Picking up the pace of change: scaling services for a changing caregiver profile

Evaluation of the California Caregiver Resource Centers service delivery and system change

Reporting Period: July 2020-June 2021

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EXECUTIVE SUMMARY

In 2019, the California Department of Health Care Services awarded the eleven nonprofit Caregiver Resource Centers (CRCs) $30 million for the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project. The aim was to "expand and improve family caregiver services and enhance CRC information technology services" between 2019 and 2022. Early in Fiscal Year 2021, the CRCs accomplished full deployment of CareNav™, an online system that includes data collection using a uniform caregiver assessment, a record of CRC services provided, consumer information, care plans, CRC forms, and secure communications. The CRCs continued to provide services and supports in the context of the COVID-19 pandemic, primarily through virtual means due to restrictions on meeting indoors. Over the past year, the project team focused on the following overall goals for this project:

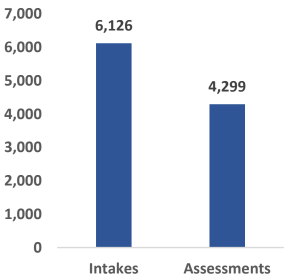
1. Monitor and optimize data quality in CareNav™, including harmonizing data definitions and reporting
2. Increase CRC staff technical capacity and technology acquisition to scale services
3. Promote uniform quality practice and availability of core CRC services statewide
4. Increase number of family caregivers served with one or more CRC services

Across all CRCs, 16,000 unduplicated family caregivers received services from professional staff in FY 2020-2021. Of those 16,000 caregivers, 6,126 were first-time (new) clients (38%) who went through intake with 4,299 moving on to full assessment and intensive services. In addition to new clients, 9,892 family caregivers returned to the CRCs (62%) and received one or more services such as family consultation, counseling, education, or vouchered services (legal, respite). The total number of open cases (the sum of new and ongoing cases in the CareNav™ record) in FY 2020-2021 totaled 32,939 across the CRC system. Importantly, these counts underestimate the actual open caseload because they are based on definitions that encompass a two-year transition window to CareNav™ during which not all CRCs were using the CareNav™ record system. The CRCs provided family consultation (25,546 units), reassessments (2,856 clients), counseling (1,379 hours), voucher services (legal: 141 hours; respite: 139,340 hours). The CRC conducted 4,927 outreach activities, reaching over 500,000 Californians in the past year.

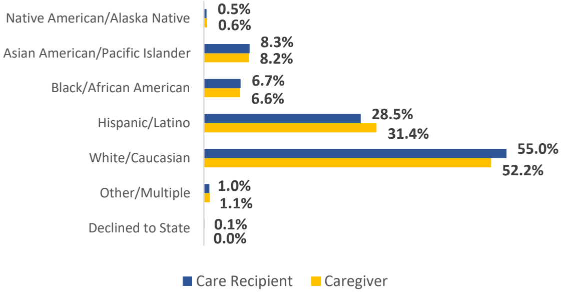
The CRCs serve diverse caregivers across the adult lifespan. Of the 4,299 caregivers who completed assessments, most were ages 45-64 years (47.7%) or 65-84 years (36.0%), and identified as female (74.9%), heterosexual (89.9%), and as married or partnered (65.4%). The CRCs serve a racially and ethnically diverse population, including white non-Hispanic (52.2%), Hispanic/Latino (31.4%), Asian American/Pacific Islander (8.2%), Black non-Hispanic (6.6%), multi-racial / other racial identity (1.1%), and Native American/Alaska Native (0.6%) caregivers.

California Caregiver Resource Centers (CCRCs) July 2020 – June 2021 Dashboard | *n* = 4,299

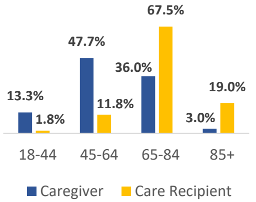
Intakes and Assessments Completed



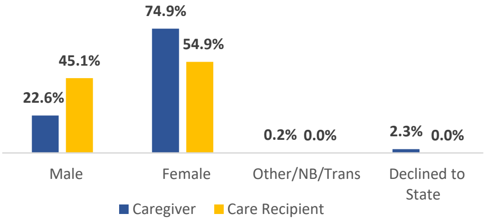
Racial & Ethnic Identity: Caregiver and Care Recipient



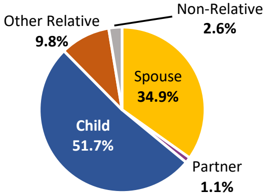
Age: Caregiver and Care Recipient



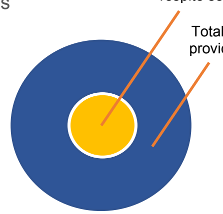
Gender: Caregiver and Care Recipient



Relationship of Caregiver and Care Recipient



Respite Hours and Services



Caregivers who received respite services = **3,259**

Total respite hours provided = **139,340**

Outreach and Education Activities

Outreach = 4,927
Direct referrals, general public information/awareness activities, provider awareness.

Education = 1,250
Programs designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.

Caregiver Supports

Family Consultation = 25,546 consultations

Support Groups = 1,993 clients

Individual Counseling Vouchers = 1,379 hours

Psycho-Educational Groups = 264 clients

Legal and Financial Consultation = 141 hours

Compared to state and national caregiver data, those served by the CRCs provided more complex and intense care, with 90.4% providing a high level of care (based on weekly care hours and number of ADL and IADL supports). Most (78.6%) assisted with at least one medical/nursing task and 72.9% spent more than 40 hours per week caregiving. Despite these heavy demands, 70% received no paid help. Caregivers experienced physical and mental health issues themselves, with over 30% reporting fair or poor health and 35% reporting worsening of health over the past year. About 20% reported moderate to severe depressive symptoms and 35% were lonely.

Taken together, findings from the evaluation point to impact as follows.

CRCs serve clients at higher risk when compared to the general population of family caregivers. Based on comparisons of characteristics of family caregivers in state and national populations, there is strong evidence of higher risk profiles in the clients served by the CRCs. As examples, CRC clients:

- engaged in more high intensity care based on caregiving hours and the number of activities of daily living and instrumental activities of daily living they support for their care recipients
- reported more adverse physical and mental health effects from the caregiving role, including loneliness and isolation
- were more likely to care for recipients with Alzheimer's Disease and Related Dementias who cannot be left alone
- were more likely to live with the care recipient
- were less likely to have paid help for caregiving
- performed more complex care and medical nursing tasks in the home; and
- were more likely to identify as Black non-Hispanic, Hispanic/Latino, Asian American/ Pacific Islander, Native American/Alaska Native or multi-racial / other and living below the federal poverty level

As a result, the CRCs provide services—including access to counseling, training, support and respite—to individuals who need and are likely to benefit from these services.

CRCs provided more services to California caregivers in FY 2020-2021 than in the previous year, in some cases with fewer staff. The volume of services provided by the CRCs—including intake, assessment, and reassessment—increased over the last fiscal year perhaps due to rising need in response to the COVID-19 pandemic. At the same time, many CRCs reported staffing shortages throughout the pandemic related to staff on family or medical leave or positions that could not be filled.

CRC program participants reflect diverse groups with important differences in their caregiving experiences. In general, caregivers identifying as Black, non-Hispanic, Hispanic/Latino, Asian American/ Pacific Islander, Native American/Alaska Native or multi-racial / other engaged in more caregiving hours and higher intensity caregiving with fewer resources. The CRCs serve a diverse caregiver population targeting services where they are needed most.

CRCs address the unique needs of the caregiver populations in their geographic catchment areas. The geographic catchment served by each CRC differs in size, population density, racial/ethnic make-up, and age distribution. The unique needs of the caregivers are better served by local CRCs with deep understanding of local services and resources. Comparisons with catchment area demographics reveal both success in reaching underserved populations and opportunities for improved outreach and engagement.

CRCs provided access to respite services exceeding 20% of the annual budget. Taken together, the eleven CRCs spent $3,426,469 on respite services in this fiscal year, comprising 23% of the $15,000,000 budget and exceeding the 10% threshold specified in the contract.

Caregivers were highly satisfied with CRC services. Clients recognized the vital role that the CRCs played in their well-being and capacity to care, particularly through the pandemic. Satisfaction ratings of services and client comments reflected strong recognition of the importance of the resources, education, and supports to caregivers across the state that the CRCs provide.

CareNav^{TM} offers a solid platform to support adaptation of the CRC service model, ongoing evaluation, and future dissemination. All eleven CRCs are now up and running with CareNav^{TM} and after extensive quality checks, we conclude that essential data are being entered consistently across sites. The data collection interface in CareNav^{TM} aligns well with site-specific workflows and can be further adapted alongside any future modifications in the CRC intervention. Data collected in CareNav^{TM} can support robust evaluation of the CRC service model going forward. With training protocols and quality checks now in place, CareNav^{TM} could be disseminated outside the CRC system to support caregiver assessment and support in other settings. Utilization data by caregivers indicates that the biggest barrier to adoption is awareness of the availability of the online platform, suggesting the need for additional time to fully adopt this new technology and further outreach and public information regarding this resource.

RECOMMENDATIONS

The CRCs are meeting vital caregiver needs across California. In the coming year, with more detailed information available through CareNav^{TM}, it will be possible to use this data to drive program decisions and improvements. For example, the following issues might be explored:

- At the site level, what methods work best for greater outreach to communities that seem to be underserved by the CRCs based on population data?
- How might public outreach and information increase awareness and use of CareNav^{TM} as a resource?

- With the high proportion of clients caring for those with memory problems and diagnoses of dementia, what are ways to reach clients who are managing other complex conditions and who may not yet be aware of CRC services?
- How could we use the data to identify those caregivers at greatest risk for a change in situation or in their own health status, so that CRC staff can be alerted more readily to prioritize these caregivers for services and more frequent reassessment?
- At the site level, what are the opportunities for program improvement in outreach, efficiency or responsiveness?

The recommendations made in last year's report in the realm of service delivery remain relevant given the status and progress of implementation of the statewide online platform. These include site-level exploration in the follow areas:

- Forecast rationale for estimated numbers of family caregivers within each CRC region who are low-income, from diverse racial groups, or are residing in rural communities
- Identify reasons and need for further outreach to, groups of caregivers served at lower rates than anticipated (e.g., low income, veterans, Hispanic/Latino populations, rural residents)
- Develop further strategies to address caregiver mental health and loneliness as well as skills in managing complex health conditions and medical/nursing tasks
- Reflect on results of satisfaction surveys for program improvement
- Identify trends, gaps in service and outcomes to support outreach strategies, funding needs, and advocacy priorities.
- Use data to assess quality and equity.
- As data is aggregated over time, develop risk profiles and explore predictive models about what services help whom the best.
- Consider translating CareNav™ into other languages to increase cultural and linguistic congruence across racial/ethnic groups.
- Use data on caregivers and services to inform implementation of the California Master Plan on Aging and other statewide planning efforts.
- Work closely with Department of Health Care Services (DHCS) to further promote caregiving service standards and quality.

ACKNOWLEDGEMENTS

This work is a collective effort with many dedicated individuals sharing a vision and contributing their time, energy, and effort to serve the caregivers of California. The evaluation team worked closely with the Family Caregiver Alliance (FCA) team (represented by Christina Irving and Kathleen Kelly) and the Quality Process (QP) team (represented by Brad Silen) throughout the evaluation design, data collection, and data verification process. We appreciate the leadership and commitment of the eleven CRC directors and the dedicated staff who participated in the implementation while delivering high quality services.

I. INTRODUCTION

California is a leader in establishing a state-wide caregiver resource network supported by an on-line platform, CareNav™. This investment by the State of California recognizes the high prevalence of caregiving in the U.S. and the vital role that caregivers (unpaid family members or friends) play as members of the health care team. About one in five Americans provides care to a family member[1].The complexity and intensity of caregiving for older adults and persons with disabilities is increasing, as the population ages and more individuals are living longer with challenges in physical, cognitive, and mental health. Caregivers enable family members and friends to live with chronic conditions in their environments of choice, assist with navigating acute health crises and hospitalizations, and provide comfort and support at the end of life. Over half of all family caregivers provide complex care including medical/nursing tasks previously performed in inpatient settings, delivering most of the care after discharge from hospitals[2]. State level data reveals that in California, 4.7 million family caregivers assist individuals over the age of 18; of these caregivers, over half (56%) are employed while providing care. These individuals provide an estimated $63 billion worth of unpaid care each year in California[3]. Caregivers remain relatively invisible in the health care system, to their employers and in their communities, yet they bear the brunt of delivering most of the long-term care for the aging population.

California Response: Caregiver Resource Centers History

The California Caregiver Resource Center (CRC) system was launched in 1984 by the Comprehensive Act for Families and Caregivers of Brain-Impaired Adults to support caregivers and care recipients. Today, the California Department of Health Care Services (DHCS) funds the 11 CRCs that provide support to family caregivers affected by chronic health conditions, including Alzheimer's Disease and Related Dementias (ADRD); other degenerative diseases which cause both physical and cognitive impairment such as Parkinson's, Huntington's, multiple sclerosis and amyotrophic lateral sclerosis; cerebrovascular diseases such as stroke, aneurysm and multi-infarct disease; brain injury due to trauma or infection; brain tumor and other brain impairing conditions. These services are available to all Californians. Individual CRCs also receive funds from county contracts, foundations, business partners and donations to provide services.

In 2019, the California Department of Health Care Services awarded the 11 nonprofit CRCs an additional $30 million for the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project to "expand and improve family caregiver services and enhance CRC information technology services." The expansion of services and deployment of CareNav™ takes place over 3 years (2019-2022). CareNav™ is a proprietary software platform developed with private funding by Family Caregiver Alliance with multiple use cases across sectors and populations. More information can be found on www.caregiver.org.

The implementation of CareNav™ and training required for start-up activities was carried out by Family Caregiver Alliance (FCA). Activities included implementing

CareNav™ throughout the state, training CRCs to use the platform, and conducting educational activities for CRCs on quality improvement, change management and use of technologies. In addition to the expansion activities, two other statewide projects were included in the augmentation, an evaluation of the implementation and program activities, and statewide outreach and marketing of the CRC system. FCA conducted a call for proposals and awarded the evaluation to UC Davis Family Caregiver Institute, Betty Irene Moore School of Nursing with oversight by Family Caregiver Alliance and awarded the statewide marketing of the CRC system to Finest City Entertainment with oversight by Southern Caregiver Resource Center.

California CRC Services

Together, the 11 CRCs serve as a point of entry to services available for caregiving families in every county of California, with each site responsible for a catchment area of 1 to 13 counties (see Figure 1a and site-specific descriptions below in Section II. Setting/Context). While each center tailors its services to its geographic area, all CRCs have core programs that provide uniform caregiver assessment, information, education, and support for caregivers. The CRCs provide services across income categories and the original enabling legislation included middle-income families who are often overlooked and few services target. The CRCs are united by shared values emphasizing choice, collaboration, innovation, quality, participation, respect, and diversity. Table 1a summarizes Core Services of the California Caregiver Resource Centers. The state website provides on-line access to all CRCs (https://www.caregivercalifornia.org/)

Figure 1a: CRC Site Catchment

Table 1a: Core Services

CRC Core Service	**Description**
Specialized Information	Advice and assistance on caregiving issues including stress, diagnoses and community resources
Uniform Caregiver Assessment	Standardized intake and assessment tools to help define and explore issues, options and information needs, to determine interventions and services for caregivers, and to provide key data for evaluation and program design
Family Consultation & Care Planning	Individual sessions and telephone consultations with trained staff to assess needs of both the person receiving care and their families, and to explore courses of action and care options for caregivers
Respite Care	Financial assistance for brief substitute care in the form of in-home support, adult day care services, short-term or weekend care, and transportation to assist families caring at home
Short-term Counseling	Family, individual and group sessions with licensed counselors to offer emotional support and help caregivers cope with the strain of the caregiving role
Support Groups	Meetings in a supportive atmosphere where caregivers share experiences and exchange ideas to ease the stress of caregiving.
Professional Training	Individually tailored workshops on long-term care, health management, public policy issues, and legal/financial issues
Legal & Financial Consultation	Personal consultations with experienced attorneys regarding powers of attorney, estate and financial planning, conservatorships, community property laws and other complex matters.
Education	Special workshops on topics such as diagnosis, treatment, long-term care planning and stress management to help caregivers cope with day-to-day concerns

Program Goals of 2019-2022 expansion

The goals of the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project are to: A) Increase service delivery; B) deploy a statewide record of caregiver assessments and services; C) Increase use of technologies to extend services; and D) promote quality practice and standardization of core services.

Timeline for CRC expansion

The 2020-2021 fiscal year is the second year of the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project that includes staff training, technology installation, service evaluation and service delivery evaluation.
Planned Activities of ***Year 2 (FY 2020-2021)*** included:

- Complete any technical changes and full installation for CRCs
- Train staff on telehealth, engagement strategies and use of social media marketing
- Set up learning collaboratives across CRCs
- Service delivery ramp up across all CRCs including cross marketing online educational programs statewide
- Collect data and evaluate service delivery for second fiscal year; circulate key findings

Plans for ***Year 3 (FY 2021-2022)*** include***:***

- Continue service delivery; make adjustments to service model based on evaluation
- Conduct evaluation of process and service delivery model and outcomes; produce report; circulate key findings

Evaluation of Program Expansion

This second annual report (for FY 2020-2021) summarizes both the process of implementation and progress on Year 2 goals, the early results of aggregated data across the California CRCs, and benchmarks CRC data to both state and national caregiver databases.

Evaluation Design and Methods

The evaluation plan was developed by UC Davis researchers at the Betty Irene Moore School of Nursing and the Family Caregiving Institute in collaboration with FCA and with input from the directors of all the California Caregiver Resource Centers. The evaluation plan and measures were approved by the UC Davis Institutional Review Board. The evaluation includes multiple data sources and methods. This report addresses two major areas of evaluation: perspectives on the process of implementation as well as early findings from statewide data sources. Table 1b summarizes all the data sources for this report and for ongoing evaluation.

Table 1b: Evaluation Data Sources

CareNav™: Intake and assessment data from July 2020 – June 2021 for analysis.
Outreach and Public Information Activities: CRC reports of public information and outreach activities conducted from July 2020 – June 2021. This includes activities such as: direct referrals, general public information, community education/public awareness (e.g., health fairs), provider awareness).
Education Activities: CRC reports of education activities conducted from July 2020 – June 2021. This includes programs designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.
Media: CRC reports of media placement (e.g., ads, PSAs) or media appearances with potential reach reported based on circulation numbers or impressions (e.g., bus ads).
Caregiver Satisfaction Surveys: Quarterly surveys of clients who have enrolled in CareNav™ or have received services from the CRC sites.
Qualitative Data: Sources include meeting notes, process observations and comments from clients, staff and leaders associated with the CRCs.
State Comparison Data: The 2019 California Health Interview Survey (CHIS) was used to benchmark CRC data with state caregiver data.
National Comparison Data: The 2019 Caregiving in the U.S. Survey was used to benchmark CRC data with national caregiver data.
CCRC Catchment Demographic Data: Both the American Community Survey (ACS) 2019 5-Year Estimate and the 2020 Decennial Census Public Law (PL) 94-171 Redistricting Data from the U.S. Census Bureau were used to benchmark CRC demographic data with catchment level data for residents 18 years and older.

All CRC sites had deployed the CareNav™ client record by the start of year 2 of the project (FY 2021-22). The evaluation team prepared quarterly and annual reports using data collected in CareNav™ and client satisfaction using survey data collected from clients served by all sites. The evaluation team engaged directly with staff at the CRC sites to validate the data, establish shared definitions for data fields, harmonize data sources, and assure the quality, accuracy and integrity of the data.

In upcoming months, the evaluation team will develop risk profiles and outcomes for potentially vulnerable sub-populations such as those with complex needs, geographic disparities and/or ethnic/racial disparities. For this work, we will leverage additional funds recently awarded from the Archstone Foundation.

Evaluation Methods

Data Extracted from CareNav™ Technology Platform

CareNav™ is a technology platform that enables comprehensive and standardized caregiver assessment, a common data set across the eleven California CRCs, and access to online caregiver resources. This software was developed by Quality Process (QP), FCA’s technology partner, and deployed across the CRC sites to reduce the variability in their existing data collection tools and software used to collect and aggregate their data about the caregivers they served and the programs they administered. A major task over the year involved harmonizing data across the sites and mapping source data fields to the CareNav™ platform to assure standardization and data integrity. During this fiscal year technical and clinical support was provided to the CRCs by QP through a new technical assistance ticket system.

Members of the QP, FCA and UC Davis evaluation teams met weekly to review reports generated by the evaluation team using data extracted from CareNav™. Through this process, UC Davis analysis protocols and algorithms were refined to assure concordance with reports generated from CareNav™ and data filters were defined for the evaluation. Twice during the year, the QP, FCA and UC Davis evaluation teams met with staff at each individual CRC site. During these meetings, site-specific reports generated by the evaluation team were shared, and the group discussed and investigated any issues where the reports did not match site records or expectations. Unexpected values, outliers, missing values, and issues with data entry were identified, investigated, and resolved. In some cases, the QP team was able to implement system-level solutions to address problems identified across multiple sites. In other cases, the sites corrected individual entries as warranted. Taken together, these meetings were highly beneficial to harmonizing data for the evaluation; understanding site-specific challenges related to staffing and CareNav™ implementation; identifying needs for future CRC training; and identifying problem variables in CareNav™ that need further refinement by the QP developers to support consistent data collection across the sites. We will continue to host these productive meetings in FY 2021-2022.

In FY 2019-2020, only three CRCs had complete CareNav™ data for all quarters of the reporting period. In FY 2020-2021, all eleven sites were fully up and running with CareNav™ and provided data for all quarters. This reflects concerted effort from the individual sites, along with the QP, FCA and UC Davis evaluation teams.

For the evaluation analysis, data were extracted from the CareNav™ platform for cases, activities and service grants during the reporting period (July 1, 2020 – June 30, 2021) and transferred from Excel to Stata statistical software (version 16; College Station, TX) for analysis. Dates and times in all evaluation data sets were converted to Pacific Standard Time and data were limited to clients in CareNav™ eligible for California DHCS funding, with the exception of the analysis of intakes which included all clients regardless of funding eligibility because this eligibility is not always known at the time of intake assessment. A small number of case records and activities previously retired/deleted or missing caregiver county of residence was removed from the analysis set.

The evaluation results include summary statistics (counts, mean, standard deviation, percentage) for the total of all cases combined across sites, as well as for each individual site. A case status summary was compiled including counts of total cases and by type (new cases, and ongoing cases with/without activity during FY 2020-2021 looking back within a two-year window). Intakes, assessments, reassessments were tallied by mode of service delivery (i.e., online-internet or email; telephone; in-person-CRC office, client home or community location; and telehealth).

Caregiver characteristics —including socio-demographic, health, and caregiving variables—are presented for the subset of caregivers who proceeded from intake to assessment, since these cases had the most comprehensive data and least amount of missing data. The breakdown for each variable is presented as a complete case analysis (i.e., focusing on non-missing data); missing data was minimal and is discussed further in the Technical Appendix.

State and National Comparisons

To benchmark the CRC caregiver characteristics, further analysis was conducted with data collected for the 2019 California Health Interview Survey (CHIS) and the national 2019 Caregiving in the U.S. Survey. Because the state survey, national survey and CRC caregiver health assessment did not always use the same measures, it was not always possible to compare health outcomes across the three data sources. Details about these comparison data sources are provided in the Technical Appendix.

Outreach, Public Information and Education Activities

The evaluation team designed a data collection tool for sites to report their activities in the areas of outreach, public information, and education. Sites provided information on a quarterly basis, detailing the activity, audience, and number of participants. These data were summarized using descriptive statistics.

Caregiver Satisfaction Surveys

The evaluation team designed a caregiver satisfaction survey in collaboration with FCA to assess satisfaction with services, confidence in caregiving, knowledge, caregiver stress, and experiences with the online platform and technology. The surveys included items rated on a five-point scale, where 1 represents the most positive response. The survey also invited comments from caregivers in an open-ended format. All clients who encountered the CRCs were invited to complete a satisfaction survey. Requests for participation were sent out each quarter by the sites and data were submitted to the Evaluation team for descriptive analysis.

Qualitative Data

Throughout the year, the evaluation team collected comments provided by staff, clients, and leaders of the CRCs as well as meeting notes and observations. These data were used in an iterative way to provide feedback and improve processes. Certain data elements (e.g., comments from clients) were entered into Dedoose software for thematic analysis. Direct quotes are provided in this report in call-out boxes.

II. SETTING/CONTEXT

Description of Sites

This section provides an overview of the 11 California Caregiver Resource Centers (see Table 2a) highlighting the counties each CRC serves, the population of the catchment area, and the geographic footprint for each CRC in square miles. Distinguishing features of each CRC are highlighted. This table, along with Figure 1a, illustrates both urban density and rural geography, posing different challenges for CRC sites coupled with the opportunity to provide services and supports tailored to regional priorities and needs. Two CRCs (Los Angeles, Orange) serve solely metropolitan counties based on Rural Urban Commuting Area (RUCA) codes. The remaining nine CRCs serve a mix of counties categorized as metropolitan, micropolitan, small town and rural. See Technical Appendix for further details about this classification of rurality.

Table 2a: Overview of the 11 California Caregiver Resource Centers

Caregiver Resource Center	Counties Served	County RUCA Categorization (n)*	Population of Catchment Area	Geographic coverage (square miles)	Notes
Bay Area	San Francisco, San Mateo, Santa Clara, Alameda, Contra Costa, Marin	Metropolitan (4) Micropolitan (1) Small Town (1)	6,628,802	3,760	Serves diverse population, urban and suburban, original site for CareNav™, resources in Spanish, Chinese, Tagalog and Vietnamese
Coast	San Luis Obispo, Santa Barbara, Ventura	Micropolitan (2) Small Town (1)	1,574,257	7,876	Hosted within a hospital/rehabilitation system, does not offer legal services
Del Mar	Monterey, Santa Cruz, San Benito	Metropolitan (1) Micropolitan (2)	767,748	5,114	Suburban and rural setting, fewer community resources. Serves significant Latino population, delivers Caregiver University education series, provides services in English and Spanish
Del Oro	Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo, Yuba	Metropolitan (7) Micropolitan (2) Small Town (3) Rural (2)	3,439,752	13,133	Large catchment area across urban and rural counties, diverse need and community resources
Inland	Riverside, San Bernardino, Inyo, Mono	Metropolitan (1) Micropolitan (1) Small Town (2)	4,592,757	40,512	Programs include caregiver supports/resources, supports to seniors living alone and PEARLS (in home treatment for depression), CBT for Late Life Depression Program, and resources in Spanish

Caregiver Resource Center	Counties Served	County RUCA Categorization (n)*	Population of Catchment Area	Geographic coverage (square miles)	Notes
Los Angeles	Los Angeles	Metropolitan (1)	10,081,570	4,058	Racially and ethnically diverse, large county with complex array of services and supports, hosted by USC Leonard Davis School of Gerontology
Orange	Orange	Metropolitan (1)	3,168,044	793	Racially and ethnically diverse, Vietnamese and Spanish Speaking staff, high housing costs
Passages	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, Trinity	Micropolitan (5) Small Town (3) Rural (1)	611,470	30,167	Programs include family caregiver support, information and access to community services, care management, ombudsman program, Medicare counseling
Redwood	Del Norte, Humboldt, Mendocino, Lake, Sonoma, Napa, Solano	Metropolitan (1) Micropolitan (4) Small Town (2)	1,396,078	12,480	Housed within a Community Action Agency
Southern	San Diego, Imperial	Metropolitan (1) Micropolitan (1)	3,496,774	8,384	Large Latino and migrant community, Delivering REACH for Spanish speaking families, resources available in Spanish. Serves as contractor for statewide CRC media/marketing campaign
Valley	Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tuolumne	Micropolitan (3) Small Town (4) Rural (1)	3,526,225	29,536	Programs include caregiver supports/resources, Medicare counseling, adult day programs, ombudsman programs

***Population and geographic data were drawn from U.S. Census Bureau tables by rolling up county level statistics.**

***County RUCA codes range from 1 (least rural) to 10 (most rural) and are categorized as Metropolitan (1-3), Micropolitan (4-6), Small Town (7-9), Rural (10). See technical appendix for further detail.**

Effects of the COVID-19 Pandemic

The COVID-19 pandemic formed a powerful backdrop for Fiscal Year 2, with widespread impact on the lives of caregivers, CRC staff, and the services and supports available for caregivers in California and beyond.

COVID-19 affects caregiver lives

All CRC sites reported observations of greater strain and stress for the clients they serve. Stressors included changes in health, financial struggles, food and housing insecurity, alterations in employment demands, social distancing, and home-schooling for children. Social isolation became a profound force, increasing the loneliness and depression for caregivers who were already at higher risk for less social connection. Interruptions in services for persons in their care, such as respite and paid caregivers, increased the demands on family caregivers. Caregivers of persons with dementia faced unique challenges in promoting safety with distancing and wearing masks when the need for these measures was not understood by the person with cognitive impairment. It is important to note that staff were also dealing with the stressors associated with the pandemic and adjusting to working from home as they provided support to caregivers, increasing the challenges experienced by this valued workforce.

Comments from CRC staff:

Caregivers are showing more isolation that is increasing depression symptoms. That feeling of being alone with no one to confide in.

COVID has disrupted necessary routines and patterns which adds undue levels of stress, strain and anxiety for family caregivers and care receivers

Clients report high financial stress related to lost jobs or wages causing worry about housing and basic essentials

COVID-19 affects services and supports

At a time when needs for support and services increased, availability in many communities waned. Some services, such as respite and in-home paid caregiving were suspended entirely. Other services, such as health care appointments, were offered as telehealth, with implications for those who do not have access to or ease with technology. With the strains in acute care, hospital processes related to visitation policies and discharge planning were also disrupted, resulting in greater stress for caregivers navigating acute health problems for themselves and their care recipient. Workforce shortages in home care affected the ability of some caregivers to secure paid assistance in the home. The dynamic nature of the pandemic created uncertainty in communication about policies, service availability and guidelines, adding to the confusion and stress experienced by family caregivers. All of these service issues were exacerbated for marginalized caregivers and those for whom English is a second language, amplifying health inequity for caregivers with greatest need.

Comments from CRC staff:

Clients appear to be in desperate need to process everything going on in our world – COVID, the fires, social injustice...as such, conversations are taking longer to ensure clients feel heard and validated.

COVID and closure of adult daycare centers, leaves caregivers managing care full-time at home in addition to working remotely and also caring for their school age children, causing anxiety as their routine is disrupted.

Caregivers in communities of color and immigrant communities have been particularly adversely affected by COVID-19 and the ways that our society is organized, including who has access to health care, has been made even more evident.

Many families who qualify for supports have not felt safe or comfortable accessing them due to concerns about COVID-19 risk to vulnerable family members.

III. POPULATION SERVED

CareNav^{TM} Data Findings

Caregiver Socio-demographic Characteristics

Across all CRCs, a total of 4,299 unduplicated caregivers completed assessments for 4,385 unduplicated care recipients during the reporting period, reflecting that some caregivers provide care for multiple care recipients. The reported percentages below reflect the percentage of the total number excluding missing values for each variable. Additional details about missing data can be found in the Technical Appendix along with methodological details about the measures used for caregiver health (e.g., UCLA Loneliness Scale, PHQ-9) and Caregiver Socio-demographic Characteristics.

Of the 4,299 caregivers who completed assessments, most were ages 45-64 years (47.7%) or 65-84 years (36.0%), and identified as female (74.9%), heterosexual (89.9%), and as married or partnered (65.4%). The most prevalent race/ethnicity was white non-Hispanic (52.2%), followed by Hispanic/Latino (31.4%), Asian American/Pacific Islander (8.2%), Black non-Hispanic (6.6%), multi-racial / other (1.1%), and Native American/Alaska Native (0.6%). Detailed sociodemographic data are presented in Appendix Table C1.

Figure 3a: Intakes and Assessments Completed

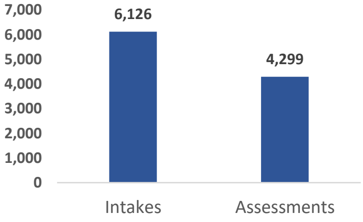


Figure 3b: Age: Caregiver and Care Recipient

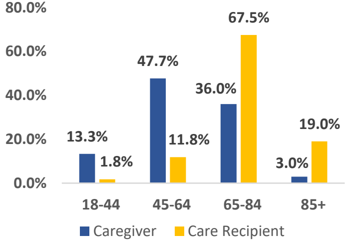


Figure 3c: Gender: Caregiver and Care Recipient

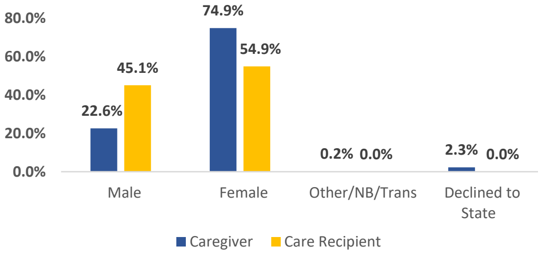


Figure 3d: Sexual Orientation

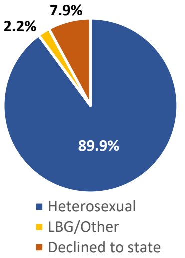
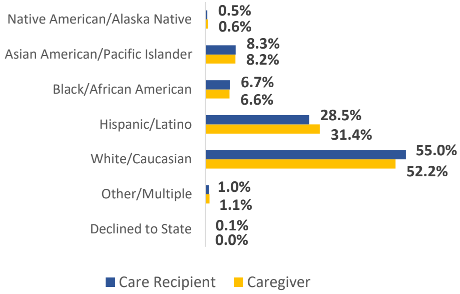


Figure 3e: Racial & Ethnic Identity: Caregiver and Care Recipient



A substantial proportion of caregivers reported earnings below the federal poverty level (17.9%), being unemployed (21.3%), living in a rural area (12.8%), or providing care to multiple recipients (18.0%), while a smaller subset reported having VA benefits (5.0%; similar to percentage in the California general population),or living alone (8.5%)[5] (Table 3a).

Table 3a: Caregiver Sociodemographic Characteristics

	n = 4,299
Highest Level of Education, %	
Some High School	5.7
High School Graduate	14.3
Some College	26.2
College Graduate	27.2
Post Graduate Degree	13.9
Decline to State	12.7
Employment Status, %	
Full time	26.3
Part time	11.1
Retired	34.0
Unemployed	21.3
Leave of absence	1.7
Decline to state/ Undefined	5.5
Caregiver Has VA Benefits, %	5.0
Earns Below Federal Poverty Level, %	17.9
Lives Alone, %	8.5
Lives in Rural Area, %	12.8
Provides Care to Multiple Care Recipients, %	18.0

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

CRC participants reflect multicultural groups with a substantial proportion providing care to multiple care recipients and living below the federal poverty level

Caregiver Socio-demographic Characteristics by Race and Ethnicity

Summary descriptions of caregiver socio-demographics characteristics are in Table 3a. They conceal differences by race and ethnicity. There were statistically significant differences by race/ethnicity for all socio-demographic variables reported, aside from the percentage of caregivers living alone, which was similar across groups, see Appendix Table C2.

While most caregivers across race/ethnicities were in the 45-64 or 65-84 year age groups, the age distribution skewed towards the younger, 18-44 year age group for Black non-Hispanic (13.1%), Hispanic/Latino (20.6%), Asian American/Pacific Islander (14.72), and multi-racial / other racial identity (21.4%) caregivers when compared with white, non-Hispanic (7.9%) and Native American/Alaska Native (6.5%) caregivers. All caregiver groups featured a nearly 3:1 relationship of female vs. male caregivers, except for greater representation of female caregivers among Hispanic/Latino caregivers (81.3%).

Few caregivers identified as other gender, non-binary or trans, and these individuals who self-identified were white non-Hispanic (0.2%) and Hispanic/Latino caregivers (0.1%). Sexual orientation was consistent across caregiver groups; however, fewer Hispanic/Latino caregivers identified as LGBT/other (0.9%) in comparison to other groups (2.1-3.6%).

Most caregivers reported completing some college or having a college degree. Post-graduate degrees were more commonly reported by Asian American/Pacific Islander (20.1%) and Black non-Hispanic caregivers (18.0%, vs. 5.3%-16.9% in other groups), while Hispanic/Latino caregivers more commonly reported not having completed high school (15.0% vs. 0%-5.8% in other groups).

The employment status of caregivers varied across racial/ethnic groups. Multi-racial / other racial identity (35.7%) and Black non-Hispanic (32.4%) caregivers had the highest full time status rates of all groups; Hispanic/Latino (16.5%) and other/multiple identifying (12.5%) caregivers had the highest rates of part-time employment; Native American/Alaska Native (48.4%) and white non-Hispanic (45.3%) caregivers had the highest retirement rates while Hispanic/Latino (19.4%) and other/multiple (19.6%) caregivers had the lowest retirement rates; Hispanic/Latino caregivers had the highest prevalence of unemployment (31.7%); and other/multiple race (7.1%) and Native American/Alaska Native (6.5%) had the highest leave of absence rates.

White non-Hispanic (70.8%) and Pacific Island or Asian American/Pacific Islander (68.2%) caregivers had the highest rates of being married/partnered while Black, non-Hispanic caregivers had the lowest (48.0%); Hispanic/Latino (13.9%) caregivers had the highest divorced/separated rates, while Native American/Alaska Native (6.5%) and Asian American/Pacific Islander (8.1%) caregivers had the lowest rates of divorce/separation; Black non-Hispanic caregivers had the highest rates of being single (32.4%), while white non-Hispanic caregivers had the lowest (13.9%); Native

American/Alaska Native caregivers had a higher widowed rate than all other caregiver groups (12.9%).

Native American/Alaska Native caregivers had higher rates of Veterans benefits compared to other caregiver groups (13.3%), while Hispanic/Latino caregivers had the lowest rates (2.4%). More Hispanic/Latino (30.3%), Native American/Alaska Native (25.8%), and multi-racial / other racial identity (23.6%) caregivers earned below the federal poverty level (FPL) than other caregiver groups, and fewer white non-Hispanic (12.7%) and Black non-Hispanic (12.7%) caregivers earned below the FPL.

Native American/Alaska Native (35.7%) and white non-Hispanic (18.9%) caregivers lived in rural areas at higher rates than other caregivers, while Asian American/Pacific Islander (3.3%), Black non-Hispanic (5.0%), and Hispanic/Latino (7.1%) caregivers were less likely to live in a rural region. Finally, Hispanic/Latino (26.3%) and multi-racial/other racial identity (24.1%) caregivers provide care for multiple care recipients at far higher rates than most other caregiving groups; whereas Native American/Alaska Native (11.1%), white non-Hispanic (13.8%), and Asian American/Pacific Islander (14.8%) caregivers provide care for multiple care recipients at lower rates.

Care Recipient Socio-demographic Characteristics

Most care recipients were older adults, ages 65-84 years (67.5%) or 85 years and above (19.0%; Appendix Table C9). Slightly more care recipients identified as female (54.9%). The largest race/ethnicity group was white non-Hispanic (55.0%) followed by Hispanic/Latino (28.5%), Asian American/Pacific Islander (8.3%), Black non-Hispanic (6.7%), multi-racial/other racial identity (1.0%), and Native American/Alaska Native (0.5%). About half of care recipients were married or partnered (51.8%) and 27% were widowed. Approximately one-quarter of care recipients reported income below the federal poverty level (24.8%) or were Medicaid eligible (25.6%). A small subset of care recipients received VA benefits (11.6%), had long-term care insurance (10.3%), or lived in a rural area (12.6%). Most care recipients lived with their caregiver (74.3%).

Caregiving Characteristics

Caregiving characteristics describe the care recipients' care needs and are shown in Table 3b. Most caregivers who completed assessments identified as the care recipient's primary caregiver (96.8%). However, nearly one-third of care recipients had multiple caregivers involved in their care (31.0%). Most caregivers were either a child (51.7%) or spouse (34.9%) of the care recipient. Just under half reported providing care for less than 2 years (45.6%) with the rest being longer-term caregivers.

Using a measure developed by AARP based on number of weekly caregiving hours and the number of activities of daily living (ADLs) and instrumental ADLS they support[4], most CRC caregivers were categorized as involved in "high" level of care situations (90.4%). Most caregivers assisted with at least one medical / nursing task (78.6%) and spent 40 or more hours per week on caregiving activities (72.9%). Despite these intense caregiving demands, 70% received no paid help and nearly half (43.8%) received no unpaid help with weekly caregiving responsibilities.

Table 3b: Characteristics of Caregiving

	***n* = 4,299**
Respondent is the Primary Caregiver, %	96.8
CR Has Multiple Caregivers, %	31.0
Caregiving Duration, %	
<2yrs	45.6
2-5yrs	24.9
>5yrs	29.5
Relationship to Care Recipient, %	
Spouse	34.9
Partner	1.1
Child	51.7
Other Relative	9.8
Non-Relative	2.6
Level of Care, %	
1	1.2
2	1.6
3	6.8
4	23.3
5	67.1
Care Intensity, %	
Low	2.8
Medium	6.8
High	90.4
Assists with Medical/Nursing Tasks, %	78.6

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; Level of care and care intensity calculated per AARP Level of Care measure using weekly caregiving hours and number of ADLs and IADLs performed (NAC & AARP 2020)**

Figure 3f: Hours of Caregiving/Week

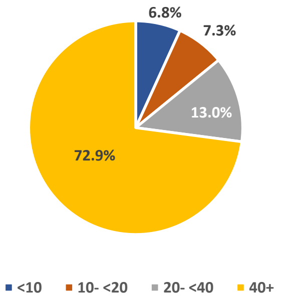
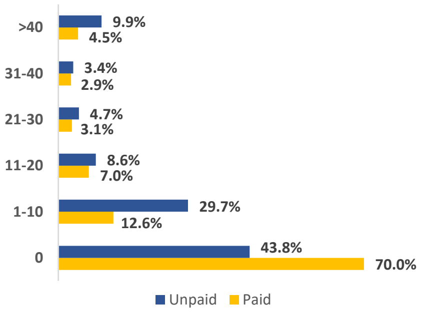


Figure 3g: Hours of Help per Week



Caregiving Characteristics by Race and Ethnicity

All racial/ethnic caregiver groups identified as the primary caregiver for their care recipient at similar rates (see Appendix Table C6). The highest rates of caring for multiple care recipients were found among Hispanic/Latino (39.8%), multi-racial / other racial identity (38.5%), and Asian American/Pacific Islander (32.3%) caregivers. Hispanic/Latino and Asian American/Pacific Islander caregivers had provided care, on average, for more years than caregivers in the other groups.

White non-Hispanic (43.1%) and Asian American/Pacific Islander (37.1%) caregivers were more likely to be spouses; Native American/Alaska Native caregivers were more likely to be partners (6.7%); multi-racial/other racial identity (69.0%) and Hispanic/Latino caregivers (62.1%) were more likely to be the children of their care recipients; Black non-Hispanic (16.7%) and multi-racial/other racial identity (15.5%) caregivers were more likely to identify as relatives; and Native American/Alaska Native caregivers were the most likely to identify as non-relatives (6.7%).

Comparable levels of care were provided across all caregiver groups, except for Native American/Alaska Native caregivers where a greater proportion performed “high” levels of care (90.9%) compared to other groups based on the AARP Level of Care Index. Hours of care provided per week were consistent across caregiver groups, with the exception of Native American/Alaska Native caregivers who provided 40 or more hours of care per week (95.5%) at a far greater rate than other groups. Native American/Alaska Native caregivers had the lowest rates of zero paid hours of help compared to other groups (61.9%), while Hispanic/Latino caregivers were least likely to have paid help during the week (74.3%). Caregivers had identifying as multi-racial/other race had the most hours of unpaid help during the week while Native American/Alaska Native caregivers had the least. Notably, Hispanic/Latino (16.9%) and Asian American/Pacific Islander (10.2%) caregivers were more likely to have 40 hours or more of unpaid help per week compared to other groups.

Almost three quarters of CRC caregivers provide more than 40 hours of care per week, except for Native American/Alaska Native caregivers, where an even higher proportion are engaged in high intensity care and have no paid help.

Assistance with Activities

Caregivers were asked about which of fifteen different daily activities they assisted care recipients with and how often they needed assistance (needs no help, a little help, help most of the time, or all the time). Table 3c reports the percentage of caregivers that needed at least some help with activities. Caregivers assisted with a median of 13 activities. Many care recipients required assistance with activities “all the time,” particularly for transportation (88.1%), shopping (84.0%), managing money (77.9%), preparing meals (74.2%), and household chores (73.9%; Appendix Table C7).

Table 3c: Caregiving Activities: “Need Help” Percentages

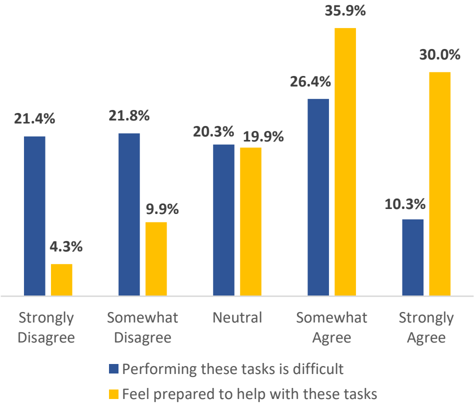
	***n* = 4,299**
Number of Activities Requiring Assistance, median (mean) %	**13 (11.6)**
Eating	56.7
Bathing/Showering	82.3
Dressing/Undressing	79.5
Grooming	74.7
Using Toilet	68.8
Incontinence (accidents)	69.3
Preparing Meals	95.4
Taking Medications	93.1
Managing Money/Finances	93.8
Household Chores	96.4
Using Telephone	75.9
Mobility	78.6
Transferring from bed/chair/car	70.2
Shopping	97.3
Transportation	96.8

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Medical/Nursing Tasks

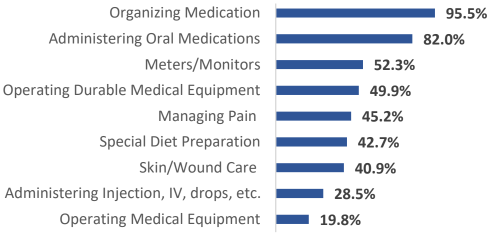
Caregivers who reported assisting with medical/nursing tasks helped with an average of four tasks (out of nine possible, Appendix Table C8). The most commonly reported medical/nursing tasks were ordering or organizing medications (95.5%), followed by administering oral medications (82.0%), managing meters or monitors (52.3%), operating durable medical equipment (49.9%), managing pain (45.2%), preparing special diets (42.7%), skin/wound care (40.9%), administering medications by injection, IV, etc. (28.5%), and operating medical equipment (19.8%).

Figure 3h: Performing Medical Nursing Tasks



There was a great deal of variability in caregivers’ perceived difficulty and preparation to do medical/nursing tasks (Figure 3h). Altogether, over one-third either “strongly” agreed (10.3%) or "somewhat" agreed (26.4%) that performing these tasks was difficult, but over half "strongly" agreed (30.0%) or "somewhat" agreed (35.9%) that they felt prepared to help with these tasks. Only a relatively small percentage (15.4%) said that they would like more information about these tasks (Appendix Table C8).

Figure 3i: Medical Nursing Tasks: Difficulty and Preparation



Care Recipient Health Needs

By far, the most common care recipient primary diagnosis among those with completed assessments was Alzheimer's Disease and Related Dementias (68.3%), followed by stroke (10.5%), "other" conditions (7.6%), Parkinson's disease (7.3%), cancer (3.5%), and brain injury (2.8%; Table 3d). However, nearly all care recipients (91.3%) had some memory loss. Consistent with this group of caregivers' high level of care intensity, nearly half of care recipients could "never" be safely left alone (46.3%), and a substantial proportion could only be left alone for less than an hour (21.6%) or several hours (25.1%). A small subgroup of care recipients exhibited wandering behaviors (15.7%). Many care recipients had health documents in place, most commonly durable power of attorney for healthcare (62.0%) and finance (59.0%), followed by advanced healthcare directives (52.8%) and do not resuscitate (DNR) orders (23.7%). However, only a very small percentage reported having a conservatorship (5.6%) or physician order for life-sustaining treatment (POLST, 5.5%).

Table 3d: Care Recipient Health Needs

	***n* = 4,299**
Primary Diagnosis, %	
Alzheimer's Disease and Related Dementias (ADRD)	68.3
Parkinson's	7.3
Stroke	10.5
Cancer	3.5
Brain Injury	2.8
Other	7.6
Memory Loss, %	91.3
Can Be Left Alone, %	
Always	7.0
Several Hours	25.1
<1hr	21.6
Never	46.3
Wandering, %	15.7
Documents in Place, %	
Conservatorship or Guardianship	5.6
Durable Power of Attorney: Health	62.0
Durable Power of Attorney: Finances	59.0
POLST	5.5
Do Not Resuscitate (DNR)	23.7
Living Will	7.6
Trust	13.6
Advance HealthCare Directive	52.8

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Caregiver Health Status

Most caregivers rated their current health status as either “good” (42.6%), or “fair” (24.6%) as opposed to excellent (6.2%), very good (20%) or poor (6.7%) (Table 3e.). Most reported that their health was about the same compared to six months ago (56.1%), with about a third reporting that their health was worse than before (34.5%).

PHQ-9 scores, indicating the presence of depressive symptoms, are based on an instrument with a series of questions about experiences (e.g., feeling sad or blue), with each item rated (0 “Not at all” to 3 “Almost all the time”). Most caregivers experienced either no symptoms (0-2, 36.6%) or mild symptoms (3-9, 43.6%). However, approximately 12% had moderate symptoms (10-14), 6% had moderate-severe symptoms (15-19), and 2% had severe symptoms (20-27).

Loneliness was assessed using the UCLA 3-item Loneliness Scale, which consists of three questions asking caregivers how often they feel that they lack companionship, feel left out, or feel isolated from others. Over one-third of caregivers in the dataset scored as lonely (34.9%).

More than half of caregivers reported being either very satisfied (26.3%) or satisfied (30.9%) with support from family. However, a substantial minority were neutral (18.3%), somewhat dissatisfied (14.9%), or very dissatisfied (9.6%).

Satisfaction with spiritual support was similar, with a slight majority of caregivers reporting being either very satisfied (32.3%) or satisfied (27.8%). However, a much larger percentage of caregivers rated their satisfaction with spiritual support as neutral (30.7%) and a much lower percentage as somewhat (6.6%) or very (2.6%) dissatisfied compared with support from family and friends.

Table 3e: Caregiver Health Status

	***n* = 4,299**
Self-Rated Overall Health, %	
Excellent	6.2
Very Good	20.0
Good	42.6
Fair	24.6
Poor	6.7
Current Health Compared to Six Months Ago, %	
Better	9.5
Same	56.1
Worse	34.5
PHQ-9, %	
0-2 (none; PHQ-9 N/A)	36.6
3-9 (minimal/mild)	43.6
10-14 (moderate)	12.1
15-19 (mod. severe)	6.1
20-27 (severe)	1.8
UCLA Loneliness Scale, %	
3-5 (not lonely)	65.1
6-9 (lonely)	34.9
Zarit Burden Interview Screening, %	
0-7 (low strain)	40.7
8-16 (high strain)	59.3
Satisfaction with Support from Family and Friends, %	
Very Satisfied	26.3
Somewhat Satisfied	30.9
Neutral	18.3
Somewhat Dissatisfied	14.9
Very Dissatisfied	9.6
Satisfaction with Spiritual Support, %	
Very Satisfied	32.3
Somewhat Satisfied	27.8
Neutral	30.7
Somewhat Dissatisfied	6.6
Very Dissatisfied	2.6

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Caregiver Health by Race and Ethnicity

The self-reported health status of caregivers differed by race and ethnicity. White non-Hispanic and other/multiple caregivers self-rated their health status higher overall than other groups. Particularly, Hispanic/Latino, Native American/Alaska Native, and Asian American/Pacific Islander caregivers rated lower health status overall than the other groups. Regarding current health compared to six months ago, multi-racial/other racial identity, Black non-Hispanic, and Hispanic/Latino caregivers rated better current health scores, whereas Asian American/Pacific Islander, Native American/Alaska Native, and white non-Hispanic caregivers rated lower scores. In all groups, most caregivers selected the “Same” or “Worse” health currently compared to six months ago.

PHQ-9 scores were similar across all racial/ethnic groups with the majority scoring in either the 0-2 (none) or 3-9 (minimal / mild) range. Asian American/Pacific Islander caregivers were the exception, having higher PHQ-9 scores compared to the other groups. Black non-Hispanic (41.9%), multi-racial/other racial identity (40.0%), white non-Hispanic (37.0%), and Asian American/Pacific Islander (36.7%) caregivers had higher loneliness scores compared to the other caregiver groups. Higher strain scores on the Zarit Burden Interview Screening were found among white non-Hispanic (61.4%), multi-racial/other racial identity (61.1%), and Black non-Hispanic (60.0%) caregivers with Asian American/Pacific Islander (71.6%) caregivers having exceptionally high burden scores compared to the other groups.

Satisfaction with spiritual support and support from family and friends was significantly different by race/ethnicity. White non-Hispanic caregivers were most likely to report being very satisfied with support from family and friends (29.3%) while Black non-Hispanic caregivers were most likely to report being very dissatisfied (17%). Black non-Hispanic and Hispanic/Latino caregivers were most likely to report being very satisfied with spiritual support (38.9% & 38.5%, respectively), while the largest percentage of white, non-Hispanic, Asian American/Pacific Islander, and multi-racial/other racial identity caregivers rated spiritual support as neutral (33%-42.9%).

CRC program participants reflect multicultural groups with important differences in their caregiving experiences and the effects on their physical and mental health.

State and National Comparisons

Caregiver Socio Demographic Characteristics

Compared to the population of California caregivers in the California Health Interview Survey (CHIS) (hereafter state), and population of national caregivers in the Caregiving in the U.S. Survey (hereafter national), CRC caregivers tended to be older with a larger percentage aged 45 - 64 years (48%; vs 44% state; 39% national) and a smaller percentage aged 18 - 44 years (13% vs 18% state; 34% national). The percentage of caregivers 65 years and older was similar in the CRCs and state data (approximately 39%) but higher than in the national data (27%) (see Table 3f).

The CRC caregivers were more diverse by race/ethnicity with 52% white non-Hispanic compared to 63% in the state survey and 60% in the national survey. A larger percentage of the CRC caregivers were female (70% vs 64% state; 60% national); on-leave from their work/unemployed or retired rather than working (60% versus 52% state; 44% national); married or partnered 68% vs 58% state; 63% national); and earned below the FPL (19% vs 8% state). A smaller percentage of the CRC caregivers lived alone (8% vs 22% state; 12% national). Approximately 13% of the CRC and state caregivers lived in rural areas compared to 31% in the national survey.

CRCs serve clients who are older, more diverse and more likely to live below the Federal Poverty Level than the general state and national population of caregivers. CRC clients are more likely to care for recipients with Alzheimer's Disease and Related Dementias who cannot be left alone.

Table 3f: Caregiver Sociodemographic Characteristics: Comparisons of California Caregiver Resource Center Population with Caregivers in State and National Surveys

CRC Sites Served	CRC Assessments FY 2020-2021 (%)	California Health Interview Survey 2019 (%)	Caregiving in the US Survey 2019 (%)
Total	**4,299**	**2,995**	**1,627**
Age in Years			
18-44	13.3	17.5	34.3
45-64	47.7	44.1	38.5
65 or older	39.0	38.3	27.2
Gender Identity			
Male	20.8	37.2	39.8
Female	70.3	62.8	60.2
Other/NB/Trans	0.2	------	------
Racial Identity			
Native American/Alaska Native	0.6	0.73	-----
Asian American/Pacific Islander	8.2	9.55	4.8
Black non-Hispanic	6.6	3.9	13.6
Hispanic/Latino	31.4	18.2	15.2
White non-Hispanic	52.2	64.6	63.6
Multi-racial / Other	1.1	3.04	2.8
Highest Level of Education			
Some High School	6.5	2.8	5.9
High School Graduate	16.4	12.3	25.2
Some College	30.1	24.1	33.9
College Graduate	31.1	38.2	20.4
Post Graduate Degree	15.9	22.6	14.6
Employment status			
Working at Job or Business	40.0	48.4	55.6
Leave, Unemployed, Retired	60.0	51.6	44.4
Relationship Status			
Married/Partnered	68.2	57.9	62.6
Divorced/Separated/Widowed	13.9	27.7	15.7
Single	17.9	14.5	21.7
Caregiver Has VA Benefits	5.0	-----	-----
Earns Below Federal Poverty Level	19.4	8.2	-----
Lives Alone	8.4	21.5	12.2
Rural Residence	12.8	14.2	30.8

***California Health Interview Survey (CHIS), 2019 - see Appendix C: Technical Details about the survey and methodology**
***Caregiving in the US Survey, 2019 - see Appendix C: Technical Details about the survey and methodology**
Response categories were collapsed as needed for comparability across the surveys. Percentages may not add to 100 due to rounding

Characteristics of Caregiving

A lower percentage of CRC caregivers cared for multiple care recipients in comparison to the caregivers in the national survey (18% vs. 24%) and a far higher percentage provided care 40 or more hours each week (73% versus 9% state; 32% national) (see Table 3g). A higher percentage of CRC caregivers were older adults ages 65-84 years (87% vs 74% state; 68% national); caring for a recipient with ADRD (68% vs. 5% state; 6% national); or caring for a child or spouse / partner (87% vs. 26% state; 24% national); whereas, a higher percentage of caregivers in the state (56%) and national surveys (77%) cared for another relative or non-relative compared to CRC caregivers (13%). In a comparison of care intensity using the Level of Care Index developed by AARP based on hours of care provided, and the number of ADLs and IADLS supported, a higher percentage of CRC caregivers (90%) provided a high level of care compared those in the national survey (41%). About 77% of CRC caregivers support care recipients by performing medical / nursing tasks in the home compared to 58% in the national survey.

Table 3g: Characteristics of Caregiving: Comparisons of California Caregiver Resource Center Population with Caregivers in State and National Surveys

CRC Sites Served	CRC Assessments FY 2020 – 2021(%)	California Health Interview Survey 2019 (%)	Caregiving in the US Survey 2019 (%)
Total	**4,299**	**2,995**	**1,627**
Cares for Multiple Care Recipients	18.0	------	23.7
Care Recipient Age			
18-44	1.8	9.3	13.2
45-64	11.8	15.5	18.8
65-84	86.5	74.3	68.0
Hours Per Week Caregiving			
<10	6.8	62.4	41.7
10 <20	7.3	15.7	10.7
20- <40	13.0	13.9	15.6
40+	72.9	9	32.0
Relationship to Care Recipient			
Spouse/Partner	34.8	19.5	16.8
Child	51.7	9.6	6.7
Other Relative	9.9	54.4	64.8
Non-Relative	2.6	13.0	11.7
Care Recipient Primary Diagnosis			
Alzheimer’s Disease and Related Dementias (ADRD)	68.3	5.1	5.7
Parkinson’s	7.3	------	1.4
Stroke	10.5	36.7	4.6
Cancer	3.5	3.8	6.4
Other	10.4	54.4	83.3

CRC Sites Served	CRC Assessments FY 2020 – 2021(%)	California Health Interview Survey 2019 (%)	Caregiving in the US Survey 2019 (%)
Total	**4,299**	**2,995**	**1,627**
Care Recipient Primary Diagnosis			
Alzheimer's Disease and Related Dementias (ADRD)	68.3	5.1	5.7
Parkinson's	7.3	------	1.4
Stroke	10.5	36.7	4.6
Cancer	3.5	3.8	6.4
Other	10.4	54.4	83.3
Received Paid Help for Caregiving	30.0	------	34.8
Care Intensity[1]	3,788	------	
Low	2.8	------	43.5
Medium	6.8	------	15.5
High	90.4	------	41.0
Assists with Medical/Nursing Tasks	78.6	------	57.7

***California Health Interview Survey (CHIS), 2019 - see Appendix C: Technical Details about the survey and methodology**
***Caregiving in the US Survey, 2019 - see Appendix C: Technical Details about the survey and methodology**
***Response categories were collapsed as needed for comparability across the surveys. Percentages may not add to 100 due to rounding**

Caregiver Health Status

Health status (rated Excellent, Very Good, Good, Fair or Poor) was used consistently across the CRC, state and national surveys with higher percentages of CRC Caregiver rating their health good / fair / or poor (74%) compared to the state (45%) or national caregivers (59%) (see Table 3h).

Because the state survey, national survey and CRC caregiver health assessment did not always use the same measures, it was not always possible to compare health outcomes across the three data sources. A higher percentage of CRC caregivers reported their health had worsened while providing care (35%) compared to the national caregivers (22%). Neither the state nor the national survey collected data using the PHQ-9 or Zarit Burden Interview Screening. In the general population, based on data collected for the National Health Interview Survey in 2019, 2.8% of adults experienced severe symptoms of depression, 4.2% experienced moderate symptoms, and 11.5% experienced mild symptoms in the past 2 weeks as measured with the PHQ-8. CRC caregivers had much higher rates of depressive symptoms using the PHQ-9 with 12% having moderate symptoms; 8% severe symptoms[6]. In the original study of the 4-item Zarit Burden Interview Screening 25% of the sample of primary caregivers of community dwelling older adults with cognitive impairment, scored 8 or higher; in the CRC data, 59% scored 8 or higher reflecting much higher burden[7].

CRC caregivers were more likely to score as lonely on the UCLA Loneliness Scale compared to respondents in the state survey (35% vs 5% state). Similarly the CRC caregivers were more likely to respond “often” to the individual items in the scale asking how often they feel lack of companionship (19% vs 6%), feel left out (14% vs 3%) or feel isolated (20% vs 4%).

Table 3h: Caregiver Health Status: Comparisons of California Caregiver Resource Center Population with Caregivers in State and National Surveys

CRC Sites Served	CRC Assessments 2020-2021 (%)	California Health Interview Survey 2019 (%)	Caregiving in the US Survey 2019 (%)
Total	**4,299**	**2,995**	**1,627**
Self-Rated Overall Health			
Excellent	6.2	16.7	10.2
Very Good	20.0	37.8	31.3
Good	42.6	30.9	38.5
Fair	24.6	11.9	17.2
Poor	6.7	2.8	2.8
Caregiving Made Health Worse	34.5	-----	21.8
UCLA Loneliness Scale			
How often feel lack of companionship			
Hardly ever	51.1	71.0	-----
Some of the time	29.5	23.2	-----
Often	19.4	5.9	-----
How often feel left out			
Hardly ever	60.1	79.4	-----
Some of the time	25.9	19.0	-----
Often	14.1	2.6	-----
How often feel isolated			
Hardly ever	49.3	79.9	-----
Some of the time	30.5	16.5	-----
Often	20.2	3.6	-----
UCLA Loneliness Scale Score			
3-5 (not lonely)	64.9	94.9	-----
6-9 (lonely)	35.1	5.1	-----

***California Health Interview Survey (CHIS), 2019 - see Appendix C: Technical Details about the survey and methodology**
***Caregiving in the US Survey, 2019 - see Appendix C: Technical Details about the survey and methodology**
***Response categories were collapsed as needed for comparability across the surveys. Percentages may not add to 100 due to rounding**

CRC clients engage in higher intensity care, report more adverse physical and mental health effects, and are more lonely than state and national caregivers

CRC Population Catchment Area Demographics Compared to CRC Service Population Demographics

Further analysis of population demographics provides information about the racial/ethnic composition, gender identity, age and living situation profiles of each catchment area. This information can inform evaluation of the extent to which the CRC sites are serving the underlying population and help identify opportunities for targeted program development, responsive to regional population characteristics.

Race/Ethnicity and Caregivers Served by Geographic Catchment

To examine race/ethnicity of the caregivers served by the CRCs, we drew from the American Community Survey (ACS) 2019 data shown in Table 3i. Overall, the California population includes 30,827,105 people over 18 years of age who primarily identify as either Hispanic/Latino (36.0%) or white non-Hispanic (37.9%). The other 23.8% is shared among Californians who identify as Asian American/Pacific Islander (16.3%), Black non-Hispanic (5.5%), multi-racial/other racial identity (4.0%), or Native American/Alaska Native (0.4%).

As summarized in Table 3i, compared to the overall California population, white non-Hispanic caregivers served by CRCs were over-represented by 15%. Hispanic/Latino, Asian American/Pacific Islander, and multi-racial/other racial identity populations were underrepresented by 7.6%, 6.5%, and 2.2% respectively. Black non-Hispanic and Native American/Alaska Native caregiver populations closely matched their representation in the overall California demographic.

Table 3i: Racial/Ethnic Identity by Catchment Population Compared to CRC Caregivers served

CRC Sites Served	**18+ Population (*N*)**	**Racial and Ethnic Identity of Catchment 18+ Population/CRC caregivers served (%)**					
		Native American / Alaska Native	**Asian American / Pacific Islander**	**Black non-Hispanic**	**Hispanic / Latino**	**White non-Hispanic**	**Multi-racial/Other**
California	**30,827,105**	**0.4/0.6**	**16.3/8.2**	**5.5/6.6**	**36.0/31.4**	**37.9/52.2**	**4.0/1.1**
Bay Area	5,351,202	0.2/0.3	31.7/20.3	5.6/11.5	21.4/18.5	36.5/47.5	4.5/1.9
Coast	1,238,747	0.3/0.3	6.9/2.8	1.7/2.8	36.5/21.4	50.6/72.2	4.0/0.6
Del Mar	595,456	0.3/0	6.0/6.1	1.8/2.4	46.2/24.4	41.6/64.6	4.0/2.4
Del Oro	2,736,441	0.6/0.4	15.1/6.6	6.2/8.4	23.6/11.1	49.1/71.9	5.5/1.5
Inland	3,478,282	0.5/0.3	8.3/4.1	7.0/19.1	47.4/36.3	33.3/39.3	3.4/0.8
Los Angeles	7,959,791	0.2/0.3	16.0/4.6	7.8/8.0	44.8/74.9	28.0/11.7	3.3/0.5
Orange	2,519,658	0.2/0.3	22.9/23.4	1.6/1.8	31.1/23.8	40.6/50.0	3.7/0.7
Passages	482,646	1.9/1.0	3.7/0	1.5/1.0	15.3/5.7	71.6/90.6	5.9/1.6
Redwood	1,117,087	1.3/1.6	8.7/3.0	5.4/4.9	23.7/11.7	55.4/76.9	5.6/1.9
Southern	2,740,968	0.4/0.2	12.6/5.5	4.4/4.6	33.5/46.0	44.7/42.5	4.5/1.0
Valley	2,606,827	0.7/1.7	7.1/2.6	3.8/5.5	50.3/24.4	34.7/65.3	3.4/0.5

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; Catchment data is drawn from the 2020: Decennial Redistricting Data by rolling up county level statistics.**

The racial and ethnic composition of CRC catchment regions varied, particularly across white non-Hispanic, Hispanic/Latino, and Asian American/Pacific Islander categories where the differences ranged by 47.4%, 37.6%, and 28.5% respectively, demonstrating the variability in racial/ethnic diversity across the counties of the state. Overall, the CRCs serve a higher proportion of White non-Hispanic, Black non-Hispanic, and Native American/Alaska Native caregivers and fewer Asian American/Pacific Islander and multi-racial/other caregivers than the state population. The following statistics are notable in terms of the representativeness of the CRC population in relation to the general population of the catchment area. They are presented in parentheses as "(general catchment percentage / CRC caregivers in catchment percentage)":

- Hispanic/Latino caregivers were served in higher proportion than the general population at Southern (33.5 / 46.0%) and Los Angeles (44.8% / 74.9%) CRCs and in lower proportion at the remaining 9 sites
- Black non-Hispanic caregivers were served in lower proportion at Passages (1.5% / 1.0%) and Redwood (5.4% / 4.9%) and in higher proportion at the remaining 9 sites
- Asian American/Pacific Islander caregivers were served at higher proportion at Orange (22.9% / 23.4%) and at lower proportion in the remaining 10 sites
- Native American/Alaska Native caregivers were served at higher proportion at Bay Area (0.2% / 0.3%), Redwood (1.3% / 1.6%) and Valley (0.7% / 1.7%), equal proportion at Coast (0.3% / 0.3%) and lower in the remaining 7 sites
- White non-Hispanic caregivers were served at lower proportions in Los Angeles (28.0% / 11.7%) and in higher proportions at the other 10 sites

CRCs address the unique needs of the caregiver populations in their geographic catchment areas. The catchments areas differ in size, population density, racial/ethnic make-up, and age distribution. Comparisons of CRC caregivers with catchment area demographics reveal both success in reaching underserved populations and opportunities for improved outreach and engagement

Gender Identity and Sex Assigned at Birth by Geographic Catchment

Table 3j compares sex assigned at birth data for the Californians ages 18 and older (30,261,351) with the gender identities of caregivers served. These categories are not directly comparable because state population data reflects sex assigned at birth rather than gender identity. Given these caveats:

- There were slightly more females (50.7%) than males (49.3%) statewide.
- Females were overrepresented in the caregiving population relative to the broader California population.
- Among caregivers, those who identify as female (74.9%) far outnumber all other caregiver gender identities combined (25.1%).

Table 3j: Gender Identity and Sex Assigned at Birth by Catchment and by CRC Caregivers Served

CRC Sites Served	18+ Population (*N*)	Sex Assigned at Birth Catchment 18+ Population (%)		Gender Identity CRC Caregivers Served (%)			
		Female	**Male**	**Female**	**Male**	**Other/NB/Trans**	**Declined to State**
California	**30,261,351**	**50.7**	**49.3**	**74.9**	**22.6**	**0.2**	**2.3**
Bay Area	5,265,507	50.6	49.4	75.5	22.5	0.3	1.7
Coast	1,228,110	50.4	49.6	74.0	25.5	0.0	0.5
Del Mar	585,080	49.8	50.2	79.7	19.0	0.0	1.3
Del Oro	2,620,197	51.3	48.7	72.3	25.7	0.2	1.8
Inland	3,400,760	50.6	49.4	78.9	21.1	0.0	0.0
Los Angeles	7,866,810	51.2	48.8	80.2	19.2	0.3	0.3
Orange	2,463,536	51.1	48.9	75.8	23.8	0.2	0.3
Passages	484,146	49.9	50.1	71.8	26.2	0.0	2.0
Redwood	1,104,689	50.9	49.1	76.4	22.8	0.3	0.5
Southern	2,722,183	49.8	50.2	73.3	17.9	0.1	8.8
Valley	2,520,333	49.8	50.2	72.5	27.4	0.1	0.0

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; Catchment data is drawn from the American Community Survey (ACS) 2019 5-Year Estimate by rolling up county level statistics.**

Of note, the U.S. Census Bureau collected population level data for both sexual orientation and gender identity (SOGI) in its most recent Health Pulse Survey (HPS) which ended October 11, 2021. No U.S. Census Bureau-sponsored survey before has collected such information. Unfortunately, the data was not available at the time this report was produced. Should this kind of data collection extend to surveys like the American Community Survey, then direct comparisons of gender identity can be made between the broader California population and caregivers served by CRCs.

Age by Geographic Catchment

Table 3k presents the age distributions of caregivers served by the CRCs relative to the broader California population aged 18 years or older by catchment. Overall, the percentage of caregivers in the 18-44 age category was significantly lower (13.3%) than the general population of Californians (49.4%). These data reveal the disproportionate representation of individuals in the 45-64 (47.7%) and 65-84 (36.0%) age categories as caregivers compared to the general population (32.4% and 15.8% respectively). Representation was similar in the 85 or older age group at 2.4% and 1.8% respectively. Los Angeles and is reaching the highest proportion of younger caregivers, with higher engagement among the 18-44 (23.5%) and 45–64 (54.0%) age groups than older caregivers. Passages is notable for serving an older clientele, at 55.7% over 65.

Table 3k: Age Ranges by Catchment and by CRC Caregivers Served

CRC Sites Served	18+ Population (*N*)	Age Ranges of Catchment 18+ Population (%)				Age Ranges CRC Caregivers Served (%)			
		18-44	**45-64**	**65-84**	**85+**	**18-44**	**45-64**	**65-84**	**85+**
California	**30,261,351**	**49.4**	**32.4**	**15.8**	**2.4**	**13.3**	**47.7**	**36.0**	**3.0**
Bay Area	5,265,507	48.7	32.9	15.8	2.5	16.7	49.4	31.6	2.3
Coast	1,228,110	47.6	32.1	17.5	2.8	8.7	41.0	46.6	3.7
Del Mar	585,080	49.7	31.8	16.1	2.3	8.0	53.3	36.7	2.0
Del Oro	2,620,197	47.2	33.0	17.3	2.5	9.3	45.6	40.5	4.6
Inland	3,400,760	50.6	32.1	15.4	1.9	10.5	50.1	37.3	2.1
Los Angeles	7,866,810	50.6	32.4	14.6	2.3	23.5	54.0	21.9	0.6
Orange	2,463,536	47.2	34.3	16.0	2.5	10.2	40.2	43.2	6.3
Passages	484,146	43.0	32.3	21.9	2.8	4.7	39.6	52.1	3.6
Redwood	1,104,689	43.6	33.9	19.9	2.7	10.9	41.9	43.0	4.2
Southern	2,722,183	51.5	31.0	15.2	2.3	16.7	52.5	29.4	1.4
Valley	2,520,333	52.6	30.7	14.6	2.0	9.4	46.7	39.9	3.9

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; Catchment data is drawn from the American Community Survey (ACS) 2019 5-Year Estimate by rolling up county level statistics.**

Population Living Alone by Geographic Catchment

Caregivers live alone at slightly lower rates when examining all ages (8.6%) than Californians ages 18 or older (10.3%; Table 3l). This pattern continued among those less than 65 years old (6.2% catchment vs. 4.7% caregivers) and among those older than 65 years (4.1% catchment vs.3.5% caregivers). Several CRCs have a higher proportion of caregivers living alone: Los Angeles (14.4%), Del Mar (13.6%), Passages (13.3%), and Orange (13.2%).

Table 3l: Lives Alone Population by Catchment and by CRC Caregivers Served

CRC Sites Served	18+ Population	Lives Alone Catchment 18+ Population			Lives Alone CRC Caregivers Served		
		All Ages	Ages 65+	Ages <65	All Ages	Ages 65+	Ages <65
	n	%	%	%	%	%	%
California	**30,261,351**	**10.3**	**4.1**	**6.2**	**8.6**	**3.5**	**4.7**
Bay Area	5,265,507	11.0	4.3	6.7	7.2	2.5	4.7
Coast	1,228,110	9.8	4.6	5.2	3.6	1.4	1.9
Del Mar	585,080	9.4	4.3	5.1	13.6	4.5	7.8
Del Oro	2,620,197	11.2	4.7	6.5	6.7	2.9	3.9
Inland	3,400,760	8.3	3.6	4.8	6.7	2.2	4.6
Los Angeles	7,866,810	10.8	3.7	7.1	14.4	4.2	9.4
Orange	2,463,536	8.9	3.9	5.0	13.2	8.2	3.3
Passages	484,146	13.8	6.6	7.3	13.3	7.1	5.6
Redwood	1,104,689	12.4	6.0	6.5	11.5	4.6	7.0
Southern	2,722,183	10.2	3.9	6.3	3.9	1.2	2.8
Valley	2,520,333	8.9	3.9	5.1	9.8	4.0	5.8

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; Catchment data is drawn from the American Community Survey (ACS) 2019 5-Year Estimate by rolling up county level statistics.**

Importantly, the comparisons summarized above benchmark the CRC caregiver population against state-wide demographic profiles which include individuals who are not caregivers. Later in the report, we provide direct comparisons of characteristics of the CRC caregiver population to survey information collected from the general population of caregivers in the California Health Interview Survey and in the nationwide sample of caregivers in the Caregiving in the United States survey.

IV. SERVICES PROVIDED

CRC Case Status Summary

In FY 2020-2021, the 11 CRCs together conducted 6,126 intakes and opened 4,122 “new cases” (site mean: 375), defined as conducting a full assessment (i.e., risk assessment questions on intake indicate a need for more intensive services and the caregiver is interested in participating in this next level of engagement) for a caregiver with no prior CRC assessment within the past two years. Another 28,817 “ongoing cases” were followed by the sites (site mean: 2,619) defined as caregivers having an assessment in the past two years; of these ongoing cases, 34% received one or more services (e.g., family consultation, reassessment, counseling, vouchered services) throughout the year.

Table 4a.: Case Status Summary – All California CRCs Combined

	FY 2020-2021
New Cases	4,122
Ongoing Cases with Activity	9,892
Ongoing Case no Activity	18,925
Total Open Cases	32,939

***Ongoing and Open Case Tallies may be incomplete based on CRC timing of CareNav adoption**
***Definitions - refer to Appendix A: Glossary**
***Inclusion Criteria – refer to Appendix C: Technical Specifications**

“Open cases” (i.e., the sum of new and ongoing cases) in FY 2020-2021 totaled 32,939 for all CRCs (site mean: 2,994). Importantly, these counts ***underestimate*** the actual CRC open caseload because they are based on definitions that encompass a two-year window during which not all CRCs were fully up and running with complete CareNav^{TM} data.

CRCs provided more services to California caregivers in FY 2020-2021 than in the previous year, in some cases with fewer staff

Activity Summary

Intake

In total, the 11 CRCs conducted 6,126 initial intakes or caregiver screenings in FY 2020-2021 (site mean: 557); reflecting an increase of 26% over FY 2019-2020 (Table 4b). Not all intake screenings move to full assessment; for instance, a case may be completed at intake if staff are able to make a referral or provide advice during the screening and the caregiver does not desire further support. Within the fiscal year, clients had one intake on average, lasting approximately 30 minutes although there was some variability in time spent on intake across the sites. Most intakes were conducted over the phone (79%) and approximately 10% were completed on-line by caregivers using the CareNav ^{TM} portal. The percentage of caregivers entering intake information directly in CareNav^{TM} was similar to that in the last fiscal year.

Table 4b: CRC Client Activity Summary – All California CRCs Combined

	FY 2020-2021	**FY 2019-2020**
Intake, *n*	6,126	4,876
Intake Delivery Mode, %		
Telephone	79.3	73.2
CRC Office	8.2	8.0
Completed On-line by Caregiver	10.1	11.6
Video/Telehealth	1.5	0.0
Other (client home, community)	0.9	-----
Assessment, *n*	4,299	3,321
Assessment Delivery Mode, %		
Telephone	79.5	64.4
CRC Office	10.0	29.1
Completed On-line by Caregiver	4.6	1.1
Video/Telehealth	5.6	0.3
Other (client home, community)	0.3	-----
Reassessment, *n*	2,856	-----
Reassessment Delivery Mode, %		
Telephone	81.4	74.5
CRC Office	13.6	10.3
Completed On-line by Caregiver	1.6	3.8
Video/Telehealth	3.3	0.5
Other (client home, community)	0.1	-----
Family Consultation, *n*	25,546	13,070
Support Group, *n*	1,993	2,626
Psycho-Education, *n*	264	873
Caregiver Education / Training, *n*	1,322	-----
In-House Individual Counseling, *n*	145	680

***Definitions - refer to Appendix A: Glossary**
***Inclusion Criteria – refer to Appendix C: Technical Specifications**

Assessment

Of the clients completing intakes, 4,299 (70%) moved forward to full assessment (site mean: 391), a 29% increase over the last fiscal year and an increase in the percentage of caregivers moving from intake to assessment from 68% in FY 2019-2020. Full assessment occurs when the risk assessment questions on intake indicate a need for more intensive services and the caregiver is interested in participating in this next level of engagement. CRCs with above average number of intakes (Bay Area, Los Angeles, Southern, Valley) also conducted above average number of assessments as did Del Oro CRC. Most clients had one assessment in the fiscal year; lasting on average from one to three and a half hours, depending on the site. Reflecting the circumstances of the COVID-19 pandemic, the percentage of assessments conducted by phone increased in FY 2020-2021 compared to FY 2019-2020 (80% versus 64%) with a corresponding drop in the percentage conducted in person (10% versus 29%).

Reassessment

Together the sites conducted 2,856 reassessments (site mean:260), following up with clients who had a full initial assessment, typically within six months. Reassessment encounters lasted, on average, a little over one hour. Most reassessments were conducted by phone (81%).

Family Consultation

In total, the CRCs completed 25,546 family consultations (site mean: 2322), with each client on average having between 4 and 21 encounters depending on the site, for an average annual duration of 1 to 5 hours.

Other Activities

Seven CRCs completed 264 psychoeducational sessions (site mean: 38); nine offered 1,322 training sessions (site mean: 147); and six offered 145 on-site individual counseling sessions (site mean: 24), largely driven by Inland, Orange and Southern CRCs.

Over the fiscal year, service volume generally increased steadily by quarter within each activity type. Variability in activities or duration by site has several possible explanations: 1) differences in overall site volume and clients eligible for DHCS funding; 2) geographic distribution of resources within the state and CRC catchment areas, leading to some services being offered “in house” rather than by referral; and 3) differences in site-specific workflow or understanding of definitions for entry into CareNav.

Service Grant Vouchers

CRCs provide vouchers for specific services to eligible clients (Table 4c). In FY 2020-2021, 714 vouchered transactions for **individual counseling** totaling 1,379 service hours ($131,451) were provided to 404 unduplicated clients; 147 vouchered transactions for **legal services** totaling 141 hours ($16,140) were provided to 147 unduplicated clients; 6,513 vouchered transactions were provided for **respite care** totaling 139,340 hours ($3,426,469) to 3,259 unduplicated clients; and 1,492 vouchered transactions for **supplemental grants** ($183,039) were provided by four CRCs to 649 clients, typically for durable medical equipment or groceries.

Table 4c: Service Grant Voucher Totals - All California CRCs Combined

	FY 2020-2021	FY 2019-2020
Counseling		
Transactions	714	140
Unique Clients	404	51
Hours	1,379	
Amount	$131,451	
Legal Consultation		
Transactions	147	158
Unique Clients	147	96
Hours	141	
Amount	$16,140	
Respite		
Transactions	6,513	1070
Unique Clients	3,259	504
Hours	139,340	
Amount	$3,426,469	
Supplemental Grants		
Transactions	1,492	
Unique Clients	649	
Amount	$183,039	

***Definitions - refer to Appendix A: Glossary**

CRCs spent $3,426,469 (or 23% of their collective budget) on respite services in this fiscal year, exceeding the 10% threshold specified in the contract

Outreach, Education and Media

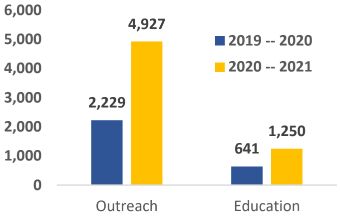
In FY 2020-2021, the 11 CRCs conducted 4,927 outreach activities and 1,250 education activities. Media placements or appearances had the potential of 57 million views based on repeated ad placements and circulation estimates. Social service or health care providers were noted as the referral source by over 60% of respondents in CareNav^{TM} (Table 4d). The 11 CRCs increased the number of outreach and education activities from the FY 2019-2020 (media was not reported in FY 2019-2020).

Table 4d: How Caregivers Learned of the CCRC Program

Medium (%)	*n* = 4,534
Social Service Provider or Agency	32
Health Care or Insurance Provider	30
CRC Direct Referral	12
Media Outreach (website, e-mail, radio, newspaper, flyers)/Social Media	9
Other (church, family, friend, word of mouth)	16
Unsure	1

***Percentages may not add to 100 due to rounding.**

Figure 4a: Outreach and Education Activities 2019-2020 and 2020-2021



Outreach

Definitions for each outreach activity can be found in Table 4e. The 11 CRCs conducted 4,972 outreach activities that reached approximately 488,462 Californians through public information sharing, meetings and presentations, and health fairs (Table 4f). Most activities (1,980) focused on public outreach and information sharing via distribution of newsletters, email blasts, and social media posts (site mean = 180) that reached 404,985 individuals. Nine CRCs also reached 61,869 individuals through participations in 658 community meetings or presentations (site mean = 82). Eight CRCs reported participation in health or resource fairs. Southern CRC reported 1,442 activities that reached 16,720 individuals. The remaining seven sites reported 26 activities (site mean = 3.7) that reached 4,888 people.

Table 4e: Outreach Definitions

Outreach Activity	Definition
Health or Resource Fairs	All health, senior or resource fairs conducted in person or virtually.
Meetings | Presentations	In-person or virtual meetings to members of the public (potential clients) and/or community groups.
Public Information:	Passive outreach via social media (Facebook and Twitter posts, Facebook live, etc.), email blasts, mailings, newsletters, etc. Activities include actual number of people reached.

Table 4f: Outreach Activities

	Health or Resource Fair		Meetings | Presentations		Public Information		Totals	
CRC	**# Events**	**# Reached**	**# Events**	**# Reached**	**# Events**	**# Reached**	**# Events**	**# Reached**
Bay Area	2	225	69	1,410	366	51,841	437	53,476
Coast			11	482	12	3,785	23	4,267
Del Mar					15	17,347	15	17,347
Del Oro	2	525	24	603	69	26,503	95	27,631
Inland	9	609	415	9,249	265	82,750	689	92,608
Los Angeles	1	5	43	36,609	707	61,686	751	98,300
Orange	6	1,015	76	5,264	140	76,923	222	83,202
Passages	2	522	2	61	120	7,348	124	7,931
Redwood					102	36,519	102	36,519
Southern	1,442	16,720		7,574	40	5680	2303	29,974
Valley	4	1,987	18	617	144	34,603	166	37,207
Total	**1,468**	**21,608**	**658**	**61,869**	**1,980**	**404,985**	**4,927**	**488,462**

Education

In total, the 11 CRCs conducted 1,250 educational activities from July 2020 – June 2021, reaching 67,148 people (Table 4g). The number of activities varied considerably by site with a range of 10 to 723. Southern CRC conducted 723 activities that reached 54,595 individuals. The remaining ten sites reported 527 activities (site mean = 53) that reached 12,553 individuals (site mean = 1,255)

Table 4g: Education Activities

CRC	Total # Activities	Total # Reached
Bay Area	77	3,005
Coast	10	115
Del Mar	26	405
Del Oro	81	1,898
Inland	181	1,328
Los Angeles	30	2,242
Orange	66	2,640
Passages	26	561
Redwood	10	160
Southern	723	54,595
Valley	20	199
Total	**1,250**	**67,148**

Activities were offered in a variety of languages other than English, including Cantonese, Mandarin, Spanish, Tagalog and Vietnamese. The CRCs partner on a shared calendar featuring on-line education activities that are accessible to caregivers from throughout California. In FY 2020-2021, 189 education activities were offered statewide, with nearly a quarter (24%) provided in a language other than English.

Media

Sites were not required to report media. However, five (Coast, Orange, Passages, Southern, Valley) reported advertisement campaigns and guest appearances with the potential of 57 million views based on repeated ad placements and circulation estimates. This includes multiple placements aimed at reaching non-English speakers.

Table 4h: Media

CRC Site	Potential Views	CRC Site	Potential Views
Coast	1,000	Southern	43,695,270
Orange	237,693	Valley	6,655,207
Passages	186,500		
Total	**425,193**	**Total**	**50,775,670**

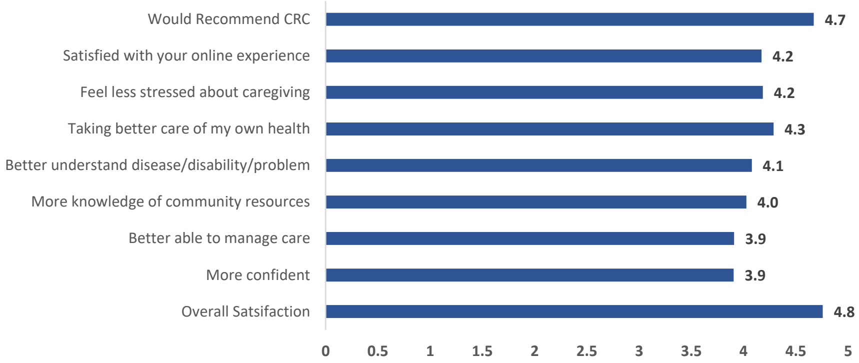
V. CLIENT AND STAFF EXPERIENCE

Client Satisfaction with Services

Satisfaction Survey

Satisfaction surveys were sent to all clients who had contact with the CRCs on a quarterly basis. For the year, 2,869 caregivers provided their feedback on services received. Caregivers are highly satisfied with their experiences with the CRCs, with 81.7% reporting they are extremely satisfied and 10.7% somewhat satisfied. The vast majority would recommend the CRC to others, with 84.2% definite and 10.3% likely to recommend. Figure 5a shows the mean scores, on a scale of 1 to 5, with 5 representing the most positive response.

Figure 5a: Satisfaction with Services | *n* = 2,869



The survey explored the impact the services had on the lives of the caregivers. Table 5a indicates that the majority of caregivers agree or strongly agree that the services give them confidence (81.6%), prepare them to manage care (82.2%), increase knowledge and awareness (86.6%), improve understanding of the disease, disability or problem (75.5%), enable them to take better care of themselves (75.0%) and result in less stress (58.3%).

Caregivers are satisfied with CRC services. Clients recognized the vital role the CRCs play in their well-being and capacity to care, particularly through the pandemic.

Table 5a: Satisfaction Surveys: Impact of Services

n = 2,869	More Confident as a Caregiver (%)	Better able to Manage Care (%)	More Knowledge and Awareness (%)	Understand the disease/disability /problem better (%)	Taking better care of self (%)	Less stressed (%)
Strongly Disagree	1.4	1.6	1.7	1.5	1.6	2.2
Disagree	1.9	2.7	2.2	2.5	3.3	6.8
Neutral	15.1	13.5	9.4	20.5	20.1	21.4
Agree	41.2	40.0	38.8	37.7	40.6	36.9
Strongly Agree	40.4	42.2	47.8	37.8	34.4	32.7

***Percentages may not add to 100 due to rounding**

Client comments about services

In addition to the formal caregiver satisfaction surveys, clients provided comments and reflections on the services they received and the impact of these services and supports on their lives. Many appreciated the full array of services that the CRCs provide, including information, support, consultation, education, and services such as respite and legal advice. Others identified one or two services that were particularly helpful to them, and engaged deeply with the CRC over time, building strength, knowledge, and the ability to cope with their situation. Table 5b includes exemplar quotes from caregivers reflecting on the ways the CRC services have improved their lives.

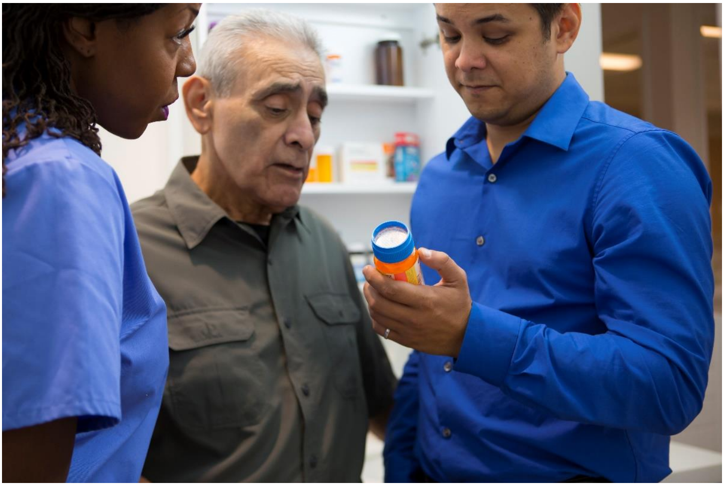


Table 5b: CRC Improving Caregiver Lives

Service Type	Quotes
Support Groups	*Amid a global pandemic, I lost my mom to terminal brain cancer and suddenly became a caregiver for my dad who is in early stages of Alzheimer's Disease. The FCA young caregivers support group has been a critical resource that has connected me to a group of amazing individuals who share their challenges, insights and empathy. It has made me realize I am not alone as I learn what it means to be a caregiver.*
Overall services	*When my parents were diagnosed to have dementia, I was overwhelmed. Family Caregiver Alliance helped me thru some of the most challenging time in providing me respite, resources, information and empowerment. I am so grateful.*
Respite	*I was able to get a break and run some errands. I'm a single father and also a full-time unpaid caregiver for my mother so life is a big juggle. I often don't have time for myself. Being able to line up adult day care is priceless.*
Overall services	*I love the support and friendships I've made with ICRC! They are a godsend to me for their classes, support groups, being available for my phone calls when things are stressful and confusing for me and the counseling the have provided for me. Caregiving is the hardest thing I have ever done and without them I would have been lost! Please continue to help us – I appreciate all of you so much!*
Overall services	*I began my journey and was given generously in every area that I and my husband desperately needed. Resources with education on dementia, loving facilitators, medical supplies, food, caregivers for my husband. Loving, accepting and understanding what my husband and I was going thru. All the Inland caregivers and dedicated staff (angels) has been right there every step of the way! We have benefited immensely! I learned soooo much on how to take care of my husband and myself. I feel more in control and have a sense of peace, guidance, and direction along this life path! Thank you again and again and again!*

Client feedback about the online platform

On the satisfaction survey, we also collected information about caregiver experiences with the online platform and the reasons given for not engaging with the online platform. Table 5c indicates that while caregivers desire the option to receive services online (76.2%), only 18.9% have used CareNav™. However, the majority of those who have used the online platform, express satisfaction (39.0% extremely satisfied and 20.1% somewhat satisfied, Figure 5b).

Table 5c: Satisfaction Surveys: Desire for and Experience with Online Platform

***n* = 2,869**	**Want Option for Online Services (%)**	**Used CareNav™ (%)**
Yes	76.2	18.9
No	12	70.7
I Don't Know	11.7	10.4

***Percentages may not add to 100 due to rounding.**

Those who did not use CareNav™ were asked about the reasons for not engaging with the online program. As observed in Figure 5c, the largest barrier to use was awareness about the program (34.0%), followed by the impression that the caregiver did not need this (17.3%). Access to internet (7.9%), lack of technology experience (14.1%) and finding the platform too confusing (2.8%) were less frequently identified as barriers.

Figure 5b: Satisfaction with CareNav™

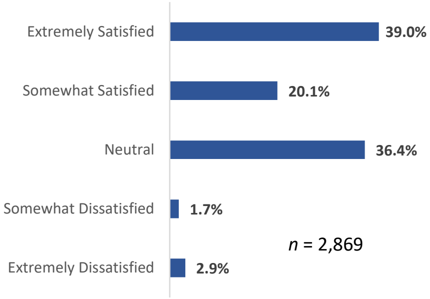
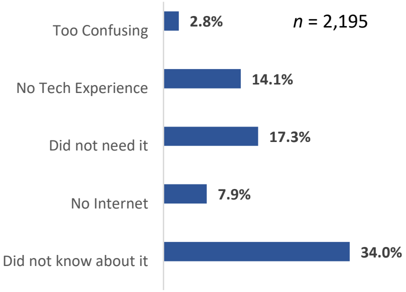


Figure 5c: Reasons for not Using CareNav™



CRC staff experiences with CareNav™

Fiscal Year 2 of this project represented a vital phase of the implementation, with full deployment of CareNav™ across the state. As described in the first annual report, implementation included a complex array of activities including leadership, culture change, staff training and preparation, technology deployment, data importing and harmonization, and beginning experience in navigating and using the system to deliver services and supports. Implementation occurred on an aggressive timeline and in the context of a pandemic and social injustice, necessitating great creativity in modifying and executing the plan, and strong commitment from leaders and staff through times of duress. It was expected that in the early months of having state-wide data, the evaluation team would play a strong role in partnering with the CRCs to assure data quality and accuracy. In statewide and individual meetings with the CRC, the evaluation team engaged in conversations about standardization of data collection practices and communication with caregivers, as well as ongoing feedback about the usability and effectiveness of CareNav™. As quarterly summaries were generated from CareNav™, the evaluation team worked with individual CRCs to review summaries for face validity, to identify and address missing data and to refine variable definitions and data entry specifications. This iterative learning process offered the opportunity to assure data integrity and to provide feedback to the CareNav™ technical team for system improvements.

All CRC sites are fully operational with CareNav™ at this time, contributing data to the state-wide record. Some faced greater technical and logistical barriers than others, associated with more frustration. Despite the challenges, all CRCs display commitment and enthusiasm for the actual and potential benefits of the system for advancing quality and equity in services for caregivers in California. The next phase of the work will focus on engaging more clients in participating in the online platform and addressing digital divide issues in access for all.

Comments from CRC staff:

Overall, my experience with CareNav™ has been positive, due to ease of access and information sharing for mutual clients, user-friendliness, and accuracy of data monitoring/collection. Some challenges have been connectivity/technical issues, difficulty for clients maintaining private environments, and not being able to observe the home environment. Glitches of CareNav™ have been fixed.. for me, CareNav™ has been helpful.

We've learned and we are learning that online delivery of content, training and facilitation is effective and becomes available to a broader geographic audience and so a hybrid approach (mix of in-person and online) is not only possible but effective.

Staff training

The leadership team for implementation sponsored extensive training opportunities for sites, including state-wide webinars, meetings with site leaders and staff and individual training and technical support to users throughout the year. This included two refresher trainings that were recorded as a resource for new staff or those requiring additional education, individual refresher sessions for sites targeting specific needs, and brief "how-to" videos based on frequently asked questions or common issues. As with any new system, training prior to deployment provides general guidance, and as users engage in the system, their learning needs become more apparent. The implementation team provided tailored supports to address variable learning needs. Overall, staff appreciate the training opportunities and found them to be helpful, both on the

CareNav™ system and also on topics such as motivational interviewing. Staff identified the need and desire for ongoing training as they become more familiar with the system and seek more advanced instruction, and as the CareNav™ system continues to be upgraded and improved, as well as relevant topics including how to address social justice issues with clients.

CareNav^{TM} offers a solid platform to support future adaptation of the CRC intervention, ongoing evaluation, and future dissemination.

Implementation of recommendations from Year 1 annual report

In last year's report several recommendations were made in the realms of implementation and data integrity. Table 5d summarizes progress on these recommendations.

Table 5d: Implementation of Recommendations from Year 1 Annual Report

Recommendation	Progress
1. Continue to engage in statewide communication and strategic planning to actualize the intention of this supplemental funding. As data become available, use the data to inform strategic decisions.	Ongoing
2. Continue efforts to address cross-site variation in data collection practices and communication with caregivers, learning from all sites and moving towards standardization where possible.	Strong improvement
3. Engage in ongoing feedback about the usability and effectiveness of CareNav™.	Ongoing
4. Sites should engage in thoughtful review of summaries generated out of CareNav™, comparing and reconciling differences with their previous data reports.	Complete
5. Differences in variable definitions were noted across the sites; efforts are underway to standardize these definitions across all CRCs. Structured meetings with CRC front line providers will facilitate in-depth examination of variable definitions and data entry specifications. Further harmonization may be required across sites.	Substantial progress, ongoing
6. Determine frequency of statewide evaluation of caregiver satisfaction with CRC services and implement regular and standardized satisfaction surveys across the state for review and incorporation of feedback at the sites.	Quarterly, implemented

VI. IMPACT

Taken together, findings from the evaluation point to impact as follows:

CRCs serve clients at higher risk when compared to the general population of family caregivers. Based on comparisons of characteristics of family caregivers and the caregiving role in state and national populations, there is strong evidence of higher risk profiles in the clients served by the CRCs. As examples, CRC clients:

- engage in more high intensity care based on caregiving hours and the number of activities of daily living and instrumental activities of daily living they support for their care recipients
- report more adverse physical and mental health effects from the caregiving role, including loneliness and isolation
- are more likely to care for recipients with Alzheimer's Disease and Related Dementias who cannot be left alone
- are more likely to live with the care recipient
- are less likely to have paid help for caregiving
- perform more complex care and medical nursing tasks in the home; and
- were more likely to identify as Black non-Hispanic, Hispanic/Latino, Asian American/ Pacific Islander, Native American/Alaska Native or multi-racial/other and living below the federal poverty level

As a result, the CRCs provide services—including access to counseling, training, support, and respite—to individuals who need and are likely to benefit from these services.

CRCs provided more services to California caregivers than in the previous year, in some cases with fewer staff. The volume of services provided by the CRCs—including intake, assessment, and reassessment—increased over the last fiscal year perhaps due to rising need in response to the COVID-19 pandemic. At the same time, many CRCs reported staffing shortages throughout the pandemic related to staff on family or medical leave or positions that could not be filled.

CRC program participants reflect multicultural groups with important differences in their caregiving experiences. In general, caregivers of color engage in more caregiving hours and higher intensity caregiving with fewer resources. The CRCs serve a diverse caregiver population targeting services where they are needed most.

CRCs address the unique needs of the caregiver populations in their geographic catchment areas. The geographic catchment served by each CRC differ in size, population density, racial/ethnic make-up, and age distribution. The unique needs of the caregivers are better served by local CRCs with deep understanding of local services and resources. Comparisons with catchment area demographics reveal both success in reaching underserved populations and opportunities for improved outreach and engagement.

CRCs provided respite services exceeding 20% of the annual budget. Taken together, the eleven CRCs spent $3,426,468 on respite services in this fiscal year, comprising 23% of the $15,000,000 budget and exceeding the 10% threshold specified in the contract.

Caregivers are highly satisfied with CRC services. Clients recognized the vital role that the CRCs played in their well-being and capacity to care, particularly through the pandemic. Satisfaction ratings of services and client comments reflect strong recognition of the role that the CRCs play in providing resources, education, and supports to caregivers across the state.

CareNav^{TM} offers a solid platform to support future adaptation of the CRC intervention, ongoing evaluation, and future dissemination. All eleven CRCs are now up and running with CareNav^{TM} and after extensive quality checks, we conclude that data are being entered consistently across sites. The data collection interface in CareNav^{TM} aligns well with site-specific workflows and can be adapted alongside any adaptations in the CRC intervention. Data collected in CareNav^{TM} can support robust evaluation of the CRC service model going forward. With training protocols and quality checks now in place, CareNav^{TM} could be disseminated outside the CRC system to support caregiver assessment and support in other settings. Utilization data by caregivers indicates that the biggest barrier to adoption is awareness of the availability of the online platform, suggesting the need for further outreach and public information regarding this resource.

VII. RECOMMENDATIONS

The CRCs are meeting vital caregiver needs across California. In the coming year, with more detailed information available through CareNav™, it will be possible to use this data to drive program decisions and improvements. For example, the following issues might be explored:

- At the site level, what are the opportunities for program improvement in outreach, efficiency, or responsiveness?
- At the site level, what methods work best for greater outreach to communities that seem to be underserved by the CRCs based on population data?
- How might public outreach and information increase awareness and use of CareNav™ as a resource?
- With the high proportion of clients with memory problems and diagnoses of dementia, what are ways to reach clients who are managing other complex conditions and who may not yet be aware of CRC services?
- How could we use the data to identify those caregivers at greatest risk for a change in situation or in their own health status, so that CRC staff can be alerted more readily to prioritize these caregivers for services?

The recommendations made in last year's report in the realm of service delivery are relevant given the current status and progress of implementation of the statewide online platform. These include exploration at the site levels in the follow areas:

- Forecast rationale for estimated numbers of family caregivers within each CRC region who are low-income, from diverse racial groups, or are residing in rural communities
- Identify reasons and need for further outreach to groups of caregivers served at lower rates than anticipated (e.g., low income, veterans, Hispanic/Latino populations, rural residents)
- Develop strategies to address high rates of caregiver mental health status and loneliness
- Reflect on results of satisfaction surveys for program improvement
- Identify trends, gaps in service and outcomes to support outreach strategies, funding needs, and advocacy priorities.
- Use data to assess quality and equity.
- As data is aggregated over time, develop risk profiles and explore predictive models about what services help whom the best.
- Consider translating CareNav™ into other languages to increase cultural and linguistic congruence across racial/ethnic groups.
- Use data on caregivers and services to inform implementation of the California Master Plan on Aging and other statewide planning efforts.
- Work closely with DHCS to further promote caregiving service standards and quality.

VIII. REFERENCES

1. National Alliance for Caregiving and AARP (2020). Caregiving in the US: 2020. Washington DC: NAC and AARP. https://www.caregiving.org/caregiving-in-the-us-2020/

2. Reinhard, SC, Young, HM, Levine, C, Kelly, K, Choula, R, and Accius, J. (2019). Home Alone Revisited: Family Caregivers Providing Complex Care. Washington DC: AARP. https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf

3. Reinhard, S, Feinberg, LF, Houser, A, Choula, R, and Evans, M. (2019). Valuing the Invaluable 2019 Update: Charting a Path Forward. Washington DC: AARP. https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

4. National Alliance for Caregiving and AARP. (2016). Caregiving in the U.S. 2015 Appendix B: Detailed Methodology. Washington, DC: NAC and AARP. https://www.caregiving.org/wp-content/uploads/2020/05/CGV016-Main-Report-Appendix-B-Detailed-Methodology-5.21.15.pdf

5. U.S. Census Bureau. *American Community Survey 1-year estimates: Census Reporter Profile page for California* (2019). Washington DC: US Census Bureau. http://censusreporter.org/profiles/04000US06-California

6. Villarroel MA and Terlizzi EP. (2019). Symptoms of depression among adults: United States, 2019. NCHS Data Brief, no 379. Hyattsville, MD: National Center for Health Statistics. 2020. https://www.cdc.gov/nchs/products/databriefs/db379.htm

7. Bédard, M., Molloy, DW, Squire, L, Dubois, S, Lever, JA, & O'Donnell, M (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist, 41(5)*:652-657

IX. APPENDIX

A. GLOSSARY

B. TECHNICAL SPECIFICATIONS

C. APPENDIX TABLES C1 – C13

A. Glossary

Table Appendix A.1.: Glossary of Terms

Terms	Definitions
Caregiver Education/ Training	Individually tailored workshops on long-term care, patient management, public policy issues, and legal/financial issues.
CareNav™	A secure, interactive electronic social care record for family caregivers.
CRC Core Services	See Table 1a in the body of the report.
Family Consultation	Individual sessions and telephone consultations with trained staff to assess needs of both the individuals who are incapacitated and their families, and to explore courses of action and care options for caregivers to implement.
Individual Counseling	Family, individual and group sessions with licensed counselors to offer emotional support and help caregivers cope with the strain of the caregiving role. This activity may take place with counselors within the CRC or by service grant vouchers for use with counselors outside the CRC.
Intake and Assessment	Standardized intake and assessment tools to help define and explore issues, options and best package of information, to determine interventions and services for caregivers, and to provide key data for evaluation and program design.
Legal Consultation	Personal consultations with experienced attorneys regarding powers of attorney, estate and financial planning, conservatorships, community property laws and other complex matters; accessed with service grant voucher.
New Case	Date of first CRC assessment is within reporting period
Ongoing Case with activity	Activity within reporting period; date of first CRC assessment within two years before reporting period
Ongoing Case without activity	No activity within reporting period; date of first CRC assessment within two years before reporting period
Psycho-education	Group workshops and classes in which participants to learn new skills to apply to cope with stress and burden in their personal lives and, with practice, to use these skills consistently enough to cause changes in their lives.
Reassessment	Includes a subset of the assessment questions, designed for follow-up approximately six months after assessment

Terms	Definitions
Respite	Financial assistance for brief substitute care in the form of in-home support, adult day care services, short-term or weekend care, and transportation to assist families caring at home for an adult with a disabling condition.
Reporting Period	Fiscal Year 2019-2020 (7/1/2019-6/30/2021) Fiscal Year 2020-2021 (7/1/2020-6/30/2021) Quarter 1: 7/1/2020-9/30/2020 Quarter 2: 10/1/2020-12/31/2020 Quarter 3: 1/1/2021-3/31/2021 Quarter 4: 4/1/2021-6/30/2021
Supplemental Grant	Supplemental Grant: service grant voucher for supportive tangible items most commonly durable medical equipment or groceries.
Support Group	On-line or in-person caregiver support groups
Total Open Cases	The sum of new cases plus ongoing cases with activity plus ongoing cases without activity

B. Technical Specifications

Inclusion Criteria

Cases were included in the evaluation analysis if:

- County if not missing / null
- Case is not deleted / retired
- Caregiver funding eligibility includes DHCS. Note this filter was not applied to intake assessment because funding eligibility is not always known at that time.

Activities were included in the evaluation analysis if:

- Activity is not deleted
- Activity duration is greater than zero (durationHours>0)
- Activity date falls within reporting period

Counts of clients, service activities (other than intake assessments) and grant vouchers distributed are limited to clients eligible for DHCS funding; therefore, these counts do not reflect the entirety of the CRC caseloads and services provided. CRCs provide additional services funded by county contracts, foundations, business partners and donations.

Service Grant Voucher Totals

Service grant voucher totals reflect entries into CareNav^{TM} by CRC staff; they are not official summaries derived from the CRC accounting systems. As such, there may be minor discrepancies between the totals presented in this report and those reported by the CRCs for other purposes.

Case Tallies

The ongoing and open cases tallies may be incomplete in this fiscal year based on the individual CRC timing of complete CareNav^{TM} adoption. These tallies rely on ascertainment of assessment in the prior two years. Not all CRCs have complete data during this two-year period; therefore, the tallies underestimate the true caseload. The denominators for the analysis of caregiver and care recipient characteristics derived from assessments and the count of assessments in the activity tables are similar, but do not match exactly. This is because the case analysis was conducted with data extracted from CareNav^{TM} at a slightly earlier date than the analysis of assessment counts. Although the reporting periods are the same, the later extraction includes a small number of assessments entered by the CRCs after the initial reporting deadline.

Missing Data

The analysis of caregiver and caregiver socio-demographic characteristics, caregiver health, caregiving variables (hours, medical/nursing tasks etc,) focused on complete case analysis (i.e., observations with non-missing data) for caregivers who had an assessment in the current fiscal year (n=4,299). Overall, missing data appears to be minimal (less than 10% for any given variable). To improve data quality and reporting, the UC Davis evaluation team is working with Quality Process and FCA to develop algorithms that accurately report the prevalence of missing data for future reports for each variable in CareNav by CRC and by activity (i.e., intake, assessment or reassessment).

Data Sources

American Community Survey

To compare the characteristics of caregivers served by the CRCs with the population characteristics of their catchment areas we used data from the American Community Survey (ACS) 2019 5-year estimates from the public use microdata sample (PUMS). The ACS is an annual, nation-wide survey conducted by the U.S. Census Bureau that collects information on a range of population characteristics, including demographic information like age, sex, and race/ethnicity, and socioeconomic characteristics like income, employment status, and educational attainment. Address-based random sampling is performed and surveys are sent by mail to selected addresses. Both 1-year and 5-year estimates are available. The 5-year PUMS includes 5 percent of the ACS household units and is weighted to represent the average population over a 5-year period.
https://www2.census.gov/programs-surveys/acs/tech_docs/pums/accuracy/2015_2019AccuracyPUMS.pdf

California Health Interview Survey

The California Health Interview Survey (CHIS) is a statewide health survey fielded by the University of California, Los Angeles Center for Health Policy Research that contains data on a wide range of health-related topics. CHIS is a population-based survey that is designed to be generalizable to the non-institutionalized population of California living in households, with information available by county, city, or zip code. Participants are randomly sampled from within geographic sampling strata using an address-based sampling approach and complete the survey online or via telephone in a variety of available languages. Oversampling is conducted to ensure adequate representation from specific race/ethnicity groups or other characteristics. Data used are from the 2019-2020 California Health Interview Survey. CHIS 2019-2020 Methodology Series: Report 1 - Sample Design. Los Angeles, CA: UCLA Center for Health Policy Research, 2021.

Caregiving in the U.S. 2020

Caregiving in the U.S. 2020 is a nationally representative survey of family caregivers conducted by the National Alliance on Caregiving (NAC) in collaboration with the American Association of Retired Persons (AARP). The survey used a random sample of caregivers from Ipsos' national, probability-based data source, KnowledgePanel®. Data were collected in 2019 and included 1,392 adults age 18 years and above who reported providing unpaid care to a relative or friend age 18 years and older to help them take care of themselves within the last 12 months. Targeted oversampling of specific racial/ethnic minority groups and older adults (age 75 years and above) was conducted online and via telephone in addition to the random sample from KnowledgePanel®. Each respondent is assigned a survey weight based on age, sex, and race/ethnicity designed to produce population estimates generalizable to the U.S. population, based on U.S. Census Bureau data from 2019.

Decennial Census Public Law (PL) 94-171 Redistricting Data

To examine the population in the CRC catchment areas by race/ethnicity we used the tables “Hispanic or Latino, and Not Hispanic or Latino by Race for the population 18 Years and Over”. PL 94-171 requires the Census Bureau to provide states the opportunity to identify the small area geography for which they need data in order to conduct legislative redistricting. Accordingly, this data provides county-level tabulations by race/ethnicity which we rolled up to the CRC catchment-level.

Further detail and documentation can be found at:
https://www.census.gov/programs-surveys/decennial-census/about/rdo/summary-files.html#P4

https://data.census.gov/cedsci/table?g=0400000US06,06%240500000&d=DEC%20Redistricting%20Data%20%28PL%2094-171%29&tid=DECENNIALPL2020.P4&hidePreview=true

Measures

Zarit Burden Interview Screening

Caregiver strain was assessed using the 4-item screening version of the Zarit Burden Interview, which assesses caregiver strain by asking how frequently the caregiver experiences the following feelings: 1) that because of the time you spend with your relative that you don’t have enough time for yourself; 2) stressed between caring for your relative and trying to meet other responsibilities (work/family); 3) strained when you are around your relative; and 4) uncertain about what to do about your relative. Caregivers respond to each item as 0 (never), 1 (rarely), 2 (sometimes), 3 (quite frequently), or 4 (nearly always), with total scores ranging from 0-16 and higher scores indicating higher levels of strain. We categorized caregivers as experiencing substantial strain if they scored 8 or above.

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist*, *41*(5), 652-657.

Patient Health Questionnaire-9 (PHQ-9)

The Patient Health Questionnaire-9 (PHQ-9) is a 9-item questionnaire that assesses depressive symptoms, including: 1) little interest or pleasure in doing things; 2) feeling down, depressed, or hopeless; 3) trouble falling or staying asleep, or sleeping too much; 4) feeling tired or having little energy; 5) poor appetite or overeating; 6) feeling bad about yourself-- or that you are a failure or have let your family down; 7) trouble concentrating on things, such as reading the newspaper or watching television; 8) moving or speaking so slowly that other people could have noticed? Or the opposite, being so fidgety or restless that you have been moving around a lot more than usual?; and 9) thoughts that you would be better off dead or hurting yourself in some way.

Caregivers report how often they have been bothered by the nine symptoms over the past two weeks, rating each item as 0 (not at all), 1 (several days), 2 (more than half the days), or 3 (nearly every day). Scores are summed, with possible scores ranging from 0-27 and higher scores indicating greater symptom burden. We categorized caregivers into one of five levels based on their total PHQ-9 scores: none (0-2); minimal/mild (3-9); moderate (10-14); moderate/severe (15-19); or severe (20-27).

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613.

UCLA-3 Loneliness Scale

Loneliness was assessed using the UCLA-3 Loneliness Scale. The UCLA-3 asks three questions about how often the caregiver has felt that they 1) lack companionship, 2) feel left out, and 3) feel isolated from others. The caregiver responds to each item on a scale from 1 (hardly ever) to 3 (often). Responses to the three questions are summed, with total scores ranging from 3-9 points. Caregivers with scores of 6 and above are categorized as experiencing loneliness.

Russell, D. W. (1996). UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. *Journal of Personality Assessment*, *66*(1), 20-40.

AARP Care Index

Level of care and care intensity were calculated using a formula developed by AARP, based on points assigned for the number of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) assisted with, and weekly hours spent on caregiving.

In CareNav^{TM}, caregivers were asked about a total of fifteen different activities and how much help the care recipient needed with each. For the purposes of calculating the level of care and care intensity, we selected the 6 activities that aligned most with the ADLs and 7 activities that aligned best with the IADLs assessed in the AARP survey. See tables B1 and B2 below for ADLs and IADLs in AARP and equivalent activities in CareNav. Caregivers were considered as assisting with an ADL or IADL if they reported that the care recipient needed at least a little help with the activity.

Table B1. Activity of Daily Living (ADL) Variables in AARP and equivalent activity variables in CareNav

AARP	CareNav
Getting in/out of bed/chair	Transferring
Getting Dressed	Dressing
Getting to and from toilet	Using Toilet
Bathing or showering	Bathing/showering
Dealing with Incontinence/Diapers	Incontinence
Feeding	Eating

Table B2. Instrumental Activity of Daily Living (IADL) Variables in AARP and equivalent activity variables in CareNav

AARP	CareNav
Finances	Managing Finances
Grocery or other Shopping	Shopping
Housework	Household chores
Preparing Meals	Preparing meals
Transportation	Transportation
Giving Medications (asks about this in the same list but doesn't tally as ADL)	Taking medications
Arranging Services, such as nurses, aides, etc.	Using Telephone

Points were then assigned based on the number of ADLs and IADLs performed consistent with the points assigned for the AARP level of care index variable (see Table B3).

Table B3. Level of Care Formula Points Assigned for Types of Care (ADLs and IADLs) Provided

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

Weekly caregiving hours were also categorized slightly differently between the two datasets. Table B4 shows the equivalent categories between AARP and CareNav, as well as the points assigned for the level of care and care intensity calculations.

Table B4: Weekly Hours Spent on Caregiving in AARP and CareNav and points assigned for level of care/care intensity calculation

AARP	CareNav	Points Assigned
0-8hrs	1-<10 + 0	1 point
9-20	11-<20	2 points
21-40	20-<30 + <40	3 points
41+	>40	4 points

Level of care and care intensity were calculated based on total scores for both types of care provided and weekly caregiving hours (see Table B5).

Table B5: Formula for calculating level of care and care intensity variables

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

Caregiving in the U.S. 2015 Appendix B: Detailed Methodology (2016). Retrieved from Washington, D. C.: https://www.caregiving.org/wp-content/uploads/2015/05/CGV016-Main-Report-Appendix-B-Detailed-Methodology-5.21.15.pdf

Rurality (RUCA Codes)

Rural-urban commuting area (RUCA) codes, a detailed and flexible scheme for delineating sub-county components of rural and urban areas, were assigned at the county level based on the sum of tract-level RUCA codes weighted by tract land area in the county. The underlying data were derived from the 2010 decennial census and the 2006-10 American Community Survey (ACS). Census tracts are used because they are the smallest geographic building block for which commuting flow estimates are available from the U.S. Census. Based on the Office of Management and Budget (OMB) definitions, RUCA codes range from 1 (least rural) to 10 (most rural). These 10 codes offer a relatively straightforward and complete delineation of metropolitan and nonmetropolitan areas based on the size and direction of primary commuting flows.

Table B6: Primary RUCA codes, 2010

Code	Classification description
1	Metropolitan area core: primary flow within an urbanized area (UA)
2	Metropolitan area high commuting: primary flow 30% or more to a UA
3	Metropolitan area low commuting: primary flow 10% to 30% to a UA
4	Micropolitan area core: primary flow within an urban cluster of 10,000 to 49,999 (large UC)
5	Micropolitan high commuting: primary flow 30% or more to a large UC
6	Micropolitan low commuting: primary flow 10% to 30% to a large UC
7	Small town core: primary flow within an urban cluster of 2,500 to 9,999 (small UC)
8	Small town high commuting: primary flow 30% or more to a small UC
9	Small town low commuting: primary flow 10% to 30% to a small UC
10	Rural areas: primary flow to a tract outside a UA or UC
99	Not coded: Census tract has zero population and no rural-urban identifier information

Using these codes, California counties were categorized as Metropolitan (codes 1 – 3),

Micropolitan (codes 4 – 6), Small town (codes 7 – 9) and Rural (code 10).

More information about RUCA codes and the data used to categorize counties is available here:

https://www.ers.usda.gov/topics/rural-economy-population/rural-classifications/#map

Racial and Ethnic Identity Categories
For consistency, we use the following category labels through the report: white non-Hispanic, Hispanic/Latino, Asian American/Pacific Islander, Black non-Hispanic, and multi-racial/other racial identity. These categories closely match those collected in CareNav^{TM} and were mapped to categories used in other data sources in the report (e.g., state and national datasets, US Census files) with only minor modifications.

C. Appendix Tables Cover Page

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Table C1: Caregiver Sociodemographic Characteristics (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Age					
18-44	13.3	13.2	12.7	14.2	13.1
45-64	47.7	46.6	44.4	49.2	50.3
65-84	36.0	37.4	38.4	34.4	34.2
85+	3.0	2.8	4.6	2.2	2.5
Gender Identity					
Male	22.6	23.1	23.9	23.7	19.7
Female	74.9	75.2	74.1	73.4	77.2
Other/NB/Trans	0.2	0.2	0.2	0.1	0.1
Declined to State	2.3	1.4	1.8	2.8	2.9
Sexual orientation					
Heterosexual	89.9	90.1	89.1	89.6	90.7
LBG/Other	2.2	3.0	2.2	1.8	2.0
Declined to State	7.9	6.9	8.7	8.6	7.3
Racial identity					
Native American/Alaska Native	0.6	0.5	0.5	0.6	0.8
Asian American/Pacific Islander	8.2	6.2	10.3	7.3	9.0
Black non-Hispanic	6.6	7.1	5.3	7.0	7.0
Hispanic/Latino	31.4	32.1	29.6	33.4	30.0
White non-Hispanic	52.2	52.1	53.4	50.8	52.6
Multi-racial / Other	1.1	1.7	1.0	0.9	0.7
Highest Level of Education					
Some High School	5.7	5.3	7.1	5.4	5.3
High School Graduate	14.3	14.5	16.8	14.5	12
Some College	26.2	27.7	23.5	26.1	27.4
College Graduate	27.2	30.2	25.8	26.2	26.9
Post Graduate Degree	13.9	13.7	13.6	13.7	14.6
Decline to State	12.7	8.7	13.2	14.1	13.8
Employment status					
Full time	26.3	25.5	24.0	27.9	27.7
Part time	11.1	11.4	10.7	11.1	11.3
Retired	34.0	34.3	35.9	31.7	34.3
Unemployed	21.3	21.3	20.3	22.5	21.2
Leave of absence	1.7	1.4	2.0	1.9	1.6
Decline to state/ Undefined	5.5	6.1	7.2	5.0	4.0
Relationship Status					
Married/Partnered	65.4	68.2	63.6	64.5	65.4
Divorced/Separated	10.5	8.9	11.4	11.4	10.5
Single	17.0	17.1	16.0	17.2	17.6
Widowed	2.6	2.3	3.0	2.3	2.8
Decline to state	4.5	3.6	6.1	4.6	3.8

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Caregiver Has VA Benefits					
Yes	5.0	4.3	4.4	5.8	5.1
No	93.1	94.0	93.5	92.6	92.7
Unsure	2.0	1.8	2.1	1.7	2.3
Earns Below Federal Poverty Level					
Yes	17.9	19.5	22.6	16.0	14.1
No	75.4	78.6	72.7	74.4	75.9
Decline to state	6.7	2.0	4.7	9.7	10.0
Lives Alone					
Yes	8.5	7.7	10.0	8.4	8.0
No	90.5	91.4	89.1	90.5	91.1
Decline to state	1.0	0.9	0.9	1.1	0.9
Rural	12.8	10.9	11.8	14.4	13.7
Provides Care to Multiple Care Recipients	18.0	15.4	18.5	17.1	21.0

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C2: Caregiver Sociodemographic Characteristics by Racial & Ethnic Identity (%) | *n* = 4,299

	All Racial and Ethnic Identity Categories	**Native American/ Alaska Native**	**Asian American / Pacific Islander**	**Black non-Hispanic**	**Hispanic / Latino**	**White non-Hispanic**	**Multi-racial / Other**	**χ2 p-value**
Total	**4,299**	**26**	**351**	**283**	**1,349**	**2,243**	**47**	
Age								**<0.01**
18-44	12.9	6.5	14.7	13.1	20.6	7.9	21.4	
45-64	47.9	41.9	49.3	53.9	55.7	42.1	55.4	
65-84	36.3	48.4	32.9	31.5	22.3	46.0	21.4	
85+	2.9	3.2	3.0	1.5	1.4	4.1	1.8	
Gender Identity								**<0.01**
Male	23.0	25.8	22.0	22.2	18.0	25.8	23.6	
Female	76.2	74.2	77.8	77.2	81.3	73.2	76.4	
Other/NB/ Trans	0.2	0.0	0.0	0.0	0.1	0.2	0.0	
Declined to State	0.7	0.0	0.2	0.6	0.6	0.8	0.0	
Sexual orientation								**0.04**
Heterosexual	93.2	96.8	93.6	91.4	94.9	92.5	92.7	
LBG/Other	2.3	3.2	2.1	3.2	0.9	2.8	3.6	
Declined to State	4.5	0.0	4.4	5.4	4.2	4.6	3.6	
Highest Level of Education								**<0.01**
Some High School	6.1	0.0	5.8	1.4	15.0	2.0	2.0	
High School Graduate	15.1	10.5	11.3	9.2	22.3	12.6	14.3	
Some College	27.3	47.4	10.1	33.7	24.9	28.8	28.6	
College Graduate	28.1	21.1	33.1	29.9	20.5	31.2	32.7	
Post Graduate Degree	13.9	5.3	20.1	18.0	5.6	16.9	16.3	
Decline to State	9.5	15.8	9.6	7.8	11.7	8.6	6.1	

	All Racial and Ethnic Identity Categories	Native American / Alaska Native	Asian American / Pacific Islander	Black non-Hispanic	Hispanic / Latino	White non-Hispanic	Multi-racial/other	χ2 p-value
Total	**4,299**	**26**	**351**	**283**	**1,349**	**2,243**	**47**	
Employment status								**<0.01**
Full time	26.5	19.4	31.0	32.4	28.5	23.7	35.7	
Part time	11.4	3.2	11.4	10.5	16.5	8.7	12.5	
Retired	35.2	48.4	32.9	31.2	19.4	45.3	19.6	
Unemployed	22.2	22.6	18.4	19.8	31.7	17.5	23.2	
Leave of absence	1.7	6.5	2.1	2.6	1.8	1.3	7.1	
Decline to state/ Undefined	3.1	0.0	4.3	3.5	2.2	3.4	1.8	
Relationship Status								**<0.01**
Married/ Partnered	65.7	64.5	68.2	48.0	60.3	70.8	61.8	
Divorced/ Separated	11.2	6.5	8.1	11.6	13.9	10.1	10.9	
Single	17.6	16.1	16.5	32.4	21.1	13.9	23.6	
Widowed	2.6	12.9	1.6	2.3	3.0	2.5	1.8	
Decline to state	2.8	0.0	5.6	5.8	1.7	2.7	1.8	
Caregiver Has VA Benefits								**<0.01**
Yes	5.1	13.3	3.3	6.3	2.4	6.7	3.7	
No	93.2	86.7	96.5	91.3	96.7	91.0	94.4	
Unsure	1.7	0.0	0.3	2.5	1.0	2.3	1.9	
Earns Below Federal Poverty Level								**<0.01**
Yes	18.6	25.8	19.7	12.7	30.3	12.7	23.6	
No	75.7	64.5	76.7	81.2	58.5	84.9	74.6	
Decline to state	5.6	9.7	3.6	6.1	11.3	2.8	1.8	

	All Racial and Ethnic Identity Categories	**Native American / Alaska Native**	**Asian American / Pacific Islander**	**Black non-Hispanic**	**Hispanic / Latino**	**White non-Hispanic**	**Multi-racial/other**	**χ2 p-value**
Total	**4,299**	**26**	**351**	**283**	**1,349**	**2,243**	**47**	
Lives Alone								0.22
Yes	8.6	13.8	5.8	9.1	7.8	9.3	16.4	
No	90.9	86.2	93.8	90.3	91.6	90.3	83.6	
Decline to state	0.5	0.0	0.5	0.6	0.6	0.5	0.0	
Rural	13.1	35.7	3.3	5.0	7.1	18.9	13.0	**<0.01**
Provides Care to Multiple Care Recipients	17.9	11.1	14.8	17.2	26.3	13.8	24.1	**<0.01**

*** Deduplicated by caregiver; percentages may not add to 100 due to rounding.**

Table C3: Caregiver Health Status (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Self-Rated Overall Health					
Excellent	6.2	6.4	5.1	7.1	6.3
Very Good	20.0	17.0	19.6	22.5	20.6
Good	42.6	42.8	44.0	41.5	42.1
Fair	24.6	26.1	25.1	22.9	24.4
Poor	6.7	7.7	6.3	6.2	6.7
Current Health Compared to Six Months Ago					
Better	9.5	9.0	10.4	8.6	9.8
Same	56.1	53.0	56.3	58.1	56.8
Worse	34.5	38.0	33.3	33.3	33.5
PHQ-9					
0-2 (none; PHQ-9 N/A)	36.6	34.4	38.9	37.2	36.2
3-9 (minimal/mild)	43.6	43.9	42.3	43.3	44.0
10-14 (moderate)	12.1	12.3	10.7	12.0	13.3
15-19 (mod. severe)	6.1	7.3	5.9	6.3	4.8
20-27 (severe)	1.8	2.1	2.2	1.2	1.9
UCLA Loneliness Scale					
3-5 (not lonely)	65.1	65.4	66.7	65.2	63.3
6-9 (lonely)	34.9	34.6	33.3	34.8	36.7
Zarit Burden Interview Screening					
0-7 (low strain)	40.7	40.0	31.1	41.7	39.9
8-16 (high strain)	59.3	60.0	58.9	58.3	60.1
Satisfaction with Support from Family and Friends					
Very Satisfied	26.3	25.1	25.9	27.7	26.3
Somewhat Satisfied	30.9	29.1	31.4	31.4	31.6
Neutral	18.3	17.7	18.3	17.9	19.3
Somewhat Dissatisfied	14.9	17.7	14.6	13.9	13.7
Very Dissatisfied	9.6	10.4	9.8	9	9.2
Satisfaction with Spiritual Support					
Very Satisfied	32.3	31.7	32.2	34	31
Somewhat Satisfied	27.8	28	28.4	27.3	27.6
Neutral	30.7	29.7	30	29.7	33.5
Somewhat Dissatisfied	6.6	8.2	6.2	6.3	5.8
Very Dissatisfied	2.6	2.4	3.2	2.8	2.2

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C4: Caregiver Health Status by Racial & Ethnic Identity (%) | *n* = 4,299

	All Racial and Ethnic Identity Categories	Native American / Alaska Native	Asian American / Pacific Islander	Black non-Hispanic	Hispanic / Latino	White non-Hispanic	Multi-racial/other	χ2 p-value
Total	**4299**	**26**	**351**	**283**	**1349**	**2243**	**47**	
Self-Rated Overall Health								**<0.01**
Excellent	6.2	4.8	1.5	3.6	6.2	7.3	2.7	
Very Good	19.3	14.3	14.9	18.5	13.3	23.1	29.7	
Good	43.0	33.3	45.3	46.2	42.8	42.4	40.5	
Fair	24.8	38.1	30.1	24.9	29.1	21.5	24.3	
Poor	6.8	9.5	8.3	6.8	8.7	5.7	2.7	
Current Health Compared to Six Months Ago								**<0.01**
Better	9.4	9.52	6.6	12.9	12.7	7.3	22.2	
Same	56.0	57.14	51.7	54.4	54.7	57.7	44.4	
Worse	34.6	33.33	41.7	32.7	32.6	35.0	33.3	
PHQ-9								0.20
0-2 (none; PHQ-9 N/A)	37.1	28.57	29.9	39.1	36.9	38.0	44.4	
3-9 (minimal/mild)	43.1	52.38	47.6	40.3	45.7	41.6	36.1	
10-14 (moderate)	11.9	9.52	12.6	10.3	10.4	12.8	13.9	
15-19 (mod. severe)	6.1	9.52	6.3	8.2	5.6	6.1	5.6	
20-27 (severe)	1.7	0	3.7	2.1	1.4	1.6	0	
UCLA Loneliness Scale								**<0.01**
3-5 (not lonely)	65.4	72.22	63.3	58.6	72.5	63.0	60	
6-9 (lonely)	34.6	27.78	36.7	41.4	27.5	37.0	40	

	All Racial and Ethnic Identity Categories	Native American / Alaska Native	Asian American / Pacific Islander	Black non-Hispanic	Hispanic / Latino	White non-Hispanic	Multi-racial/other	χ2 p-value
Total	**4299**	**26**	**351**	**283**	**1349**	**2243**	**47**	
Zarit Burden Interview Screening								**<0.01**
0-7 (low strain)	41.0	57.14	28.4	39.9	49.2	38.5	38.9	
8-16 (high strain)	59.0	42.86	71.6	60.1	50.8	61.5	61.1	
Satisfaction with Support from Family and Friends								**<0.01**
Very Satisfied	26.3	21.1	17.9	18.3	24.8	29.3	27.8	
Somewhat Satisfied	30.4	26.3	34.9	32.8	30.4	29.4	33.3	
Neutral	18.5	15.8	26.2	15.7	17.5	18.3	22.2	
Somewhat Dissatisfied	15	21.1	17.1	16.2	16.7	13.7	5.6	
Very Dissatisfied	9.8	15.8	4	17	10.5	9.3	11.1	
Satisfaction with Spiritual Support								**<0.01**
Very Satisfied	32.7	40	28.2	38.9	38.5	29.7	25.7	
Somewhat Satisfied	27.7	20	24.5	29.7	27.7	28.2	14.3	
Neutral	30.5	25	42.4	21	24.3	33	42.9	
Somewhat Dissatisfied	6.5	15	4.1	7	6.6	6.5	14.3	
Very Dissatisfied	2.6	0	0.8	3.5	2.9	2.7	2.9	

*** Deduplicated by caregiver; percentages may not add to 100 due to rounding.**

Table C5: Characteristics of Caregiving (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Respondent is the Primary Caregiver	96.8	97.0	97.6	96.4	96.4
CR Has Multiple Caregivers	31.0	29.1	30.8	31.7	32.0
Caregiving Duration					
<2yrs	45.6	39.6	48.7	47.6	45.7
2-5yrs	24.9	26.3	23.1	24.7	25.3
>5yrs	29.5	34.1	28.2	27.7	29.0
Relationship to Care Recipient					
Spouse	34.9	37.3	38.3	31.8	33.0
Partner	1.1	1.2	1.1	0.9	1.1
Child	51.7	51.3	47.4	54.3	53
Other Relative	9.8	8.4	10.5	9.5	10.7
Non-Relative	2.6	1.9	2.7	3.5	2.2
Level of Care[1]					
1	1.2	0.9	0.8	1.8	1.3
2	1.6	1.3	1.8	1.6	1.8
3	6.8	6.1	7.9	7.2	5.8
4	23.3	23.3	22.3	23.9	23.5
5	67.1	68.6	67.2	65.4	67.6
Care Intensity[1]					
Low	2.8	2.1	2.6	3.5	3.1
Medium	6.8	6.1	7.9	7.2	5.8
High	90.4	91.8	89.5	89.3	91.1
Assists with Medical/Nursing Tasks					
Yes	78.6	76.9	75.4	78.9	83.1
No	20.1	22.0	23.1	19.7	15.8
Unsure	1.3	1.1	1.5	1.4	1.1
Hours Per Week Caregiving					
<10	6.8	6.5	7.5	7.0	6.2
10- <20	7.3	8.1	6.7	7.1	7.4
20- <40	13.0	12.3	12.9	14.3	12.1
40+	72.9	73.2	72.9	71.6	74.2
Hours of Paid Help Per Week					
0	70.0	68.4	69.7	71.2	70.3
1-10	12.6	12.2	12.4	11.7	14.1
11-20	7.0	8.9	6.0	6.7	6.3
21-30	3.1	3.3	3.2	3.2	2.9
31-40	2.9	3.0	3.8	2.6	2.1
>40	4.5	4.1	4.8	4.5	4.4

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Hours of Unpaid Help Per Week					
0	43.8	46.2	43.3	41.8	43.9
1-10	29.7	30.2	31.8	28.7	28.2
11-20	8.6	8.0	8.7	8.5	9.0
21-30	4.7	4.4	4.8	5.6	3.9
31-40	3.4	2.6	4.1	3.7	2.9
>40	9.9	8.5	7.3	11.7	12.1

***Deduplicated by care recipient; percentages may not add to 100 due to rounding; [1] Level of care and care intensity calculated per AARP Level of Care measure using weekly caregiving hours and number of ADLs and IADLs performed (NAC & AARP 2020)**

Table C6: Characteristics of Caregiving by Racial and Ethnic Identity (%) | *n* = 4,299

	All Racial and Ethnic Identity Categories	Native American / Alaska Native	Asian American / Pacific Islander	Black non-Hispanic	Hispanic / Latino	White non-Hispanic	Multi-racial/other	χ2 p-value
Total	**4,299**	**26**	**351**	**283**	**1,349**	**2,243**	**47**	
Respondent is the Primary Caregiver	97.0	96.8	96.3	98.6	96.4	97.3	96.6	0.22
CR Has Multiple Caregivers	31.0	20.7	32.2	24.7	39.8	26.7	38.5	**<0.01**
Caregiving Duration								**<0.01**
<2yrs	46.0	55.2	44.6	48.8	42.4	47.6	55.6	
2-5yrs	25.0	13.8	29.4	25.9	22.8	25.6	24.1	
>5yrs	29.0	31	26	25.3	34.8	26.8	20.4	
Relationship to Care Recipient								**<0.01**
Spouse	34.9	33.3	37.1	24.2	23.6	43.1	15.5	
Partner	1.1	6.7	0.2	1.2	0.6	1.4	0.0	
Child	51.7	43.3	53.4	55.6	62.1	44.5	69.0	
Other Relative	9.6	10	7.7	16.7	11.2	7.9	15.5	
Non-Relative	2.7	6.7	1.6	2.3	2.5	3.1	0.0	
Level of Care[1]								0.29
1	1.2	0	0	1.1	1.1	1.4	2.6	
2	1.7	0	0.4	2.3	1.7	1.8	0.0	
3	6.7	0	4	7.2	7.5	6.6	10.5	
4	23.3	9.1	22.1	25	24	23.2	18.4	
5	67.1	90.9	73.5	64.4	65.7	67	68.4	
Care Intensity[1]								0.12
Low	2.9	0	0	3.4	2.8	3.3	2.6	
Medium	6.3	0	4	7.2	7.5	6.6	10.5	
High	90.4	100	95.6	89.4	89.7	90.2	86.8	

	All Racial and Ethnic Identity Categories	Native American / Alaska Native	Asian American / Pacific Islander	Black non-Hispanic	Hispanic / Latino	White non-Hispanic	Multi-racial/Other	χ2 p-value
Total	**4,299**	**26**	**351**	**283**	**1,349**	**2,243**	**47**	
Assists with Medical/Nursing Tasks								**0.05**
Yes	78.4	86.4	85.3	83.1	77.8	77	75.7	
No	20.3	13.6	13.3	16.5	20.5	21.8	21.6	
Unsure	1.3	0	1.4	0.4	1.7	1.2	2.7	
Hours Per Week Caregiving								0.54
<10	6.8	0	4	6.7	7.7	6.9	2.6	
10- <20	7.2	4.6	6.1	7.5	7.1	7.4	10.3	
20- <40	13.0	0	14.1	13.5	13.4	12.7	15.4	
40+	73.0	95.5	75.8	72.3	71.9	73.1	71.8	
Hours of Paid Help Per Week								**0.01**
0	69.9	61.9	70.6	72.7	74.3	67.1	69.2	
1-10	12.6	19.1	10	11.6	9.1	14.9	12.8	
11-20	6.9	9.5	7.8	7.1	5.6	7.4	7.7	
21-30	3.3	9.5	5.2	2.6	3.7	2.7	5.1	
31-40	3.0	0	3	2.6	3.3	2.9	0.0	
>40	4.4	0	3.4	3.4	4.1	5	5.1	
Hours of Unpaid Help Per Week								**<0.01**
0	44.0	61.9	39.4	47.2	37.5	47.7	35.9	
1-10	29.6	28.6	29.9	27	26.4	31.7	25.6	
11-20	8.7	0	10.2	9.1	9.1	8.1	20.5	
21-30	4.6	0	5.5	4.2	5.8	3.9	7.7	
31-40	3.3	4.8	4.7	4.6	4.2	2.5	5.1	
>40	9.7	4.8	10.2	7.9	16.9	6.1	5.1	

***Deduplicated by caregiver; percentages may not add to 100 due to rounding. [1] Level of care and care intensity calculated per AARP Level of Care measure using weekly caregiving hours and number of ADLs and IADLs performed (NAC & AARP 2020).**

Table C7: Caregiving Activities (%) | ***n* = 4,299**

	All Quarters	**Q1**	**Q2**	**Q3**	**Q4**
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Number of Activities Requiring Assistance, median (mean)	13 (11.6)	13 (12.0)	13 (11.8)	13 (11.3)	13 (11.5)
Eating					
Needs No Help	43.04	42.8	40.7	47.1	41.4
Needs Reminders/ A Little Help	23.4	22.3	25.8	21.2	24.1
Needs Help Most of the Time	17.3	18.7	15.2	16.0	20.0
Needs Help All the Time	16.0	16.2	17.3	15.8	14.4
Undefined	0.3	0.0	1.1	0.0	0.0
Bathing/Showering					
Needs No Help	16.4	14.6	17.5	17.3	16.1
Needs Reminders/ A Little Help	18.4	16.3	18.3	18.0	21.2
Needs Help Most of the Time	21.6	23.2	16.9	23.9	22.5
Needs Help All the Time	42.3	45.6	42.8	40.8	40.3
Undefined	1.3	0.4	4.6	0.0	0.0
Dressing/Undressing					
Needs No Help	20.3	19.1	19.5	21.9	20.4
Needs Reminders/ A Little Help	23.4	22.4	24.7	22.0	24.5
Needs Help Most of the Time	23.8	24.6	19.9	24.3	26.5
Needs Help All the Time	32.3	33.8	34.8	31.8	28.6
Undefined	0.3	0.0	1.1	0.0	0.0
Grooming					
Needs No Help	25.6	22.7	25.2	27.4	26.8
Needs Reminders/ A Little Help	25.0	24.0	24.7	25.8	25.4
Needs Help Most of the Time	21.0	22.7	19.8	20.5	21.0
Needs Help All the Time	28.4	30.6	30.4	26.3	26.8
Using Toilet					
Needs No Help	30.9	30.5	30.3	32.1	30.6
Needs Reminders/ A Little Help	19.8	19.7	19.2	19.3	21.0
Needs Help Most of the Time	18.9	18.9	17.7	19.1	20.2
Needs Help All the Time	30.1	30.9	31.7	29.5	28.2
Undefined	0.3	0.0	1.1	0.0	0.0
Incontinence (accidents)					
Needs No Help	30.8	32.6	30.0	31.5	29.3
Needs Reminders/ A Little Help	19.9	17.6	18.8	20.8	22.0
Needs Help Most of the Time	15.7	13.9	15.3	16.8	16.4
Needs Help All the Time	33.7	35.8	35.9	30.9	32.3
Preparing Meals					
Needs No Help	4.2	4.2	4.9	4.3	3.3
Needs Reminders/ A Little Help	5.9	5.4	6.0	5.9	6.5
Needs Help Most of the Time	15.3	13.1	22.1	12.4	13.0
Needs Help All the Time	74.2	77.3	65.7	77.4	77.3
Undefined	0.4	0.0	1.4	0.0	0.0

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Taking Medications					
Needs No Help	6.4	6.1	5.9	6.8	6.9
Needs Reminders/ A Little Help	13.8	10.7	15.8	14.1	14.3
Needs Help Most of the Time	16.4	14.3	22.8	14.1	14.2
Needs Help All the Time	62.9	68.9	53.7	65.0	64.7
Undefined	0.5	0.0	1.8	0.0	0.0
Managing Money/Finances					
Needs No Help	5.4	5.0	6.1	6.8	3.4
Needs Reminders/ A Little Help	5.1	5.7	5.0	5.4	4.1
Needs Help Most of the Time	10.8	7.6	19.0	7.7	8.0
Needs Help All the Time	77.9	81.6	66.8	80.1	84.5
Undefined	0.8	0.1	3.1	0.0	0.0
Household Chores					
Needs No Help	3.3	2.8	2.8	4.4	3.2
Needs Reminders/ A Little Help	7.1	5.1	7.2	7.9	8.0
Needs Help Most of the Time	15.4	13.9	22.9	12.2	12.3
Needs Help All the Time	73.9	78.2	66.0	75.6	76.6
Undefined	0.3	0.0	1.1	0.0	0.0
Using Telephone					
Needs No Help	23.0	24.5	20.2	25.8	21.4
Needs Reminders/ A Little Help	18.0	16.3	18.2	18.0	19.5
Needs Help Most of the Time	18.9	16.2	23.6	18.7	16.8
Needs Help All the Time	39.0	42.4	34.4	37.5	42.2
Undefined	1.1	0.6	3.7	0.0	0.0
Mobility					
Needs No Help	21.0	21.3	21.6	21.3	19.7
Needs Reminders/ A Little Help	21.9	19.6	23.5	21.6	23.0
Needs Help Most of the Time	25.6	25.2	23.1	26.7	27.6
Needs Help All the Time	31.1	33.9	30.6	30.5	29.7
Undefined	0.3	0.0	1.3	0.0	0.0
Transferring from bed/chair/car					
Needs No Help	29.5	27.3	28.7	30.6	31.4
Needs Reminders/ A Little Help	21.3	20.0	22.4	21.1	21.3
Needs Help Most of the Time	20.1	20.9	18.9	21.0	20.0
Needs Help All the Time	28.8	31.9	28.9	21.0	27.3
Undefined	0.3	0.0	1.1	0.0	0.0
Shopping					
Needs No Help	2.1	2.7	1.8	2.1	1.9
Needs Reminders/ A Little Help	3.1	3.1	2.9	3.0	3.4
Needs Help Most of the Time	10.2	7.5	19.2	6.1	7.4
Needs Help All the Time	84.0	86.7	73.7	88.8	87.3
Undefined	0.7	0.0	2.5	0.0	0.0

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Transportation					
Needs No Help	3.0	3.2	2.7	2.9	3.0
Needs Reminders/ A Little Help	1.9	1.4	2.3	2.0	1.8
Needs Help Most of the Time	6.8	4.3	17	2.0	3.2
Needs Help All the Time	88.1	91.1	76.9	93.1	92.0
Undefined	0.3	0.0	1.1	0.0	0.0

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C8: Medical Task Performance Among Caregivers (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Performing these tasks is difficult					
Strongly Disagree	21.4	22.7	23.6	18.7	20.9
Somewhat Disagree	21.8	23.1	19.7	22	22.3
Neutral	20.3	19.2	20.3	20.7	20.6
Somewhat Agree	26.4	27.7	24	28.1	25.2
Strongly Agree	10.3	7.3	12.3	10.4	10.9
I feel Prepared to help with these tasks					
Strongly Disagree	4.3	3.1	5.3	5	3.8
Somewhat Disagree	9.9	9.7	9.6	9.9	10.2
Neutral	19.9	19.6	19.4	20.5	19.9
Somewhat Agree	35.9	36.3	34	36.2	36.9
Strongly Agree	30.0	31.3	31.6	28.5	29.1
Would Like More Information About Tasks	15.4	15.2	14.8	15.2	16.4
Number of Tasks Performed, mean (median)	4.0 (2.0)	3.8 (2.0)	4.1 (3.0)	4.1 (3.0)	4.0 (2.0)
Tasks Performed					
Ordering or Organizing Medication	95.5	96	95.8	95	95.2
Administering Oral Medications	82.0	80.9	80.3	82.6	84
Meters/Monitors	52.3	49.8	53.3	54.7	50.9
Operating Durable Medical Equipment	49.9	48.6	49.5	51.8	49.3
Managing Pain	45.2	42.1	43.9	48.1	45.8
Special Diet Preparation	42.7	39.6	43.6	42.5	45
Skin/Wound Care	40.9	41.1	42.3	40	40.4
Administering Medications by Injection, IV, drops, etc.	28.5	26.1	32.1	25.8	30.3
Operating Medical Equipment	19.8	17.6	19	21	21.3

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C9: Care Recipient Sociodemographic Characteristics (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Age					
18-44	1.8	1.7	1.5	1.9	2.1
45-64	11.8	13.0	11.9	11.5	10.4
65-84	67.5	67.3	66.2	67.7	68.5
85+	19.0	18.1	20.4	18.9	18.6
Gender					
Male	45.1	45	47.0	44.2	44.4
Female	54.9	55.1	53.0	55.8	55.6
Undefined	0.00	0.0	0.1	0.0	0.0
Racial or Ethnic Identity					
White non-Hispanic	55.0	52.8	59.0	53.6	54.5
Black non-Hispanic	6.7	7.7	4.9	6.9	7.2
Hispanic/Latino	28.5	30.4	25.0	30.7	28.0
Asian American/Pacific Islander	8.3	7.4	9.7	7.4	8.4
Native American/Alaska Native	0.5	0.3	0.7	0.5	0.6
Multi-racial/Other	1.0	1.5	0.7	0.8	1.0
Decline to State	0.1	0.0	0.0	0.0	0.3
Relationship Status					
Married/Partnered	51.8	52.8	52.8	49.7	52.3
Divorced/Separated	9.6	9.6	9.9	10.3	8.6
Single	7.3	7.2	6.7	7.9	7.4
Widowed	27.0	26.5	26.2	27.5	28.0
Decline to State	4.3	3.9	4.5	4.7	3.8
Annual Income, %					
>50K	16.1	15.1	14.7	18.3	15.8
25-<50K	21.0	20.9	22.0	20.5	20.7
12-<25k	23.8	22.8	23.3	25.2	23.8
<12K	16.2	19.8	18.0	14.7	12.2
Decline to State	22.9	21.4	22.0	21.2	27.5
Income Below Federal Poverty Level					
No	69.3	72.3	68.6	66.8	69.6
Yes	24.8	24.7	26.6	24.6	23.5
Decline to State	5.9	3.1	4.7	8.6	6.9
Medicaid Eligible					
Yes	25.6	24.7	28.1	26.1	24.7
No	64.3	67.3	64.5	63.5	62.3
Unsure	10.1	8.9	7.4	10.4	12.9
VA Benefits					
Yes	11.6	10.6	10.8	13.4	11.5
No	85.0	85.7	87.1	82.9	84.5
Unsure	3.4	3.8	2.1	3.6	4.0
Has Long-Term Care Insurance	10.3	9.3	90.3	10.8	11.2
Rural	12.6	9.7	11.7	14.9	13.6

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Lives Alone					
Yes	10.9	10.4	10.5	12.6	9.9
No	88.8	89.2	89	87.2	90
Decline to State	0.3	0.4	0.5	0.3	0.1
Lives with Caregiver	74.3	76.3	74.5	72.4	74.2

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C10: Care Recipient Health Needs (%) | *n* = 4,299

	All Quarters	Q1	Q2	Q3	Q4
Total	**4,299**	**1,019**	**963**	**1,175**	**1,142**
Primary Diagnosis, %					
Alzheimer's Disease and Related Dementias (ADRD)	68.3	68.2	66.1	68.1	70.3
Parkinson's	7.3	7.1	7.9	8.0	6.7
Stroke	10.5	8.7	11.8	10.2	11.4
Cancer	3.5	3.1	4.2	3.6	3.2
Brain Injury	2.8	3.1	3.6	2.4	2.1
Other	7.6	9.8	6.5	7.7	6.4
Memory Loss, %	91.3	91.1	90.6	91.6	92
Can Be Left Alone, %					
Always	7.0	7.3	6.8	7.6	6.2
Several Hours	25.1	27.4	24.2	24.2	24.8
<1hr	21.6	20.6	24.2	21.5	20.4
Never	46.3	44.8	44.9	46.7	48.7
Wandering, %	15.7	15.2	14.5	16.8	16.3
Documents in Place, %					
Conservatorship or Guardianship	5.6	4.5	3.2	5.6	4.9
Durable Power of Attorney: Health	62	58.6	64.5	60.7	63.1
Durable Power of Attorney: Finances	59	56.9	61.4	56.7	62.8
POLST	5.5	4.0	6.5	6.9	4.5
Do Not Resuscitate (DNR)	23.7	20.2	25.0	24.6	24.9
Living Will	7.6	9.4	7.4	7.7	6.0
Trust	13.6	15.0	12.2	14.6	12.2
Advance HealthCare Directive	52.8	49.7	53.7	53.3	54.9

***Deduplicated by caregiver; percentages may not add to 100 due to rounding**

Table C11: Case Status Summary Fiscal Year 2020 - 2021 by Quarter and by Caregiver Resource Center

Quarter 1	**Total**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
New Cases	919	102	45	31	142	24	161	85	43	52	155	79
Ongoing Cases with Activity	1,983	189	125	127	430	200	497	285	2	15	9	104
Ongoing Case no Activity	3,841	773	417	141	898	315	704	368	3	69	10	143
Active Cases	6,743	1,064	587	299	1,470	539	1,362	738	48	136	174	326
Quarter 2	**Total**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
New Cases	935	98	78	35	107	97	117	78	31	40	154	100
Ongoing Cases with Activity	2,265	200	139	113	395	197	566	276	22	84	108	165
Ongoing Case no Activity	4,493	791	435	171	1013	304	793	438	46	121	165	216
Active Cases	7,693	1,089	652	319	1,515	598	1,476	792	99	245	427	481
Quarter 3	**Total**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
New Cases	1,147	107	69	31	101	81	107	66	51	122	253	159
Ongoing Cases with Activity	2,612	215	185	166	412	266	541	265	58	81	212	211
Ongoing Case no Activity	5,109	812	475	206	1068	361	836	487	77	161	319	307
Active Cases	8,868	1,134	729	403	1,581	708	1,484	818	186	364	784	677
Quarter 4	**Total**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
New Cases	1,121	111	35	37	113	107	96	62	54	113	242	151
Ongoing Cases with Activity	3,032	221	196	158	474	310	503	293	62	181	347	287
Ongoing Case no Activity	5,482	708	466	237	1016	369	771	486	128	283	572	446
Active Cases	9,635	1,040	697	432	1,603	786	1,370	841	244	577	1,161	884

All Quarters	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	Los Angeles	Orange	Passages	Redwood	Southern	Valley
New Cases	4,122	375	418	227	134	463	309	481	291	179	327	804	489
Ongoing Cases with Activity	9,892	899	825	645	564	1,711	973	2,107	1,119	144	361	676	767
Ongoing Case no Activity	18,925	1,720	3,084	1,793	755	3,995	1,349	3,104	1,779	254	634	1,066	1,112
Active Cases	32,939	2,994	4,327	2,665	1,453	6,169	2,631	5,692	3,189	577	1,322	2,546	2,368

***Ongoing and Open Case Tallies may be incomplete based on CRC timing of CareNav adoption**

***Definitions - refer to Appendix A: Glossary**

***Inclusion Criteria – refer to Appendix C: Technical Specifications**

Table C12: CRC Client Activity Summary by Quarter and CRC - Fiscal Year 2020-2021

Intake	Total	Bay Area	Coast	Del Mar	Del Oro	Inland	Los Angeles	Orange	Passages	Redwood	Southern	Valley
Q1	1,425	187	106	40	161	102	328	92	41	57	224	87
Q2	1,354	160	142	34	126	91	256	87	30	85	235	108
Q3	1,660	233	153	35	113	108	173	102	50	120	363	210
Q4	1,687	257	98	30	123	103	160	133	65	139	349	230
Total FY 2020-2021	6,126	837	499	139	523	404	917	414	186	401	1,171	635
Annual Number per client, mean (SD)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)
Annual Duration in Hours per client, mean (SD)	0.5 (0.4)	0.5 (0.6)	0.5 (0.4)	0.4 (0.3)	0.6 (0.4)	0.5 (0.4)	0.4 (0.3)	1.0 (0.5)	0.6 (0.5)	0.5 (0.5)	0.4 (0.3)	0.5 (0.4)
Assessment	**All CRCs**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
Q1	1,019	104	52	31	192	24	161	120	43	55	155	82
Q2	963	103	83	35	111	97	119	84	31	42	154	104
Q3	1,175	112	76	31	104	84	109	68	52	125	253	161
Q4	1,142	112	39	37	121	109	96	64	55	115	242	152
Total FY 2020-2021	4,299	431	250	134	528	314	485	336	181	337	804	499
Annual Number per client, mean (SD)	1.1 (0.3)	1.0 (0.1)	1.1 (0.3)	1.0 (0.1)	1.6 (0.76)	1.0 (0.0)	1.0 (0.1)	1.0 (0.2)	1.0 (0.2)	1.1 (0.3)	1.0 (0.0)	1.0 (0.2)
Annual Duration in Hours per client, mean (SD)	2.4 (1.0)	3.1 (0.9)	1.6 (0.7)	2.1 (0.7)	1.7 (0.9)	1.6 (0.6)	2.8 (0.4)	2.0 (0.3)	1.0 (0.4)	1.7 (0.6)	2.9 (0.5)	3.5 (1.0)
Reassessment	**All CRCs**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
Q1	737	18	14	24	241	65	71	65	27	39	120	53
Q2	537	46	6	22	147	60	16	36	69	1	78	56
Q3	718	39	39	39	187	44	95	28	44	14	108	81
Q4	864	60	49	17	266	70	49	61	43	30	130	89
Total FY 2020-2021	2,856	163	108	102	841	239	231	190	183	84	436	279
Annual Number per client, mean (SD)	1.2 (0.4)	1.0 (0.2)	1.1 (0.3)	1.2 (0.4)	1.4 (0.6)	1.0 (0.1)	1.0 (0.1)	1.1 (0.3)	1.1 (0.3)	1.1 (0.3)	1.1 (0.4)	1.2 (0.4)
Annual Duration in Hours per client, mean (SD)	1.4 (0.6)	1.1 (0.6)	1.0 (0.5)	1.2 (0.6)	1.5 (0.6)	1.1 (0.4)	1.7 (0.5)	2.0 (0.2)	0.6 (0.3)	1.2 (0.5)	1.3 (0.7)	1.7 (0.5)

Family Consultation	All CRCs	Bay Area	Coast	Del Mar	Del Oro	Inland	Los Angeles	Orange	Passages	Redwood	Southern	Valley
Q1	5,371	410	240	393	692	660	899	554	136	241	854	292
Q2	6,514	389	319	304	629	709	1001	532	174	1173	856	428
Q3	6,512	416	363	388	671	686	924	519	201	734	1100	510
Q4	7,149	437	348	363	794	897	974	645	175	767	1157	592
Total FY 2020-2021	25,546	1,652	1,270	1,448	2,786	2,952	3,798	2,250	686	2,915	3,967	1,822
Annual Number per client, mean (SD)	10.0 (13.9)	4.3 (4.3)	4.9 (3.9)	12.7 (12.5)	6.4 (6.4)	21.3 (21.6)	20.8 (22.8)	10.3 (8.2)	4.3 (4.0)	3.9 (5.9)	8.8 (10.3)	7.9 (7.5)
Annual Duration in Hours per client, mean (SD)	3.3 (3.6)	1.3 (1.5)	1.8 (1.7)	3.8 (3.3)	2.7 (2.9)	5.3 (4.6)	5.0 (4.1)	6.8 (4.0)	1.5 (1.6)	1.2 (1.8)	2.9 (3.0)	3.2 (3.0)
Support Group	**All CRCs**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
Q1	413	37	17	31	2	79	90	43	39	26	37	12
Q2	486	40	31	26	-----	78	94	70	40	33	58	16
Q3	543	55	33	32	14	82	90	67	44	49	62	15
Q4	551	44	24	31	13	88	96	54	38	75	68	20
Total FY 2020-2021	1,993	176	105	120	29	327	370	234	161	183	225	63
Annual Number per client, mean (SD)	5.4 (6.2)	2.94	3.5 (2.8)	4.7 (3.4)	6.9 (7.0)	4.8 (5.9)	6.9 (9.1)	3.7 (3.2)	6.2 (4.8)	4.0 (4.8)	7.2 (6.6)	4.2 (3.1)
Annual Duration in Hours per client, mean (SD)	9.1 (8.7)	11.8 (10.3)	4.6 (4.1)	6.2 (4.3)	4.6 (2.5)	7.8 (7.1)	14.0 (18.8)	7.7 (9.2)	10.8 (9.1)	7.7 (9.7)	12.9 (10.1)	8.7 (6.7)
Psycho-education	**All CRCs**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
Q1	33	-----	-----	-----	1	26	-----	3	3	-----	-----	-----
Q2	77	-----	-----	-----	-----	44	-----	10	2	21	-----	-----
Q3	64	10	-----	-----	-----	30	5	-----	-----	19	-----	-----
Q4	90	10	-----	-----	-----	49	9	13	-----	9	-----	-----
Total FY 2020-2021	264	20	-----	-----	1	149	-----	26	5	49	-----	-----
Annual Number per client, mean (SD)	5.1 (4.5)	3.9 (1.6)	-----	-----	1.0 (NA)	6.1 (5.7)	3.0 (1.4)	1.2 (0.4)	3.7 (0.6)	5.9 (0.5)	-----	-----
Annual Duration in Hours per client, mean (SD)	8.3 (4.9)	-----	-----	-----	2.5 (NA)	9.4 (5.8)	7.2 (3.4)	2.5 (1.9)	7.3 (1.1)	8.8 (0.7)	-----	-----

Caregiver Education/Training	All CRCs	Bay Area	Coast	Del Mar	Del Oro	Inland	Los Angeles	Orange	Passages	Redwood	Southern	Valley
Q1	221	21	-----	67	1	70	-----	62	-----	-----	-----	-----
Q2	430	29	-----	35	-----	48	-----	315	-----	-----	-----	3
Q3	321	1	-----	27	49	42	7	189	-----	-----	-----	6
Q4	350	7	-----	9	47	69	45	120	6	18	-----	29
Total FY 2020-2021	1,322	58	-----	138	97	229	52	686	6	18	-----	38
Annual Number per client, mean (SD)	2.3 (2.3)	2.3 (2.1)	-----	1.6 (1.5)	3.2 (3.8)	3.1 (3.7)	4.1 (1.9)	1.9 (1.3)	1.5 (0.6)	1.4 (0.6)	-----	1.6 (1.0)
Annual Duration in Hours per client, mean (SD)	2.2 (2.2)	3.7 (2.3)	-----	2.3 (1.7)	2.9 (2.4)	3.1 (2.3)	5.8 (3.2)	1.4 (1.6)	1.8 (1.0)	2.8 (1.2)	-----	2.2. (1.4)

Individual Counseling	**All CRCs**	**Bay Area**	**Coast**	**Del Mar**	**Del Oro**	**Inland**	**Los Angeles**	**Orange**	**Passages**	**Redwood**	**Southern**	**Valley**
Q1	27	-----	-----	-----	-----	17	-----	3	-----	-----	7	-----
Q2	32	-----	-----	1	1	13	-----	3	-----	4	10	-----
Q3	45	-----	-----	-----	-----	9	-----	16	-----	1	19	-----
Q4	41	1	-----	3	1	12	-----	2	-----	-----	22	-----
Total FY 2020-2021	145	1	-----	4	2	51	-----	24	-----	-----	58	-----
Annual Number per client, mean (SD)	3.8 (2.9)	-----	-----	1.7 (1.2)	3.5 (3.5)	5.3 (3.3)	-----	1.1 (0.3)	-----	1 (NA)	4.7 (2.0)	-----
Annual Duration in Hours per client, mean (SD)	3.9 (2.6)	-----	-----	4.0 (2.0)	5.0 (6.7)	4.5 (2.9)	-----	2.2 (1.7)	-----	0.4 (0.2)	4.7 (2.0)	-----

***Definitions - refer to Appendix A: Glossary**

***Inclusion Criteria – refer to Appendix C: Technical Specifications**

Table C13: Service Grant Vouchers by Quarter and CRC - Fiscal Year 2020 - 2021

	Counseling				Legal Consultation				Respite				Supplemental		
Quarter 1	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Amt**
Bay Area	22	15	53	$5,300	5	5	3	$450	35	27	1276	$26,943	5	3	$144
Coast	79	37	112	$11,852	0	0	0	$0	65	40	1573	$48,356	0	0	$0
Del Mar	0	0	0	$0	9	9	9	$900	14	14	733	$15,401	0	0	$0
Del Oro	6	6	52	$1,105	1	1	1	$100	52	44	1348	$34,833	0	0	$0
Inland	0	0	0	$0	0	0	0	$0	58	41	1704	$31,415	170	154	$25,459
LA	0	0	0	$0	0	0	0	$0	11	3	205	$31,415	0	0	$0
Orange	0	0	0	$0	0	0	0	$0	45	21	677	$11,799	7	7	$2,906
Passages	4	3	17	$1,825	2	2	2	$350	131	62	2545	$69,818	0	0	$0
Redwood	0	0	0	$0	0	0	0	$0	1	1	23	$563	0	0	$0
Southern	0	0	0	$0	5	5	5	$575	26	24	580	$15,336	0	0	$0
Valley	4	4	13	$950	4	4	4	$300	265	173	3810	$78,431	0	0	$0
Total	**115**	**65**	**247**	**$21,032**	**26**	**26**	**24**	**$2,675**	**703**	**450**	**14474**	**$364,310**	**182**	**164**	**$28,509**
Quarter 2	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Hrs**	**Amt**	**Grants**	**Clients**	**Amt**
Bay Area	26	17	54	$5,400	3	3	3	$450	49	33	1544	$35,485	2	2	$502
Coast	108	55	147	$16,100	0	0	0	$0	371	187	5884	$177,436	0	0	$0
Del Mar	1	1	2	$200	17	17	17	$1,700	36	36	2178	$52,014	0	0	$0
Del Oro	41	20	87	$5,865	5	5	5	$600	87	46	1646	$44,207	0	0	$0
Inland	0	0	0	$0	0	0	0	$0	100	70	3318	$59,834	10	7	$832
LA	0	0	0	$0	0	0	0	$0	102	47	1174	$26,994	6	6	$593
Orange	0	0	0	$0	0	0	0	$0	188	56	1891	$53,964	11	11	$8,282
Passages	2	2	10	$1,300	0	0	0	$0	157	68	2397	$65,049	0	0	$0
Redwood	0	0	0	$0	4	4	4	$380	18	13	945	$19,562	0	0	$0
Southern	0	0	0	$0	8	8	8	$845	199	70	2866	$72,875	0	0	$0
Valley	15	15	68	$6,020	0	0	0	$0	216	147	4793	$95,289	0	0	$0
Total	**193**	**110**	**368**	**$34,885**	**37**	**37**	**37**	**$3,975**	**1523**	**773**	**28636**	**$702,709**	**29**	**26**	**$10,209**

Quarter 3	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Amt
Bay Area	40	22	64	$6,400	9	9	8	$1,125	38	25	950	$19,942	8	6	$910
Coast	80	43	135	$14,750	0	0	0	$0	446	207	6276	$186,709	0	0	$0
Del Mar	0	0	0	$0	9	9	9	$1,000	56	56	3057	$72,372	0	0	$0
Del Oro	50	26	66	$5,610	7	7	7	$800	280	111	5413	$138,644	0	0	$0
Inland	0	0	0	$0	0	0	0	$0	69	47	1887	$37,005	6	7	$772
LA	0	0	0	$0	0	0	0	$0	102	43	2112	$48,270	403	74	$22,923
Orange	2	2	7	$525	0	0	0	$0	389	86	3838	$114,253	25	16	$18,063
Passages	21	14	62	$8,050	3	3	3	$525	136	71	2320	$63,027	0	0	$0
Redwood	0	0	0	$0	2	2	2	$190	50	21	2366	$45,517	0	0	$0
Southern	0	0	0	$0	7	7	7	$680	162	72	2878	$70,455	0	0	$0
Valley	9	9	43	$3,870	2	2	2	$250	359	228	8941	$187,818	0	0	$0
Total	**202**	**116**	**377**	**$39,205**	**39**	**39**	**38**	**$4,570**	**2087**	**967**	**40038**	**$984,012**	**442**	**103**	**$42,668**

Quarter 4	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Amt
Bay Area	51	30	93	$9,300	8	8	9	$1,275	51	36	1936	$49,999	12	12	$2,303
Coast	21	15	20	$2,070	0	0	0	$0	323	155	5028	$150,495	0	0	$0
Del Mar	3	3	10	$940	8	8	8	$800	72	72	6383	$151,096	0	0	$0
Del Oro	97	42	167	$14,195	10	10	6	$575	345	159	7646	$157,420	0	0	$0
Inland	0	0	0	$0	0	0	0	$0	71	52	3007	$49,061	68	64	$12,656
LA	0	0	0	$0	0	0	0	$0	85	49	2038	$46,879	672	246	$56,491
Orange	4	3	11	$825	0	0	0	$0	497	141	14112	$390,673	82	30	$29,673
Passages	19	12	42	$5,525	2	2	2	$350	211	91	3071	$84,729	0	0	$0
Redwood	0	0	0	$0	4	4	4	$380	88	44	3849	$83,646	0	0	$0
Southern	0	0	0	$0	11	11	11	$1,190	167	73	3191	$73,874	0	0	$0
Valley	9	8	44	$3,474	2	2	2	$350	290	197	5931	$137,566	5	4	$530
Total	**204**	**113**	**387**	**$36,329**	**45**	**45**	**42**	**$4,920**	**2200**	**1069**	**56192**	**$1,375,438**	**839**	**356**	**$101,653**

All Qs	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Hrs	Amt	Grants	Clients	Amt
Bay Area	139	84	264	$26,400	25	25	23	$3,300	173	121	5706	$132,369	27	23	$3,859
Coast	288	150	414	$44,772	0	0	0	$0	1,205	589	18761	$562,996	0	0	$0
Del Mar	4	4	12	$1,140	43	43	43	$4,400	178	178	12351	$290,883	0	0	$0
Del Oro	194	94	372	$26,775	23	23	19	$2,075	764	360	16053	$375,104	0	0	$0
Inland	0	0	0	$0	0	0	0	$0	298	210	9916	$177,315	254	232	$39,719
LA	0	0	0	$0	0	0	0	$0	300	142	5529	$153,558	1,081	326	$80,007
Orange	6	5	18	$1,350	0	0	0	$0	1,119	304	20518	$570,689	125	64	$58,924
Passages	46	31	131	$16,700	7	7	7	$1,225	635	292	10333	$282,623	0	0	$0
Redwood	0	0	0	$0	10	10	10	$950	157	79	7183	$149,288	0	0	$0
Southern	0	0	0	$0	31	31	31	$3,290	554	239	9515	$232,540	0	0	$0
Valley	37	36	168	$14,314	8	8	8	$900	1,130	745	23475	$499,104	5	4	$530
Total	**714**	**404**	**1379**	**$131,451**	**147**	**147**	**141**	**$16,140**	**6513**	**3259**	**139,340**	**$3,426,469**	**1492**	**649**	**$183,039**

***Definitions - refer to Appendix A: Glossary**

***"Grants" is defined as the number of grant transactions that took place.**