San Francisco Department of Aging & Adult Services
January 2019

Caregiver Profile and Needs Assessment

CONTENTS

Report by the San Francisco Human Services Agency – Planning Unit

INTRODUCTION

In November 2016, San Francisco voters passed legislation to establish the Dignity Fund, creating a protected funding stream for social services that support seniors, adults with disabilities, and their caregivers. As part of the Dignity Fund charter amendment, a planning and funding cycle was instituted that begins with a community needs assessment to support a subsequent four year funding plan. Both the funding and planning processes are managed by the Department of Aging and Adult Services (DAAS), the City agency tasked with administering social services to these populations.

DAAS completed the first **Dignity Fund Community Needs Assessment (DFCNA)** in Spring 2018. Key components of the DFCNA included community research and an equity analysis to identify systems level strengths and gaps in service delivery for older adults and adults with disabilities. The DFCNA also included a preliminary analysis of the needs of caregivers, who play a critical role in supporting older adults and adults with disabilities so they can remain in their homes and communities; a recommendation of this report was that DAAS conduct a more focused exploration of this population to better understand the challenges and pressures felt by caregivers.

Thus, **this report seeks to build on the DFCNA by providing a more comprehensive analysis that is solely focused on caregivers**. The first section of this report is the caregiver profile, which details the program utilization patterns and demographic characteristics of caregivers participating in community-based services funded by DAAS. Next, this report details the type of supports caregivers frequently provide and the needs expressed by caregivers. The report concludes by summarizing key findings and offering recommendations.

Please note: While caring for older adults and adults with disabilities depends upon the commitment of both informal and professional caregivers, data used for this report is limited to informal caregivers. As a result, the findings from this report should be applied to **informal caregivers**, **defined as family or friends caring for an older adult or person with disability, typically without financial compensation.**

Key findings from this analysis include:

- **Latino caregivers may be underrepresented in DAAS Office the on Aging (OOA) services.** Latinos represent 15% of San Francisco’s population but constitute just 8% of OOA caregivers.
- **Caregivers seeking support are most commonly caring for persons with a primary diagnosis of dementia.** Over 60% of caregivers indicated a primary diagnosis of dementia for the individuals they care for; approximately half of these were reported to have Alzheimer’s disease.
- **Caregiving is a fulltime commitment and most caregivers report receiving little to no help.** Sixty-eight percent of caregivers indicated they provide care at least 40 or more hours per week, and 66% indicated they receive some but not enough help with caregiving tasks.
- **Caregivers reported high levels of stress and indicated they have little time to care for themselves.** Approximately 60% of caregivers reported nearly always or frequently having no time for themselves due to their responsibilities as caregivers and 62% stated they nearly always or frequently are stressed as a result of managing their caregiver role and other responsibilities.
- **Caregivers expressed limited knowledge of caregiver support services and how they can access support services.** Sixty-one percent of caregivers stated either it is not at all true they know where to get support as a caregiver or that it was only a little bit true they know where to find support as a caregiver. Additionally, 62% of caregivers stated either it was not at all true or that it was only a little bit true that services are available to support caregivers.

BACKGROUND

DIGNITY FUND COMMUNITY NEEDS ASSESSMENT

The **Dignity Fund** was established via a charter amendment passed by San Francisco voters as Proposition I in 2016. The legislation contained three major components:

- **Protected funding**: Established a funding set-aside for services that support seniors and adults with disabilities to live in and engage with their communities. Based on existing funding levels, the set-aside began with baseline funding of $38 million, and the charter amendment requires the City to increase this funding by $33 million over ten years.
- **Planning and funding Cycle**: Developed a four-year planning and funding cycle. The cycle begins with a Community Needs Assessment to assess needs and analyze equity in service provision. This assessment supports the subsequent creation of a funding plan that outlines how funding will be allocated over the next four years.
- **Oversight**: Created an Oversight and Advisory Committee to advise DAAS on administration of the Dignity Fund. This body is supported by a Service Provider Working Group that advises on the perspective and needs of community-based organizations that serve seniors and adults with disabilities.

The first Dignity Fund Community Needs Assessment (DFCNA) was completed in FY 2017-18.[1] This project involved extensive community outreach and engagement:

FY 2017-18 DFCNA: Community Engagement

Community Engagement Method	Participation Levels
Community forums	11 forums (one in each supervisorial district) with 462 attendees
Focus groups with specific populations of interest	29 focus groups with 282 participants
Population survey	1,112 responses from community members
Provider survey	266 responses from service providers

Findings from the DFCNA highlighted the need for DAAS to focus attention on caregiver support services and explore service utilization trends of caregivers currently accessing services. Focus group participants recommended enhanced outreach efforts to promote awareness of available services, discussing the need for respite care and support services and expressing concern that caregivers with limited English proficiency in particular need additional support or outreach.

Based on the DFCNA findings, DAAS has used Dignity Fund money to augment its portfolio of caregiver support services, including the development of respite care services and enhancement of outreach and support services. This report is intended to provide DAAS with additional information about caregivers currently served by the Department and needs expressed by those seeking services.

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[1] The full report and corresponding material is available on the DAAS website: http://sfdaas.org

DESCRIPTION OF DATA

The findings in this report were produced using three quantitative data sources. The table below provides the data source, description of each data source, and the number of unique observations in each dataset.

Data Sources: Caregiver Profile and Needs Assessment

Data source	Description	Participants
OOA FY 2017-18 client enrollment data	Client enrollment data containing demographic and program/service enrollment information	552
Family Caregiver Alliance (FCA) assessment data FY 2017-18	Data derived from the caregiver assessment issued by FCA containing over 200 questions to assess caregiver responsibilities, needs, and health	275
DFCNA Consumer Survey 2018	Consumer survey administered as part of the DFCNA 2017-18 that reached 1,127 consumers and **40 caregivers**	40

Please note the following:

- Office on the Aging (OOA) client enrollment data contained nearly complete responses for most demographic items, while the Family Caregiver Alliance (FCA) assessment data is less complete.
- Differences in the total number of observations reported for items in the FCA are the result of fluctuations in the number of responses to each FCA assessment question; consumers may not respond to every question in the assessment. This variation is not believed to bias or skew the information in this analysis.
- Also note, the DFCNA Consumer Survey 2018 only contained 32 caregiver responses, therefore caution is advised when attempting to generalize these findings to the larger caregiver population.

For a more complete description of data limitations please see the limitations portion of this report (p.13).

PROFILE OF OOA CAREGIVERS

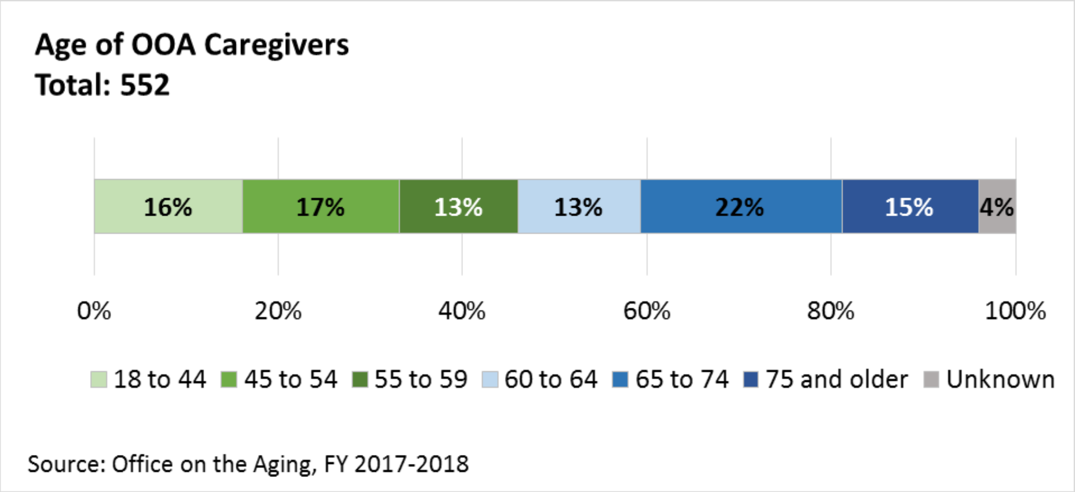
This section provides an overview of caregivers who participated in programs and services funded through the Department's Office on the Aging, which partners with over 60 community-based organizations each year to provide over 40 services to older adults, people with disabilities, veterans, and caregivers.

In FY 2017-18, OOA served a total of 552 unduplicated caregivers. These individuals were identified as caregivers based on at least one enrollment in an OOA service focused on informal caregivers who support older adults and people with disabilities. This section begins with a demographic overview of caregiver clients, followed by a summary of service enrollments.

DEMOGRAPHIC PROFILE

AGE

Half of caregivers supporting an older adult or person with disabilities are older adults themselves. Most commonly, they are between age 65 and 74 (22% of all caregivers). Notably, about a third of caregivers are under age 55.

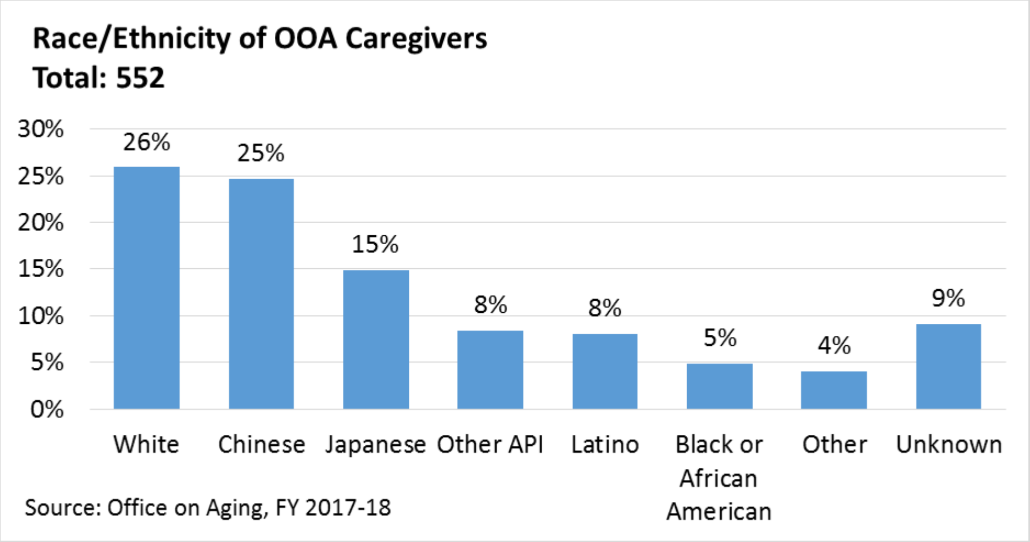


Source: Office on the Aging, FY 2017-2018

RACE/ETHNICITY

The racial/ethnic demographics of caregivers are generally consistent with San Francisco's overall demographics. **Persons accessing OOA caregiver services are predominantly white and Asian Pacific Islander (API).** Almost half (48%) belong to an API ethnic group.

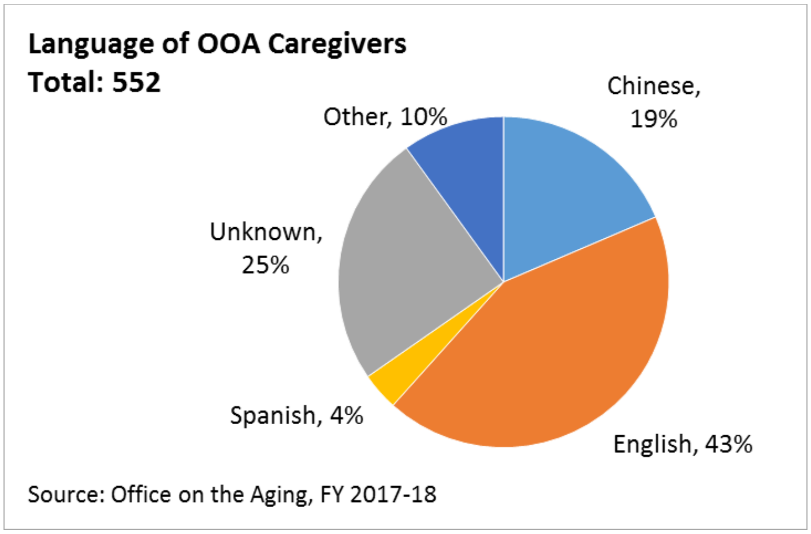
As shown in the chart on the following page, the most common single ethnic group is White (26%), followed by Chinese (25%). Notably, **the Latino population is potentially underrepresented**: they comprise 15% of San Francisco's overall population[2] but account for 8% of caregivers accessing services. These trends may in part reflect targeted outreach efforts to engage the API community last year and that two of the agencies providing caregiver services focus on API populations.



Source: Office on Aging, FY 2017-18

PRIMARY LANGUAGE

Most commonly, **OOA caregivers reported English as their primary language (43% of clients).** About one in four have a primary language as a Chinese dialect (19%). Only four percent of caregivers listed Spanish as their primary language, as compared to 11% of San Francisco's overall population.[3] However, it should be noted that language data was missing for a large proportion of caregivers: 26%.



Source: Office on the Aging, FY 2017-18

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[2] Source: ACS 2013-2017 5 Year Estimates

[3] Ibid.

SEXUAL ORIENTATION AND GENDER

Many caregivers enrolled in OOA support services identified with a sexual orientation other than straight: 20%. About half identified as straight or heterosexual. This likely reflects that a key provider of caregiver support services is focused on serving the LGBTQ population. Notably, a large proportion of caregivers had incomplete or missing sexual orientation data (26%).

Office on the Aging FY 2017-18: Caregiver Sexual Orientation

Gay/Lesbian/ Same-Gender Loving	Bisexual	Not listed/ All other	Straight/ Heterosexual	Declined to answer	Incomplete/ Missing	Total
101	7	3	282	17	161	571
18%	1%	1%	51%	3%	26%	100%

Source: Office on the Aging, FY 2017-18

The majority of OOA caregivers are female: 66%. About 1.4% reported a gender identity that is different from the sex assigned at birth, including those who are genderqueer.

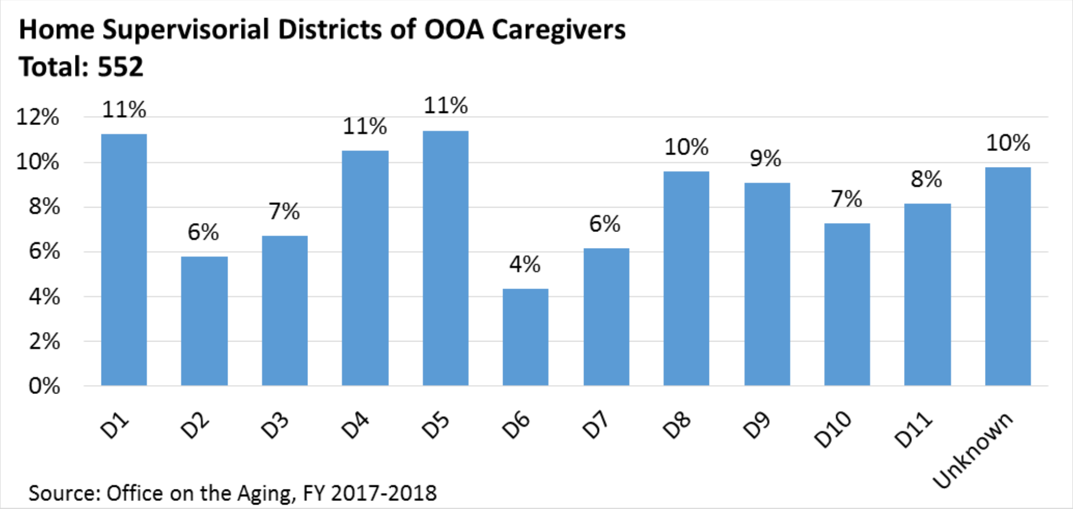
Office on the Aging FY 2017-18: Caregiver Gender

Female	Male	Genderqueer, Gender non-binary	Trans Female	Trans Male	Decline to State	Incomplete/ Missing	Total
362	172	3	1	1	1	12	552
66%	31%	1%	0.2%	0.2%	0.2%	2%	100%

Source: Office on the Aging, FY 2017-18

CAREGIVER LOCATION

Caregivers accessing services live throughout the City. Areas with the highest portions of clients include: District 1 (Richmond), District 4 (Sunset), and District 5 (Inner Sunset, Haight-Ashbury, Fillmore/Western Addition, Japantown).

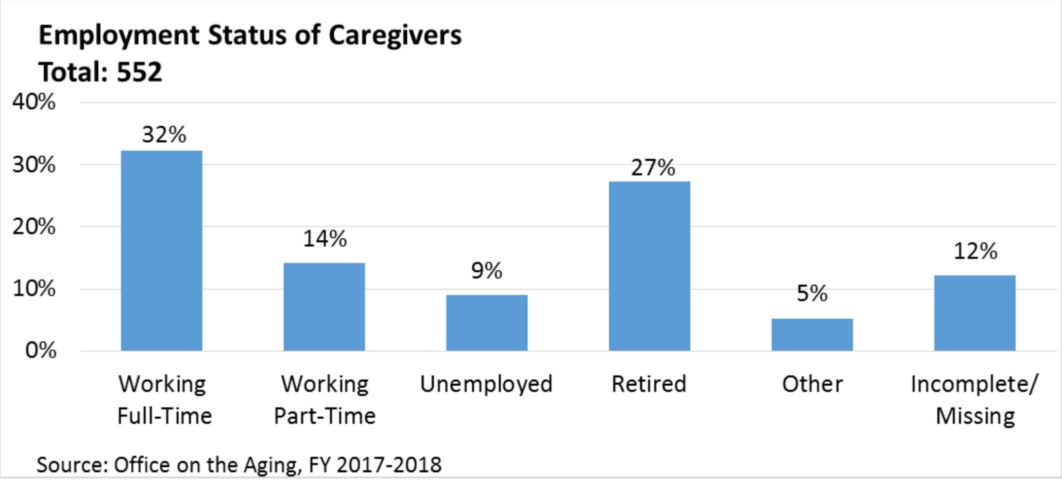

Home Supervisorial Districts of OOA Caregivers
Total: 552

Source: Office on the Aging, FY 2017-2018

INCOME AND EMPLOYMENT

About 20% of caregivers accessing OOA services were identified as low-income, based on affirmative response to at least one of the following fields: income below 185% FPL, receipt of SSI benefits, or Medi-Cal enrollment. However, over 20% were missing responses to these questions, making it difficult to draw definitive conclusions.

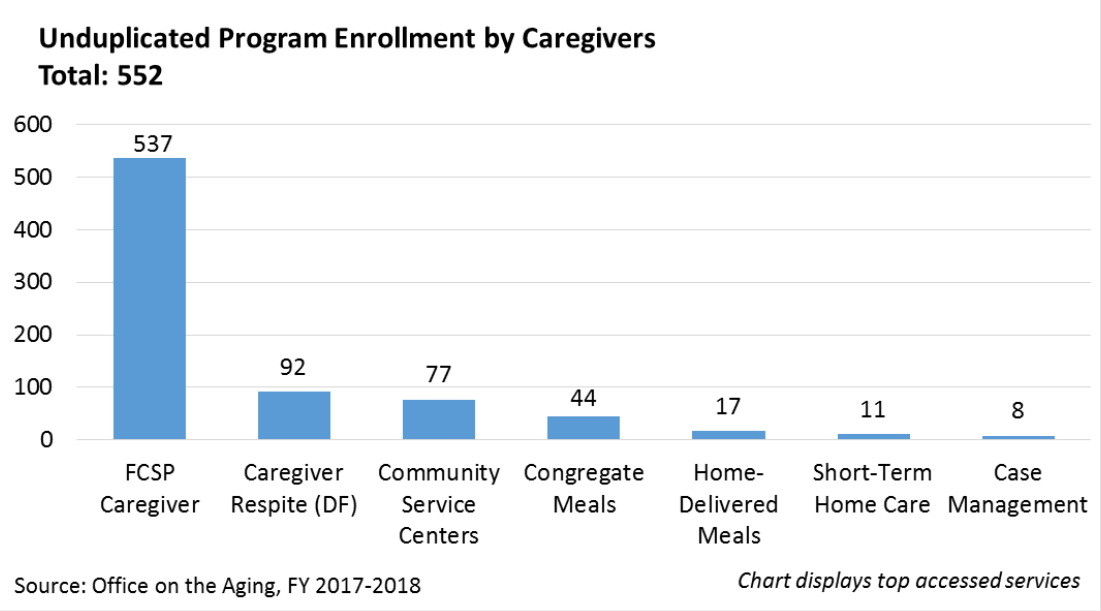
Over half are in the labor force with a third of caregivers report that they work fulltime. About a quarter are retired, which aligns with the age profile discussed earlier in this report.



Source: Office on the Aging, FY 2017-2018

SERVICE ENROLLMENTS

The vast majority of caregiver clients participated in the Family Caregiver Support (FCSP) program, which provides a variety of services to address common challenges and needs faced by caregivers. The second most frequently accessed program was the newer Caregiver Respite program, which funds in-home care or attendance at a Day Program for the care recipient to give a break from caregiving. Caregivers also access mainstream OOA services, including visiting Community Service Centers and meal programs.

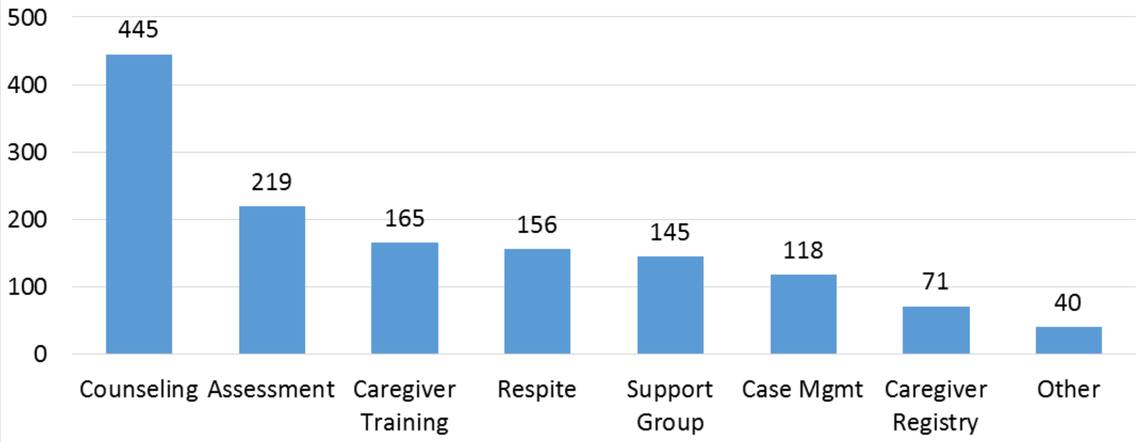


Source: Office on the Aging, FY 2017-2018

Chart displays top accessed services

Delving deeper into the specific types of services that caregivers use in the caregiver programs provides further insight into these service utilization trends. **The most commonly accessed service is counseling, used by 81% of caregivers.** About 40% participated in in-depth assessments to identify their needs, and a third participated in training programs to improve their ability to support their care recipient. Many also access support groups and individualized case management services.

Unduplicated Enrollment in Caregiver Support Programs
Total: 552



Source: Office on the Aging, FY 2017-18

CAREGIVER NEEDS

This section highlights needs expressed by caregivers who completed the FCA assessment 2017-18 or the DFCNA 2017-18 Consumer Survey. The FCA assessment is administered at time of intake, when caregivers are first contacting FCA to request support.

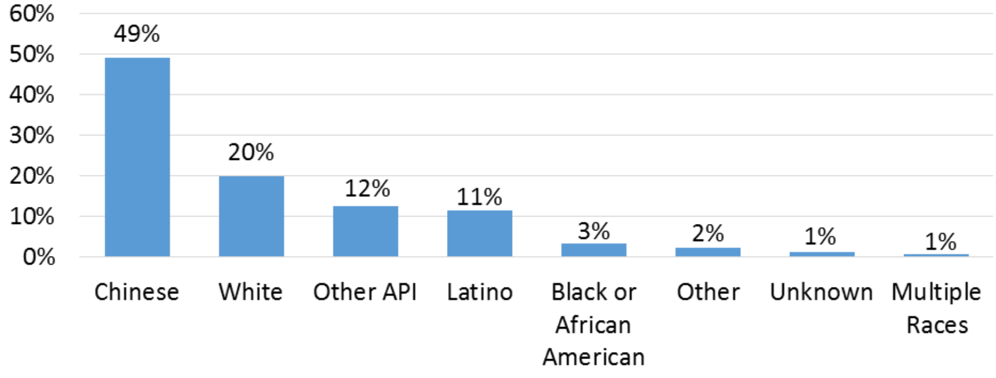
Common sentiments expressed by caregivers include:

- Duties associated with caregiving increase stress and leave them with little time for themselves;
- They receive little to no paid or unpaid help with caregiving tasks; and
- They have limited knowledge about programs and services available to support them.

FAMILY CAREGIVER ALLIANCE CLIENT ASSESSMENTS

The largest racial/ethnic group of FCA caregiver respondents was Chinese (49%), followed by White (20%). The large number of API caregivers represented in the FCA data may be a result of a specific outreach campaign to engage this community in San Francisco in the last year.

Race/Ethnicity of FCA Caregiver Respondents
Total: 273



Source: 2017-18: Family Caregiver Alliance Assessment

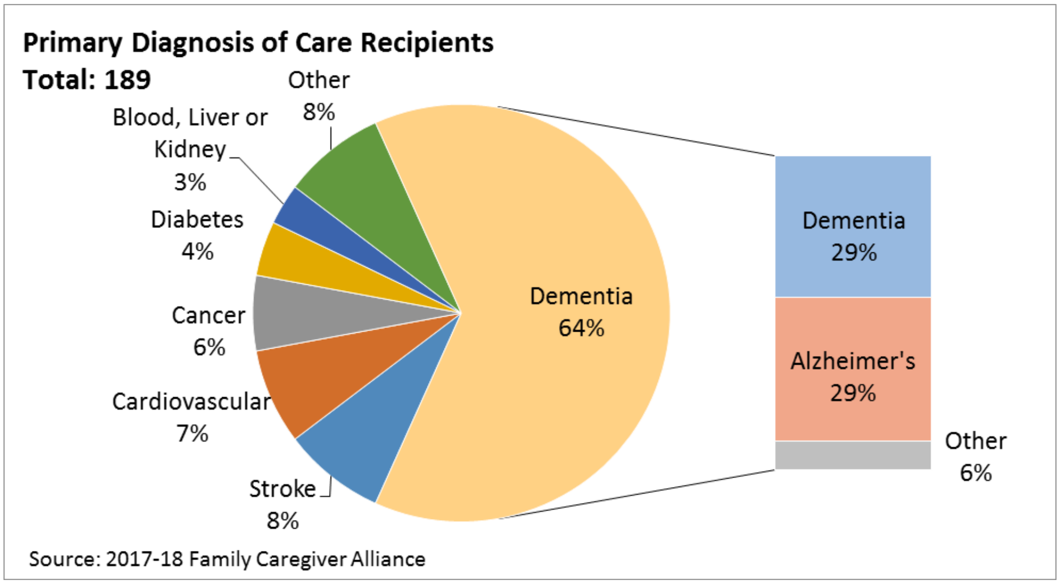
Additional demographic characteristics of FCA respondents include:

- **Language**: Most FCA respondents speak English (62%). At least 34% speak Chinese and have limited English proficiency. About two percent speak Spanish (2%). This data reflects English proficiency; recent enhancements to the FCA data tool to collect primary language data will support future analysis of caregivers preferred language.
- **Gender**: Most FCA respondents are female (76%).
- **Age:** Over half of FCA caregiver respondents are under age 60 (54%). They are mostly middle aged (28% are between ages 45 and 52, and 17% are between age 55 and 59).

The needs of these caregiver respondents are described on the following pages.

CARE RECEIVER PRIMARY DIAGNOSIS

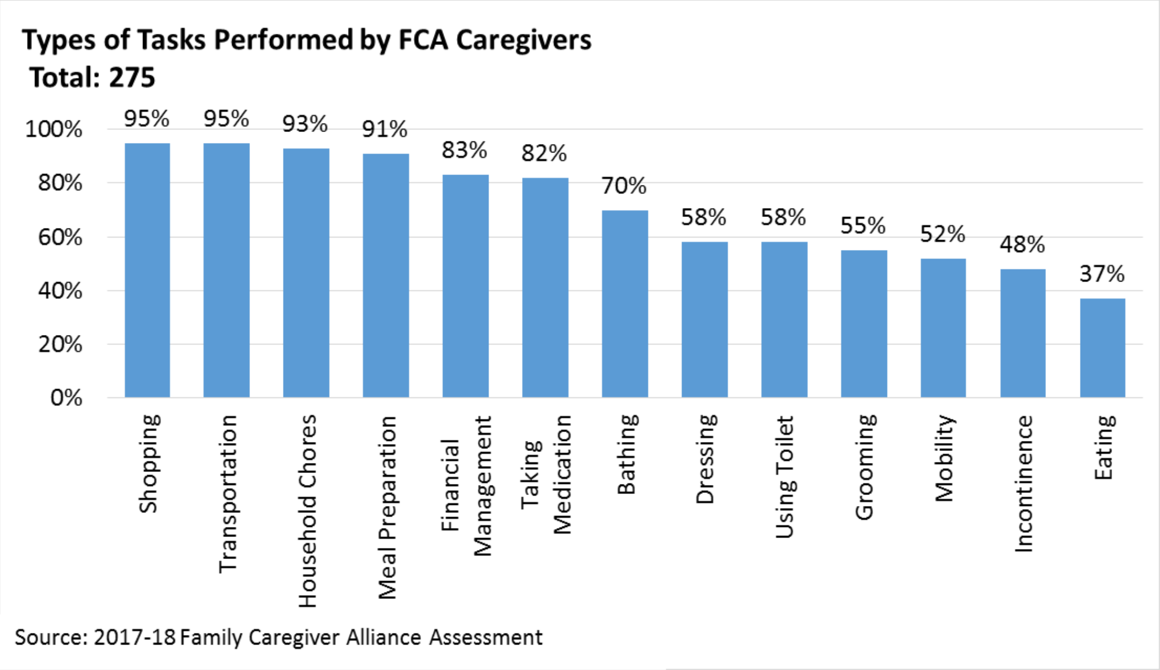
The most common primary diagnosis of care receivers is dementia. Dementia accounted for 63% of care receivers' primary diagnosis, and the type of dementia most commonly reported was Alzheimer's (29%). After dementia, the next most frequently occurring primary diagnosis for care receivers was stroke (8%) and cardiovascular illness (7%).



Source: 2017-18 Family Caregiver Alliance

CAREGIVER TASKS

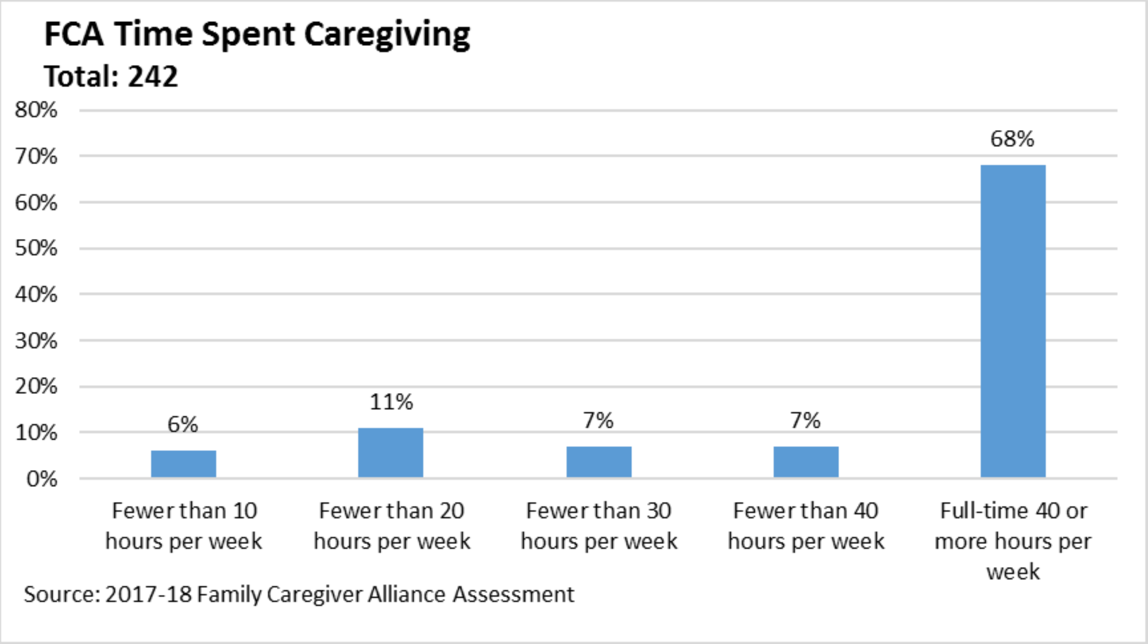
Caregivers perform a variety of tasks for their care recipients. **The most commonly reported tasks are instrumental activities of daily living**, such as shopping (95%), transportation (95%), household chores (93%), and meal preparation (91%).



Source: 2017-18 Family Caregiver Alliance Assessment

TIME SPENT CAREGIVING

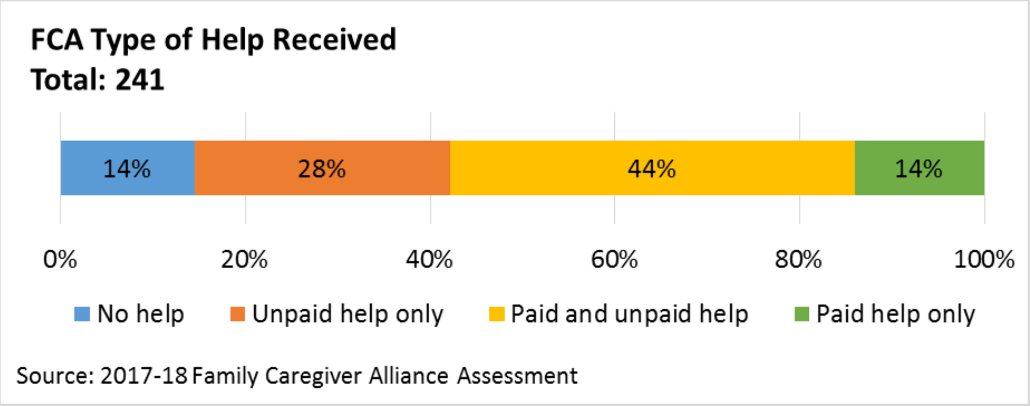
As indicated in the previous section, caregivers provide a variety of tasks and in most circumstances, these tasks are very time consuming. **Of caregivers surveyed, 68% indicated they provide care 40 or more hours per week (fulltime).** Only 17% of caregivers stated they provide care less than half time or 20 hours per week.



Source: 2017-18 Family Caregiver Alliance Assessment

HELP WITH CAREGIVING DUTIES

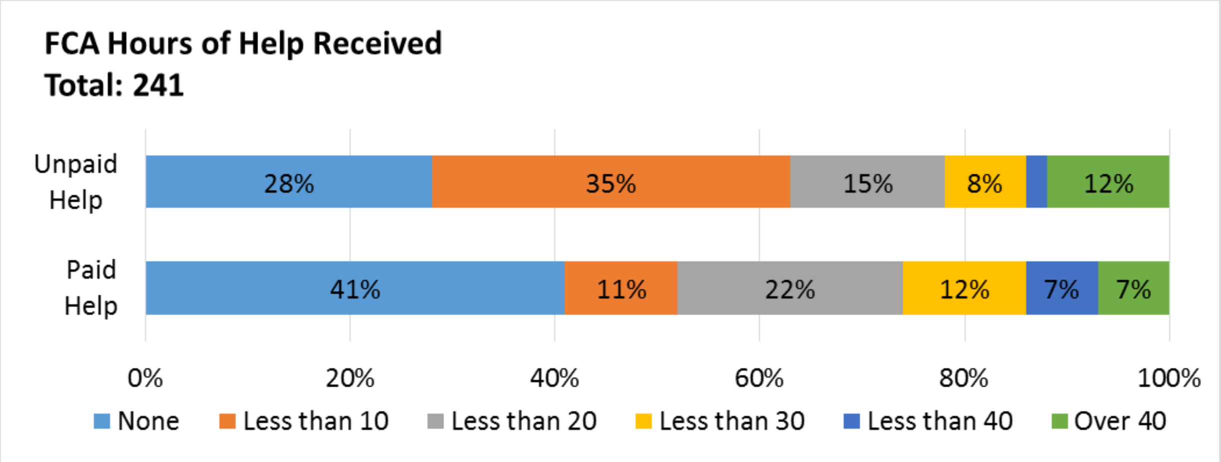
Many caregivers reported receiving some type of weekly help with caregiving duties, most commonly a mix of paid and unpaid help. Overall, 86% reported receiving some type of help with caregiving weekly, while 14% indicated they receive no help with caregiving.



Source: 2017-18 Family Caregiver Alliance Assessment

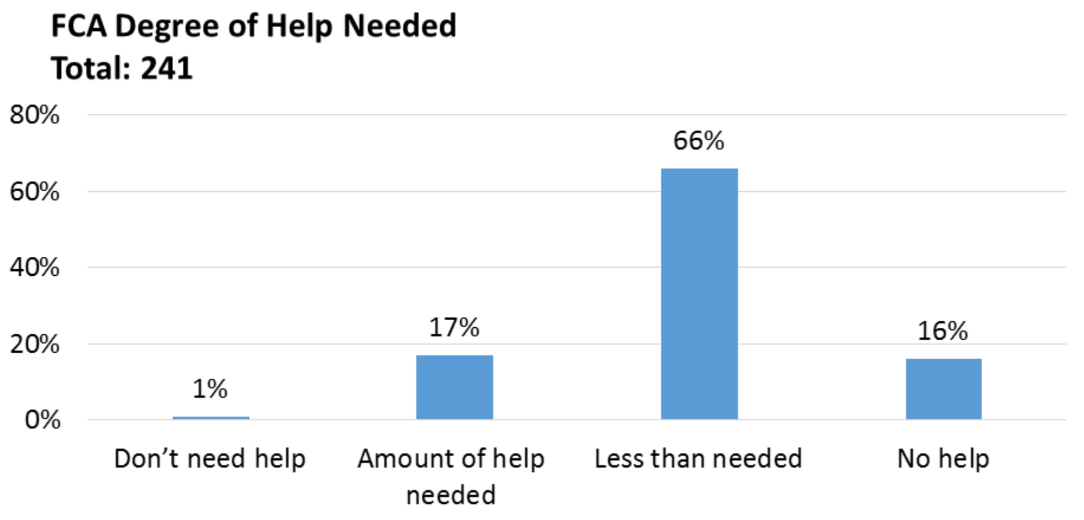
However, although most caregivers receive some form of weekly help with caregiving, the number of hours of help is relatively low. Most caregivers indicated they receive no help or fewer than 10 hours of help per week with their caregiving duties.

Amount of help varies by paid care and informal support. About 41% of caregivers do not receive any paid help. About 28% of caregivers have no unpaid help, meaning that about 72% do receive at least a little informal support.



Source: 2017-18 Family Caregiver Alliance Assessment

Caregivers who completed the FCA assessment made it clear **the amount of help they receive is not the amount of help they feel they need.** Two-thirds of respondents indicated they receive less help than is needed with caregiving tasks. Sixteen percent indicated that they receive no help at the current time. Only 17% indicated they receive the amount of help they need with caregiving tasks. An additional one percent indicated that they do not need help. Given that the FCA assessment is completed at the time caregivers are first reaching out for services, these trends make sense.

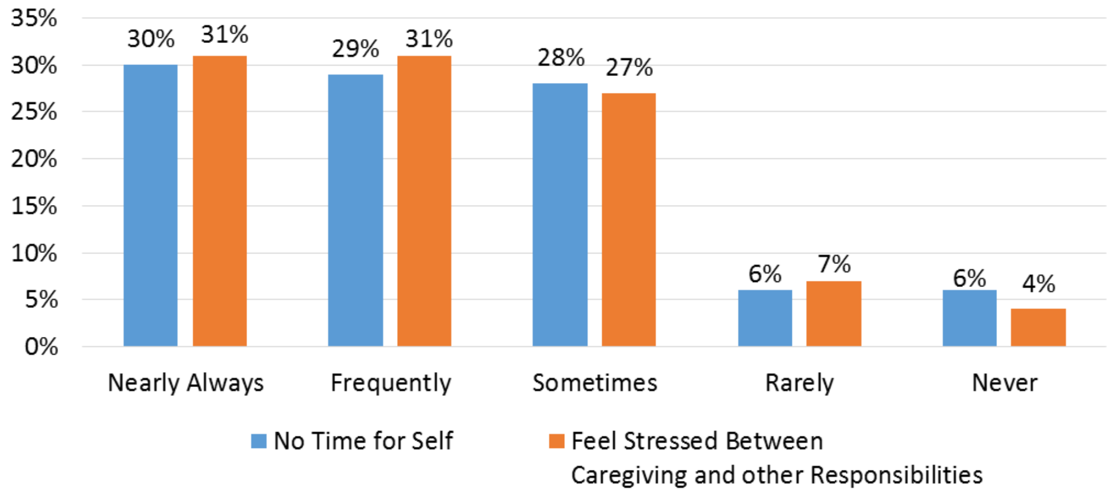


Source: 2017-18 Family Caregiver Alliance Assessment

SELF CARE AND STRESS

Not surprisingly, given the time exerted on caregiving and relatively few hours of help with their caregiving tasks, caregivers stated **they have no time for themselves and reported experiencing high levels of stress**. Their responses to questions on these topics were nearly identical. Most caregivers (59%) stated they nearly always or frequently feel they have no time for themselves, and 62% of caregivers stated that they nearly always or frequently feel stressed between caregiving and other responsibilities.

FCA No Time for Self and Stress Between Caregiving and Other Responsibilities
Total: 218

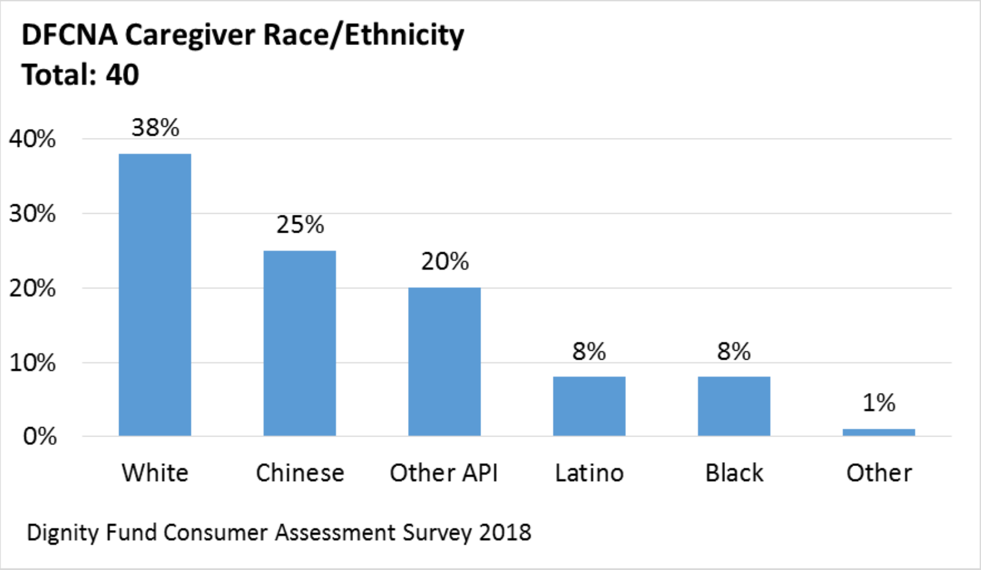


Source: 2017-18 Family Caregiver Alliance Assessment

DIGNITY FUND CAREGIVER SURVEY

This section highlights the perception of caregivers regarding the availability and accessibility of caregiver support services in San Francisco. This information comes from the Dignity Fund Consumer Assessment Survey (conducted in 2018 as part of the DFCNA). While this portion of the survey was completed by only 40 caregivers, the information provides preliminary insight into caregiver awareness of services.

Almost half of caregivers who completed the DFCNA survey were API (25% Chinese and 20% from other API groups). The largest single ethnicity was White (38%).

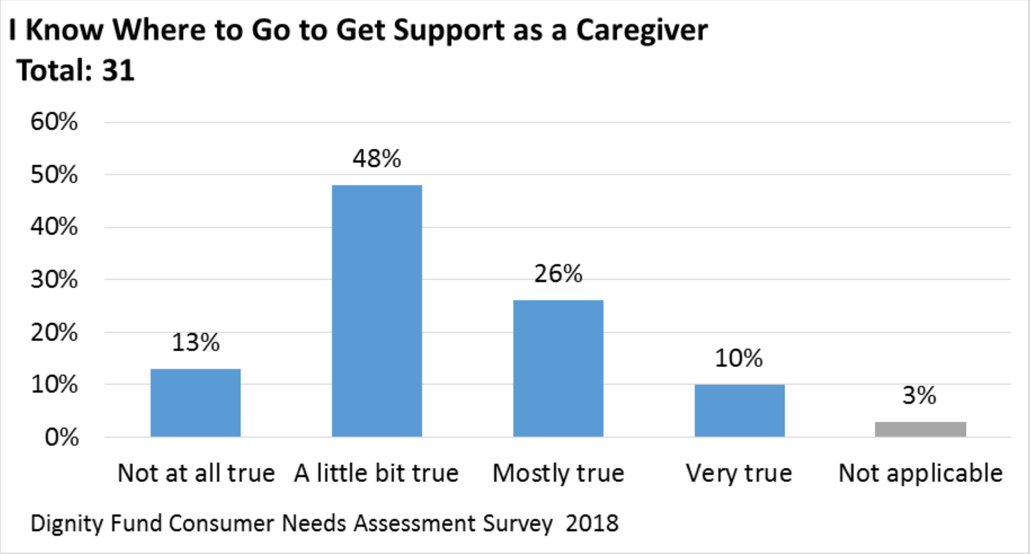


Additional demographic characteristics of DFCNA respondents include:

- **Language**: Most indicated English as their spoken language (75%) followed by Cantonese (13%).
- **Gender**: The majority of DFCNA caregiver respondents were female (68%).
- **Age**: Most were under age 60 (73%); about a quarter were between age 55 and 59.

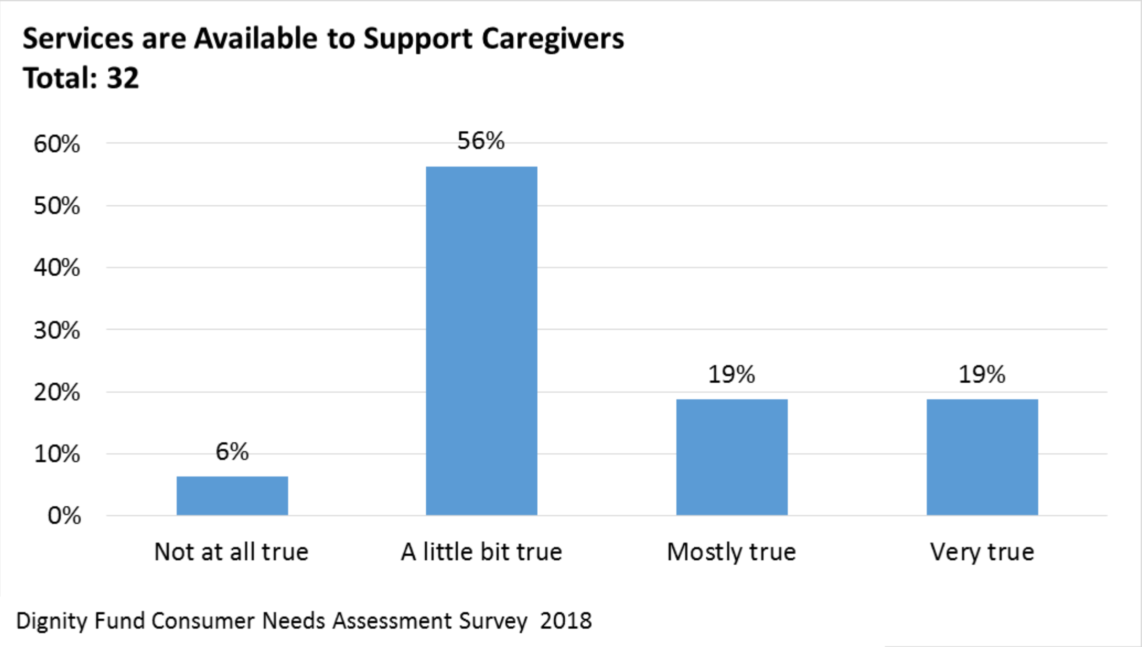
CAREGIVER KNOWLEDGE OF SUPPORT SERVICES

Caregiver responses to the DFCNA 2017-18 Consumer Survey, revealed **many caregivers do not know where to find support as a caregiver, and many caregivers do not believe adequate services are available to support them**. As shown below, 61% of caregivers stated it was either "not at all true" or only "a little bit true" they know where to get support as a caregiver.



CAREGIVER PERCEPTIONS OF SERVICE AVAILABILITY

Most **caregivers expressed limited confidence in the availability of caregiver support services**. Approximately 62% of caregivers stated either it was "not at all true" or only "a little bit true" that services are available to support caregivers. About 38% of caregivers stated it was "mostly true" or "very true" that services are available to support caregivers.



LIMITATIONS: CAREGIVER SAMPLE AND DATA COMPLETION

The limitations of the data used in this analysis are explained in this section to provide context for the reader and to aid in the interpretation of the results.

Most notably, the caregiver demographics and the reported needs represent caregivers with time and inclination to seek out the services funded by DAAS. This may introduce some level of bias if caregivers who have connected with an OOA service or completed an FCA assessment are systemically different than those who do not participate. While these limitations are evident, it should be noted that trends identified in this report of caregivers having little time for themselves, experiencing high levels of stress, and needing increased support are well documented in existing literature on caregivers.[4]

Additionally, as with all quantitative studies, limited sample sizes and missing data pose challenges to determining how well findings can be generalized to a larger population. The problem of limited sample size is most evident in the analysis from the DFCNA consumer survey (in the "Knowledge of Caregiver Support Services" portion of this report), in which the number of responses was limited (a total of 40 respondents with 32 or fewer responses to individual questions). A sample size of 30 is generally recognized as the lowest boundary of what is acceptable for most statistical research.[5] However, the findings from this section demonstrate a clear trend and should be recognized as providing preliminary evidence that caregivers have limited knowledge about the availability and accessibility of support services. Further investigation into caregiver knowledge of support services (e.g., with a larger sample of caregivers) would support greater confidence in the results presented here.

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[4] Schubert, C. C., Boustani, M., Callahan, C. M., Perkins, A. J., Hui, S., & Hendrie, H. C. (2008). Acute care utilization by dementia caregivers within urban primary care practices. *Journal of General Internal Medicine*, 23(11), 1736-1740.

[5] Hogg, R.V., Tanis, E., (2015). Probability and Statistical Inference, Ninth Edition.

KEY FINDINGS AND RECOMMENDATIONS

This report has illustrated the demographic profile of OOA enrolled caregivers, the needs and challenges expressed by caregivers, and the extent to which caregivers are aware of services available to support them. The results indicate that most caregivers are devoted to caregiving fulltime, receive little to no help, and are frequently stressed due to demands associated with caregiving. Caregivers also expressed limited knowledge of services available to support them. The key findings from this report are explained below in greater depth along with corresponding recommendations for how the existing OOA service system can respond to each finding.

Latino caregivers represent a small portion of OOA caregiver participants and may be underrepresented in DAAS Office on Aging services.

Service providers participating in focus groups for the FY 2017-18 DFCNA expressed concern that caregivers with a primary language other than English may need additional outreach or support to access services. This analysis has found that, although Latinos represent 15% of San Francisco's overall population, they consisted of just 8% of OOA service participants. While this trend may reflect cultural variation in family structures and support networks, DAAS should consider connecting with service providers and community leaders in the Latino community to explore if greater outreach or other strategies are needed to link Latino caregivers to OOA services.

DAAS should also review service utilization trends in its newer caregiver respite support services to determine how new outcome objectives – focused on participation of caregivers with limited English proficiency – have worked to support participation from this group.

Caregivers seeking support are most commonly caring for a person with a primary diagnosis of dementia.

Over 60% of caregivers who completed the FCA assessment indicated the primary diagnosis of the person they care for is some form of dementia. Approximately half of the individuals diagnosed with dementia were reported to have dementia related to Alzheimer's disease. As previous research has found, caring for someone with dementia is demanding and has been associated with depression and negative health outcomes.[6] The prevalence of caregivers supporting individuals with Alzheimer's disease or dementia highlights the importance of dementia-focused programming, including information and support resources, as well as Alzheimer's Day Care Resource Centers.

Caregiving is a fulltime commitment for caregivers and many indicate they receive little or no help.

Most caregivers (68%) indicated that caregiving is a fulltime commitment and stated they receive not enough help (66%) or no help (16%) with caregiving tasks. This reality underlies the importance of maintaining existing supports for caregivers, such as Respite Care to provide a brief period of relief for overly-burdened caregivers. Additionally, since many caregivers are providing fulltime care and are within their peak financial earning years, opportunities that link caregivers to financial supports, such as CalFresh, should be considered.

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[6] Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. The Gerontologist, 35(6), 771-791.

Caregivers reported high levels of stress and indicated they have little time to care for themselves.
Sixty-two percent of caregivers indicated they nearly always or frequently are stressed as a result of balancing caregiving duties with other responsibilities. Almost 60% of caregivers reported nearly always or frequently having no time for themselves due to their responsibilities as caregivers. These findings support the need to maintain a comprehensive caregiver service system and specifically services such as counseling, support groups, and respite care that support caregiver health and wellness.

Caregivers expressed limited knowledge of caregiver support services and where they can access services.
Caregiver participants in the DFCNA consumer survey indicated a perception that services are not available to support caregivers. These responses indicate many caregivers have a limited understanding of what services are available to them and how they can access support services. This finding suggests that a need to improve awareness and accessibility of services. This could be conducted through general informational campaigns to raise general awareness about the existence of DAAS and its service partners, so that when people begin to need services they know to reach out to the department. Targeted outreach could leverage existing touchpoints, such as the healthcare field, to reach those who are currently caregivers in order to connect families with resources in order to preempt feelings of burnout and to support those already feeling overly-burdened.