregiver needs. This urgency was underscored by the COVID-19 pandemic, which illuminated the limited and fragile network of currently available caregiver services, especially for communities of color—issues highlighted in the 2018 report, *Picking Up the Pace of Change in California: A Report from the California Task Force on Family Caregiving* (California Task Force on Family Caregiving) and the 2021 *California Master Plan for Aging* (California Department of Aging, 2021). It is important to note that the pandemic equally revealed the formidable digital divide and resulting service access barriers for many caregivers.

The San Francisco Department of Disability and Aging Services (DAS) has identified reaching out to and engaging family caregivers, including those representing diverse communities, as a priority. Family Caregiver Alliance (FCA) which serves as the Bay Area CRC for six counties (Alameda, Contra Costa, Marin, San Francisco, San Mateo, and Santa Clara counties), supports this important goal. With funding from the Metta Fund, FCA conducted a study of San Francisco family caregivers in 2021. The primary study objectives were to assess the needs of and gaps in services and supports for family caregivers, with special attention directed to assessing the needs of ethnically diverse and underserved family caregivers.

Study components included qualitative interviews with leading caregiver service providers, and a survey of FCA San Francisco family caregivers (n=90) caring for adults (aged 18 years and older) living with neurodegenerative and complex health conditions. The study offers a snapshot of the needs and challenges faced by San Francisco caregivers today, complementing a survey of caregiver needs and challenges conducted by DAS in 2019.

This issue brief presents key study findings and recommendations—building on Task Force and Master Plan recommendations—that advocate for policy changes that support the health and well-being of San Francisco family caregivers. The recommendations are additionally structured to assist family caregivers help care recipients remain in their homes and communities for as long as possible.

Our hope is that everyone who believes that family caregivers are essential members of society will ask local and state public officials to adopt and implement these recommendations.

Sincerely,

Kathleen Kelly  
Executive Director  
Family Caregiver Alliance

# State of Caregiving in the City and County of San Francisco

## Introduction

Benjamin Franklin said, “In this world nothing can be said to be certain, except death and taxes.” To this truism we think it’s fair to add **Caregiving**. Rosalynn Carter emphasizes this point with her famous quote, “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.”

When the world was turned upside down by the COVID-19 pandemic, the vulnerability and social isolation of family caregivers, especially those caring for loved ones with complex health conditions at home, such as dementia, underscored just how many Americans are family caregivers today. Equally important, the experience of many caregivers of color mirrored longstanding systemic health and social inequities and health disparities, and the widening gap between the haves and have nots. During the pandemic, the coordination and delivery of community and social services moved largely online. Because many low-income caregivers lack the financial and technical ability to use the Internet, they were unable to access needed services. COVID highlighted this gap in communities across the country, as well as the number of care recipients and caregivers who depend on adult day programs and in-home respite care.

For many years caregiving was not talked about as an “issue,” either for the people receiving or providing care, or by the institutions serving them. That has changed. Caregiving is mainstream. Family caregivers and the care they provide to family members, friends, and neighbors (includes “families of choice”) have garnered the attention of health and social service organizations, providers, and public officials. Today, one in five American adults is caring for another adult.<sup>1</sup> Yet, the gulf between what caregivers need—physical, social, financial, and educational resources—and a reliable infrastructure to support all caregivers including middle income families remains elusive. It is time to act.

With COVID-19 still a part of everyday life, the California Task Force on Caregiving 2018 report, *Picking Up the Pace of Change in California*, produced seven prescient recommendations.<sup>2</sup> What mattered most to caregivers in 2018 is even more relevant today: supporting the *financial wellbeing* of family caregivers; ensuring *accessible caregiver information*, education, and training; increasing access to *affordable caregiver services and supports*; and *integrating* family caregivers into hospital processes.

In addition to creating a blueprint for responsive policymaking to improve the lives of caregivers throughout the state, the work of the Task Force informed the [2021 California Master Plan for Aging](#). The

Master Plan outlines five goals for 2030 that ensure that older Californians, an increasingly diverse demographic, will have opportunities to live longer, continue contributing to their communities, and thrive without fear of economic insecurity.<sup>3</sup> Goal 4, *Caregiving That Works*, identifies three strategies to support family caregivers with special attention to groups that disproportionately provide family caregiving: lower-income women and women of color.

There are close to five million family caregivers in California providing essential support to family members and friends with little or no outside support. Together they provide approximately four billion hours of care to adults with limitations in daily activities. The estimated economic value of their unpaid contributions is \$63 billion.<sup>4</sup> As impressive as these numbers are, the more remarkable story is what these members of every community in the state do day in and day out for loved ones.

California's statewide system of 11 Caregiver Resource Centers (CRCs) was established over 30 years ago as a responsive model of services and programs grounded in the empowerment framework, which recognizes and supports caregivers and their decision-making capacity. Caregivers served by CRCs are given tools that help them identify and use personal strengths to enhance their caregiving competence and self-efficacy and to reduce caregiver burden, stress, and loneliness.

To promote uniform quality and availability of core services statewide, in 2020, the CRCs implemented CareNav™, an online system that supports the following: data collection using a uniform caregiver assessment, a record of CRC services provided, the capacity to securely develop individualized care plans and tailored resources for caregivers, and an interactive portal for caregivers to communicate securely with CRC staff. Evaluation of CareNav™ and other CRC data for FY 2020-2021, summarized in the October 2021 report, [Evaluation of Service Delivery and System Change by the California Caregiver Resource Centers](#), highlighted that 78.6% of caregivers served by a CRC assist with at least one medical/nursing task, 72.9% spend more than 40 hours a week caregiving, 37.4% are working full or part time, and approximately 18% earn below the federal poverty level.<sup>5</sup>

Among caregivers served by CRCs statewide, 52.2% are white non-Hispanic, 31.4% are Hispanic/Latino, 8.2% are Asian American/Pacific Islander, 6.6% are Black non-Hispanic, 1.1% are multi-racial/other racial identity, and 0.6% are Native American/ Alaska Native.

The report underscored that not only do CRCs serve a racially and ethnically diverse population, but CRC

caregivers also present a higher risk profile than the general population of caregivers. Several reasons account for this. CRC caregivers engage in more high intensity care (based on caregiving hours and the number of activities of daily living and instrumental activities of daily living that they support for their

*FY 2020-2021 CRC system service data highlights:*

- ▶ 33,000 caregivers received support
- ▶ 6,126 caregiver intakes
- ▶ 4,299 caregiver assessments
- ▶ 25,546 family consultations
- ▶ 139,340 total respite hours

care recipients); report more adverse physical and mental health effects from the caregiving role, including loneliness and isolation; are more likely to live with the care recipient; are less likely to have paid help for caregiving; and are more likely to live below the federal poverty level.

As the Bay area CRC, Family Caregiver Alliance (FCA) is committed to understanding these stories and responding to family caregiver needs. With a mission to improve the quality of life for family caregivers and the people who receive their care, FCA has provided services, programs, and supports to caregivers in six Bay Area counties for over 40 years. With funding from the Metta Fund, in 2021, FCA conducted a family caregiver study that included interviewing leading San Francisco caregiver service providers and surveying FCA San Francisco family caregivers caring for adults (aged 18 years and older) living with neurodegenerative and complex health conditions. The primary interview and study objectives were to 1) identify family caregiver needs, available services, and gaps in services in San Francisco; and 2) identify actionable recommendations to improve caregiver services and supports.

This issue brief presents key study findings and recommendations to close gaps in caregiver services and supports in San Francisco, built on the California Task Force on Caregiving and the California Master Plan for Aging recommendations.

## City and County of San Francisco: Caregiver Needs

Approximately 875,000 people call San Francisco home.<sup>6</sup> Like Alameda County across the bay, San Francisco is among the most diverse counties in the country with regard to race, ethnicity, sexual orientation, language, and culture. Residents aged 18 and older account for 87% of the total population (757,415); however, the fastest growing age group in the City and County of San Francisco is adults aged 60 and older. They represent more than a quarter of the population (185,756). Just as significant, the estimated number of caregiver adults (aged 18 and older) in San Francisco is 90,057 and the estimated economic value of the unpaid care they currently provide is approximately \$1 billion.<sup>4</sup>

Often described as resource-rich, San Francisco has a strong public service infrastructure complemented by a robust array of health and social service community-based organizations. Public agencies serving the city include the San Francisco Department of Public Health, the San Francisco Human Resources Agency, and the San Francisco Department of Disability and Aging Services (DAS). DAS is also the state-designated Area Agency on Aging (AAA) for San Francisco. In their AAA role, DAS focuses on the needs of older adults and their caregivers. Even with the benefits and support these organizations offer, critical service and support gaps remain for family caregivers caring for older adults and persons with disabilities.

National studies on family caregivers, have documented several of these key gaps. Communities lack resources to support persons living with cognitive impairment including Alzheimer’s disease, and their caregivers, so they can continue to live in their homes and communities. Services to meet the needs of an increasingly diverse caregiver population are also limited. And because many caregivers find themselves knee-deep in their caring role often without ever calling themselves a “caregiver,” they may be unaware of services available to help them. Health and social service professionals too may never have asked them what they need or what kind of care they provide. Because the United States population is living longer with serious illness and the number of family caregivers is increasing, responding to the diverse needs of family caregivers must be an imperative for every community.

In 2019, DAS presented a caregiver profile and needs assessment analysis.<sup>7</sup> The assessment is part of the Dignity Fund charter amendment. The Dignity Fund legislation, passed by San Francisco voters, is a protected funding stream for social services that supports seniors, adults with disabilities, and their caregivers. Every four years, DAS completes a detailed assessment of the needs of these populations to identify strengths and gaps in services. Data reported in the caregiver needs assessment analysis revealed that Alzheimer’s disease and Alzheimer’s-related dementias (AD/ADRD) are a major concern for the city. A majority of care recipients (63%) had a primary diagnosis of dementia, with Alzheimer’s disease reported as the most common type. Most caregivers stated that their caregiving responsibilities were a fulltime commitment and that they received little to no help with caregiving.

The needs assessment also highlighted the diversity of San Francisco older adults (aged 60 and older) and their caregivers. Among caregivers accessing DAS Office on Aging (OOA) services, the majority were white and Asian/Pacific Islander.<sup>7</sup> Latinos represented 15% of San Francisco’s overall population in 2019, but only eight percent of Latino caregivers received OAA services. The analysis also reported that 20% of caregivers enrolled in OAA services identified with a sexual orientation other than straight.

DAS’s caregiver profile and needs assessment analysis concluded with several recommendations: support more dementia-focused programming; link caregivers to financial supports, information and assistance, support groups, counseling, and respite care to reduce caregiver stress and burden; and outreach to the Latino community to ensure caregivers are linked to language and culturally concordant caregiver services and supports. These recommendations are part of Goal 1 of DAS’s Area Plan 2021-2024, *Maintain a robust network of community-based services for older people and adults with disabilities*, under the strategy “strengthen the caregiver network, including enhanced support for informal caregivers and supporting a robust provider workforce in the In-Home Supportive Services (IHSS) program” (IHSS provides 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; many family members serve as IHSS providers).<sup>8</sup>

Note: One additional issue that significantly affects the lives and well-being of many San Francisco residents that merits mentioning is affordable housing. Research consistently shows that housing stability, quality, safety, and affordability all affect health outcomes—physical, mental, and emotional.<sup>9</sup> DAS has made affordable housing for older adults and persons with disabilities a top legal priority and equity issue to ensure that all San Franciscans have the ability to age with dignity in the community, with the care they need and deserve. While these efforts hold promise, it is important to recognize that family caregivers and home care aides too are impacted by rising housing costs. Many are finding it increasingly prohibitive to live in or near the city to support those who need their care.

## Family Caregiver Study: Interview and Survey Findings

Although the full impact of the COVID-19 pandemic will take years to assess and understand, the effects of the crisis were immediately felt in every neighborhood and every community across the country. Overnight, hospitals and health systems shifted how they cared for patients, directed resources, and deployed staff. Community organizations followed suit, adjusting in-person operations to virtual ones. These transitions affected older and disabled adults, who prior to the pandemic attended adult day programs. They also impacted family caregivers who rely on these and other respite services for needed breaks. Adult day programs are associated with increased socialization, quality of life, and reduced depression for care recipients, as well as reduced levels of stress and burden for family caregivers.

The pandemic took all these supports away. In its wake, care recipients and caregivers suffered. Daily routines for each were profoundly disrupted. Caregivers who formerly had a break when family members attended adult day programs or received respite care in the home, found themselves caring 24-7 days a week. Unable to receive help even from family during the pandemic, they assumed the responsibility of providing more care than usual, which resulted in increased loneliness, isolation, and caregiver burden. The effect on care recipients was equally devastating. Without the structural supports of adult day programs, congregate meals and dementia café's, which offer socialization and purposeful activities, many care recipients with dementia experienced an accelerated cognitive decline during COVID-19.

To ensure that caregivers stayed connected to vital caregiver services and supports during the pandemic, FCA transitioned all in-person services to virtual (phone, video conferencing, connecting via Facebook) and significantly increased the number of caregiver support groups and check-in calls with caregivers.

Table 1 presents a summary of key demographics of San Francisco family caregivers served by FCA between January 1, 2016, and December 14, 2021.



**Table 1. San Francisco Family Caregivers: Key Demographics (n=2478)**

Caregiver Race/Ethnicity		Relationship of Caregiver to Care Recipient	
Asian/Pacific Islander	40.5%	Child	59.4%
White	29.2%	Spouse	27.0%
Hispanic/Latino	11.7%	Related/Other	8.0%
African American	10.1%	Non-related	2.4%
More than 1 race	1.0%	Partner	1.3%
Native American	0.3%		
Caregiver Gender		Age of Caregiver	
Female	75.4%	18-44	8.8%
Male	23.2%	45-64	47.1%
Other	0.1%	65-84	38.7%
		85+	5.0%
Employment		Caregiver Sexual Orientation	
Full-time	32.6%	Straight	62.7%
Unemployed	20.9%	Gay	2.0%
Retired	20.1%	Bisexual	0.4%
Part-time	14.6%	Lesbian	0.4%
Leave of Absence	1.7%	Questioning	0.1%
		Not Listed	0.5%
Care Recipient Lives with Caregiver		Care Recipient Medicaid Eligible	
Yes	67.9%	Yes	49.4%
No	29.0%	No	37.1%
		Unsure	7.6%

Most FCA caregivers are women, between the ages of 45 and 84, caring for and living with a parent. They are predominantly Asian/Pacific Islander and white, employed full- or part-time, and straight. Twenty percent are either retired or unemployed. Approximately half of care recipients are eligible for Medi-Cal, indicating that they are low-income.

To complement this profile of San Francisco family caregivers, FCA conducted a family caregiver study—interviews with leading San Francisco caregiver service providers and a survey of FCA San Francisco family caregivers—to assess current caregiver needs, gaps in services, and opportunities to close them.

## Interview Findings

**Gaps in Family Caregiver Services and Supports.** Interviewees valued the array of programs serving San Francisco care recipients and family caregivers but reported they can be strengthened and expanded.

► **Access and Affordability.** San Francisco’s adult day service system includes the following:

- **5 Adult Day Programs (ADPs)** provide daycare services to adults needing assistance with non-medical activities of daily living and to people who may have cognitive impairments.
- **4 Alzheimer’s Day Care Resource Centers (ADCRC)** provide daycare services and support to individuals with dementia and their families.
- **9 Community-Based Adult Services (CBAS)** programs provide community-based day health services to older persons and adults with chronic medical, cognitive, or mental health conditions and/or disabilities who are at risk of needing institutional care.
- **4 Program of All-Inclusive Care for the Elderly (PACE)** centers provide comprehensive medical and social services delivery system using an interdisciplinary team approach for eligible Medi-Cal and Medicare beneficiaries.

***Note:** The models listed above represent different service categories. The number of programs listed for each model, however, does not reflect what is currently available in the community. Some programs fit multiple service categories. In addition, a number of non-licensed day programs operate in San Francisco.*

Given the prevalence of older San Franciscans with cognitive impairment and complex health conditions, the current adult day service system is inadequate. Moreover, the cost of services is a barrier for many care recipients. Medi-Cal covers the cost of CBAS programs for low-income older and disabled adults but does not provide a similar benefit for ADPs. For the “hidden poor,” individuals whose income is above the federal poverty level but below a basic standard of living, accessing either program is often financially prohibitive. Older adults with incomes or assets too high to qualify for public programs and Medi-Cal’s share of cost, but who cannot afford to pay out of pocket for these services without risk of falling into poverty, are also unable to benefit from them.

“The biggest gap in family caregiver services is the lack of services—respite, home care—for middle-income people. If the care recipient does not qualify for IHSS and the caregiver cannot afford this care, they are out of luck.”  
– Caregiver Stakeholder

The mosaic of subsidized respite and caregiver services funded through the National Family Caregiver Support Program (NFCSP) and other funding sources (e.g., programs provided by Family Caregiver Alliance, Institute on Aging, Jewish Family and Children’s Services, Kimochi, Inc., Self-Help for the Elderly, SteppingStone, Openhouse, IHSS) have provided a critical lifeline of support, but many family caregivers find they cannot afford the additional help they need to support and care for their loved ones at home.

- ▶ **Information and Navigation.** For many family caregivers, the role of being a caregiver takes shape over time. It may begin with providing transportation to a doctor appointment, a little bit of physical assistance navigating stairs, or minor cognitive assistance such as organizing bills to be paid. Although health care providers may be aware of care recipients’ changing needs, they often do not know or ask how much help

the family caregiver is providing. This can leave caregivers feeling further isolated and alone. And because there is no definitive start to a caregiver's journey, many individuals don't think to seek out help or to ask for resources available to help them—including counseling and mental health supports—or are unable to access ones that meet their needs. Caregivers benefit from having information and assistance to navigate services and support system, especially those who represent diverse backgrounds or for whom using services (in-person or virtual) is difficult.

- **Language and Cultural Concordance.** Gaps in information and navigation services for San Franciscans of color, especially for the Latino community, and limited support for the LGBTQ+ community is an equity issue. Providing services that meet the needs of these communities, culturally and linguistically, must be prioritized.
- **Digital Divide.** COVID-10 revealed the stark reality of limited communications and technology access (computers, smart phones, Internet) for many caregivers—an issue mediated by race, education, and poverty. The pandemic shifted the major thoroughfare of community information and supports from in-person programs and interactions to online platforms, leaving many caregivers without needed connections. The Community Living Campaign's SF Tech Council and a number of individual service organizations in San Francisco are working to address this divide, but the gap is not easy to close. Policy changes and community interventions are needed to increase access to electronic devices, the Internet, and technology education and training programs, for all caregivers with a special focus on low-income caregivers.<sup>10</sup>

- ▶ **Agency Collaboration.** This theme emerged as both a gap and an opportunity. While there is some coordination and collaboration among community organizations serving family caregivers, it is less than what is needed to promote a more seamless service delivery system.

**Opportunities to Close the Gaps in Family Caregiver Services and Supports.** The top two opportunities to close gaps were: 1) promote agency collaboration, and 2) provide more education and training to family caregivers and agencies providing services to family caregivers.

- ▶ **Agency Collaboration.** To encourage agency collaboration, organizations serving family caregivers should meet more frequently to promote cross-agency referrals and coordination that benefit caregivers. These efforts could be modeled on the Dignity Fund Oversight and Advisory Committee (OAC) and the San Francisco Long-Term Care Coordinating Council (LTCCC). Both use collaboration to achieve their aims: the former to support services to meet the identified needs of the community; the latter advises the Mayor and City on policy, planning, and service delivery issues to promote an integrated and accessible long-term care system for older adults and persons with disability.

- ▶ **Provide Education/Training to Family Caregivers and Agency Staff.** Both caregivers and program staff working with caregivers feel more comfortable and confident when they receive education and training appropriate to their roles. Caregivers experience greater feelings of competence and reduced depression, stress, and anxiety when they have the tools and skills to manage their caregiving demands. Similarly, program staff who feel knowledgeable about and prepared for working with family caregivers are better able to understand, support, and work effectively with them.

*“There are a lot of resources for caregivers, but it's still not enough to meet the need and I don't think people know about them. There are a number of people that support family caregivers through care management or dementia programs, but sometimes it takes a while to try to figure out the right place.”*

– Caregiver Stakeholder

**Who Should be at the Table?** Four groups were singled out as important stakeholders that should be at the table to discuss gaps in services for family caregivers and the opportunities to close them.

- People with disabilities and representatives of community-based organizations serving people with disabilities.
- Family caregivers representing diverse communities (African American, LGBTQ+, Latino) and organizations serving family caregivers from these communities.
- Representatives of health and hospital systems.
- Agencies providing direct support to care recipients and family caregivers.

## Survey Findings

FCA distributed a brief survey, translated into Spanish and traditional and simplified Chinese to 900 family caregivers who received services through FCA between FY 2016 – FY 2021, to capture family caregiver experiences across a range of themes (note: 90 family caregivers completed the survey).

- ▶ **Support Systems.** Caregivers identified multiple sources of support: family (spouses, adult children, etc.) (69%), paid in-home care (39%), community-based organizations (27%), and friends and neighbors (25%).
- ▶ **Sources of Information.** Caregivers reported receiving caregiving or caregiver information from multiple outlets: 51% reported getting caregiver information through word of mouth, 38% from online sources (Google, organization website, etc.), and 29% from brochures or newsletters.
- ▶ **Length of Time Providing Care.** When asked how long they had been providing care for a family member or friend, 31% of caregivers reported 1 to 3 years, 27% said 4 to 6 years, and 23% said more than 7 years. A small subset reported providing care for over 20 years.

- ▶ **Advice to Other Caregivers in Similar Situation.** Sixty-two caregivers responded to this item. From the responses, three primary recommendations for caregivers in a “similar situation” emerged.
  - **Connect with Local Organizations.** Caregivers cited the following organizations as vital sources of support for family caregivers: FCA, IHSS, Catholic Charities, Alzheimer's Association, 211, the VA.
  - **Ask for Help and Practice Self-Care.** A crystallized piece of advice for other caregivers was to both ask for help—pushing through any discomfort that this may cause—and practice self-care.
  - **Seek Legal and Financial Planning Support.** Respondents highlighted the maze of legal and financial issues associated with caring for a family member. To address these challenges head on, they encouraged family caregivers to seek legal and financial assistance early in their caregiving journey.
  
- ▶ **Missing Resources for Family Caregivers.** Fifty-five caregivers identified the following missing resources and supports for family caregivers in San Francisco:
  - **Help Connecting to Services**

*“I guess I could use more support connecting to services, like support groups, adult-day programs, disease specific organizations—for more support and information. I’m doing a lot and need time to myself, but I need help staying on track. Support can help me feel a little less overwhelmed and better about what I get done and help me prioritize and pace things on my To Do list.”*
  - **Financial Support**

*“Money! It’s almost impossible for a non-wealthy person to afford care, especially 24-hour care; it’s equally difficult for paid caregivers to earn a living wage. A comprehensive side-by-side comparison of financial help options (e.g., home equity line of credit, reverse mortgages) would be helpful.”*
  - **Caregiver Support Groups/Gathering Places**

*“A gathering place for people who are caregivers and their loved one affected by dementia. Old friends often shy away from the situation, so it is absolutely vital to keep a social life.”*
  - **Educational/Medical Training and Programs**

*“Training for caregivers on the basic skills of moving, feeding, and giving meds to someone who is unable to move.”*
  
- ▶ **The “Reality” of Caregiving.** When asked to share other information about their caregiving experiences, two themes captured the “reality” of caregiving for many respondents:
  - **Caregiving is Hard**

*“It would have helped a lot if I had some kind of training in the beginning, before his [care recipient’s] condition escalated into full blown dementia. Dealing with bowel and bladder incontinence, “sundowning” syndrome, irrational speech and behavior, anger, physical and verbal abuse directed at me, all of this was bewildering and so painful. It could have been alleviated with just a little training. This is the hardest job I’ve ever had. I’m 77 years old, caring for my 91-year-old husband. I can’t help but wonder: Who will take care of me?”*

- **Caregiving Creates Financial Hardships**

*"We moved back to SF after living away for almost 10 years, knowing that the Bay Area had more resources. But it's expensive and we have struggled. I had to retire early to care for my [partner]. All the workshops and events I've attended in San Francisco have placed me on lots of email lists, so I periodically get valuable information and resources from them. I'm so glad we live here now."*

## Recommendations

Four primary recommendations to close gaps in San Francisco's service network for family caregivers emerged from analysis of the San Francisco family caregiver study. They build on the California Caregiver Task Force and Master Plan for Aging recommendations.

**Recommendation 1:** Ensure diverse communities have access to family caregiver services and supports that are culturally and linguistically respectful.

- **Action Item:** Assist organizations (e.g., ADPs, CBAS, ADCRCs) serving care recipients and family caregivers with developing diversity, equity, and inclusion (DEI) practices in hiring and retention, team culture and composition, and service delivery. Promote staff training in cultural competency and humility.
- **Action Item:** Identify underserved and underrepresented family caregivers and communities from family caregiver data (demographics, service usage, zip codes), and develop a plan to expand access to caregiver services and supports for these caregivers.

**Recommendation 2:** Advocate for and provide an array of quality-driven affordable community-based services for all caregivers, especially working caregivers who typically require full-day services to maintain employment.

- **Action Item:** Map existing caregiver services, funding status, geographic reach, and service hours to create a countywide tool for assessing caregiver service needs (demand) with available resources (supply).
- **Action Item:** Advocate for expanded quality driven affordable community-based services for all caregivers.
- **Action Item:** Create an ad-hoc family caregiver workgroup of the Long-Term Care Coordinating Council (LTCCC) to promote coordination of caregiver services across San Francisco, especially for family caregivers in underserved communities. The workgroup would additionally be tasked with identifying and addressing systemic barriers to equity and inclusion for diverse family caregivers and promoting increased funding for San Francisco-based family caregiver programs.

**Recommendation 3:** Increase caregiver access to adult day and respite programs.

- **Action Item:** Expand the number of affordable respite care programs, inside and outside the home.
- **Action Item:** Advocate for county subsidies to adult day programs to increase access to these services for care recipients and caregivers who cannot afford them, including subsidies for care

recipients and caregivers who are ineligible for Medi-Cal funded CBAS programs but who cannot afford to pay out-of-pocket for these services without risk of falling into poverty.

**Recommendation 4:** Identify and integrate family caregivers into health care and social service systems, to equip them with easily accessible and relevant information, education, training, and support specific to their situation.

- **Action Item:** Assess and address barriers caused by technology adoption and affordability, language and literacy comprehension, and a lack of understanding of how to navigate service delivery systems of care.
- **Action Item:** Identify and support caregivers engaged in complex care tasks (i.e., medication management, operating durable medical equipment such as a catheter, Hoyer lift, etc.). Provide the assistance they need (i.e., education, training) to perform these tasks confidently; aid caregivers in navigating healthcare transition processes (moving from one setting to another including from hospital to home or rehabilitation to home).

## Conclusion

As a vibrant city and county with a strong public infrastructure and network of community-based organizations, San Francisco has the capacity to narrow the gaps in services and supports for family caregivers. Through policy changes, agency collaboration, and increased local, state, and federal funding for family caregiver services, San Francisco can ensure that all family caregivers have access to culturally and linguistically concordant services, information, education, training, and support. The recommendations and action items presented in this brief provide a framework to begin this process.

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