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

4th Annual Report
Evaluation of the California Caregiver Resource Centers' service delivery and system change

Reporting Period: July 2022-June 2023
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Acknowledgements

"From the day one, when I called...the phone number on that page, it was almost like I was a balloon that needed to pop, and they were able to slowly let the air out and give me some peace, some confidence, some backup by having the respite care, and some techniques, and knowledge, and a shared sense of being by being in the group."

– CRC Caregiver

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The photos included in this report cannot be copied or reused for other purposes.

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. In Fiscal Year 2021, ongoing annual funding was established at $15 million. The aim was to "expand and improve family caregiver services and enhance CRC information technology services" between 2019 and 2022. Early in Fiscal Year (FY) 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.

Across all CRCs, 13,904 unduplicated family caregivers received services from professional staff in FY 2022-2023. The CRCs provided one or more services such as family consultation, counseling, education, or vouchered services (counseling, legal, respite, supplemental) to 7,010 family caregivers. The CRCs provided family consultations (158,177 instances), "in-house" counseling (204 caregivers), and vouchered services (counseling: 217 caregivers; legal: 147 caregivers; respite 1,848 caregivers; supplemental: 230 caregivers) as well as 11,991 outreach activities. Almost 28,000 participants enrolled in CRC educational offerings.

The infographics on the next page summarize characteristics of people served and the nature of services provided. The CRCs serve diverse caregivers across the adult lifespan. In FY 2022-2023, 5,782 caregivers completed full assessments. The majority were between 45 and 84 years old (43% aged 65-84 and 42.2% aged 45-64), identified as female (76.9%) and were married or partnered (69.4%). The CRCs serve a diverse population who identify as American Indian & Alaska Native (0.6%), Asian American & Pacific Islander (9.9%), Black/ African American (8.2%), Hispanic/ Latino (24.7%), and non-Hispanic White (55.4%). The majority were heterosexual (97.2%) with 2.8% identifying as LGBTQ.

Caregivers support persons with a range of health conditions, with 68% having a diagnosis of Alzheimer's Disease or a related disorder, followed by stroke (10.2%), "other" conditions (8.1%), Parkinson's Disease (7.5%), cancer (3.5%), and brain injury (2.7%). Those served by the CRCs provide complex and intense care, with 90.5% providing a high level of care (based on weekly care hours and number of activities of daily living (ADLs) and instrumental ADLs supported). Most (79%) assisted with at least one medical/nursing task, with 43.5% reporting that performing these tasks is difficult. CRC caregivers devote a great deal of time to their role, with 73.2% spending more than 40 hours per week caregiving. Despite these heavy demands, 69.4% received no paid help and 47.9% received no help from family or friends.

California Caregiver Resource Centers (CCRCs) July 2022 – June 2023 Dashboard | *n* = 4,038

Intakes and Assessments Completed

- Intakes: 6,360
- Assessments: 4,038
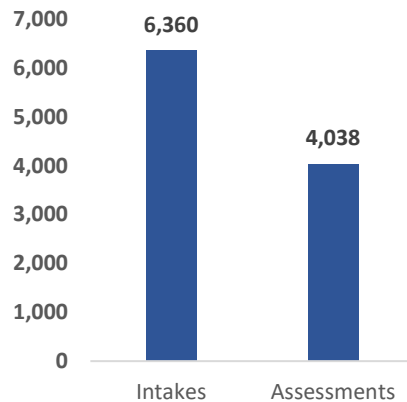
Racial & Ethnic Identity: Caregiver and Care Recipient
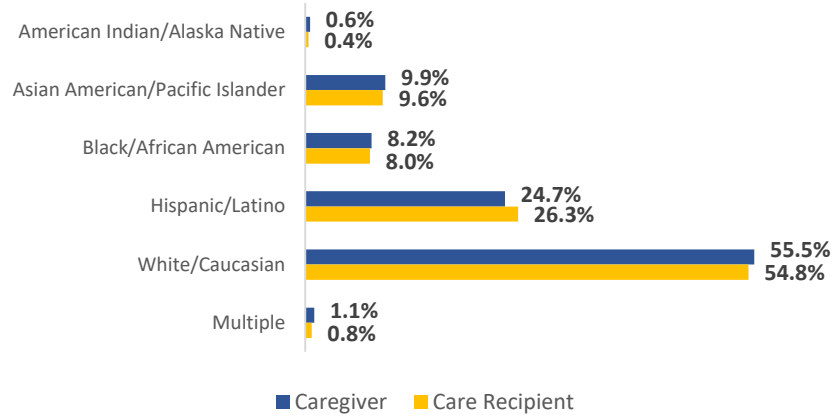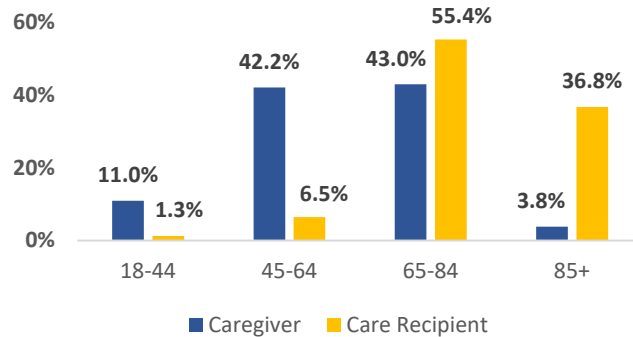
	Caregiver	Care Recipient
American Indian/Alaska Native	0.6%	0.4%
Asian American/Pacific Islander	9.9%	9.6%
Black/African American	8.2%	8.0%
Hispanic/Latino	24.7%	26.3%
White/Caucasian	55.5%	54.8%
Multiple	1.1%	0.8%

Age: Caregiver and Care Recipient

	Caregiver	Care Recipient
18-44	11.0%	1.3%
45-64	42.2%	6.5%
65-84	43.0%	55.4%
85+	3.8%	36.8%

Gender: Caregiver and Care Recipient

	Caregiver	Care Recipient
Female	76.9%	54.9%
Male	22.9%	45.1%
Other/NB/Trans	0.2%	0.0%

Relationship of Caregiver and Care Recipient

- Other Relative: 11.7%
- Non-Relative: 2.8%
- Spouse: 35.4%
- Child: 48.4%
- Partner: 1.8%
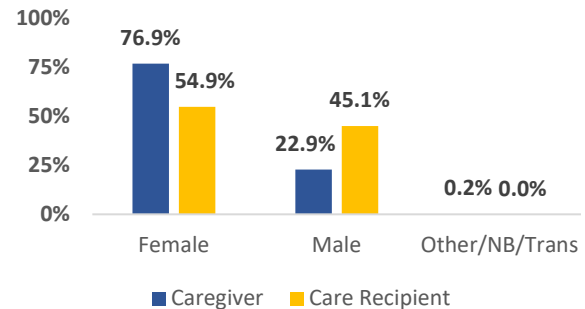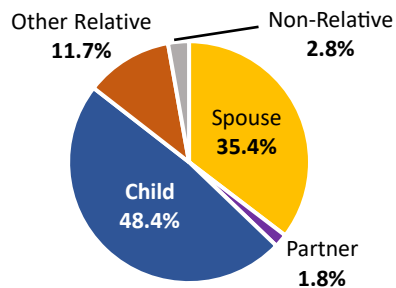
Respite Hours and Services

Caregivers who received respite services = **1,848**

Total respite hours provided = **112,982**

Outreach and Education Activities

Outreach = 11,991
Direct referrals, general public information/awareness activities, provider awareness.

Education = 1,916
Programs designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.

Caregiver Supports

Family Consultation = 158,177 consultations

Support Groups = 1,172 clients

Individual Counseling Services = 421 clients

Legal and Financial Consultation = 147 clients

Supplemental Service Vouchers = 230 clients

Caregivers experienced health issues themselves. Among CRC caregivers, only around 6.2% report being in excellent and 19.6% in very good health, with one-third reporting that their health is worse than it was 6 months ago. Approximately 1 in 5 experience moderate to severe depressive symptoms, and significant loneliness, while 60.5% experience high caregiving strain. On the positive side, 31.6% report being very satisfied with support from family and friends, while 44.7% are very satisfied with the spiritual support they receive. Some caregivers made employment modifications to accommodate their caregiving responsibilities, with 6.8% reducing work hours, 4.9% quitting their current job, and 2.7% taking early retirement.

Fiscal Year 2023 was the fourth year of the augmentation cycle for the CRCs. In the past year, the CRCs:

- Improved CareNav™ data quality and utilization of data to make decisions.
- Increased outreach and educational programming, including state-wide offerings in multiple languages.
- Enhanced outreach to diverse communities.

IMPACT

Successful implementation of CareNav™ across all CRC sites has enabled collection of detailed information about almost 19,000 caregivers since 2019. Importantly, the caregivers represent diverse communities and circumstances. Coupled with longitudinal data, this investment has actualized the potential to understand the caregiver experience and disparities in outcomes. This report contains detailed analysis of data from FY 2022-2023 as well as synthesis of data since 2019. Major findings include:

CRCs serve caregivers who provide complex, intense, and time-consuming care. Caregivers are often the primary or only caregiver in the situation and commonly have little family or paid support.

Caregivers highly value the support provided by the CRCs. They are highly satisfied and emphasize the crucial impact of the personal interaction and coordinating role of family consultants, who establish a trusting relationship and provide guidance and support. Family consultants facilitate readiness to accept help and identify vital resources including respite, support groups, legal/financial consultation and education. Caregivers report they feel supported, gain confidence and skills and learn to manage demands and stress. Combined, CRC resources improve mental health, reduce stress and increase the capacity of caregivers to engage in their vital role.

Inequities exist in the distribution of caregiving demands, resources and outcomes. Older caregivers compared to younger caregivers, those who identify in racial and ethnic groups other than White non-Hispanic, and those with income below the FPL compared to higher income have greater caregiving demands, fewer resources and more adverse outcomes.

The CRCs have substantially increased their outreach and education over the past year. Public outreach increased and educational program offerings nearly doubled,

including statewide programs in English and other languages. CRCs have realized efficiencies in delivery because base funding has remained the same over the past three years, without cost-of-living adjustments. Further expansion would likely require enhanced investment.

CareNav™ implementation is advancing. Sites are increasingly using data for program decision-making. However, caregiver adoption of CareNav™ is similar to last year, with awareness and technical support as major barriers. Those who use the online platform are very satisfied.

Longitudinal analysis of caregivers enrolled in CRCs reveal **improvements in caregiver outcomes**, including burden, loneliness and depressive symptoms. These outcomes generally occur in the context of worsening of the care recipient's condition. Accordingly, the positive differences reported, while sometimes small in magnitude, are very meaningful. The reported differences align directly with the elements of the CCRC service model. At assessment, care consultants identify problems and intervene to provide resources and services tailored to address the underlying issues. These positive changes underscore the impact of the CRC service model on the lives of family caregivers and the importance of ongoing investment in these services.

RECOMMENDATIONS

The CRCs have expanded their services and are using CareNav™ data in important ways to inform decisions and strategy. We recommend consideration of the following:

At the CRC site level:
- Use CareNav™ data to improve program quality and responsiveness and refine outreach efforts to reach sub-populations that have yet to benefit from the CRC services and supports
- Develop strategies to increase caregiver awareness and utilization of CareNav™ as a resource

At the CRC system level:
- Participate in reviewing data to develop plans to address disparities in caregiver experience, services and outcomes and to develop an equity plan for caregivers
- Collaborate to identify priority health issues for additional programming and develop strategies to address these issues
- Continue to identify opportunities for collaboration that leverage strengths across the system, for example, sharing bilingual staff across regions

At the state level (California Department on Aging):
- Consider enhanced funding to enable further service expansion with annual cost of living adjustments to all contracts for services
- Prioritize funding for increasing diversity, equity, and inclusion with investments in linguistic and cultural refinements of resources and supports already available in the CRC system
- Use data on caregivers and services to inform implementation of the California Master Plan on Aging and other statewide planning efforts
- Collaborate with CRCs to advance caregiving service standards and quality

I. INTRODUCTION AND METHODS

Family caregiving for an older adult or a person with disabilities is a common experience, with about one in five households engaged in this vital support.[1] Family caregivers are diverse in age, race/ethnicity, gender, employment status and income. They share a common commitment to enabling family members and friends to live with chronic conditions in their environments of choice. Collectively, they provide complex and intense care, assist with navigating acute health crises and hospitalizations, and provide comfort and support at the end of life. Indeed, they provide most of the care after discharge from hospitals and most long-term care.[2] 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] Yet caregivers are relatively invisible in the health care system, to their employers and in their communities, and often lack information and support necessary to enact their critical role for their families and for society.

Since 1984, California has been a leader in recognizing and supporting family caregivers, starting with the establishment of the California Caregiver Resource Center (CRC) system through the Comprehensive Act for Families and Caregivers of Brain-Impaired Adults. In 2019, California reinvested in a state-wide caregiver resource network supported by CareNav™, an online platform, in funding entitled "*Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile.*" In FY21, ongoing annual funding was established at $15 million. CareNav™ is a proprietary software platform developed with private funding by Family Caregiver Alliance with multiple use cases across sectors and populations (www.caregiver.org). In 2021, California again led the nation by establishing the Master Plan for Aging (https://mpa.aging.ca.gov/), including "Caregiving that Works" as one of the five bold goals for 2030. These investments by the State of California recognize the vital role that caregivers (unpaid family members or friends) play as members of the health care team and position this state well to support the major goals of the 2022 National Strategy to Support Family Caregivers (https://acl.gov/CaregiverStrategy).

The UC Davis Family Caregiving Institute at the Betty Irene Moore School of Nursing was engaged as the evaluator of the implementation of the statewide online system and enhancements to the California Caregiver Resource Centers. This is the fourth annual report of this important effort. We provide a brief overview of the California Caregiver Resource Centers and the evaluation approach before reporting on major findings from the past year.

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 I-a). 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 targeted by few services.

Figure I-a: Site Catchment

The CRCs are united by shared values emphasizing choice, collaboration, innovation, quality, participation, respect, and diversity. Core services include specialized information, uniform caregiver assessment, family consultation and care planning, respite care, short-term counseling, support groups, professional training, legal and financial consultation and education. Some sites offer additional programming, depending on diverse funding sources and affiliated programs. The state website provides on-line access to all CRCs with information about the services and programs they provide (https://www.caregivercalifornia.org/).

Program Goals of 2019-2023 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 2022-2023 fiscal year is the fourth 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 for Year 4 (FY 2022-2023) included*:*

- 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 fourth annual report (for FY 2022-2023) summarizes the results of aggregated data across the California CRCs regarding population served, services provided, CRC client and staff satisfaction and experience, a spotlight on equity, CRC outcomes and impact.

Evaluation Design and Methods

The evaluation plan was developed by UC Davis researchers at the Betty Irene Moore School of Nursing in the Family Caregiving Institute in collaboration with FCA and with input from the directors of all the California CRCs. The evaluation plan and measures were approved by the UC Davis Institutional Review Board. The evaluation includes multiple data sources and methods. Table I-a summarizes all the data sources for this report and for ongoing evaluation, more information is available in Appendix A.

Table I-a: Evaluation Data Sources

CareNav™: Intake and assessment data from July 2022 – June 2023 for general analysis. Supplemental analysis of outcomes and complexity of care using data from January 2019 – October 2023.
Outreach and Public Information Activities: CRC reports of public information and outreach activities conducted from July 2022 – June 2023.
Education Activities: CRC reports of education activities conducted from July 2022 – June 2023.
Media: CRC reports of media placement or media appearances with potential reach reported based on circulation numbers or impressions.
Caregiver Satisfaction Surveys: Quarterly surveys of caregivers who have enrolled in CareNav™ or have received services from the CRC sites.
Qualitative Data: Individual client interviews and comments collected on surveys.
CRC Staff readiness survey: Anonymous survey of CRC staff conducted in summer 2023 assessing knowledge about CareNav™, and preparation and confidence regarding the implementation process.

Throughout this reporting period, all CRC sites contributed CareNav™ data. The evaluation team prepared quarterly and annual reports using data collected in CareNav™ and survey data collected from caregivers served by all sites. The evaluation team engaged directly with staff at the CRC sites to validate the data and assure the quality, accuracy, and integrity of the data. In this report, the terms "caregiver" and "client" are used interchangeably.

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 assure data quality, 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. Each quarter, site-specific data regarding services provided were shared with the CRC sites. Sites had a two-week window to verify the data. Very few issues were identified during this fiscal year. All were minor and resolved following investigation in the weekly data quality meetings. As applicable, the QP team was able to implement system-level solutions to address problems identified across multiple sites. In other cases, sites corrected individual entries as warranted. Overall, the meetings and data quality findings suggest the feedback process for data quality monitoring is successful.

For the evaluation analysis, data were extracted from the CareNav™ platform for cases, activities, and service grants during the reporting period (July 1, 2022 – June 30, 2023) 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 CRC clients in CareNav™ eligible for California CDA funding with the exception of the analysis of intakes which included all CRC clients because funding 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 2022-2023 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, caregiver's home or community location; and telehealth). Caregiver characteristics —including sociodemographic, 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). Reported percentages reflect the total number excluding missing values for each variable. Missing data were minimal and are discussed further in the Appendix B, along with methodological details about standardized measures (e.g., UCLA Loneliness Scale, PHQ-9), and caregiver sociodemographic characteristics.

CareNav^{TM} Spotlight on Equity Analyses

In this report, we conduct deeper analysis on the intersectionality of race/ethnicity, age, gender, income level and rural/urban residence. For these analyses, we used data from CareNav^{TM} from the period 01/01/2019 – 08/15/2023.

CareNav^{TM} Spotlight on Complex Care

The data for this analysis were drawn from CareNav^{TM} on October 4, 2023. The analysis sample was restricted to caregivers whose assessments were conducted on or after January 1, 2019 when all eleven CRCs had fully deployed CareNav^{TM} in their workflows (n=28,062 assessments) and to caregivers who had only one assessment (n=18,990 unique caregivers). Caregivers with multiple assessments may be engaged in more than typical intensity of care. Variables selected for analysis are further described in the Appendix B, and included:

- ✓ Supporting activities of daily living and instrumental activities of daily living [any activities supported (% and counts); activities supported all the time (% and counts)]
- ✓ Performing medical and nursing tasks (MNT) in the home [tasks supported (% and counts), finding tasks difficult (%), feeling unprepared (%), needing more information (%)]
- ✓ Managing memory and behavior problems [problems managed (% and counts)]

Descriptive statistics (means, percentages) were used to summarize each measure. To identify characteristics associated with providing complex care, logistic regression was used to model binary measures and negative binomial regression to model counts, controlling for specific caregiver and caregiving characteristics (care recipient age, caregiver age, rurality, caregiver gender, caregiver race and ethnicity, care recipient living below federal poverty level, living with the care recipient). Statistical significance was set at 0.05.

CareNav^{TM} Outcome Analysis

The data for this analysis were drawn from CareNav^{TM} on October 4, 2023. The cohort was limited in three ways. First, we restricted the analysis to caregivers whose assessments were conducted on or after January 1, 2019 when all eleven CRCs had fully deployed CareNav^{TM} in their workflow (n=28,062 assessments). Second, we limited the sample to caregivers who had just one assessment and one reassessment during this time period (n=6,181). Caregivers who have multiple reassessments (approximately 10% of the sample) may be engaged in more intense caregiving than is typical and will be examined separately in future analyses. Finally, we focused on caregivers whose reassessment followed the assessment by no less than 30 days and no more than 285 days so that there was enough time, but not too much time between assessments, to measure change plausibly based on CRC care consultant intervention (n=4881 caregivers).

Variables selected for analysis were measured at both assessment and reassessment. These measures, further described in the Appendix B, included:

- Caregiver burden, measured with the Zarit Burden Index Short Form (4 items)
- Depressive symptoms, measured with the PHQ-9 instrument (9 items)
- Loneliness, measured with the UCLA Loneliness Scale (3 items)
- Receipt of any paid help, %
- Receipt of any unpaid help, %
- Caregiving hours per week
- Caregiver satisfaction with help from family and friend, social support and spiritual support

Descriptive statistics (McNemar's tests and paired t-tests) were used to compare the measures at assessment and reassessment with statistical significance set at 0.05.

Outreach, Public Information and Education Activities

Sites reported their activities in the areas of outreach, public information, and education using a standardized tool, providing information on a quarterly basis, detailing the activity, medium, audience, and number of participants. These data were summarized using descriptive statistics.

Caregiver Satisfaction Surveys

Caregiver satisfaction surveys assessed 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 5 represents the most positive response. The survey also invited comments from caregivers in an open-ended format. All caregivers who encountered the CRCs during the year 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– Individual client interviews

The evaluation team conducted individual interviews with 28 caregivers recruited from the CRC sites. Caregivers who had completed an intake assessment at one of the CRCs were eligible. Sites were asked to refer potential participants to the evaluation team, with a focus on recruiting across age groups and to represent both diversity of race/ethnicity and rural/urban caregivers. The evaluation team offered either Zoom or phone interviews. The interviews, conducted between June and August 2023, elicited perspectives on their experiences as caregivers, their interactions with the CRC, what has been most helpful, their impressions of CareNav™, and ideas for improvement. Audio-recorded interviews were transcribed, audited, then imported into Dedoose qualitative data analysis software. Qualitative descriptive methods were used to analyze the transcripts. Five members of the research team reviewed the transcripts and developed initial codes and definitions. Four team members coded the transcripts, then met regularly with the fifth member to discuss coding decisions, refine code definitions, reach consensus about the coding, and identify themes, sub-themes, and relationships among ideas. The team maintained an audit trail of codes and refinements.

Readiness survey

All staff from the 11 CRCs were invited to complete anonymous on-line readiness surveys between July and September 2023. Demographic data were collected using a separate link, to support the anonymity of participants and included gender, age, and ethnicity. The 11-item readiness survey assessed preparation and confidence regarding the implementation process and self-efficacy using a 5-point scale (1 represents the most negative and 5 the most positive response). Six items using the same scale were added this year to assess developmental implementation phase (presented in the previous annual report). Each participant was asked to rate their current CareNav™ utilization and their willingness to expand CareNav™ utilization according to previously identified functionalities. The survey also assessed perceptions about ongoing training and support. Open-ended questions identified benefits and concerns about CareNav™, and efforts made to serve caregivers from diverse communities.

Quantitative data were analyzed using descriptive statistics using the SPSS statistical package (version 27; IBM Corporation). We used one way ANOVA (with Bonferroni adjustment for multiple comparisons 0.05/comparisons) to explore differences in scores across sites, roles and hiring date. Open-ended responses to the survey were coded and analyzed using qualitative descriptive methods. We created subsamples of longitudinal data for those respondents who also completed a baseline readiness survey in 2020 and FY 2021-2022 (presented in previous annual reports). We compared baseline and FY 2021-2022 scores with current scores using the Wilcoxon signed rank test.

II.   POPULATION SERVED

Caregiver Sociodemographic Characteristics

A total of 5,782 caregivers completed intakes or assessments in FY 2022-2023 across the 11 CRCs. Most caregivers were in the 65–84-year (43.0%) age range followed by the 45–64-year age range (42.2%) (Figure II-a). Caregivers most commonly identified as female (76.9%) (Figure II-b) and married/partnered (69.4%). Table II-a provides detailed sociodemographic data and Table II-b presents income, employment changes, and insurance status.

Figure II-a: Caregiver and Care Recipient Age
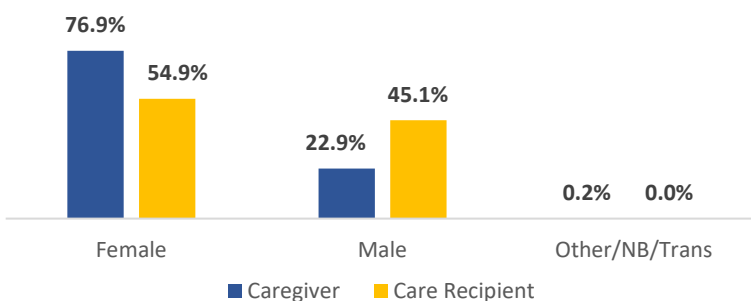
Figure II-b: Caregiver and Care Recipient Gender
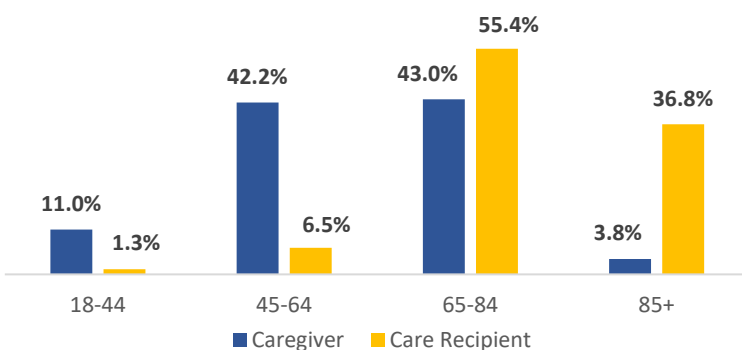
Figure II-c: Caregiver and Care Recipient Racial & Ethnic Identity
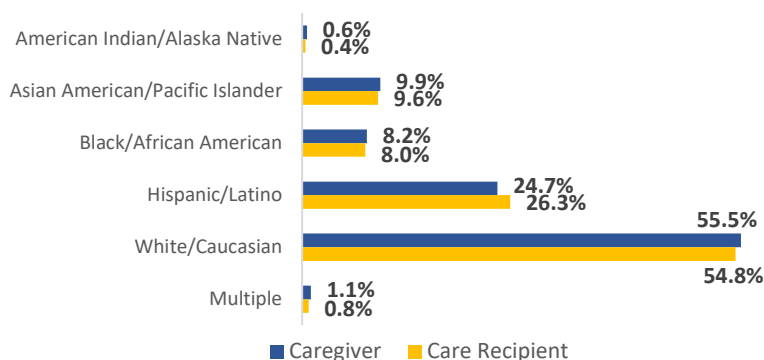
Table II-a: Caregiver Sociodemographic Characteristics

n= 5,782	%
Primary Language	
English	92.1
Spanish	6.3
Other	1.6
Highest Level of Education	
Some High School	2.6
High School Graduate	14.3
Some College	27.9
College Graduate	38.0
Post Graduate Degree	17.2
Marital Status	
Married/Partnered	69.4
Separated/Divorced	9.1
Single	18.5
Widowed	3.0
Employment Status	
Full Time	29.4
Part Time	10.9
Retired	41.0
Unemployed	15.9
Leave of Absence	2.6
Caregiver Lives Alone	7.5
Caregiver Lives in Rural Area	4.4
Identifies as Primary Caregiver	95.0
Other Caregiving Responsibilities	
Care for a child	7.1
Care for a child with a disability	1.1
Care for an adult with a disability	2.6
Other	3.3

*Among completed assessments; deduplicated by caregiver; percentages may not add to 100 due to rounding

This diverse population includes caregivers who identify as American Indian & Alaska Native (0.6%), Asian American & Pacific Islander (9.9%), Black/ African American (8.2%), Hispanic/ Latino (24.7%), and non-Hispanic White (55.4%) (Figure II-c). The majority were heterosexual (97.2%) with 2.8% identifying as LGBTQ. On average, CRC caregivers were highly educated, with 38.0% reporting a college degree and 17.2% reported a graduate degree.

A majority of CRC caregivers report that they are the care recipient's primary caregiver (95.0%). A small percentage have additional caregiving responsibilities, such as caring for a child (7.7%), disabled child (1.1%), disabled adult (2.6%), or other (3.3%) responsibility. A large percentage of caregivers reported being retired (41.0%), but many worked full-time (29.4%) or part time (10.9%), and 15.9% were unemployed.

Caregiving did not impact employment status for most caregivers (73.3%), but others reported that they decreased hours (6.8%), quit a job (4.9%), or took early retirement (2.7%) due to caregiving responsibilities.

Among caregivers who reported household income (n=1,747), most reported earning $70,000 or less per year (68.8%) and 16% reporting income below the Federal Poverty Level.

Table II-b: Caregiver Sociodemographic Characteristics

n= 5,782	%
Household Income	
under $13,200	8.0
$13,200-$20,000	6.6
$20,000-$30,000	11.2
$30,000-$40,000	13.9
$40,000-$55,000	15.8
$55,000-$70,000	13.3
$70,000-$80,000	8.4
$80,000-$90,000	6.4
$95,000-$110,000	5.0
$110,000-$120,000	3.1
$120,000-$135,000	8.3
Employment Change Due to Caregiving	
No Change	73.3
Decreased Hours	6.8
Other	6.6
Quit Job	4.9
Family Leave	3.1
Early Retirement	2.7
Began Working	0.8
Increased Hours	0.7
Laid Off	0.6
Changed Jobs	0.5
Declined Promotion	<1.0
Income Below FPL	16.0
Insurance Type	
Medicare	53.6
Medicaid/MediCal	18.5
VA Insurance	2.7
Uninsured	3.1
Other/Self-Pay	6.6
Long Term Care Insurance	9.5

*Among completed assessments; deduplicated by caregiver; percentages may not add to 100 due to rounding

The most common health insurance coverage among caregivers was Medicare (53.6%) followed by Medicaid/MediCal (18.5%). However, around 3% of caregivers reported being uninsured.

> *"My folks have long-term healthcare insurance. If they needed 24-hour care...the amount that my mom receives would cover less than a third of that total cost, so there is a crisis...Women are stepping forward, and literally working themselves to the grave to care give, or families are going bankrupt." – CRC Caregiver*

Care Recipient Sociodemographic Characteristics

A majority of care recipients were older adults in the 65-84-year (55.4%) or 85+ year (36.8%) categories. Just over half identified as female (54.9%). The race/ethnicity of care recipients was non-Hispanic White (54.8%), followed by Hispanic/ Latino (26.3%), Asian American/ Pacific Islander (9.6%), Black/ African American (8.0%), multiracial (0.8%), and American Indian/ Alaska Native (0.4%) (Figure II-c). Most care recipients were either married (54.4%) or widowed (27.0%). Their caregivers were most often adult children (48.8%) or spouses (35.5%), followed by other relatives (11.7%), non-relatives (2.8%) and partners (1.8%) (Figure II-d).

A majority of care recipients were covered by Medicare (86.5%) and about one-quarter were covered by Medicaid/MediCal. Around one in five care recipients reported income below the Federal Poverty Level. Detailed care recipient sociodemographic characteristics are presented in Table II-c.

Figure II-d: Relationship of Caregiver and Care Recipient
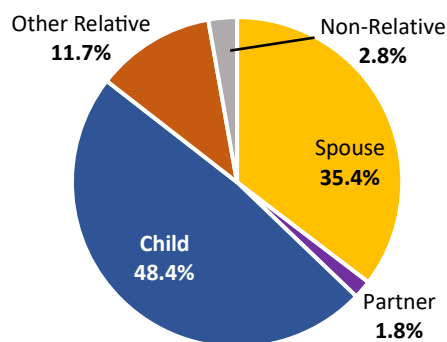
Table II-c: Care Recipient Sociodemographic Characteristics

n= 5,944	%
Care Recipient Age (yrs.)	
18-44	1.3
45-64	6.5
65-84	55.4
85+	36.8
Care Recipient Gender Identity	
Female	54.9
Male	45.1
Care Recipient Race/Ethnicity	
American Indian/Alaska Native	0.4
Asian American/Pacific Islander	9.6
Black/African American	8.0
Hispanic/Latino	26.3
White, non-Hispanic	54.8
Multiple	0.8
Care Recipient Marital Status	
Married/Partnered	54.4
Separated or Divorced	10.4
Single	8.2
Widowed	27.0
Care Recipient Lives in Rural Area	7.8
Care Recipient Lives Alone	10.4
Care Recipient is a Veteran	15.3
Care Recipient is Medicaid Eligible	
Yes	23.7
No	65.0
Unsure	11.4
Insurance Type	
Employer Insurance	3.6
Medicare	86.5
Medicaid/MediCal	24.4
VA Insurance	5.3
Uninsured	0.8
Other/Self-Pay	1.8
Long Term Care Insurance	8.9
Income Below FPL	20.3

*Among completed assessments; deduplicated by care recipient; percentages may not add to 100 due to rounding

Care Recipient Health

Table II-d provides details about care recipient health. The most common primary diagnoses for care recipients included Alzheimer's Disease and Related Dementias (67.9%) followed by stroke (10.2%), "other" conditions (8.1%), Parkinson's Disease (7.5%), cancer (3.5%), and brain injury (2.7%) (Figure II-e).

Figure II-e: Care Recipient Primary Diagnosis
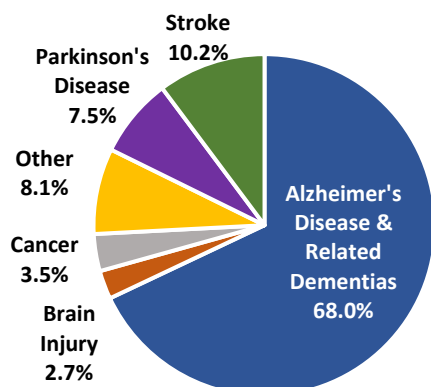
Care recipients had a mean of 3.6 comorbid chronic conditions. Caregivers reported that for the majority of care recipients (87.3%), the medical condition is worsening. Almost all care recipients (91.5%) experience some degree of memory loss, and nearly two-thirds require constant care, able to be left alone for less than an hour (21.3%) or not at all (41.4%).

Table II-d: Care Recipient Health

n= 5,944	%
Number of Comorbid Chronic Conditions Mean 3.6, SD 2.0	
0	2.6
1	7.9
2	20.3
3	23.9
4 or more	45.3
Medical Condition is Worsening	87.3
Experiences Memory Loss	91.5
Care Recipient Can Be Left Alone	
Always	8.3
Several Hours	29.0
<1 Hour	21.3
Never	41.4
Care Recipient Wanders	15.6
Documents in Place	
Advanced Health Care Directive	75.3
Durable Power of Attorney, Financial	57.5
Durable Power of Attorney, Healthcare	75.3
Guardianship/Conservatorship	5.2
Living Will	75.3
Physician Orders for Life-Sustaining Treatment (POLST) or Do Not Resuscitate (DNR)	31.7
Trust	42.9
Unsure of Documents in Place	14.2

*Among completed assessments; deduplicated by care recipient; percentages may not add to 100 due to rounding

Care recipients have fairly high levels of health service use: Nearly two-thirds had 3 or more outpatient visits, about half had at least one emergency department (ED) visit, and one-third had at least one hospitalization in the past 6 months (Figure II-f). Most care recipients had at least some healthcare documents in place, most commonly advanced health care directives, healthcare durable power of attorney, and living wills

Figure II-f: Care Recipient Health Service Use

(75.3%), financial durable power of attorney (57.5%), trusts (42.9%), and POLST or DNR orders (31.7%).

Characteristics of Caregiving

Caregiving characteristics, reported in Table II-e, describe the care recipient's healthcare needs and the nature of care provided by the caregiver. Nearly one-third of caregivers have been in their role for more than five years, one-quarter between two and five years, with the rest in the caregiving role less than two years. CRC caregivers engage in intense and complex care, with 73.2% providing care 40 hours per week or more, and 83.2% performing medical/nursing tasks. According to AARP's Care Intensity Index (calculated based on assistance with activities and weekly caregiving hours), 90.5% of CRC caregivers would be classified as providing high intensity caregiving. Despite these responsibilities, most caregivers (69.4%) receive no paid help, and only about half (52.1%) receive any unpaid help. About one quarter of the caregivers also report receiving no help from family and friends, and 54.5% report receiving less help than needed.

"...I never prepared for something like this... I always thought I was going to do it, but now I realize that if I get ill or something happens to me, I need to have someone else that my mother knows and that she feels confident to see her and be with her." **– CRC Caregiver**

~

"That was very hard, very difficult. They told me to get someone to help me, but my mother got so anxious, so dependent, that she didn't even want me to be away from her because she was afraid, and she didn't want to be alone if something happened." **– CRC Caregiver**

Table II-e: Characteristics of Caregiving

n= 5,944	%
Duration of Caregiving	
<2 Years	43.2
2-5 Years	26.8
>5 Years	30.1
Caregiver Performs Medical/ Nursing Tasks	83.2
Level of Care (AARP)*	
1-3	9.5
4	23.9
5	66.6
Care Intensity (AARP)*	
Low Intensity	3.1
Medium Intensity	6.4
High Intensity	90.5
Caregiving Hours Per Week	
0-10	6.6
11-20	7.4
21-39	12.9
40+	73.2
Paid Help Hours Per Week	
0	69.4
1-10	13.4
11-20	7.6
21-30	3.3
31-40	2.1
40+	4.1
Unpaid Help Hours Per Week	
0	47.9
1-10	30.7
11-20	8.2
21-30	3.6
31-40	2.9
40+	6.6
Perceived Help from Family & Friends	
Amount Needed	16.1
Don't Need Help	1.8
Less Than Needed	54.5
No Help	27.7

*Among completed assessments; deduplicated by care recipient; percentages may not add to 100 due to rounding; see Appendix B for calculation of AARP variables

Assistance with Activities

Direct Care Activities

Caregivers indicated how frequently the care recipient required help with fifteen direct care activities (no help, a little help, help most of the time, or help all the time). Table II-f reports the percentage of care recipients who needed any help and the percentage who needed help all the time for each task. Care recipients required at least some help with a median of 13 activities and help all the time with a median of 7 activities. Activities with the highest percentages requiring assistance were transportation, shopping, housekeeping, and managing money/finances, and preparing meals with the percent requiring any assistance ranging from 95.0%- 96.2% and the percent requiring assistance all the time ranging from 77.0%-90.9%.

Medical/ Nursing Tasks

Among the 3,203 caregivers (79%) who reported performing medical/ nursing tasks, they assisted with a median of 4 tasks (Table II-g), most commonly organizing medications (93.4%), administering oral medications (75.2%), managing meters/ monitors (48.0%), managing durable medical equipment (45.6%), and preparing special diets (36.4%) (Figure II-g). Around one-third somewhat agreed and 12.9% strongly agreed that performing these tasks was difficult, although most also somewhat (34.4%) or strongly (27.0%) agreed that they felt prepared to carry out these tasks.

Table II-f: Assistance with Activities

Activity (n = 5,944)	Needs Any Help (%)	Needs Help All the Time (%)
Bathing	81.5	44.2
Dressing	78.0	34.4
Eating	54.5	15.1
Grooming	75.6	30.4
Housekeeping	95.2	77.0
Incontinence	70.1	35.0
Managing Medications	92.4	68.2
Managing Money/Finances	95.0	82.5
Mobility	73.9	32.1
Preparing Meals	94.7	77.4
Shopping	95.9	85.7
Toileting	67.0	31.2
Transferring	67.8	30.5
Transportation	96.2	90.9
Using Telephone	77.2	43.7
Total Number *Mean (SD)*	11.7 (3.8)	7.4 (4.4)
Total Number *Median*	13	7

*Among completed assessments; deduplicated by care recipient; percentages may not add to 100 due to rounding

Table II-g: Assistance with Medical/Nursing Tasks

n= 3,203	%
Mean Number of Tasks *(SD)*	4.1 (2.1)
Median Number of Tasks	4
Total Number of tasks, %	
1-3	43.1
4-6	40.2
7-10	16.7
Finds Medical/Nursing Tasks Difficult, %	
Strongly Disagree	17.6
Somewhat Disagree	14.5
Neutral	22.4
Somewhat Agree	32.6
Strongly Agree	12.9
Feels Prepared for Medical/Nursing Tasks, %	
Strongly Disagree	4.2
Somewhat Disagree	11.9
Neutral	22.6
Somewhat Agree	34.4
Strongly Agree	27.0

*Among caregivers who reported performing medical/ nursing tasks; deduplicated by care recipient; percentages may not add to 100 due to rounding

Figure II-g: Tasks Performed by Caregivers who Reported Performing Medical/ Nursing Tasks

Task	Percentage
Organize Medications	93.4%
Administer Oral Medications	75.2%
Manage Meters and Monitors	48.0%
Manage Durable Medical Equipment	45.6%
Manage Pain	37.8%
Prepare Special Diets	36.4%
Skin/Wound Care	33.3%
Administer Injections	23.5%
Manage Medical Devices or Equipment	15.5%
Other	5.4%
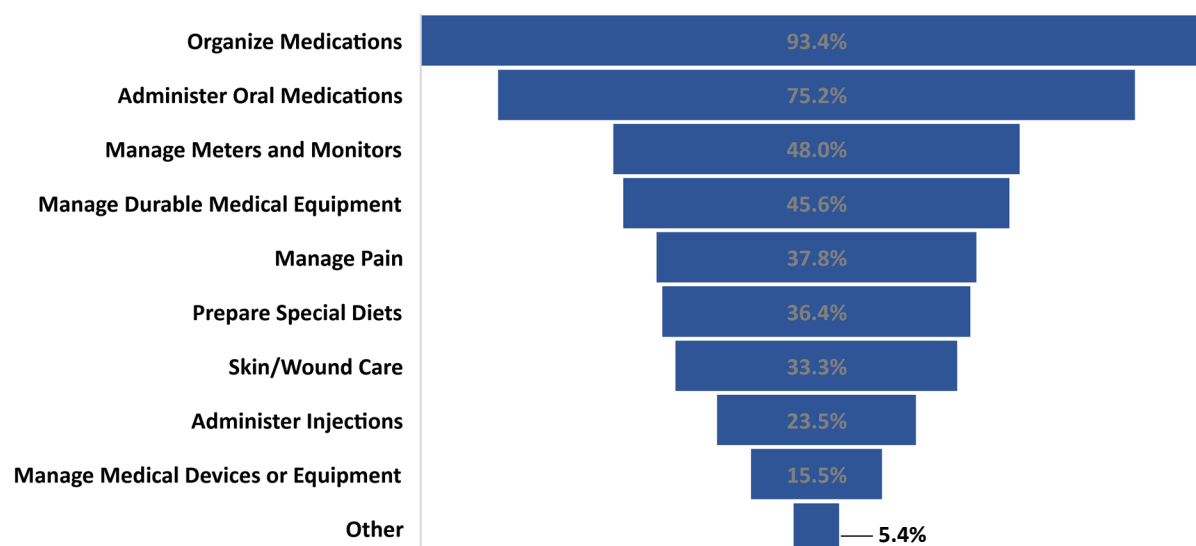
"The care I provide has to be for everything. I prepare her meals, I change her, bathe her, I inject her, check her blood, administer her medications, everything… Both [my parents] take a lot of medications. I have to inject their insulin, check their sugar levels, give them their inhalers. My father has oxygen 24 hours a day… If I have to go out during the day, I inject my mother in the morning, and I try to come back when I have to...administer medication." – CRC Caregiver
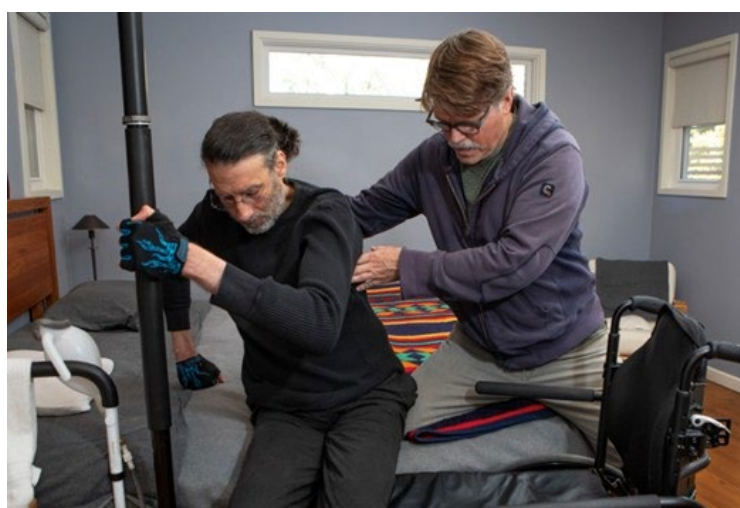
Behavior Problems Checklist

Caregivers who reported that the care recipient exhibited problems with memory or confusion-related behaviors (n= 3,392) completed a memory and behavior problems checklist, indicating which of 15 behaviors occurred and the degree to which it bothered them (Table II-h). The most commonly reported behaviors were trouble remembering recent events (78.1%), forgetting what day it is (71.4%), asking the same question over and over (68.0%), and losing or misplacing things (58.8%). The behaviors most often described as "extremely bothersome" included arguing/irritability/complaining (22%), being aggressive to others verbally (21.4%), engaging in dangerous behaviors (21.1%), and waking the caregiver or others up at night (20.2%).

Table II-h: Behavior Problems Checklist

n= 3,392	Occurred in Past Week (%)	If yes, how much has this bothered or upset you? (%)		
Problems with:	Yes	Extremely	Moderately	Not at All
Asking the same question over and over	68.0	15.8	50.0	34.2
Trouble remembering recent events	78.1	16.7	43.9	39.5
Trouble remembering significant past events	45.8	13.9	42.2	43.9
Losing or misplacing things	58.8	19.9	45.4	34.7
Forgetting what day it is	71.4	14.7	33.9	51.4
Starting, but not finishing, things	47.9	17.3	42.8	39.8
Difficulty concentrating on a task	56.7	17.0	43.7	39.3
Destroying property	6.8	10.7	15.4	73.9
Doing things that embarrass you	17.2	15.2	33.1	51.7
Waking you or others up at night	38.1	20.2	38.8	41.0
Talking loudly and rapidly	13.3	12.5	23.5	63.9
Engaging in dangerous behavior	14.9	21.1	22.6	56.3
Threats to hurt others	5.0	10.6	10.9	78.4
Aggressive to others verbally	21.6	21.4	33.3	45.3
Arguing, irritability/complaining	44.1	22.3	46.4	31.3

*Among caregivers who reported experiencing memory-related behavior problems; deduplicated by care recipient; percentages may not add to 100 due to rounding

Caregiver Health & Caregiving Outcomes

The stress of caregiving can impact the health and wellbeing of family caregivers. Among CRC caregivers, only around 6.2% report being in excellent and 19.6% in very good health, with one-third reporting that their health is worse than it was 6 months ago. Approximately 1 in 5 experience moderate to severe depressive symptoms, and significant loneliness, while 60.5% experience high caregiving strain. On the positive side, 31.6% report being very satisfied with support from family and friends, while 44.7% are very satisfied with spiritual support (Table II-i.1).

More than half of caregivers have at least one chronic condition, with nearly one quarter having 3 or more. Most commonly identified condition categories were "other" (57.1%), anxiety (44.1%), sleep disorders (33.9%), and depression (31.9%). Most caregivers had at least some healthcare documents in place, most commonly advanced healthcare directives, healthcare durable power of attorney, and living wills (67.6%) (Table II-j).

Table II-i.2: Caregiver Health and Caregiving Outcomes

n= 5,782	%
Medical Conditions	
Anxiety	44.1
Arthritis	21.7
Cancer	4.8
Cardiovascular Disease	9.5
Depression	31.9
Diabetes	11.7
Gastrointestinal	8.6
Chronic Pain	24.9
HIV AIDS	0.2
Kidney Disease	1.8
Liver Disease	1.5
Other Health Condition	57.1
Parkinson's Disease	0.4
Respiratory Condition	6.0
Sleep Disorder	33.9
Stroke	1.0
Mean Total Number of Medical Conditions *(SD)*	1.4 (1.8)
Number of Medical Conditions	
0	45.8
1	16.7
2	14.5
3 or more	23.0
Documents in Place	
Advanced Healthcare Directive	67.6
Durable Power of Attorney, Financial	47.2
Durable Power of Attorney, Healthcare	67.6
Living will	67.6
POLST/DNR	25.6
Trust	48.8
Unsure	19.9

*Among completed assessments; deduplicated by caregiver; percentages may not add to 100 due to rounding

Table II-i.1: Caregiver Health and Caregiving Outcomes

n= 5,782	%
Self-Reported Health Status	
Excellent	6.2
Very Good	19.6
Good	40.8
Fair	27.1
Poor	6.3
Current Health Compared to Six Months Ago	
Better	8.6
Same	56.6
Worse	34.8
PHQ-9 (Depressive Symptoms)	
None	38.2
Minimal/Mild	42.6
Moderate	13.2
Moderate/Severe	4.6
Severe	1.5
UCLA-3 Loneliness Scale	
Not Lonely	77.5
Lonely	22.5
Zarit Burden Interview	
<8 (low strain)	39.5
8+ (high strain)	60.5
Satisfaction with Support from Family and Friends	
Very Satisfied	31.6
Neutral	32.5
Somewhat Dissatisfied	21.0
Very Dissatisfied	14.9
Satisfaction with Spiritual Support	
Very Satisfied	44.7
Neutral	43.1
Somewhat Dissatisfied	8.6
Very Dissatisfied	3.5

*Among completed assessments; deduplicated by caregiver; percentages may not add to 100 due to rounding

"She asked me though if I considered suicide, and I said yes [crying]. It's something I'm not proud about, but oh, I was tired." – CRC Caregiver

Nearly two-thirds of caregivers reported having an outpatient healthcare visit in the last 6 months, 13% had one or more ED visits, and 5% had at least one overnight hospital stay (Figure II-h).

Figure II-h: Caregiver Health Service Use, Last 6 Months

Summary

CRCs serve caregivers who provide complex, intense, and time-consuming care. Caregivers are often the primary or only caregiver in the situation and commonly have little family or paid support. Caregivers support persons with a range of health conditions, including a large population of persons with Alzheimer's Disease or a related disorder. Almost all caregivers served by CRCs provide a high level of care and devote a great deal of time to their role. Despite these heavy demands, most received no paid help and almost half received no help from family or friends.

Caregivers experience health issues themselves, with the majority reporting fair or poor health, and one-third reporting that their health is worse than it was 6 months ago. Approximately 1 in 5 experience moderate to severe depressive symptoms, and significant loneliness, while two thirds experience high caregiving strain.

More than half have been caregiving for over 2 years, and about 40% remain in the workforce, indicating the intensity of caregiving demands. Of those still working, about 15% made employment modifications to accommodate their caregiving responsibilities, thus increasing potential financial strain.

"It's really big.... caregiving is physically, mentally and emotionally demanding. The emotional element is a big part of it…" – CRC Caregiver

III. SERVICES PROVIDED

CRC Case Status Summary

In FY 2022-2023, the 11 CRCs together provided services for 13,904 unduplicated family caregivers. They conducted 6,360 intakes (site mean: 578) and opened 3,895 "new cases" (site mean: 354), 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). In each quarter, the sites also followed an average of 7,010 "ongoing cases with activity" (site mean: 637), defined as caregivers having an assessment in the past two years and receiving one or more services each quarter (e.g., family consultation, reassessment, counseling, vouchered services) throughout FY 2022-2023. Another 11,162 cases were "open with no activity", having an assessment in the last two years but no services in FY 2022-2023.

Table III-a: Case Status Summary – All California CRCs Combined

	FY 2022-2023
New Cases	3,895
Ongoing Cases with Activity	7,010
Ongoing Cases no Activity	11,162
Total Open Cases	12,278

* Definitions - refer to Appendix A: Glossary
* Inclusion Criteria – refer to Appendix B: Technical Specifications
* Case Status Counts – refer to Appendix B: Technical Specifications.

CRCs provided more consultations, support groups, and counseling to California caregivers in FY 2022-2023 than in the previous years.

"Open cases" (i.e., the sum of new and ongoing unique cases) in FY 2022-2023 totaled 12,278 for all CRCs (site mean: 1,116) (Table III-a). This year for this first time, these counts reflect full CareNav™ implementation for the past two years and complete data from all sites.

Intake

The 11 CRCs conducted a total of 6,360 initial intakes or caregiver screenings in FY 2022-2023 (site mean: 578; Table III-b). Of these, approximately 39% were initiated by the caregivers using the CareNav™ portal. 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.

Table III-b: Caregiver Activity Summary – All California CRCs Combined

	FY 2022-2023	FY 2021-2022	FY 2020-2021
Intake, _n_	6,360	6,648	6,126
Assessment, _n_	4,038	4,433	4,299
Reassessment, _n_	3,501	3,326	2,856
Family Consultation, _n_	158,177	133,666	126,312
Support Group, _unique caregivers_	1,172	1,054	920
Individual Counseling, in house _unique caregivers_	204	174	119
Individual Counseling, vouchered _unique caregivers_	217	267	--

* Definitions - refer to Appendix A: Glossary
* Inclusion Criteria – refer to Appendix B: Technical Specifications
* Unreported Delivery Mode – refer to Appendix B: Technical Specifications

Assessment

Of the caregivers completing intakes, 4,038 (63%) moved forward to full assessment (site mean: 367). Most caregivers had one assessment completed this fiscal year. 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.

Reassessment

Together the sites conducted 3,501 reassessments (site mean: 318), following up with caregivers who had a full initial assessment, typically within six months.

Family Consultation

In total, the CRCs completed 158,177 family consultations (site mean: 14,380), with each caregiver on average having between 2 to 17 encounters.

"...Having that family consultant is really key to the services... because they know what's available. They can figure out what you need, and they match. They're like a matchmaker." – CRC Caregiver

Support Groups

1,172 unique caregivers participated in professionally led support groups across all 11 sites (site mean: 107). These services are facilitated by licensed social workers and do not include peer-led support groups.

Individual Counseling

Seven CRCs (Coast, Del Mar, Del Oro, Inland, Orange, Southern and Valley) provided "in-house" counseling sessions for 204 unique caregivers (site mean: 29) and seven (Bay Area, Coast, Del Oro, Los Angeles, Passages, Redwood, Valley) offered individual counseling vouchers to 217 unique caregivers in the community (site mean: 31). Overall, 421 unique caregivers were offered individual counseling sessions by all eleven CRCs through either "in-house" services or grant vouchers.

Variability in the reported activities by site has several possible explanations: 1) differences in overall site volume and caregivers eligible for CDA 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™.

"I think most definitely. From the day one, when I called...the phone number on that page, it was almost like I was a balloon that needed to pop, and they were able to slowly let the air out and give me some peace, some confidence, some backup by having the respite care, and some techniques, and knowledge, and a shared sense of being by being in the group." – CRC Caregiver

Service Grant Vouchers

The CRCs provide vouchers for specific services to eligible caregivers (Table III-c). In FY 2022-2023, 572 vouchered transactions for counseling services totaling 1,051 hours ($100,338) were provided to 217 unique caregivers; 149 vouchered transactions for legal services totaling 172 hours ($22,726) were provided to 147 unique caregivers; 6,626 vouchered transactions were provided for respite care totaling 112,982 hours ($3,124,253) to 1,848 unique caregivers; and 491 vouchered transactions for supplemental grants ($173,615) were provided by six CRCs to 230 caregivers, typically for durable medical equipment or groceries.

In FY 2022-2023, total CRC spending for vouchered services declined. During the COVID-19 pandemic, staffing shortages freed up funds that the CRCs redeployed for additional respite and supplemental grants to caregivers. Accordingly, these declines reflect a return to prior spending patterns. However, there have been no cost-of-living adjustments to the contracted services, reducing the relative value of every dollar spent. Remarkably, the CRCs continue to prioritize respite spending at a similar rate and their service activity level is at or beyond prior years.

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

	FY 2022-2023	FY 2021-2022	FY 2020-2021
Counseling			
Transactions	572	716	714
Unique Caregivers	217	267	--
Hours	1,051	1,344	1,379
Amount	$100,338	$134,938	$131,451
Legal Consultation			
Transactions	149	169	147
Unique Caregivers	147	165	--
Hours	172	196	141
Amount	$22,726	$24,695	$16,140
Respite			
Transactions	6,626	6,801	6,513
Unique Caregivers	1,848	2,080	--
Hours	112,982	119,378	139,340
Amount	$3,124,253	$3,223,778	$3,426,469
Supplemental Grants			
Transactions	491	531	1,492
Unique Caregivers	230	344	--
Amount	$173,615	$130,765	$183,039

* Definitions - refer to Appendix A: Glossary
* Unique caregiver counts are not available for FY 2020 - 2021 due to issues with data completeness in CareNav™

CRCs spent $3,124,253 (or 21% of their collective budget) on respite services in this fiscal year, exceeding the 10% threshold specified in the contract.

Outreach and Education

In FY 2022-2023, the 11 CRCs and State CRC conducted 11,991 outreach activities and 1,916 education activities. There was a 20% increase since last year in reported public information and outreach activities (including social media posts) and presentations or meetings in the community this fiscal year. The number of reported education activities nearly doubled from 1,039 (FY 2021-2022) to 1,916 this year. Moreover, classes offered statewide jumped from 214 in FY 2020-2021 to 725 in FY 2022-2023 (Figure III-a).

Figure III-a: Statewide Classes Offered

■ Programs in English ■ Programs in Additional Languages
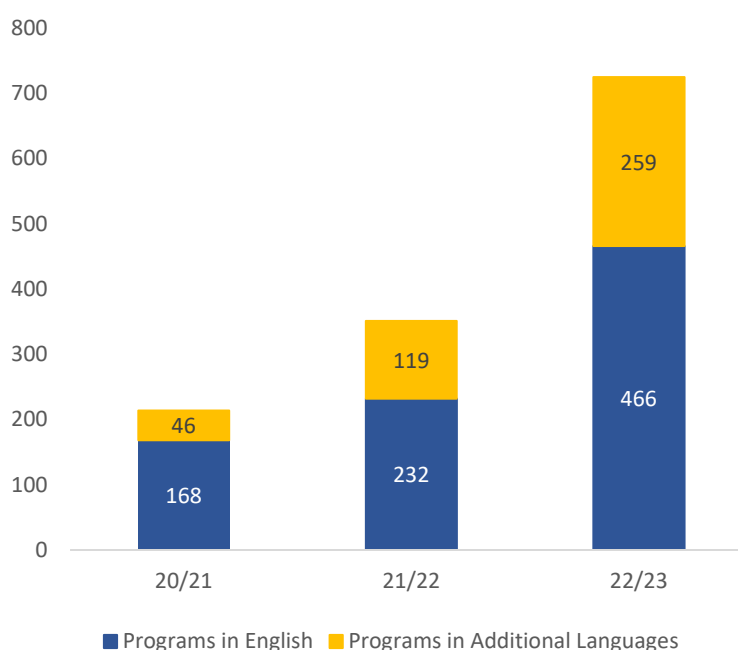
This section includes state-wide activities conducted by an outside organization ("State CRC"). Definitions related to outreach and education activities can be found in Appendix E.

"The classes and courses are awesome. The quality is just so good. I've learned so much, and it's made me be a better caregiver. I've learned that I'm not alone...It was good to know that our family wasn't this odd family that's having difficulty." – CRC Caregiver

Site-Specific Outreach Strategies

CRCs' outreach and marketing plans are tailored to their geographic catchment areas, populations served, and service needs of their region. CRCs had the option to include a narrative describing their unique approaches to outreach and efforts to reach diverse groups and target subpopulations. Please see Appendix E. for more information.

Outreach

Table III-d and Table III-e summarize outreach activities. Use of social media (Table III-d) was the most frequent mode of outreach (n = 5,863). Together, the 11 CRCs and State CRC conducted 6,128 outreach activities (Table III-e) reported as: meetings or presentations (n =3,534), health fairs (n =1,588) and public information or outreach (n =1,006). The CRCs saw a return to in-person gatherings with only 33.4% of meetings/fairs held virtually during this reporting period vs 87.1% in FY 2021-2022.

Social Media

Social media is utilized extensively by sites as part of CRC outreach campaigns (Table III-d). Almost all sites (*n* =10) and the State CRC use Facebook, and 75% use four or more social media platforms to promote their services. The CRC sites and State CRC together reported 5,863 social media outreach activities in FY 2022-2023, with 242,802 "subscribers" (also referred to as "followers", "friends" or "contacts") across six platforms. This is nearly a 300% increase from the previous year (FY 2021-2022 = 86,048). The number of subscribers varies substantially by site. The Bay Area CRC has a significant national following, which is reflected in their subscriber numbers (*n* = 172,830). The remaining sites that used social media noted a range of subscribers from 1,176 to 14,391, compared to 385 to 10,188 in FY 2021-2022.

Facebook continues to be the most frequently used social media platform by CRCs with 2,507 posts reported across sites in FY 2022-2023. This is followed by Instagram (*n* = 1,769), X (formerly Twitter) (*n* = 758) and LinkedIn (*n* = 687); YouTube (*n* = 108) is used less frequently. One site, Del Mar, began using TikTok this year and reported 124 followers and 17 posts.

Table III-d: Social Media Use

Site	Facebook	X	Instagram	YouTube	TikTok	LinkedIn	Posts Other
	Followers | Posts						
Bay Area	55,293 | 152	26,780 | 212		85,091 | 29		5,666 | 114	0
Coast							0
Del Mar	5,287 | 390		792 | 238		124 | 17		0
Del Oro	5,479 | 217	1,060 | 100	1,605 | 249	335 | 8		824 | 27	0
Inland	8,808 | 430	143 | 0	1,230 | 171	80 | 1			0
LA	2,187 | 198	1,453 | 144	1,322 | 177	663 | 12		7 | 10	0
Orange	3,596 | 160		1,694 | 146	2,173 | 9		406 | 142	12
Passages	1,176 | 137						3
Redwood	384 | 2		857 | 99	76 | 4			2
Southern	5,776 | 383	1,381 | 5	5,452 | 360	1,182 | 27		600 | 18	0
Valley	4,236 | 272	157 | 140	1,340 | 174			1,914 | 227	0
State CRC	1,574 | 166	756 | 157	2,611 | 155	478 | 18		754 | 149	0
Total	**93,796 | 2,507**	**31,730 | 758**	**16,903 | 1,769**	**90,078 | 108**	**124 | 17**	**10,171 | 687**	**17**

"It's a great service. I'm really glad I found out about them...I didn't know they existed...I didn't know there was such a thing... I'm thankful I found out about it." – CRC Caregiver

Fairs, Meetings and Public Information or Outreach

Health and Resource Fairs: All CRCs reported participation in health or resource fairs. Southern CRC classifies and records all in-person, informational outreach as a "health fair". They do not distinguish traditional "health fairs" from such activities as tabling at a public library in their tracking system. In FY 2022-2023, Southern reported 1,358 health fairs that reached 37,747 individuals. The remaining ten sites reported 230 activities (site mean = 23) that reached 54,200 people. Only 2% of health fairs were conducted virtually versus 89% in FY 2021-2022.

Meetings/Presentations: The CRCs held over 3,500 (*n* = 3,534) meetings / presentations during this reporting period with a third conducted virtually (vs 87.1% in the previous year). 80.8% were designed to reach diverse and underserved populations.

Public Information or Outreach: All sites reported some type of monthly communication to individuals in their contact lists. Sites reported public information or outreach activities such as monthly newsletters, periodic emails blasts and one-time notices regarding new services that targeted consumers, community members and providers (Table III-e).

Table III-e: Fairs, Meetings, Public Information or Outreach

Site	Health or Resource Fair		Meetings / Presentations		Public Information/ Outreach		Totals	
	# Events	Exposure	# Events	# Reached	# of Distributions	# Contacts	# Events	# Reached
Bay Area	18	1182	63	901	21	8,974	102	11,057
Coast	12	1,525	48	1,522	9	3,875	69	6,922
Del Mar	7	849	25	1,659	53	7,881	85	10,389
Del Oro	22	1,842	181	2,114	24	40,692	227	44,648
Inland	60	9,530	615	17,561	313	98,545	988	125,636
Los Angeles	7	257	269	951	67	22,920	343	24,128
Orange	31	21,220	109	6,939	34	361,865	174	390,024
Passages	12	1,185	122	965	159	62,405	293	64,555
Redwood	19	4,450	183	1,569	133	26,324	335	32,343
Southern	1,358	37,747	1,783	47,321	66	26,013	3207	111,081
Valley	42	12,160	133	3,959	107	85,705	282	101,824
State CRC	0	0	3	147	20	16,947	23	17,094
% D or U	97.0%		80.8%					
% Virtual	2.2%		33.4%					
Total	1,588	91,947	3,534	85,608	1,006	762,146	6,128	939,701

 * D or U refers to Diverse or Underserved Audiences

 * Definitions - refer to Appendix E: Outreach and Education Narratives Table E2

Education Activities

Together, the CRCs reach a large audience with their education activities. In this fiscal year, the CRCs conducted 1,916 education activities statewide that were attended by almost 28,000 people (Table III-f). Nearly 92 percent of the activities were conducted virtually. The number of activities conducted by site varied from 5 to 1,178 with median of 57 across the 11 CRCs.

Statewide Activities

The CRCs partner on a shared calendar featuring on-line education activities that are accessible to caregivers across California. In addition to site-level education activities, a total of 725 classes were offered FY 2022-2023 statewide, more than double those offered in FY 2020-2021. Of those classes, half were offered in a language other than English.

Media

Sites use a variety of media channels to promote caregiver services, including media appearances; print, radio and television, and internet ads; outdoor advertisements (e.g., ads on benches, billboard), and public service announcements. The number of channels used by site ranges from 0 to 7 (Table III-g).

Table III-f: Education Activities

Site	Total Activities	Total # of Participants
Bay Area	51	1,500
Coast	5	145
Del Mar	15	343
Del Oro	68	1,767
Inland	233	2,199
LA	67	2,694
Orange	168	4,446
Passages	46	826
Redwood	28	2,687
Southern	1,178	10,571
Valley	57	821
% D or U	**86.0%**	
% Virtual	**91.5%**	
% Phone	**0.2%**	
Total	**1,916**	**27,999**

* D or U refers to Diverse or Underserved Audiences
* Definitions - refer to Appendix E: Outreach and Education Narratives Table E2

Table III-g: Media Channels Used to Promote Services | Fiscal Year

Site	Print ad	Radio ad	Television ad	Internet ad	Outdoor	Media Appearance	PSA
Bay Area	✔	✔	✔	✔	✔	✔	✔
Coast	✔						
Del Mar	✔		✔		✔	✔	✔
Del Oro							
Inland							
LA	✔						✔
Orange	✔	✔	✔	✔	✔	✔	✔
Passages	✔	✔	✔	✔			
Redwood	✔		✔				
Southern		✔		✔	✔	✔	✔
Valley	✔	✔	✔	✔	✔		✔
State CRC					✔		✔
Total	8	5	6	4	6	3	7

Referral Source

As part of the intake, care consultants ask caregivers how they heard about CRC services (Figure III-b). Social service (26%) and health care (24%) providers are the leading source of referrals, followed by word of mouth from family and friends (16%), media outreach (13%), and direct referrals from the CRCs (9%).

Figure III-b: Referral Source for FYs 20/21, 21/22, and 22/23
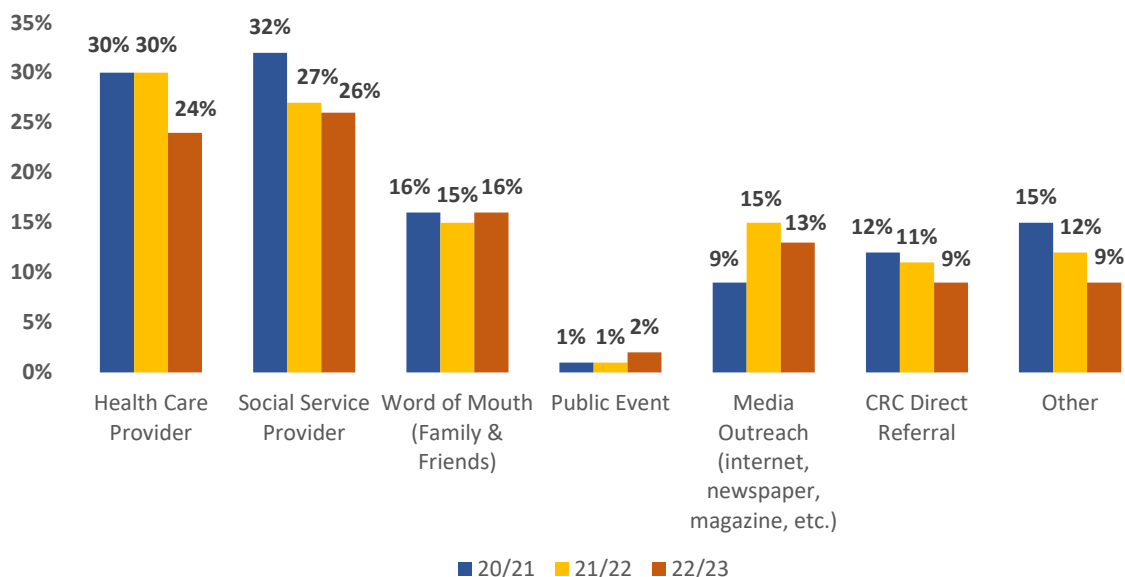
Summary

The CRCs have substantially increased their outreach and education over the past year. Public outreach increased and educational program offerings nearly doubled, including statewide programs in English and other languages. CRCs have realized efficiencies in delivery because base funding has remained the same over the past three years, without cost-of-living adjustments. Further expansion would likely require enhanced investment. The following quotes illustrate the impact that outreach and services have on caregivers who are not yet ready to accept help and those who are:

"I'm the helper. I don't get help from others. Asking for help, it's hard. That was a real personality change for me. One of my college roommates said, the world is off its axis because you're asking for help... I've done a lot of growing in two years." **– CRC Caregiver**

"It really has made such a difference in my life... when I'm happy, I'm better at helping him [care recipient]. If I'm on empty, he's getting nothing… it's such a valuable resource to have. I would love to see this continue and grow." **– CRC Caregiver**

IV.   CAREGIVER EXPERIENCE

Caregiver Satisfaction Survey

Description of participants

Satisfaction surveys were sent via mail or e-mail on a quarterly basis to all caregivers who had some form of contact with the CRCs. For the year, 2,229 caregivers provided their feedback on services received. We did not collect demographic data in these anonymous surveys. In addition to responding to the survey items, caregivers were invited to make comments about the services. Caregivers provided 1,210 comments about the services. Forty comments were provided in Spanish. The comments address overall CRC services (519, 40%), and/or specific services, mainly family consultation (259, 20%), respite care (178, 14%), training and education (96, 7%), support groups (85, 7%), counseling (54, 4%). A few comments addressed CareNav™, assessment, equipment, financial and legal consultations, other grants (except for respite). Forty percent of the comments (548) describe how services helped and the impact of the services on caregiver and care recipient experiences. Eighteen percent of the comments (233) reflect challenges and future suggestions. An additional 381 comments address reasons for not using CareNav™.

Survey results

Caregivers are highly satisfied with their CRC experiences; with 79% reporting they are extremely satisfied and 14% somewhat satisfied (Table IV-a). The vast majority would recommend the CRC to others, with 84% definitely and 10% likely to recommend. Results from this year are very similar to the previous two fiscal years.

Table IV-a: Satisfaction Surveys: Impact of Services for FYs 20/21, 21/22, and 22/23

Response Options	Overall Satisfaction (%)			Response Option	Recommend CRC to Friend or Family Member (%)		
	FY 20/21	FY 21/22	FY 22/23		FY 20/21	FY 21/22	FY 22/23
	n = 2,869	*n* = 2,624	*n* = 2,229		*n* = 2,869	*n* = 2,624	*n* = 2,152
Strongly Satisfied	81.7	78.6	78.9	Definitely Recommend	84.2	83.7	84.1
Somewhat Satisfied	10.7	13.5	13.6	Probably Recommend	10.3	10.1	10.0
Neutral	3.5	4.2	3.9	Neutral	3.5	3.7	4.1
Dissatisfied	1.6	1.6	1.3	Probably Not Recommend	1.0	1.3	0.8
Extremely Dissatisfied	2.6	2.2	2.2	Definitely Not Recommend	0.9	1.1	0.9

*Percentages may not add to 100 due to rounding.

The survey explored the impact the services had on the lives of the caregivers, with mean scores displayed in Table IV-b. Scores range from 1 (Strongly Disagree) to 5 (Strongly Agree) with 5 indicating the most positive impact. Scores remain consistent across years. The results indicate strong impact in confidence, ability to manage care,

access community resources, understand the disease/disability and issues, care for their physical and mental health, and feel less stressed.

Table IV-b: Satisfaction Surveys: Mean scores for FYs 20/21, 21/22, and 22/23

Item	FY 20/21 *n* = 2,869	FY 21/22 *n* = 2,624	FY 22/23 *n* = 2,254
More Confident as a Caregiver	4.17	4.15	4.18
Better Able to Manage Care	4.19	4.17	4.19
More Knowledge and Awareness	4.29	4.30	4.31
Understand the Disease/Disability/Problem Better	4.08	4.06	4.10
Taking Better Care of Self	4.03	3.98	4.06
Less Stressed	3.91	3.83	3.92

"I swear if they weren't in my life I just wouldn't have as many smiley days as I do have." – CRC Caregiver

Focused Interviews

Description of Participants

We interviewed twenty-eight caregivers from 10 CRCs, three in Spanish. Of these caregivers, fourteen (50%) caregivers are partners/spouses of the care recipient, twelve (43%) are adult children and two reported other relationships with the care recipient. Six (21%) caregivers indicated that they are currently working, eighteen (64%) indicated provided 24/7 are for the caregivers. These caregivers had all completed assessments and engaged in one or more CRC services. Table IV-c summarizes the demographic characteristics of the interview participants.

Caregiver Experiences with Services

Findings about caregiver experiences include comments on satisfaction surveys and individual client interviews.

Reasons for Initial Contact with the CRC

Caregivers reached out to CRCs for various reasons, including changes in the health and functional abilities of the care recipient, the recognition of stress or health concerns for themselves, because they were seeking a specific service or support, and when another family member identified the need for additional supports.

Cognitive change or a diagnosis of dementia motivated some caregivers to seek further information about the disease and its trajectory, as well as how to care for and support a person with dementia. They sought insight from the CRCs about what to expect and how to plan ahead. Others called the CRCs when they were looking for specific services such as legal assistance or wanted access to respite care or were seeking information and potential financial assistance for care options such as assisted living or paid caregivers at home.

Caregivers also reached out for help when they felt overwhelmed and stressed, often triggered by growing intensity in the caregiving situation related to increased care demands. These demands sometimes included the development of conflict within the family or challenge in the ability of the caregiver to continue working. While some working caregivers had support from their employer, such as providing Family and

Table IV-c: Interview participant characteristics

Characteristic (n = 28)	n (%)
Age	
26-35	2 (7.1)
36-45	0
46-55	5 (17.9)
56-65	9 (32.1)
66-75	8 (28.6)
76-85	3 (10.7)
Gender	
Female	19 (67.9)
Male	9 (32.1)
Racial identity*	
African American or Black	2 (7.1)
Asian	1 (3.6)
Hispanic/Latino	5 (17.9)
Native American	1 (3.6)
Pacific islander	1 (3.6)
White or Caucasian	18 (64.3)
Sexual orientation	
Heterosexual	26 (92.9)
LGBTQ+	2 (7.1)
Geographical area	
Urban	6 (21.4)
Suburban	13 (46.4)
Rural	8 (28.6)

*****Percentages may not add to 100 due to multiple racial identities and due to missing data**

Medical Leave (FMLA), this was not adequate for those providing intense care. Sometimes other family members encouraged caregivers to seek additional support as they witnessed the toll caregiving was taking on the primary caregiver. Some caregivers were experiencing health concerns of their own and wanted to find extra support so they could continue caring, or to identify resources as they planned for the future.

Caregivers shared their initial reluctance to seek help, hoping to manage on their own, but ultimately realizing that they needed more support to manage their situation and the stresses they experienced. They referred to having to shift their perceptions about themselves from the person helping to one who also needs help, particularly if they were also in a professional role of helping others. Many reflected that it takes time to recognize that one needs help and to be ready to accept support. One caregiver who was encouraged by the MS community several times to contact the CRC stated,

> *"The first time I heard about them, I just poo-pooed it and didn't really need them - a couple of years ago. It was through someone else mentioning, again, through a referral and how great they were for them. This might add to the process of getting, accepting help - the time it takes to recognize the needed help and being able to accept it."*

Another caregiver stated,

> *"Opening up to all that, with the [CRC name] coming into my life, it had to be me that accepted it, even though my daughter found it."*

Referral Sources

Caregivers found the CRCs in a number of different ways. **Health care providers** for the person with dementia were very helpful when they made a referral for the caregiver, particularly when the caregiver was not aware of their own needs nor the resources that could be available to them. In some cases, the caregiver's primary care provider recognized depression in the caregiver and made the referral for counseling and support. Psychologists referred caregivers for additional support. Social workers played an important role in identifying needs in caregivers and providing information about CRC programs and services.

A variety of **community agencies** connected caregivers to the CRCs, including librarians, senior resource centers, meal programs, adult day care programs, disease-based associations (such as for Parkinson's Disease, Multiple Sclerosis, Alzheimer's Disease) and the social security office. These referrals were particularly effective when the staff member at the agency could describe how the CRC could address a need that the caregiver had identified, reinforcing the importance of educating community agencies about the scope and services of the CRCs. When the CRC was involved more formally with a community agency, the referral was even more effective. Listings in local senior resource guides in the form of pamphlets in health care offices were helpful for some caregivers in locating the services.

Word of mouth, in the form of referrals from peers, friends, families and members of their places of worship, was a powerful source of information, especially when they provided instruction on how to make contact. In some instances, it was particularly helpful when friends or families contacted the CRC and asked them to reach out to the caregiver. Several caregivers actively referred friends and family to the CRCs because they saw such benefit in this resource and recognized the needs in others. Some found the CRCs with internet searches and signed in through CareNav™. One caregiver reported that,

> *"I really needed help, I was crying, and just went to the internet searched using keywords and emailed everyone who might help. I literally just would email…and saying, "Can you help me? Can anyone help? Is there anything you can do? Can you help me in any way?" It literally was just a cry for help."*

Caregivers also identified opportunities for improved outreach to community agencies, citing instances of agencies in their local community that they expected would know about CRCs not knowing or making appropriate referrals. These included In-Home Supportive Services (IHSS) and the local hospital. Several indicated that they wished they had known about the services sooner, but they had been totally unaware of the CRCs as a community resource.

Perspectives about CRC services and impact for caregivers

The most frequently discussed services were family consultations, respite care, support groups and training and education, with an emphasis of the crucial impact of the supporting/personal interaction and coordinating role of the family consultant. For many, the CRCs provide the most important contact outside the home, and these caregivers value staff checking in with them. The CRCs were described as "lifesaving" and "life changing" by many participants. Overall, caregivers expressed deep appreciation for this resource, both lauding the compassion, expertise and kindness of the staff and the availability of supports and services across the trajectory and unpredictability of their needs.

Caregivers described their process of establishing a relationship with the CRCs, starting with an intake interview, followed by a comprehensive assessment recorded in CareNav™, development of an action plan, referral to appropriate services or supports, and subsequent check-ins. Caregivers report accessing services in multiple ways, over the phone, via e-mail, by using the website and in-person. During the initial intake, the CRC family consultant typically gathered information, introduced the services the CRC offers or made referrals, and followed up with written or e-mailed information. Following the full assessment, the caregiver and family consultant agreed to initial actions. The assessment also established eligibility for vouchers for certain services such as respite, counseling and legal consultation. These grants were administered by the CRC with services provided by external entities.

Overall Impact for Caregivers. Caregivers identified multiple ways the CRCs had improved their situation and their lives. The words "lifesavers" and "life-changing" were repeated across interviews. First and foremost, caregivers felt heard and understood. Many had previously been dealing with their situations alone and felt isolated and unsupported. The family consultants conveyed compassion and assisted the caregivers to prioritize their needs and to identify potential solutions. The advice that the family consultants gave was highly valued and reassuring. Many valued having a sense of what to expect in the future, and with anticipatory guidance, having a plan to address new challenges. By connecting with the CRCs, caregivers felt more visible and cared for, and with the supports available, were able to focus more on self-care. For some, engagement with the CRCs meant reestablishing or maintaining ties with others in the family and friend circle, in the community and at work, increasing meaningful connection and reducing isolation. Most report having better mental health, being more confident in the role, feeling less stressed and anxious, and able to be more present for the person in their care. The personal contact and problem-solving that the CRCs provided during the COVID-19 pandemic was critical for many caregivers, who experienced financial and social hardships and greater isolation. Some caregivers anticipate continuous CRC impact along the trajectory of the care recipient's condition.

The following quotes reflect common sentiments across the interviews:

"The staff in the CRC…are professional and very compassionate, understanding and reassuring. This is supportive and appreciated."

"CRC is pretty much the only ones I do have to talk to. Like I've said a thousand times, they've been so helpful to teaching me and preparing me and helping me cope. It's really been an extremely useful thing."

"I came into CRC unexpecting and not knowing really what it was all about, and I've just been just completely in awe of what they've offered and done and supported in the last two years. I honestly don't think I could have done this without them."

"I have taken advantage of what they have available, and I feel like I have benefit and grown because of that…I don't think I could have come this far without them. I really needed their support because being full-time, night and day caregiving for anybody is hard. It's hard work… to not have support from outside would be really claustrophobic."

"Thank God I have them. Thank God for their compassion. Thank God I can do the Zoom. Thank God. Just thank God."

"They walk in the journey with you, and that's a big support 'cause most people are isolated."

"From the day one, when I called…the phone number on that page, it was almost like I was a balloon that needed to pop, and they were able to slowly let the air out and give me some peace, some confidence, some backup by having the respite care, and some techniques, and knowledge, and a shared sense of being by being in the group."

Impact for Care Recipients. In addition to benefits to themselves, caregivers discussed benefits to the individuals in their care. Because the caregivers felt better prepared and more able to manage their own stress, they saw improved mental health and connection with care recipients. Many who chose respite, adult day care or paid help, felt restored, more patient and able to be more loving and compassionate. They reported improved relationships with the care recipient and an increase in pleasant events. There were direct effects for care recipients who received respite care or adult day care, through greater socialization, more varied activities and more attention to their health and well-being. CRCs also facilitated access to services such as Meals on Wheels, home modification and specialized equipment that improved physical health and functioning.

Almost all caregivers mentioned and appreciated the family consultants and respite care, followed by training and education. About 75% of the interviewees discussed support groups and about half identified counseling sessions as helpful. The following sections summarize perspectives on specific services and supports. Table IV-d summarizes the impressions caregivers shared about specific services and the impact they had on their lives.

Table IV-d: Caregiver Experience and Impact of Specific Services

Service	Caregiver Experience	Impact
Family Consultation	Feel heard and that they matter Counselor is experienced, responsive, warm, caring, supportive, encouraging, knowledgeable, compassionate Help to brainstorm and make decisions Safe place for getting good advice, learning Validating/reassuring caregiver emotions Understanding of complex situations and care recipient condition. Anticipatory guidance Having an action plan and supporting following through Increased awareness of services, easier access to services Timely and regularly available consultations	Someone to talk to, less lonely Addresses caregiver self-care Enables ongoing engagement at work, leisure, service Encouragement to accept help from others Made life more manageable Better mental health – more confident, secure, less stress and anxiety, more hope Enjoying time with the care recipient Better atmosphere for care recipient Able to continue being a caregiver and providing better care for the care recipient
Respite	Peace, knowing there is backup Ability to attend to other duties, such as shopping, chores Retreat and restoration Realize that others can help with intense care Socialization, and enjoyable activities for the care recipient	Better mental health -more relaxed, less anxious Able to take care of own health needs Able to rest, sleep, restore Enables caregiver to work and see friends and other family members Sense of wellbeing and hope More joy for the care recipient
Support groups	Warm, safe, and comfortable space Shared experience and support Learned strategies from others going through similar experiences Acknowledgement from other caregiversHelped make decisions Encouraged self-care	Building confidence Feel less alone, less isolation Expand social network Improved relationship with care recipient Reduced stress, improved mood, increased patience and strength
Education/ Training	Valuable information for caregiving Shared experience and support Guidance for decision-making and long-term planning Management of unexpected caregiving situations Better access to services (help with navigation)	Increased capacity to care and to prepare for the future Reassurance and reduced stress Reduced isolation and frustration Better care for the care recipient
Counseling	Emotional support and guidance Help prioritizing decisions and actions Help dealing with expectations Improved communication skills	Reduced stress, anxiety and better coping strategies Personal growth, becoming a better person Improved interpersonal relationships Reassurance of having a plan for the future
Equipment/ Supplies	Assessment of needs and potential solutions Procurement of equipment and supplies Timely and flexible supply	Relief and support for providing care Increased safety for caregiver and care recipient
Legal-financial	Information and advocacy Access to expertise	Resolving legal matters Developing plans for future

Family consultation

Almost all caregivers identified their family consultant as a vital resource, describing them as professional, compassionate, and understanding of complex situations. Importantly, they were trusted and available for conversation, advice, and support. Many caregivers mentioned the importance of feeling heard, affirmed, and knowing that they were not alone. Family consultants typically established a safe space for an ongoing relationship and planned a series of conversations. They guided caregivers through identifying needs and actions, taught new strategies to approach complex situations, provided information and perspective. These caregivers captured the sentiments of their peers,

> " I think they're lifesavers in terms of having someone that understands caregiving and can help you because you feel so isolated, you feel so, alone in your own process. When you talk to someone that can help you work through those issues or concerns or thoughts 'cause it's not always a good feeling."

> "If they can continue just doing great at checking in, just—they just let me know that I matter and my mom matters and all that. I think they're doing a fantastic job. Just asking me, "What else do you need?"

Family consultants customized their interactions according to client preferences, connecting via phone, Zoom, in person, or e-mail. Continuity and responsiveness contributed to building effective relationships that combined addressing current needs, while anticipating future challenges and planning ahead to avoid a crisis. Regular check-ins enabled the caregiver to share updates and identify new resources. In some instances, caregivers needed time to accept help and the ongoing conversation enabled them to become ready to take action as they developed trust and the family consultant provided encouragement and continued to offer potential support. Family consultants worked with clients to determine eligibility and alternatives for services, provided referrals for legal or financial assistance, suggested appropriate equipment and supplies, and assisted with navigating complex systems, such as housing and MediCal/Medicare.

Challenges. Because of the close relationship between caregivers and family consultants, staff turnover posed the most significant challenge for clients. This challenge was mitigated when the family consultant made an introduction to the new staff member, and when new consultants were well prepared for the role. Some caregivers commented on family consultants with less experience not being as responsive and proactive as those with more experience and their concerns about the workload of the family consultants. Variability in the follow-up intervals was a concern for some caregivers who wished to have more frequent check-ins. One caregiver was on a waiting list for an assessment.

Impact. The relationships with the family consultant had a major impact for caregivers. The personal connection and continuity of relationship was reassuring and enabled the

caregiver to establish trust so that they could share difficult experiences and emotions. The family consultants contribute to better mental health, lower anxiety and loneliness and a greater ability of the caregiver to focus on their own mental and physical health and to engage with others. When caregivers feel cared for, they are better able to provide care for others, creating a more supportive environment.

Respite Care

The CRCs administer vouchers for respite care and according to eligibility and available funds, authorize a certain number of hours for a given period of time. These funds can support in-home paid help or local agencies providing respite care, such as adult day programs or adult day health care. Family consultants assist those who are not eligible for payment vouchers or have greater need than available funds to identify alternative sources of respite care and potential ways to fund this service, including identifying sliding scale options and paying out-of-pocket. Caregivers value this resource as an opportunity to restore energy, attend to important life activities, and to share the responsibility with others. They use their respite time to rest, take care of themselves including health care appointments, running errands, and spending time with friends and family. Paid helpers provide companionship and personal and instrumental care for the care recipient and can assist with household and yard chores. Some caregivers are able to secure enough respite to work or to have a short vacation. Respite care was particularly important for caregivers who could not leave their family members unattended. Many reported initial reluctance to take advantage of this service as they were concerned about the care recipient adjusting and about whether someone else could provide appropriate care. In many cases, the family consultant played an important role in identifying appropriate respite services or paid caregivers, reassuring the client and helping them manage the adjustment period for themselves and the care recipient. This caregiver expressed a common theme,

> *"I was so focused on taking care of him that I was not thinking about myself. All I could think of was him. I was extremely tired, short-tempered, just—I didn't realize I was starting to run on empty."*

Challenges. One of the greatest challenges was readiness to accept this service by the caregiver or the care recipient, given the complex nature of the caregiving situation and the needs of the care recipient. This was a particular concern in the context of dementia, when the caregiver has intimate knowledge of the care recipient and is able to communicate effectively and anticipate care needs. Sometimes the caregiver was responsible for finding an appropriate qualified, speaking care recipient's language paid caregiver, taking time and energy. Some grappled with coordinating schedules between their household and the paid caregiver or substation of the paid caregiver. Commonly, there was an adjustment period for both the caregiver and care recipient, exacerbated when there was staff turnover. Some caregivers preferred to use less time than the minimum block of time specified by the agency or home care worker. Costs of agency personnel can be prohibitive for caregivers paying privately for respite. A second major challenge is availability of funds for respite care and paid caregivers. Grant sources are unpredictable and not available continuously, with fiscal funding caps.

Impact. When caregivers establish a satisfactory arrangement for respite, they benefit in many ways from this service. Most report improved mental health, reduced stress and anxiety, and felt restored and re-energized to continue. There was a sense of relief that someone else could help. They were able to spend time with others, experiencing broader support and engaging in enjoyable and meaningful interactions. Caregivers report better self-care, the ability to pursue healthy activities such as sleep, walking or swimming, improved management of their own health, and greater ability to address pressing health concerns, including having health care appointments and preventive care. Many recognized that when they were able to care for themselves, they were in a better position to care for their family members, with more patience and compassion, and to sustain their energy in the face of physical and mental demands. Several caregivers indicated that respite enabled them to ensure that the needs of other family members were met, contributing to a healthier family. Others were able to keep working, generating income and engaging in meaningful activity. As three caregivers said,

"It took such angst out of my life to know that that was available."

"It's important that you guys know how valuable a service this is for those of us who literally looked around and said, 'Oh, my gosh. What do I do now? How do I manage this? It's so overwhelming."

"You can be your own person for a while. to feel the happiness of a cup of coffee out somewhere or meeting a friend and chatting for a while or spending time with the family. It adds the joy back, otherwise it is sucked out constantly. It allows you to fill yourself back up again so that you can face tomorrow and the next day and the next day."

"The benefit of respite hours is not only the hours of respite themselves, but al so the anticipatory feeling of it before, and also good feelings afterwards."

Support Groups

CRCs host support groups where caregivers gather to discuss their situations, learn from peers, and expand their network of resources. CRC staff facilitate the support groups and offer both in-person and Zoom meetings, typically once or twice a month. Indeed, during the pandemic, the capacity to engage over Zoom was a vital resource for caregivers, enabling them to maintain social ties and a connection to advice and support during a very challenging time. CRCs are creative in the options for in-person meetings, including hosting the meeting in a park where participants can walk, or planning outings for the group such as boat trips or tours of botanical gardens. Support groups vary in their focus, with some addressing caring for a person with dementia, others targeting a specific caregiver audience (such as adult children) and others encouraging more than one member of the family to attend. Caregivers appreciate professionally led or moderated groups, both for the expert facilitation and for the expertise of the CRC staff.

Caregivers report many benefits of engaging in this resource, including emotional support and learning about how others cope with being a caregiver and how they

manage specific challenges in providing care, such as dealing with difficult behaviors. They become more aware of informational and practical resources as well as self-care strategies. Together, members of support groups engage in problem solving, with the group contributing ideas when a member poses a personal challenge. Hearing about the experiences of others enables caregivers to anticipate potential future issues and develop plans to address these possibilities. The groups build community and connection, reducing a sense of isolation for participants and providing reassurance and normalization of the complex experiences and feelings that caregivers have. They are a safe place to have conversations that are often not welcome in other social circles. Support groups also discuss self-care and provide encouragement to caregivers to develop a plan to assure that they are maintaining their own physical and mental health. For some, support groups are the springboards for friendships that develop outside of meetings. As these caregivers said,

"If it wasn't [for] the support groups, I honestly don't know where I would be at this time."

"I am at the point in my caring where my person is in a skilled nursing facility. The caregiving does not stop. It changes, and it still takes a lot of work. I am very grateful that you have support group for caregivers with placed care receivers. It helps us to connect with others and share experiences and advice. It validates what we are going through and helps us to see situations from different points of view. The moderator is very helpful, listens, and provides guidance."

Challenges. Decisions about the focus, structure or audience for support groups carry pros and cons – while creating parameters around the purpose enables deeper discussion, these parameters limit applicability to the broader community of caregivers. It is helpful to have options available within CRCs. For example, delivery methods meet different needs. Zoom meetings are convenient for caregivers who cannot leave their family members alone, they save driving time, and they enable participation of caregivers from a broader geographic region. However, tech literacy and internet connectivity can be a challenge, particularly in rural areas. Timing and length of the sessions are considerations for working caregivers or caregivers of persons with dementia. Many caregivers desire in-person connection and prefer to be together physically for support group meetings. Some support groups preclude ongoing participation for caregivers whose care receiver dies – this decision is controversial as the caregiver loses connection with close support group ties. Some caregivers report that hearing about the problems others face can be overwhelming and stressful, however, others state that hearing about worse situations puts their own problems into perspective and facilitates readiness. Moderator skill and style makes a difference, with the most expert support group leaders facilitating discussion among the group vs. the less skilled moderators who interact directly with group members, but do not encourage exchange among the group. At times, CRCs are not able to meet the demand and caregivers are placed on a waiting list to join a support group. In these instances, they are referred to other agencies, such as disease-focused associations or hospice, who

offer support groups if available. Finally, full participation in the support group can be difficult when a care recipient cannot be left alone. Low attendance in the group limits its value.

Impact. Support groups had several important impacts for caregivers. They provide a network of individuals who understand and who share the journey, reducing isolation and stress. They are a source of information and a place for working through difficult decisions. They build skills in caregiving and provide a safe space to express challenges in caregiving and family relationships and learn about solutions from others.

Education and Training

Educational resources meet a major need and reason caregivers contact CRCs. CRCs offer an array of education and training topics in various formats including in person or online classes, online videos or fact sheets, and printed materials. These resources include both stand-alone short features and extended courses. Family consultants and support group facilitators also send customized educational information to caregivers via e-mail and the CRC websites contain materials and links to additional resources. Individual CRCs provide education and training locally and many resources are available statewide. The enactment of a statewide calendar, publicized through all CRCs has expanded the range of programs available to all caregivers. Many classes are provided in several languages including Spanish, Chinese, Japanese, Korean, and more, expanding the reach of programs. Working caregivers and those who cannot leave the person in their care appreciate the flexibility and convenience of online resources and asynchronous materials.

Topics include information about the health conditions of care recipients, including causes, trajectory and strategies to promote optimal health and function. With the high prevalence of dementia among CRC caregivers, there is detailed information about Alzheimer's Disease and Related Disorders. Other common conditions include neurological disorders and Parkinson's Disease. There are many offerings that address the caregiving role, from practical information about how to give care to how to manage the role and stressors of caregiving. Classes and resources also provide anticipatory guidance around legal and financial considerations, assisting caregivers to develop long-term plans, make important decisions, enroll in appropriate benefits, and secure the requisite documents, such as power of attorney and advance directives, to assure enactment of their plans. Another domain addresses family dynamics, optimizing communication and dealing with loss and grief. Caregivers had positive feedback,

> *"Care workshop was great. I appreciate the contacts and resources I've been made aware of for when I will need them."*

Challenges. In-person caregiver conferences were seen as highly valuable, and these have been on hold during the pandemic. Some caregivers preferred having a conversation about their particular concern rather than receiving educational materials. Matching the content with the educational needs and priorities is sometimes difficult, as caregivers may not be ready to learn about sensitive aspects such as advanced stages

of a condition, or end-of-life planning. As with other online resources, internet availability and digital literacy can be a barrier to access. Some caregivers reported security concerns about downloading software such as Zoom. Both the scheduled time and the length of programs can pose challenges for caregivers engaged in either providing care or working. Remote options provide solutions for geographical access, timing concerns and reduce costs (e.g., paid caregivers, gas). Some caregivers would appreciate having the Zoom webinars available on demand to accommodate various time constraints.

Impact. These programs are highly valued by caregivers as they provide practical guidance for navigating their complex role, improve their skill and capacity to provide care, increase their confidence and encourage self-care. Education provides reassurance that normalizes challenges and equips caregivers to manage more effectively. Interactive classes also provide social support as participants share their experiences. As with support groups, the ability to pivot to online classes assured this ongoing resource was available during the COVID-19 pandemic. While this option eliminated the rewards of in-person connection, it provided a valuable lifeline during a time of additional stress.

Counseling

Family consultants can make referrals for individual counseling, usually a grant for 6-8 sessions (1-1.5 hours each) with a psychologist, social worker, or licensed marriage/family counselor. Most sessions are conducted over the phone or Zoom, with some provided in person. The counseling service is dependent on grant availability and is highly valued by those who cannot afford to pay privately for counseling. Family consultants also made referrals to outside resources, such as mental health benefits included in the caregiver's insurance, or other community programs and services providing counseling, such as hospice.

Challenges. Caregivers reflected that their own caregiving priorities and readiness to pursue a referral for counseling was a barrier initially and they appreciated the persistence of the family consultant. Lack of availability of counseling services both through the CRC and insurance limited access for some. The costs of counseling beyond the grant precluded participation by low-income caregivers.

Impact. Caregivers reported many ways that counseling helped, including managing family dynamics more effectively, identifying important decisions, developing action plans, gaining skills and techniques for managing stress. Counselors assisted caregivers to prioritize what to focus on now, what to plan for in the future and what to let go. In sessions, caregivers were able to address interpersonal concerns with the care recipient, including improving the relationship by addressing issues such as communication, intimacy and the losses associated with the advancing disease. They also gained insights in managing other concurrent life events and challenges. For example, one caregiver said,

"Cognitive Behavioral counseling helped me to better understand my frustrations as a caregiver, my reactions and how better to deal with circumstances."

Equipment and Supply

The CRCs help caregivers to identify the equipment and supplies that they need to support the care recipient and provide guidance for procuring needed resources. In some cases, CRC staff visit the home to perform an environmental assessment so that they can recommend modifications to improve function. They identify equipment such as a bath chair, recliner, lift chair, wheelchair, grab bars, or hospital bed. They also assist with supplies such as nutrition shakes, wipes, bed pads and incontinence products. In some cases, the equipment and supplies are not covered by Medicare or MediCal and the CRC provides them to caregivers through grant funding. CRC staff are also knowledgeable about community resources and make appropriate referrals.

Challenges. As with other services, some caregivers reported initial reluctance to accept equipment and supplies suggested by CRC staff. Even when the caregiver requests equipment, such as a wheelchair or walker, the care receiver may not choose to use this resource.

Impact. Caregivers reported relief when they were able to identify a need and procure equipment and supplies to support their care.

Legal-financial consultation

Caregivers expressed an intense need for legal consultation services. They appreciated both education about legal issues and appropriate actions and also legal consultation to assist them in executing their decisions. CRC staff provide individual information about legal and financial considerations but are not able to provide legal consultation or financial advice. Depending on funding, CRCs can provide vouchers for approximately 2 hours of legal consultation, usually with an elder law attorney. This initial consultation assists the caregiver to identify legal issues, such as advance directives or forming a trust, and can start the process.

Challenges. Caregivers emphasized the insufficiency of the services that are currently provided or mediated by the CRC. They appreciate the information provided by the CRCs but would like more private legal consultation. The services are costly and not extensively available. In some cases, caregivers are not able to take advantage of the service due to navigation challenges.

Impact. Some caregivers had utilized legal consultation and found it to be helpful in resolving legal matters or in planning ahead and preparing appropriate documents.

Caregiver Experience with CareNav^{TM} 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 IV-e indicates that most caregivers were offered online services (82%) and a quarter of caregiver respondents (25%) indicated having used the CareNav^{TM} system. There was an initial increase from the first year to the second in use, but in the past year, the increase was not substantial.

Table IV-e: Satisfaction Surveys: Caregiver Engagement with Online Services & CareNav^{TM} for FYs 20/21, 21/22, and 22/23

Response Categories	Were Offered Online Services (%)			Used CareNav^{TM} (%)		
	FY 20/21 *n* = 2,869	FY 21/22 *n* = 2,624	FY 22/23 *n* = 2,125	FY 20/21 *n* = 2,869	FY 21/22 *n* = 2,624	FY 22/23 *n* = 2,144
Yes	76.2	80.5	81.6	18.9	24.6	24.9
No	12	9.0	8.6	70.7	64.2	64.8
I Don't Know	11.7	10.4	9.8	10.4	11.2	10.3

*Percentages may not add to 100 due to rounding.

Figure IV-a shows that the majority of caregivers who did use CareNav^{TM} were satisfied with the experience (extremely satisfied, 50% and somewhat satisfied, 33%). This reflected a similar pattern as last fiscal year's data. Those who did not use CareNav^{TM} were asked about the reasons for not engaging with the online program. As observed in Figure IV-b, the largest barrier to use was awareness about the program (31%), followed by the impression that the caregiver did not need this (19%) and lack of technology experience (14%). Access to internet (4%) and finding the platform too confusing (2%) were minimal barriers.

Figure IV-a: Satisfaction with CareNav^{TM}

	2020 - 2021 n = 484	2021 - 2022 n = 340	2022 - 2023 n = 513
Extremely Satisfied	39.0%	50.6%	49.7%
Somewhat Satisfied	20.1%	33.0%	33.1%
Neutral	36.4%	12.8%	13.1%
Somewhat Dissatisfied	1.7%	2.3%	2.7%
Extremely Dissatisfied	2.9%	1.4%	1.4%
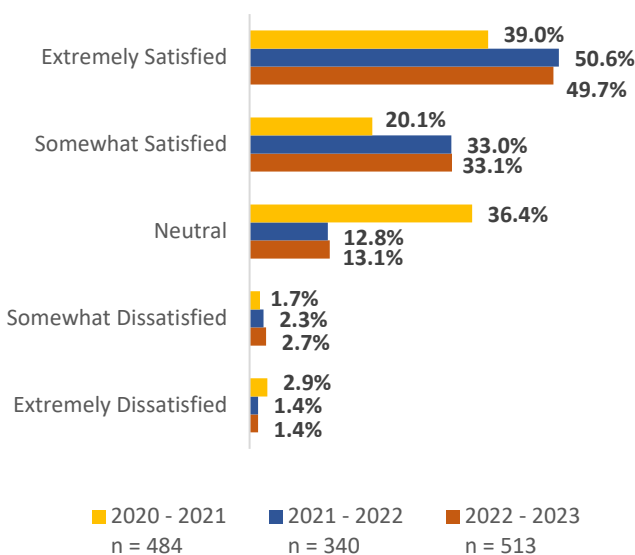
Figure IV-b: Reasons for not Using CareNav^{TM}

	2020 - 2021 n = 1,488	2021 - 2022 n = 1,170	2022 - 2023 n = 1,220
Too Confusing	2.8%	3.3%	1.5%
No Technical Experience	14.1%	13.7%	13.8%
Did Not Need it	17.3%	18.4%	19.1%
No Internet	7.9%	5.1%	4.0%
Did Not Know About it	34.0%	31.4%	31.6%
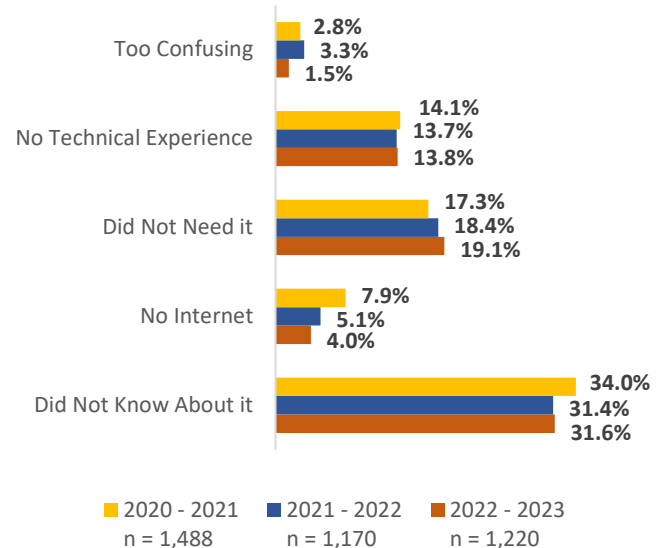
Caregiver comments about CareNav™ echo the survey findings regarding awareness. Not knowing about the option to engage online remains the largest barrier to adoption. Some indicated that they had heard about CareNav™, but then received a call and were interviewed by the family consultant rather than using the online system. Others reported being told it was simply a way to register with the CRC and were not informed of the features of the program, including navigation of services. Several indicated that they are interested and would like to learn more about the platform and would be more likely to use it if the family consultant encouraged them to pursue this resource.

Others who did not use CareNav™ discussed their reluctance to use technology, particularly the time it takes to navigate through a website to find what they are looking for. Related to this barrier was a lack of confidence in using technology, with a concern about what it would take to learn how to use it more effectively. Several indicated that they preferred to phone the CRC and talk to a person when they have a complex question.

Some survey participants indicated that they do not use CareNav™ since they are either new to caregiving or very experienced caregivers, care recipient condition improved, or they are engaged with other beneficial services or modes of communication with the CRC. A few others raised accessibility concerns, including visual impairment, learning disabilities, lack of appropriate phone or computer device, need for assistance to navigate the technology, the variety of services offered or the language. A few mentioned internet instability challenges.

Those who engaged with CareNav™, described using the platform to access services, get information about upcoming events and programs, and access videos and informational resources. A few commented that they appreciated the tailoring of videos and information to their individual situation, the availability of information at the time they need it, and the links that enable greater engagement with other resources in the community. A satisfied caregiver described full use of CareNav™ including completing an assessment, scheduling and rescheduling services, accessing online learning programs, and communicating with CRC staff. They commented that it is easier to get a response via e-mail than by phoning the CRC.

"I don't know how I would've survived COVID without [the CRC]. They have been the one source of... constant support, even if it was all virtually...Other nonprofits that have been here for a long time have closed down entire programs...I honestly think they've been my lifesaver." – CRC Caregiver

Equity

Three important equity issues emerged in the interviews with caregivers. The first centers on access, both digital and language access. The digital divide, particularly internet access for rural communities and digital literacy among caregivers with less technology experience was an issue for access to online programs offered by CRCs. Participants who spoke Spanish highlighted the benefits of having access to family consultants and educational materials in their own language, improving their comfort in participating and fostering a trusting relationship. It is important to note that we did not interview caregivers whose primary language was not Spanish or English. As caregivers discussed the primacy of the relationship with the family consultant, and the time it takes to develop enough trust to discuss important issues, the issue of language congruence comes to the fore.

> *"You need this one person that is going to have the time, the patience, understanding, and at the end of the day, that you're gonna trust that person and open up to be able to be honest in the conversations of what's going on, so that he can respond, or he can refer if I need to go into a higher level of conversation and need of assistance."*

The second equity issue centered on respectful and culturally congruent engagement during training. One caregiver identified an experience in a state-wide virtual session where the presenter responded to a sensitive question in a way that undermined trust. They acknowledged the difficulty of establishing mutual understanding in this format. As CRCs serve diverse caregivers, and provide vital information, ongoing attention to inclusiveness is vital to foster trust and optimal communication. Another caregiver described gender and cultural congruency with the family consultant as the main facilitator for establishing a meaningful long-term relationship.

The third equity issue centers on distributive justice, particularly with limited resources. This was highlighted in relation to respite services, which are dependent on available funds. Caregivers discussed the uncertainty associated with availability of this support and asked for greater transparency on the criteria for awarding vouchers. This issue is a statewide distributive justice issue, as these funds are made available at the county level, with more resources provided depending on geography. One caregiver suggested,

> *"A more fair way to distribute respite grants - it can be a ranking system that evaluates people's situation. This system should take into account the complexity of the CR condition, but also work status of the CG. Working CGs should also be prioritized because it contributes to the society. More explicit waitlist would be beneficial. Currently the CRC staff has a lot of discretion on who they give the grant to. The CG also doesn't know when to ask for the grant, since there's no rule. the scoring system would also save CGs time, that they now spend on figuring out when to ask about the grants."*

Caregiver Suggestions for Program Improvement or Enhancement

Caregivers were highly satisfied with the CRC programs and predominately focused on enhancements to programs. Most emphasized the importance of additional funding to support and grow vital caregiver services, within and beyond the CRCs. Many expressed concerns about the overall costs of caregiving, including costs of care, equipment and supplies and lost income when caregivers can no longer work. They grappled with legal and financial planning and sought greater assistance with their individual situations to enact action plans and to access resources. Navigation of public assistance was challenging, particularly establishing eligibility. These two caregivers said,

> *"The longevity of getting through every day…It's very tough. It's very tough, caring for someone else and not getting—and not knowing what the next day, if I'm gonna have enough food to feed this entire family, take care of my mom, keep her alive, keep her all the things, like just—it's that. Just like, how do I get through? If I don't get MediCal, I don't know what I'm gonna do."*

> *"Money is the biggest problem - the caregivers are losing money for their own retirement, for social security. Society relies on caregivers to sacrifice their own financial health and there is no program to compensate their retirement, even if they retire early due to caregiving responsibilities."*

A number of suggestions focused on increasing availability of community support for caregivers. Some caregivers who did not qualify for vouchers did not have the financial resources to pay privately and desired paid help in the home or counseling. Others identified transportation as a barrier in their community.

Caregivers also recognized that CRC resources are limited, as there were sometimes delays in accessing CRC staff and waitlists for certain programs. Several suggested flexible office hours so they could access their family consultant more readily when they had a pressing issue. They also had programming suggestions around making support groups and education more available in the evening hours for working caregivers or those who are engaged in care all day.

They suggested more advertising and promotion of the CRCs overall, and promotion of specific offerings such as education sessions and support groups to increase community awareness of this important resource. However, a couple of caregivers recognized that the CRCs may not have sufficient staffing to meet the demands resulting from additional promotion.

Caregivers indicated that they would like to know more about CareNav™ and what it provides. Several would appreciate technical support and education about how to navigate the website and access the services available through CareNav™. They recognized the convenience of having this platform and would like to overcome the barriers of not knowing how to navigate the system. Table IV-f provides a summary of caregiver suggestions for consideration.

Table IV-f: Caregiver Suggestions

Service	Suggestion
Overall	• More funding for services – increase availability of vouchered services • Better promotion and advertising of CRCs and their services • Improved staffing to increase responsiveness and personal contact • Educate health professionals and agencies to make referrals to CRCs • Increased programming to address end-of-life care • Services for both caregiver and care recipient together – social, volunteer, counseling • Disaster preparedness – addressing local risks such as floods or wildfires • Technology support to navigate website, Eventbrite and Zoom • Transportation support for care receiver • Physical and social activities for the care recipient
Family Consultation	• Availability of "drop-in" office hours • In-home visits by nurse or care manager • Contingency planning should caregiver become unable to care • Engagement with care recipient to encourage them to go to day care or accept paid help • Curating resources – knowing what is currently available and tailoring to client
Respite	• Greater transparency and fairness in how respite grants are distributed • Broader services, such as housekeeping or gardening • More total hours of respite • More continuous availability of respite grants • Shorter periods of respite (vs. 4-hour minimum time)
Support groups	• Offer support groups in different neighborhoods • More frequent meetings • Alternate meeting times to accommodate working caregivers and caregiving routines • More retreats/events for caregivers • Supporting caregivers after the care recipient is deceased
Education/ Training	• Hands-on education – demonstration of techniques, such as managing behaviors • More workshops and evening classes • Take home summaries of lessons • More promotion of available classes • More availability of recorded zoom classes • More variability in topics
Counseling	• Emotional support and counseling for the care receiver or for the couple
Equipment/ Supplies	• More funding for equipment and supplies
Legal-financial	• Assistance with identifying housing options and associated costs for long-term planning • Financial planning and assistance • Initial legal consultation through CRC to identify legal priorities • Long-term care insurance • Assistance in getting on MediCal and navigating other insurance • Funding for family mediation
CareNav™	• Provide information about the availability and features of CareNav™ • Training on how to access and navigate the platform • Family consultants to encourage use by caregivers

Finally, caregivers prioritized disaster preparedness as an important issue, particularly in rural areas. Caregivers were eager for assistance in planning for the specific natural disaster threats in their geographic area, whether they be floods, storms or wildfires. With planned power outages, they grappled with access to food, water, and air conditioning. They discussed the challenges of preparing for and experiencing evacuations with care recipients with complex needs and would appreciate education about how to prepare, including having adequate medications and supplies in the event of an evacuation. While local programs address general community need, they thought that the CRC could aid local agencies in planning for families with complex caregiving situations, such as availability of accessible bathrooms for caregivers to assist care recipients. Post-disaster, caregiving families face challenges in finding appropriate living arrangements during damage repair.

Summary

Caregivers express deep appreciation for the services and support provided by the CRCs. They indicate that the CRCs are vital to their ability to manage care and stay healthy in the process. The benefits include improved mental health, increased capacity to provide care through improved skills and confidence, and access to services that promote effective decision-making and provide respite. The relationship with the family consultant is key, as these staff develop a personal connection and can guide caregivers across the trajectory of their caring. Caregivers mentioned that the CRC staff are at capacity, and they question whether they could serve more people, as the existing clients sometimes experience delays in accessing staff or programs.

Services such as respite, counseling and legal/financial consultation are also significant in the lives of caregivers. Availability of these services is significantly affected by funding – with limited resources even for those who are eligible financially, and prohibitive costs for those who do not qualify for assistance. Commonly, caregivers are initially reluctant to take advantage of services and the encouragement of family consultants and other family members promotes acceptance.

Lack of awareness of CRC programs and services is a barrier to optimizing access to these resources. Furthermore, deployment of CareNav™ has leveled off at about 25% utilization among CRC clients, in most part due to lack of awareness and the need for technical support.

Finally, caregivers identify disaster planning as a priority for both CRC involvement in community preparedness and in assisting caregivers to develop appropriate disaster plans in response to natural disasters and in navigating the challenges of evacuation if necessary.

V.   STAFF EXPERIENCES WITH CARENAV™

Description of Sample

Between 4 and 18 staff from each site participated in the online survey, totaling 118 respondents: 43 administrators, 73 clinical support staff members, and 2 opted not to provide role data. Some participants had completed surveys in previous years, and we included them in longitudinal analysis. In 2020, a subsample of 24 participants (10 administrators and 14 clinical support staff members) from eight of the sites completed surveys, and in 2022 a subsample of 44 participants (15 administrators and 29 clinical support staff members) from all eleven sites completed the survey. Sixteen participants hired before 2020 (6 administrators, 10 clinical support staff members) from seven of the sites contributed data at all three time points. This enabled longitudinal analyses, to compare staff and leadership knowledge and beliefs, self-efficacy, and readiness for change from 2020 to 2023. Table V-a summarizes demographic characteristics of the current and previous participants.

Implementation process progress

This fiscal year was the second year that all CRCs contributed a full data set from CareNav™, entering all their client data for activities (e.g., intakes, assessments, reassessments, training) and service grants. The CRCs continued to make progress on cultural and procedural changes for operational integration. Participants provided rich information about the benefits and challenges of CareNav™ utilization, technical issues and efforts made to serve

Table V-a: Demographic characteristics of the survey participants

Participant characteristics	Readiness survey 2022 (*n* =73)* %	Readiness survey 2023 (*n* = 105)** %
Age		
25 or under	8.2	1.0
26-35	39.7	37.1
36-45	20.5	25.7
46-55	9.6	10.5
56-65	16.4	12.4
Over 65	5.4	5.7
Decline to answer		7.6
Gender		
Female	80.8	81.0
Male	15.1	12.4
Genderqueer / Gender Non-binary		1.9
Irrelevant and doesn't concern how I perform my job function		1.0
Decline to answer	4.1	3.8
Racial identity**		
African American or Black	4.1	4.8
Asian	13.7	15.2
Hispanic/Latino	39.7	37.1
Native American	1.4	1.9
Pacific islander		1.0
White or Caucasian	43.8	35.2
Other		1.9
Decline to answer/mis	8.2	8.6
Irrelevant to the way I perform my job		1.0

* Of 114 survey respondents, 73 demographic surveys were submitted.
** Of the 118 survey respondents, 105 demographic surveys were submitted.
** Percentages may not add to 100 due to multiple racial identities

caregivers from diverse communities. In this section, we summarize leadership and staff knowledge, self-efficacy and readiness for change, as well as current developmental phases of implementation and expectations for expansion of its utilization.

Staff and leadership knowledge and beliefs, self-efficacy, and readiness for change

Overall, participants had very positive attitudes toward implementation of CareNav™, with a total readiness score of 4.30 (SD 0.46) on a scale of 1 to 5 where 5 is the most positive. Average responses to all items were in the positive range (Table V-b).

Table V-b: Readiness survey

Item	Mean (N=112)
Knowledge and beliefs about CareNav™	
CareNav™ improves the ability to record services	4.4
CareNav™ provides tailored and accessible information for caregivers*	3.8
Clients should be given a range of service delivery options to ensure they select one that works best for them	4.8
Self-efficacy	
Prepared to use CareNav™*	4.3
Confident to use CareNav™	4.4
Capable to use CareNav™*	4.5
Readiness for change	
Positive with the expansion of CRC services**	4.4
Positive with using CareNav™*	4.1
Willing to do new things	4.4
Everyone on staff regularly uses CareNav™*	4.6
Know where to obtain help	3.5
Developmental phases of CareNav™ implementation	
Use CareNav™ data to understand the needs of diverse clients	3.7
Clinical support	
Use CareNav™ to guide assessments and enter data in real time	4.3
Encourage clients to access CareNav™ through the portal	3.1
Would like to expand use of CareNav™ to coordinate clients support	3.8
Administration	
Use CareNav™ data to make decisions regarding the CRC site and its programs	3.6
Would like to expand use of CareNav™	4.3
*n=111; **n=109	

Developmental phases of CareNav™ implementation

Two-thirds of the participants (n=69, 62%) used CareNav™ data to understand the needs of diverse clients (e.g., in terms of race/ethnicity, geography, sexual orientation, gender identity, income). They report using these data to implement various strategies, including collecting demographic data, targeting grant funding and outreach based on a comparison between intake data and census demographics, improving linguistic access, staff training and expansion of resources available in CareNav™. Table V-c summarizes more strategies used to serve caregivers from diverse communities.

Table V-c: Strategies used to serve caregivers from diverse communities

Theme	Examples
Staff training	**Regular, on-going** statewide CRC diversity and inclusion trainings for all employees **Training topics**: Diversity and culture; how to better serve diverse communities **Impact**: Using inclusive language; Increased awareness to serve diverse caregivers
Various media to provide resources and services	Using service delivery/technology to serve caregivers with various abilities and resources **Provision of information**: Mailing documents to clients who have limited tech literacy/comfort or have limited internet connection; Offering options to complete assessment, access timesheets and information, use personal dashboard on CareNav™. **Caregivers-staff meetings**: Provision of in-person, phone and online meetings with clients based on their preference. Home visit option.
Programming and services	**Provision of various types of services** tailored to caregivers needs; Locating resources and building understanding to navigate their journey. **Community services**: Identify community resources; provide information and assistance **Support groups and education services**: virtual and in-person; covering diverse topics; targeted to diverse communities, e.g., LGBTQ+, multiple languages support groups
Specific linguistic accommodations	**Multi-lingual staff**: Hiring bi/multi-lingual staff representing diverse population served, including Spanish, Vietnamese-speaking staff. **Staff training** in offering services to communities who do not speak English. **Development/provision of services in multiple languages**: Programming, educational classes/workshops, support groups; translated materials and videos **Inform caregivers** about the availability of translated resources. **Using translation/interpretation services** to provide information and referral. **Targeted funding**: Using CareNav™ data to identify gaps in serving clients speaking other languages and seeking funding to expand services to these communities. **Impact**: caregivers can access information they need in preferred language.
Outreach in diverse communities	Participation in community networking events (e.g., health fairs, conferences, resource fairs, events at churches, parks, community centers, schools, food distribution sites); Bi-lingual staff attendance; Promotion/provision of education via mass media **Partnerships with community organizations**: organizations serving diverse populations; Tribal communities; Other service providers; CBAS centers; Office hours at a social service agency hub office. **Targeted outreach**: Using caregiver demographic data, target outreach efforts to more agencies that primarily work with Black/African American, Latinx, Asian, and/or LGTBQ+ communities in certain counties.
Barriers and recommendations	Ensure asking demographic questions in CareNav™ and accurately gathering the data; Language barrier in CareNav™ use; More training

"I think it was very beneficial that I speak to him [family consultant] in Spanish. I feel very comfortable. He's a good listener, has really been supportive. You need a friend...that is experienced in what they know is coming, and I don't, and so that I can be prepared." **– CRC Caregiver**

"A caregiver who spoke both Mandarin and English…used Google Translate to understand materials. I provided her with reading materials translated into "Simple Chinese" and explained that these materials are available for both reading and listening. She was delighted with this information because it allowed her to apply what she learned to her caregiving role." **– CRC Staff**

We assessed the developmental phase of CareNav™ implementation for participants with clinical support roles (n=70) and participants with administrative roles (n=41) separately according to their CareNav™ anticipated use case. Most of the participants with clinical support roles (n=56, 80%) used CareNav™ to guide assessments and enter data in real time and two-thirds (n=43, 61%) would like to expand use of CareNav™ to coordinate client support. Only a third (n=23, 33%) of the clinicians report that they encourage clients to access CareNav™ through the portal. These findings resonate with the client satisfaction survey indicating lack of knowledge and encouragement by the family consultant as reasons for not using CareNav™. Half of the participants with administrative roles (n=23, 56%) reported using CareNav™ for decision making regarding the CRC site and its programs (e.g., targeted outreach, program offerings) and two-thirds of them (n=30, 73%) are willing to expand the use of CareNav™ (e.g., generating new reports, using data for program improvement, making decisions). Half of the participants agreed that the overall CareNav™ training and support is useful (n=60, 54%) and meets their needs (n=53, 47%).

The open-ended questions revealed benefits and concerns related to CareNav™. The most frequently identified benefits were ease of use and access. Participants appreciated CareNav™ features, including the client portal, report generation and assessment, as well as their functionalities, particularly client records case and caseload management. The most commonly identified concerns were technical issues and the desire to have more broad functionality. They also expressed concerns about client engagement with CareNav™ and running reports. Table V-d summarizes the benefits and concerns with examples.

Table V-d: Benefits and concerns of using CareNav^{TM}

Theme	Benefits	Concerns
Ease of use	Navigation, search, data entry, organizing and storage Fast, clear, user friendly, efficient Easy to use for clients	Too many steps for some functions; Labor intensive and not flexible enough Takes time to learn, particularly for clients Difficult to use for caregivers
Security	Paperless, HIPPA Compliant, secure data; Client verification; Password management	
Access	Accessible to all staff, remote connection, confidential; real time	Internet instability, particularly in rural areas – less accessible for clients, system interruptions
Data quality	County specific data; can easily view client information; Ability track and use data	Lost data; Difficulty obtaining or extracting data Missing or inaccurate data
Centralization/ standardization	All information in one place	Variability between sites in the way they use it; Statewide data integrity and consistency
Training	Easy to use menu to get help; Easy to learn.	Do not know how to fully use the software; Not enough training, information and resources focused on different staff and leadership needs; Unused features due to lack of training
CareNav^{TM} development		Not being able to adapt the platform to specific needs; Updates or changes are made with insufficient notification
Features		
Assessment	Simple; standardized; Unified across CRCs; comprehensive; Able to complete in real time;	Too structured; Too long; Uncomfortable with gender and race questions.
Report generation	Comprehensive; Easy to access and run reports internally. Purposes: Tracking clients; caregiver and care recipient characteristics; target outreach to underserved communities; assess caseloads and staff productivity	Complex/ confusing report query; not being able to generate needed reports; Lack of confidence on the reports data; Unable to generate advanced reports
Client portal	Information accessible 24/7 for caregivers; Communication with CRC staff; Access to care plan and other online sources; Allows self-direction, intake before formal appointment; Caregivers feel more involved, saves time.	Underused: Clients who are not tech savvy, lack digital access, not interested; lack of tech support; lack of knowledge how to personalize CareNav^{TM} and help clients start using more. Insufficient content on certain topics.
Functionalities		
Client records	Uploading documents; View and write case notes; Fast documentation; Organized client information archived in one place; Avoid duplicated records	
Case and caseload management	Easy to track client records, activities, and vouchers; helps recollection; Track trajectories; Easy coordination among team in real time; Consistency; Track staff work/time, billing revenue	Difficult to track clients who completed assessment on their own; insufficient voucher management and financial tracking tools within program; difficulties integrating with other systems and other contract requirements

Comparisons across sites, roles and hiring dates

This analysis showed that two sites had significantly lower scores in two items: Feeling prepared to use CareNav™ (Mean = 3.5, SD = 1.0 vs. Mean = 4.6, SD = 0.5) and knowing where to obtain help (Mean = 2.5, SD = 1.1 vs. Mean = 4.3, SD = 1.0 and Mean = 1.8, SD = 0.8 vs. Mean = 4.3, SD = 1.0). Comparing the scores across roles and dates of hiring showed no significant differences.

We compared scores for participants who participated in the 2020 pre-training survey, two-years after training and the current survey. The Wilcoxon signed rank test showed significant increases in self-efficacy (preparedness and capability) while significant decreases in the belief that CareNav™ provides tailored and accessible information for caregivers between pre-training and three-years after training (Figure V-a). Friedman's test examining repeated measures of a subsample of participants with data from all three time points (n=17) showed similar trends for preparedness, capability, and tailored services provided by CareNav™. All scores remained stable and high between FY 2021-2022 and FY 2022-2023.

Figure V-a: Baseline and three-years after comparison of knowledge and beliefs, self-efficacy, and readiness for change
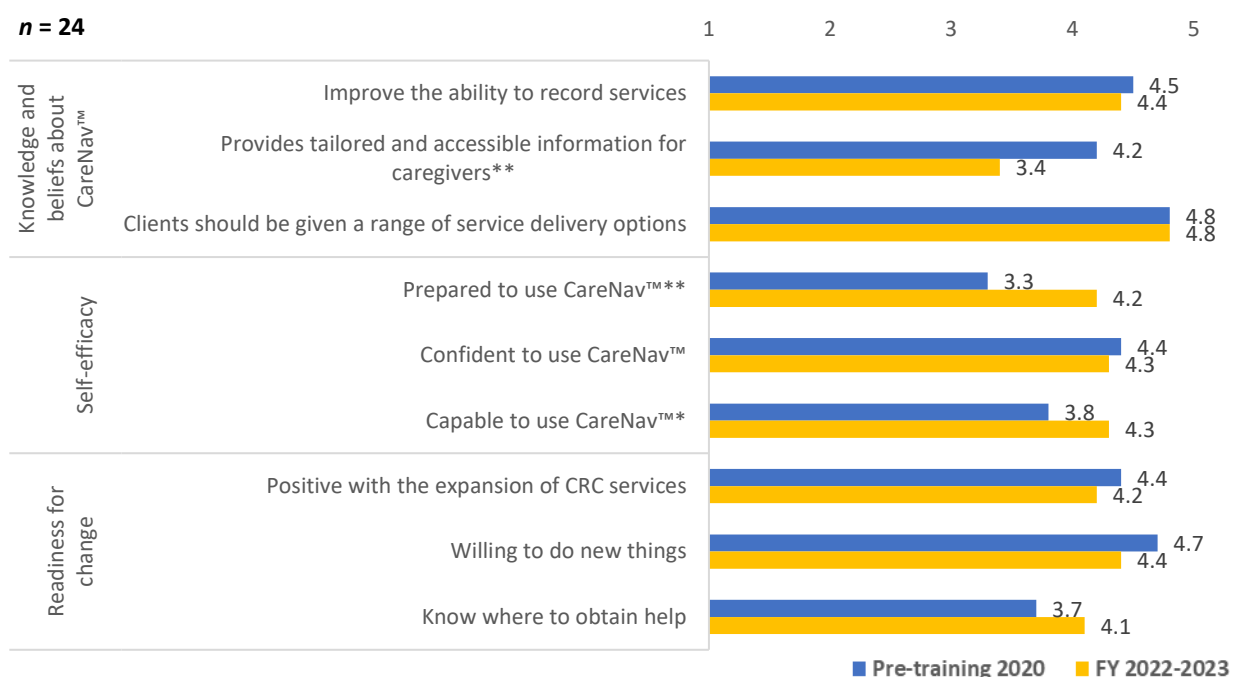
Wilcoxon signed rank test significance: *P<.05; **P<.01
Scale: 1=Very negative/strongly disagree; 2=Somewhat negative/disagree; 3=Neutral; 4=Somewhat positive/agree; 5=Very positive/strongly agree

Summary

CareNav™ implementation is advancing. Sites are increasingly using data for program decision-making. However, caregiver adoption of CareNav™ is similar to last year, with awareness and technical support as major barriers. Both caregivers and staff report low encouragement by family consultants to facilitate CareNav™ use. Those who use the online platform are very satisfied.

VI.   SPOTLIGHT ON EQUITY AND COMPLEXITY

Caregiver Demands, Resources, and Outcomes by Socio-demographic Characteristics

Below we examine the distribution of items in CareNav™ selected to reflect caregiving demands, resources and outcomes within specific caregiver socio-demographic subgroups. Specifically, each item is displayed graphically by caregiver age group (18-44 years, 45-64 years, 65-84 years, 85 years above), by race and ethnicity (Asian and Pacific Islander, Black non-Hispanic, Hispanic or Latino and White non-Hispanic), and by income (above versus at/below the federal poverty level (FPL)). We also examined each item by rural versus urban residence finding no differences and therefore do not present these comparisons in figures. Subgroup-specific snapshots are also provided in Appendix D including, for each subgroup, the figures for all items examined. Both the figures in this section and Appendix D are produced by CareNav™ data from period 01/01/2019 – 08/15/2023. This analysis brings visibility to the unique experiences and needs in caregiver subgroups and provides valuable information to inform targeted interventions to support the needs of diverse caregivers.

Caregiving Demands

Caregiving intensity is measured with an index developed by the AARP and National Alliance on Caregiving (see Appendix B). This measure, based on the hours of caregiving provided each week and the number of activities of daily living (ADLs) and instrumental ADLs that the caregiver supports, is categorized as high, medium, or low intensity. Most CRC caregivers provide high intensity care (>87%). This percentage increases with age, reaching 94.5%

Figure VI-a: Caregiving Intensity

in the oldest age group. By race and ethnicity, 90% of White non-Hispanic and Hispanic and Latino caregivers provide high intensity care; 91% of Black non-Hispanic caregivers and about 93% of Asian and Pacific Islander caregivers provide high intensity care. A slightly higher percentage of caregivers living at or below the federal poverty level provide high intensity care compared to those with income above the FPL (93% versus 90%) (Figure VI-a).
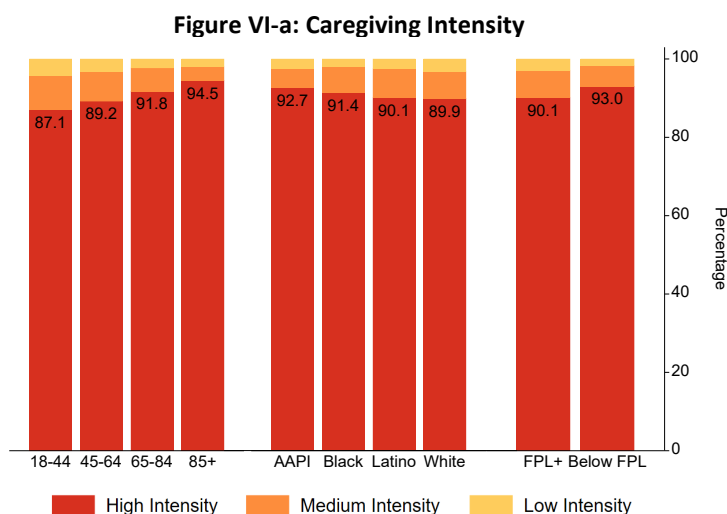
The percentage of caregivers providing 40 hours or more of care each week (Figure VI-b) identifies those engaged in caregiving activities at least full-time. This percentage increases steadily from 63% in the youngest caregiver group to 87% in the oldest group. By race and ethnicity about 78% of Asian and Pacific Islander caregivers provide at least 40 hours of care, followed by 75% of Black non-Hispanic, 74% of White non-Hispanic and 73% of Hispanic or Latino caregivers. A higher percentage of caregivers with income at or below the FPL provide 40 hours of more of care each week (80%) compared to those with income above the FPL (73%).

Figure VI-b: 40+ Hours of Caregiving per Week

Category	Percentage
18-44	62.5
45-64	68.1
65-84	80.6
85+	86.9
AAPI	77.5
Black	74.7
Latino	72.6
White	73.8
FPL+	72.8
Below FPL	80.5
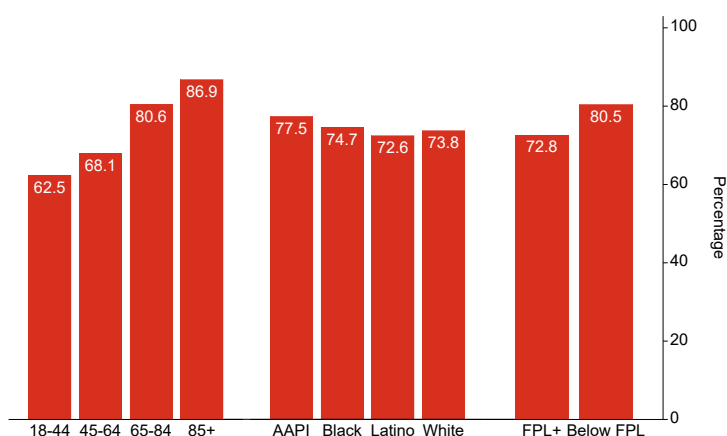
Approximately 79% of caregivers served by the CRC perform medical/nursing tasks in the home including administering medications, wound care, and preparing special diets. On average, younger caregivers perform approximately 4.3 tasks (Figure VI-c), with the oldest caregivers performing 3.7. Asian American and Pacific Islander caregivers perform 4.6 tasks, followed by Hispanic and Latino caregivers at 4.4 tasks, Black non-Hispanic caregivers at 4.2 tasks and White non-Hispanic caregivers at 3.9 tasks. Caregivers with income below the FPL perform 4.5 tasks on average compared to 4.1 tasks among those with income at or above the FPL.

Figure VI-c: Medical Nursing Tasks

Category	Mean Task Count
18-44	4.3
45-64	4.2
65-84	4.0
85+	3.7
AAPI	4.6
Black	4.2
Latino	4.4
White	3.9
FPL+	4.1
Below FPL	4.5
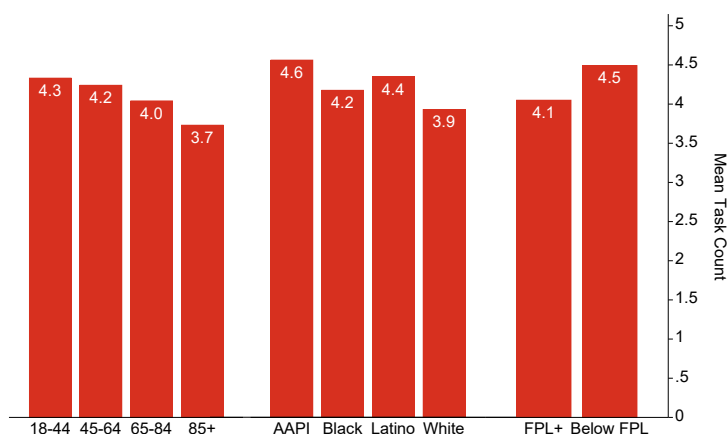
Caregiver Resources

A large percentage of CRC caregivers have no unpaid help—meaning no assistance from family or friends. This percentage is highest for caregivers 65 to 84 years of age (52%) and those 85 years and older (50%) (Figure VI-d). By race and ethnicity, White non-Hispanic caregivers have the highest percentage with no unpaid help (51%) followed by Black non-Hispanic (44%), Asian American and Pacific Islander caregivers (42%) and Hispanic or Latino caregivers (39%). A higher percentage of caregivers with income at or below the FPL (49%) have no unpaid help (49%) compared to those with income below the FPL (46%).

Figure VI-d: Zero Hours of Unpaid Help

18-44	45-64	65-84	85+	AAPI	Black	Latino	White	FPL+	Below FPL
40.1	41.7	52.2	45.7	41.6	44.2	39.4	51.1	46.4	48.6
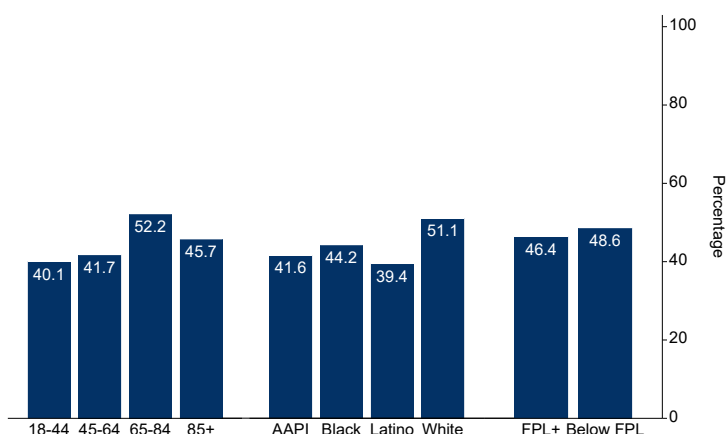
Having no paid help is the most common among caregivers who are 18-44 years of age (74%) while the least common is among those 85 years and above (59%) (Figure VI-e). Hispanic or Latino caregivers have the highest percentage of having no paid help (70%) followed by Black non-Hispanic caregivers (68%), White non-Hispanic (64%) and Asian American and Pacific Islander caregivers (63%). A higher percentage of caregivers with income below the FPL have no paid help (74%) compared to those with income at or above the FPL (64%).

Figure VI-e: Zero Hours of Paid Help

18-44	45-64	65-84	85+	AAPI	Black	Latino	White	FPL+	Below FPL
74.1	65.4	64.8	59.0	63.0	68.2	70.4	63.5	63.9	73.5
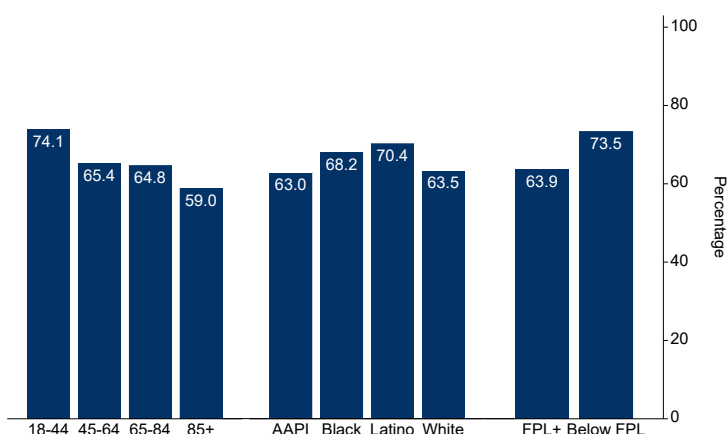
CRC caregivers between 18-44 years of age (51%) followed by those ages 45-64 (49%) report their satisfaction with social supports as very dissatisfied, dissatisfied, or neutral (as opposed to satisfied or very satisfied) compared to those 65-84 (43%) and 85 years of age or above (32%) (Figure VI-f). Asian American and Pacific Islander caregivers and Black non-Hispanic caregivers reported the highest percentages of very dissatisfied to neutral scores (49%)

Figure VI-f: Satisfaction with Social Supports

Category	Very Dissatisfied-Neutral	Satisfied-Very Satisfied
18-44	51.0	49.0
45-64	49.3	50.7
65-84	43.2	56.8
85+	32.2	67.8
AAPI	49.2	50.8
Black	49.4	50.6
Latino	47.1	52.9
White	44.5	55.5
FPL+	44.5	55.5
Below FPL	53.9	46.1

followed by Hispanic and Latino (47%), and White non-Hispanic caregivers (45%). A higher percentage of caregivers below the FPL report very dissatisfied to neutral scores (54%) compared to those with incomes at or above the FPL (45%).

Similarly, the satisfaction with social support scores, caregivers ages 18-44 reported greater levels of very dissatisfied to neutral scores (52%) followed by caregivers ages 45-64 (42%); however, a greater percentage of caregivers 85 and above reported these kinds of scores (39%) compared to caregivers ages 65-84 (37%) (Figure VI-g). Notably, though not shown here, a much smaller percentage of caregivers across age groups scored very dissatisfied or

Figure VI-g: Satisfaction with Spiritual Supports

Category	Very Dissatisfied-Neutral	Satisfied-Very Satisfied
18-44	51.6	48.4
45-64	42.2	57.8
65-84	36.7	63.3
85+	39.1	60.9
AAPI	47.0	53.0
Black	29.4	70.6
Latino	34.6	65.4
White	43.2	56.8
FPL+	40.8	59.2
Below FPL	40.5	59.5
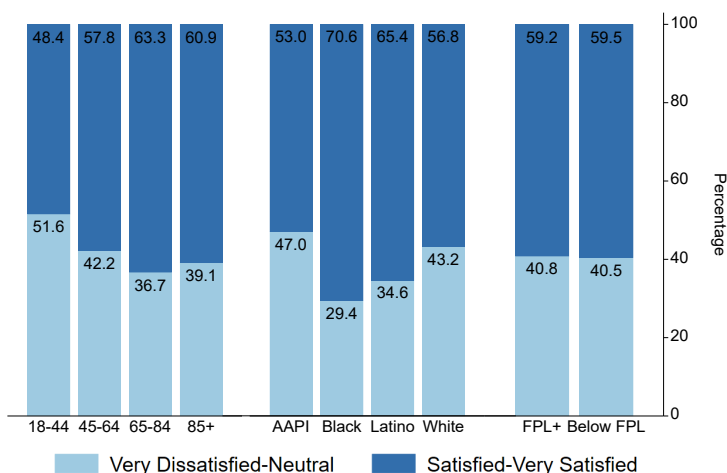
dissatisfied. A far greater percentage of caregivers reported feeling neutral about their spiritual supports compared to their social supports. Asian American and Pacific Islander caregivers felt the most dissatisfied or neutral about their spiritual supports (47%) followed by White non-Hispanic (43%), Hispanic and Latino (35%), and Black non-Hispanic (30%) caregivers. Both caregivers at or above the FPL and below the FPL reported similar levels of dissatisfaction to neutrality regarding their spiritual supports (41%).

Caregiver Outcomes

A higher percentage of CRC caregivers aged 85 years and older (36%) report their own health status as fair or poor (as opposed to good, very good or excellent) compared to those aged 18-44 (34%), 65-84 (34%) and 45-64 years of age (35%) (Figure VI-h). Higher percentages of Asian American and Pacific Islander caregivers (41%), Hispanic or Latino caregivers (40%), and Black non-Hispanic caregivers (37%) report fair or poor health compared to White non-Hispanic caregivers (30%). A higher percentage of caregivers with income at or below the FPL report fair or poor health (46%) compared to those with income above the FPL (32%).

Figure VI-h: Self-Reported Health
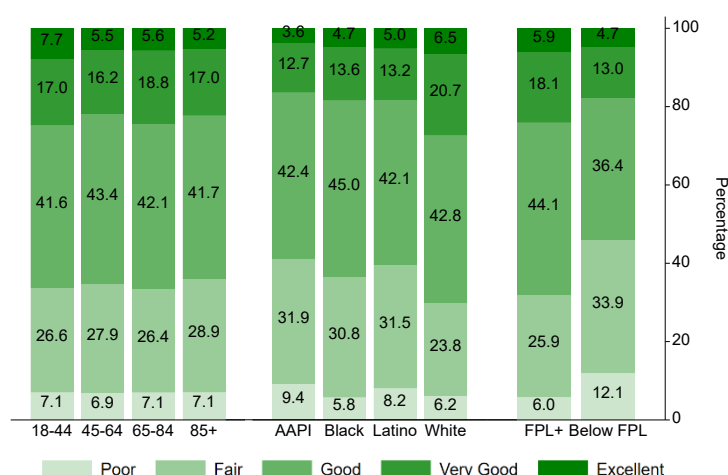
The percentage of caregivers reporting that their health was worse than it had been in the previous year, rose steadily with age from 29% among those 18-44 years of age to 35% of those 85 years and older (Figure VI-i). By race and ethnicity, the group with the highest percentage reporting worse health than in the previous year was Asian American and Pacific Islander caregivers (39%), followed by White, non-Hispanic caregivers (32%), Hispanic or Latino caregivers (31%) and Black, non-Hispanic caregivers (30%). A higher percentage of caregivers with lower income reported fair or poor health (35%) compared to those with higher income (32%).

Figure VI-i: Health Status Change

Using the PHQ-9 scores (see Appendix B) which indicate symptoms associated with depression, a higher percentage of caregivers in the youngest age group had moderate to severe depressive symptoms (25%) and this percentage dropped steadily with age to 13% among those 85 years and older (Figure VI-j). A higher percentage of Asian American and Pacific Islander caregivers reported moderate to severe depressive symptoms (22%) compared to the other racial and ethnic groups (18-19%). Caregivers with income at or below the FPL were more likely to report moderate to severe depressive symptoms when compared to those with higher income (25% versus 18% respectively).

Figure VI-j: Caregiver Depressive Symptoms (PHQ-9)

	18-44	45-64	65-84	85+		AAPI	Black	Latino	White		FPL+	Below FPL
Minimal-None	75.5	78.8	82.7	86.7		77.7	81.5	81.8	80.6		81.8	75.2
Severe-Moderate	24.5	21.2	17.3	13.3		22.3	18.5	18.2	19.4		18.2	24.8

Legend: ▢ Severe-Moderate ▢ Minimal-None
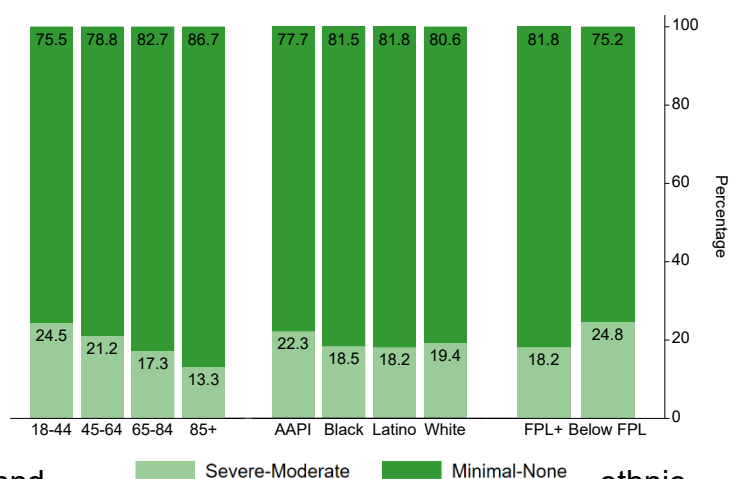
"I worry about my parents and my child, but I worry the most about myself, right now because I'm getting sick. I have been neglecting myself a lot..." – CRC Caregiver

~

"There's nobody to relieve me. It became quite clear to me that I was tired. I was neglecting my own health. I was preoccupied with his, and my need to make him happy...the thing I miss most is being a wife. I'm not a wife anymore...I am a cook. I am a helper. I am the gardener. I'm the housekeeper. I'm the shopper. I'm the person who takes care of the cars and makes sure they get their oil changes...I do a hundred percent, plus be responsible for him, and so I realized how I was tired." – CRC Caregiver

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Family Caregivers Providing Complex Care

Data collected in the on-line technology platform, CareNav™ at assessment include measures describing caregiving tasks and intensity. These data can be used to understand the extent to which CCRC caregivers are engaged in complex care tasks in the home, and further to identify characteristics that predict which groups of caregivers are providing complex care. This information can, in turn, help to identify caregivers at risk who may have unmet need for additional support and resources. Building on the question "What are the caregivers doing?" in the Home Alone Model (Figure VI-k), this analysis[1] explores the following question: What socio-demographic characteristics and caregiving characteristics are associated with caregivers providing complex care? The following analyses include data collected between January 1, 2019, and October 4, 2023.[2]

Figure VI-k: Home Alone Model: Caregivers Providing Complex Care
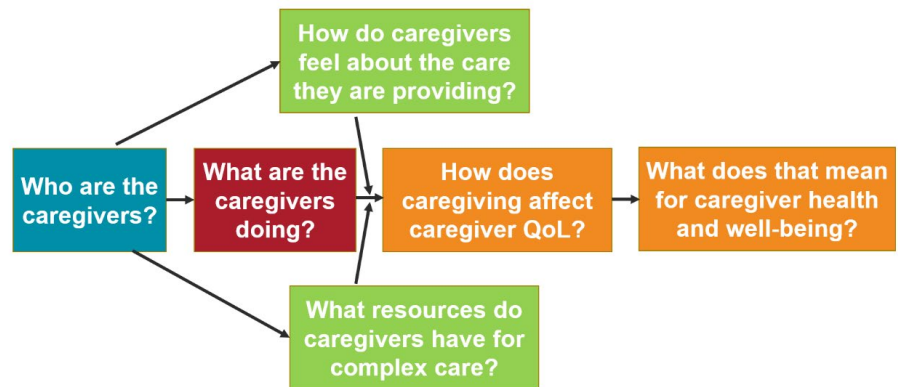
Provision of Complex Care

The first analysis explores which caregivers are providing the most complex care. Results of the negative binomial regression model of counts of all ADLs and iADLs together showed that:

- ✓ Caregivers of people with income below the FPL support 3% more ADLs and iADLS than caregivers of people with income at or above the FPL
- ✓ Compared to caregivers reporting White, non-Hispanic race and ethnicity, those reporting their race and ethnicity was:
    - o Black, non-Hispanic support 5% more ADLs and iADLs
    - o Hispanic or Latino support 4% more ADLs and iADLs
    - o Asian or Pacific Islander support 7% more ADLs and iADLs
    - o Other or two or more support 3% more ADLs and iADLs
- ✓ Compared to caregivers caring for someone lived alone, those living with the care recipient supported 15% more ADLs and iADLs

Performing Medical or Nursing Tasks

The second analysis explored which caregivers are performing Medical/Nursing Tasks (MNTs). Results of the negative binomial regression model of counts of MNTs among those performing MNTs showed that:

- ✓ Older caregivers aged 65-84 years performed 8% fewer MNTs and those aged 85 and older performed 26% fewer MNTs than caregivers ages 45 years or younger.
- ✓ Caregivers of people with income below the FPL performed 13% more MNT than those of people with income at or above the FPL.
- ✓ Compared to caregivers reporting White, non-Hispanic race and ethnicity, those reporting their race and ethnicity was:
    - ✓ Black, non-Hispanic performed 17% more MNT
    - ✓ Hispanic or Latino performed 13% more MNT
    - ✓ Asian or Pacific Islander performed 20% more MNT
    - ✓ Other or two or more performed 6% more MNT
    - ✓ Compared to caregivers caring for someone who did not live alone, those caring for someone who lives alone performed 35% fewer MNTs
- ✓ Caregivers of veterans performed 6% more MNT than caregivers of civilians
- ✓ Caregivers who lived with the care recipient performed 35% more MNT than caregivers of recipients who lived alone

Among caregivers who performed MNTs, 35% found the tasks difficult, felt unprepared or reported needing more information. Results of logistic regression, identified the following groups more likely to report that they found the tasks difficult, felt unprepared or needed more information:

- ✓ Caregivers of people with income below the FPL compared to at or above (29% higher odds)
- ✓ Caregivers identifying as Asian or Pacific Islander or other/2 more race and ethnicity (37% higher odds) compared to White, non-Hispanic (80% higher odds)
- ✓ Female caregivers compared to males (25% higher odds)
- ✓ Caregivers of veterans compared to caregivers of civilians (21% higher odds)
- ✓ Urban dwelling compared to rural dwelling caregivers (25% higher odds)

Managing Memory or Behavior Problems

The third analysis explored managing care recipient memory or behavior problems. Results of the negative binomial regression model of counts of memory and behavior problems managed showed that:

- ✓ Caregivers of people with income below the FPL managed 9% more memory and behaviors problems than caregivers of people with income at or above the FPL.

- ✓ Compared to caregivers reporting White, non-Hispanic race and ethnicity, those reporting their race and ethnicity Asian or Pacific Islander or Other or two or more managed 9% and 8% more memory and behavior problems, respectively
- ✓ Compared to caregivers caring for someone who did not live alone, those living with the care recipient managed 6% more memory and behavior problems
- ✓ Female caregivers supported 5% more memory and behavior problems than male caregivers.
- ✓ Caregivers of veterans managed 5% fewer memory and behavior problems compared to caregivers of civilians.
- ✓ Rural dwelling compared to urban dwelling caregivers managed 9% more memory and behavior problems.

"The challenge with health care for people is ... if you're really rich, you can afford anything you want. If you're really super poor, the government's got tons of programs which cost nothing. If you make just a little bit of money, then they say, "Oh, you're too rich. We're not gonna help you." ... they look at your income. They say, "Oh, you're not destitute. You don't get anything."" **– CRC Caregiver**

Summary

Inequities exist in the distribution of caregiving demands, resources and outcomes. Older caregivers compared to younger caregivers, those who identify in racial and ethnic groups compared to White non-Hispanic, and those with income below the FPL compared to higher income tend to have greater caregiving demands, fewer resources and more adverse outcomes.

A large percentage of CRC caregivers provide complex care in the home across all measures examined. Importantly, the distribution of complex care provision is not equal with caregivers who identify in racial and ethnic groups other than White, non-Hispanic; caregivers of individuals with low income; and those who live with the care recipient performing complex care tasks disproportionately. These groups of caregivers may have more unmet needs and require more support. CRC supportive care interventions have potential to reduce disparities in a large population of caregivers at risk.

"I think what struck me the most that every age, every culture, every religion, every color was represented at that get-together. We aren't alone, and that is something that we've gotta get out there somehow to let people understand they're not alone." **– CRC Caregiver**

VII.   OUTCOMES

Using CareNav™ Data to Track Outcomes for Family Caregivers from Assessment to Reassessment

Background

Data collected in the on-line technology platform, CareNav™, offers a unique opportunity to follow caregiver outcomes over time. The data includes socio-demographic and caregiving characteristics collected at intake when caregivers first reach out to the CRCs. For some caregivers, the information shared by care consultants at intake fully addresses their needs. For approximately 70% of the caregivers completing intakes, further service is required, and these caregivers continue to complete a full assessment usually the same day or within a week or two.

Assessment data, collected by care consultants and recorded in CareNav™, includes details about the care recipient, the context of caregiving, and caregiver socio-demographic and health characteristics. The assessment includes standardized instruments measuring caregiver burden, depression, and loneliness. Of the caregivers completing assessment, approximately one third return for reassessment, where a subset of the assessment data including some of the standardized measures is collected again, usually within six months.

This analysis describes selected outcomes at assessment (Time 1) and again at reassessment (Time 2) to examine change over time. These analyses include data collected between January 1, 2019 and October 4, 2023. The average time from assessment to reassessment was 189 days (SD=51; range 31-285) or about six months.

Caregiver Burden

Average scores on the Zarit Burden Index – Short Form (ZBI-SF) were significantly lower at reassessment than at assessment (mean assessment score: 8.3; SD=3.7; range 0 – 16; mean reassessment score: 8.0; SD=3.7; range 0 – 16; p<0.01) (Figure VII-a). This means that caregivers rated their overall burden as slightly lower at Time 2 based on the combination of the 4 items in the scale ("uncertain what to do", "no time for themselves" "feeling stressed" and "feeling strained").

Figure VII-a: Caregiver Burden – Zarit Burden Score (4-Item)
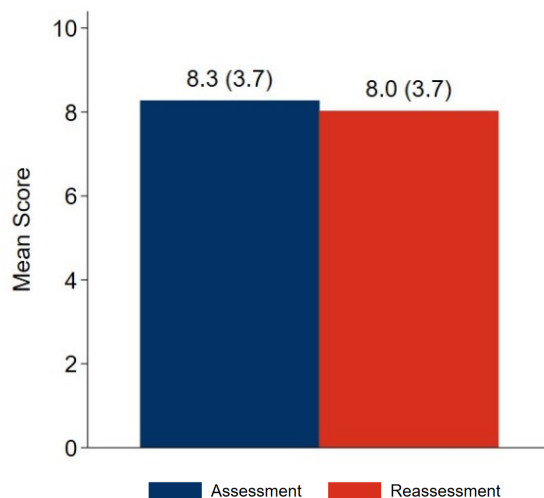
This small difference in the overall mean score was driven by significant differences in two items on the ZBI-SF. More caregivers were "never" or "rarely" uncertain what to do at reassessment compared to assessment (48.1% versus 43.7%; p<0.01) (Figure VII-b) and fewer caregivers said they frequently or nearly always had no time for themselves (48.07% versus 50.52%; p<0.01) at reassessment compared to assessment (Figure VII-c).

Figure VII-b: Caregiver Uncertain What To Do (%)
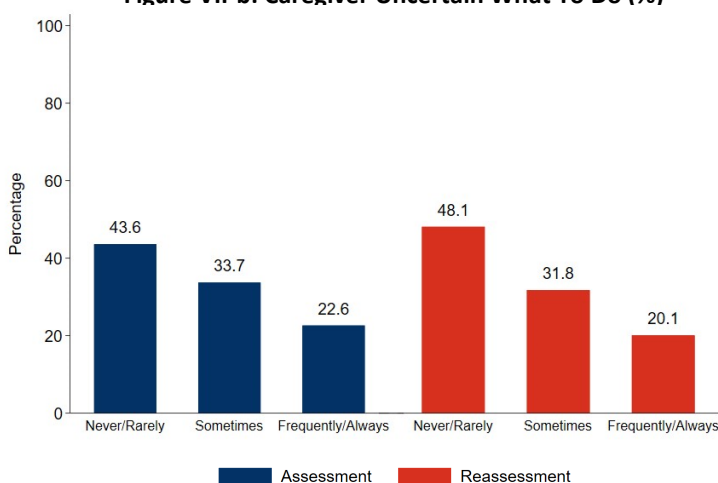
Loneliness

Average scores on the UCLA Loneliness Scale were significantly lower at reassessment compared to reassessment, meaning lower reports of loneliness at Time 2 compared to Time 1. The magnitude of this difference was however very small (mean assessment score: 4.9; SD=2.0; range 0 – 9; mean reassessment score: 4.8; SD=2.0; range 0 – 9; p<0.01) (Figure VII-d).

Figure VII-c: Caregiver Has No Time for Self (%)
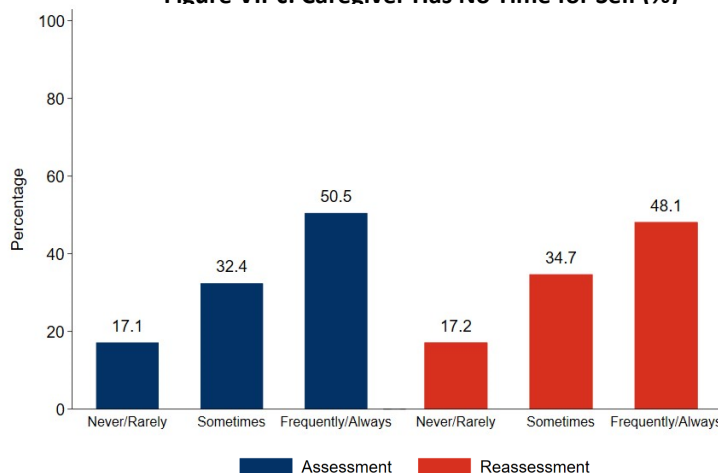
Two of the three individual items in the UCLA Loneliness Scale changed significantly from assessment to reassessment. Specifically, there were small declines in the percentage reporting they "often" lacked companionship (19.1% versus 18.8%; p=0.02) or "often" felt isolated (18.2% versus 17.9%; p<0.01). The percentage reporting that they felt left out was similar at assessment and reassessment.

At assessment and reassessment, the percentage of caregivers categorized as "lonely" on this scale was similar at approximately 21%.

Figure VII-d: Mean UCLA Loneliness Scale
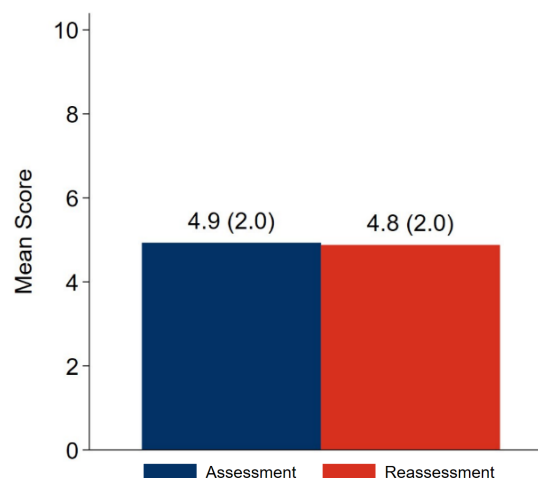
Depressive Symptoms

Average scores on the PHQ-9 (Figure VII-e) were significantly lower at reassessment than at assessment (mean assessment score: 5.9; SD=5.0; range 0 – 27; mean reassessment score: 5.5; SD=4.9; range 0 – 27; p<0.01) indicating that caregivers reported somewhat fewer depressive symptoms at Time 2 than at Time 1.

Figure VII-e: Mean PHQ-9 Score

Of the nine items in the PHQ-9 instrument, five showed significant shifts toward better scores. The percentage reporting "more than half the days or nearly every day" declined from assessment to reassessment for having little interest or pleasure doing things (16.8% to 14.4%; p<0.01), feeling down, depressed or hopeless (20.9% versus 18%; p<0.01), having poor appetite or overeating (15.5% versus 14.0%; p<0.01), feeling bad about oneself/feeling like a failure/letting yourself or family down (12.1% versus 9.5%; p<0.01) and trouble concentrating on things, such as reading the newspaper or watching television (12.4% versus 11.8%; p=0.02). There were no differences in this percentage from assessment to reassessment for the other four PHQ-9 items (trouble falling/staying asleep; feeling tired or having little energy; moving or speaking so slowly or the being fidgety or moving around a lot; thoughts you would be better off dead or of hurting yourself).

There were no significant differences in the categorical distribution of the PHQ-9 scores as mild, moderate, or severe depressive symptoms between assessment and reassessment.

Caregiving Hours and Help

Caregivers reported no difference in the hours of unpaid help between assessment and reassessment (Figure VII-f); however, there was a significant increase in the hours of paid help they received (p<0.01) (Figure VII-g). At assessment, 83% had no paid help whereas this percentage declined to 78% at reassessment. Similarly, 6.4% of caregivers reported 30 or more hours of paid help at assessment and this percentage increased to 8.6% at reassessment (p<0.01).

Figure VII-f: Unpaid Help (%)

There was a small concomitant increase in the percentage of caregivers reporting their own hours of caregiving as less than 20 hours per week (12.1 versus 13 %; p=0.01). At the same time, approximately 75% of caregivers still provided 40 hours or more of caregiving per week at both assessment and reassessment. A higher percentage of caregivers reported they were dissatisfied with help from family and friends at reassessment compared to assessment (22.5% versus 18.5%; p<0.01). Caregivers reported no differences in their satisfaction with their social and spiritual support between assessment and reassessment.

Figure VII-g: Paid Help (%)

	Assessment	Reassessment
No Paid Help	83.3	77.7
Some Paid Help	16.7	22.3
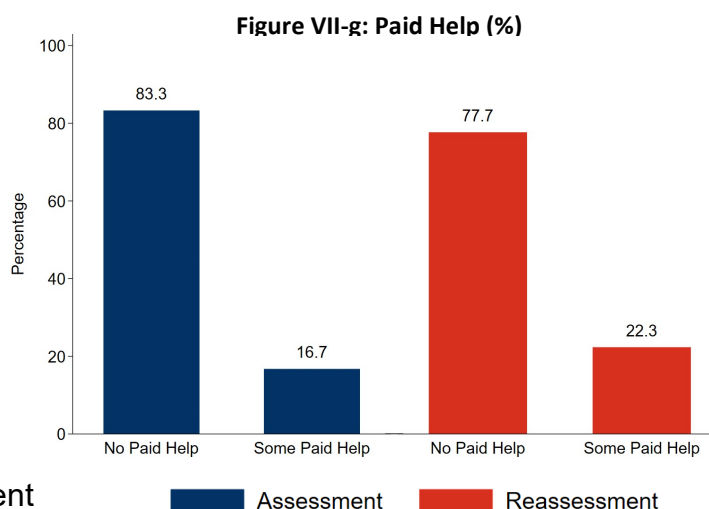
Summary

The differences in caregiving characteristics and caregiver outcomes reported here generally occur in the context of a worsening of the care recipient's condition. Accordingly, the positive differences reported, while sometimes small in magnitude, are very meaningful. At the same time, these are unadjusted comparisons and do not account for potential confounding variables such as the unequal distribution of socio-demographic or health characteristics. Even still, the reported differences align directly with the elements of the CCRC service model. At assessment, care consultants identify problems and intervene to provide resources and services tailored to address the underlying issues. They provide in-house or vouchered counseling services that could lead to fewer depressive symptoms and lower PHQ-9 scores; referrals to support groups that could reduce loneliness; referrals to in-home support services and respite care that increase the hours of paid help received; referrals to legal services and supplemental grants that taken together with other supports and resources could reduce caregiver burden. These positive changes are remarkable and timely in this cohort of help-seeking caregivers, most of whom are providing full-time care themselves amid worsening care recipient health and growing dissatisfaction with support from family and friends. Taken together, these positive changes underscore the impact of the CRC service model on the lives of family caregivers and the importance of ongoing investment in these services.

"... as a caregiver, you have very, very limited time. When you figure out all the things you need to do, and there's only 24 hours in the day, you're like, okay. If I had 36 hours in a day, I still couldn't get it all done…" – CRC Caregiver

VIII.   IMPACT AND RECOMMENDATIONS

Successful implementation of CareNav™ across all eleven CRC sites has enabled collection of detailed information about almost 19,000 caregivers since 2019. Importantly, the caregivers represent diverse communities and circumstances. Coupled with longitudinal data, this investment has actualized the potential to understand the caregiver experience and disparities in outcomes. This report contains detailed analysis of data from FY 2022-2023 as well as synthesis of data since 2019. Major findings include:

CRCs serve caregivers who provide complex, intense, and time-consuming care. Caregivers are often the primary or only caregiver in the situation and commonly have little family or paid support.

Caregivers highly value the support provided by the CRCs. They are highly satisfied and emphasize the crucial impact of the personal interaction and coordinating role of *family consultants,* who establish a trusting relationship and provide guidance and support. Family consultants facilitate readiness to accept help and identify vital resources including respite, support groups, legal/financial consultation, and education. Caregivers report they feel supported, gain confidence and skills and learn to manage demands and stress. Combined, CRC resources improve mental health, reduce stress, and increase the capacity of caregivers to engage in their vital role.

Inequities exist in the distribution of caregiving demands, resources and outcomes. Older caregivers compared to younger caregivers, those who identify in racial and ethnic groups other than White non-Hispanic, and those with income below the FPL compared to higher income have greater caregiving demands, fewer resources and more adverse outcomes.

The CRCs have substantially increased their outreach and education over the past year. Public outreach increased and educational program offerings nearly doubled, including statewide programs in English and other languages. CRCs have realized efficiencies in delivery because base funding has remained the same over the past three years, without cost-of-living adjustments. Further expansion would likely require enhanced investment.

CareNav™ implementation is advancing. Sites are increasingly using data for program decision-making. However, caregiver adoption of CareNav™ is similar to last year, with awareness and technical support as major barriers. Those who use the online platform are very satisfied.

Longitudinal analysis of caregivers enrolled in CRCs reveal **improvements in caregiver outcomes**, including burden, loneliness, and depressive symptoms. These outcomes generally occur in the context of worsening of the care recipient's condition. Accordingly, the positive differences reported, while sometimes small in magnitude, are very meaningful. The reported differences align directly with the elements of the CCRC service model. At assessment, care consultants identify problems and intervene to

provide resources and services tailored to address the underlying issues. These positive changes underscore the impact of the CRC service model on the lives of family caregivers and the importance of ongoing investment in these services.

Recommendations

The CRCs have expanded their services and are using CareNav^{TM} data in important ways to inform decisions and strategy. We recommend consideration of the following:

At the CRC site level:
- o Use CareNav^{TM} data to improve program quality and responsiveness and refine outreach efforts to reach sub-populations that have yet to benefit from the CRC services and supports
- o Develop strategies to increase caregiver awareness and utilization of CareNav^{TM} as a resource.

At the CRC system level:
- o Participate in reviewing data to develop plans to address disparities in caregiver experience, services and outcomes and to develop an equity plan for caregivers
- o Collaborate to identify priority health issues for additional programming and develop strategies to address these issues
- o Continue to identify opportunities for collaboration that leverage strengths across the system, for example, sharing bilingual staff across regions.

At the state level (California Department on Aging):
- o Consider enhanced funding to enable further service expansion with annual cost of living adjustments to all contracts for services
- o Prioritize funding for increasing diversity, equity, and inclusion with investments in linguistic and cultural refinements of resources and supports already available in the CRC system
- o Use data on caregivers and services to inform implementation of the California Master Plan on Aging and other statewide planning efforts
- o Collaborate with CRCs to advance caregiving service standards and quality

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

APPENDICES

A. Glossary

The Appendix A glossary is an evolving list of definitions and terminology to help clarify CCRC services and the metrics collected.

Table A1: 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 I-b 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.
Reassessment	Includes a subset of the assessment questions, designed for follow-up approximately six months after assessment.
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.

Terms	Definitions
Reporting Period	Fiscal Year 2019-2020 (7/1/2019-6/30/2020) Fiscal Year 2020-2021 (7/1/2020-6/30/2021) Fiscal Year 2021-2022 (7/1/2011-6/30/2022) Fiscal Year 2022-2023 (7/1/2022-6/30/2023) Quarter 1: 7/1/2022-9/30/2022 Quarter 2: 10/1/2022-12/31/2022 Quarter 3: 1/1/2023-3/31/2023 Quarter 4: 4/1/2023-6/30/2023
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 unduplicated count of caregivers who have had their first assessment: • During one of this fiscal year's quarters. • Within the past two years of any of this fiscal year's quarters

B. Technical Specifications

Appendix B outlines the analytical methods, criteria, sources, and definitions applied for the analyses presented in this report.

Inclusion Criteria

The following criteria are applied to the cases and activities CareNav™ datasets. These impact the analyses in the Executive Summary; Chapter II: Population Served; Chapter III: Services Provided (with exception to the Outreach and Education section); Chapter VI: Special Populations; Appendix C: Appendix Tables C1 – C4; and Appendix D: Caregiver Subgroup Snapshots.

Cases were included in the evaluation analysis if:

- County if not missing / null
- Case is not deleted / retired
- Caregiver funding eligibility includes DHCS or CDA. 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 caregivers, service activities (other than intake assessments) and grant vouchers distributed are limited to caregivers eligible for DHCS or CDA 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.

Case Status Counts

All totals reported in Table III a: Case Status Summary – All California CRCs Combined represent unduplicated counts of caregivers who have had an assessment within the two years before each respective quarter. A caregiver is no longer an ongoing case in later quarters of the same fiscal year if those quarters lie outside of the two-year window of the most recent assessment. A given caregivers can be categorized as a new case, an ongoing case with activity, and ongoing case without activity at various points across quarters. The same caregiver can be counted in up to four categories but is always counted as an open case. Thus, the pool of caregivers remains fixed at 10,887 total open cases for this year. Please see Table B1 for example cases of how counts are conducted.

Table B1: Caregiver Case Status Journey Examples

Quarter	Caregiver 1	Caregiver 2	Caregiver 3	Caregiver 4
Most recent assessment within previous two years?	No	Yes	No	Yes
Q1	First Assessment	No Activity	No Activity	No Activity
Q2	Activity	No Activity	No Activity	No Activity
Q3	Activity	No Activity	No Activity	No Activity
Q4	No Activity	Activity	First Assessment	No Activity
FY Case Summary	• New Case • Ongoing Case with Activity • Ongoing Case without Activity • Open Case	• Ongoing Case with Activity • Ongoing Case without Activity • Open Case	• New Case • Open Case	• Ongoing Case without Activity • Open Case

Case Tallies

The ongoing and open cases tallies may be incomplete in this fiscal year based on the individual CRC timing of complete CareNav™ 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™ 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.

Service Grant Voucher Totals

Service grant voucher totals reflect entries into CareNav™ 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.

Caregiver Demands, Resources, and Outcomes by Socio-demographic Characteristics and Caregiver Subgroups

These analyses are based on the CareNav™ case files and are thus subject to the same inclusion criteria as specified at the beginning of this appendix. Data from 01/01/2019 - 08/15/2023 were used to increase the sample sizes for each subgroup and variable intersection. Thus, sample sizes ranged from 564 - 12,055 caregivers at the subgroup level when examining their relationships with key variables.

Delivery Mode

Delivery modes (i.e., telephone, CRC office visits, online, video/telehealth, etc.) for intakes, assessments, and reassessments are not presented in this annual report. We identified data quality issues related to how this is currently recorded in CareNav™. Specifically, we found that the "online" status of caregivers who initiate or complete forms through the online CareNav™ portal appear to be overwritten when clinicians modify or submit any elements of these forms. Thus, there is no current way to delineate the true distribution of delivery modes. In ongoing efforts, QP, UC Davis and FCA are collaborating to address this issue and to clarify classification priorities given that some forms are completed after engagement through multiple delivery modes.

Missing Data

The analysis of caregiver and caregiver sociodemographic 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 = 4,038). 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).

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™, 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 B2 and B3 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 B2: 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 B3: 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 B4).

Table B4: 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 B5 shows the equivalent categories between AARP and CareNav™, as well as the points assigned for the level of care and care intensity calculations.

Table B5: 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 B6).

Table B6: 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.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-us-appendix-b-detailed-methodology.pdf

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™ 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

Appendix C contains detailed breakdowns of the Chapter III: Services Provided CareNav™ tables (Tables C1 – C4) and the Chapter IV: Caregiver Experience Satisfaction Survey tables (Tables C5 – C14) by site.

Table C1: Case Status Summary by Quarter and CRC - Fiscal Year 2022 - 2023

Quarter 1	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
New Cases	1,026	93	122	75	41	118	89	127	72	37	79	184	82
Ongoing Cases with Activity	3,550	323	224	129	155	455	424	564	316	240	253	486	304
Ongoing Case no Activity	4,833	439	666	338	131	478	261	431	304	81	338	1,117	688
Active Cases	9,409	855	1,012	542	327	1,051	774	1,122	692	358	670	1,787	1,074
Quarter 2	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
New Cases	795	72	89	43	36	113	103	73	70	27	42	126	73
Ongoing Cases with Activity	3,646	331	264	156	193	374	458	617	346	148	243	509	338
Ongoing Case no Activity	4,846	441	646	341	103	536	292	344	259	167	385	1123	650
Active Cases	9,287	844	999	540	332	1,023	853	1,034	675	342	670	1,758	1,061
Quarter 3	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
New Cases	958	87	117	51	55	117	95	83	73	38	94	138	97
Ongoing Cases with Activity	3,756	341	281	143	216	447	441	641	385	167	249	447	339
Ongoing Case no Activity	4,606	419	619	320	81	470	315	275	213	144	387	1154	628
Active Cases	9,320	847	1,017	514	352	1,034	851	999	671	349	730	1,739	1,064
Quarter 4	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
New Cases	1,116	101	110	71	49	166	140	71	60	60	120	166	103
Ongoing Cases with Activity	3,570	325	262	132	193	466	462	564	440	152	218	400	281
Ongoing Case no Activity	4,620	420	648	312	128	466	306	325	164	145	410	1085	631
Active Cases	9,306	846	1,020	515	370	1,098	908	960	664	357	748	1,651	1,015

Fiscal Year	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
New Cases	3,895	354	438	240	181	514	427	354	275	162	335	614	355
Ongoing Cases with Activity	7,010	637	618	323	357	896	744	931	604	365	491	1013	668
Ongoing Case no Activity	11,162	1,015	1218	636	418	1281	972	1278	835	423	806	2051	1244
Active Cases	12,278	1,116	1328	707	467	1447	1112	1349	895	483	926	2217	1347

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

* Definitions - refer to Appendix A: Glossary

* Inclusion Criteria – refer to Appendix C: Technical Specifications

* Activity reporting dates by quarter: Q1 = 7/1/2022-9/30/2022; Q2 = 10/1/2022 - 12/31/2022; Q3 = 1/1/2023-3/31/2023; Q4 = 4/1/2023-6/30/2023

* All totals represent deduplicated counts. Caregivers could occupy the new cases, ongoing cases with activity, and ongoing cases without activity categories at various points across quarters. Therefore, the same caregiver can be counted in up to four categories, including total open cases, but the pool of caregivers remains fixed at 10,887 total open cases for the year.

* Data extraction date: 08/15/2023

Table C2: CRC Caregiver Activity Summary by Quarter and CRC - Fiscal Year 2022-2023

Intake	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
Quarter 1	1,640	149	366	90	41	128	158	168	118	49	103	303	116
Quarter 2	1,422	129	312	120	36	124	207	100	119	27	99	165	113
Quarter 3	1,612	147	380	100	79	124	158	110	139	33	154	193	142
Quarter 4	1,686	153	370	163	52	171	211	74	99	58	135	219	134
Fiscal Year	**6,360**	**578**	**1,428**	**473**	**208**	**547**	**734**	**452**	**475**	**167**	**491**	**880**	**505**
Assessment	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
Quarter 1	1,060	96	125	78	41	125	91	128	75	37	93	184	83
Quarter 2	825	75	91	44	36	125	103	76	73	27	46	126	78
Quarter 3	995	90	121	52	56	125	96	85	76	38	100	139	107
Quarter 4	1,158	105	110	78	49	180	140	75	68	60	124	166	108
Fiscal Year	**4,038**	**367**	**447**	**252**	**182**	**555**	**430**	**364**	**292**	**162**	**363**	**615**	**376**
Reassessment	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
Quarter 1	828	75	27	22	23	258	89	56	86	77	44	89	57
Quarter 2	753	68	38	28	33	136	72	98	100	63	36	75	74
Quarter 3	987	90	50	24	54	199	68	161	79	77	87	90	98
Quarter 4	933	85	25	36	45	225	127	143	71	75	38	68	80
Fiscal Year	**3,501**	**318**	**140**	**110**	**155**	**818**	**356**	**458**	**336**	**292**	**205**	**322**	**309**
Family Consultation	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
Quarter 1	35,911	3,265	1,105	845	1,481	2,987	6,592	7,043	5,663	1,044	2,921	4,261	1,969
Quarter 2	34,879	3,171	990	770	1,840	2,612	6,249	6,598	7,202	753	2,234	3,791	1,840
Quarter 3	42,565	3,870	1,297	790	2,309	2,512	6,910	9,435	9,567	1,074	2,543	4,073	2,055
Quarter 4	44,822	4,075	1,369	895	2,252	2,927	8,197	8,588	11,523	1,098	2,229	3,815	1,929
Fiscal Year	**158,177**	**14,380**	**4,761**	**3,300**	**7,882**	**11,038**	**27,948**	**31,664**	**33,955**	**3,969**	**9,927**	**15,940**	**7,793**

Support Group (Unique Caregivers)	Total	Mean	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passage	Redwood	Southern	Valley
Quarter 1	614	56	54	36	31	13	77	125	86	48	65	71	8
Quarter 2	598	54	58	36	32	13	92	107	77	52	56	64	11
Quarter 3	638	58	57	51	28	23	90	125	66	59	68	61	10
Quarter 4	627	57	58	40	25	16	68	122	69	62	84	65	18
Fiscal Year	1,172	107	98	90	53	42	146	220	141	107	129	114	32

* Unique caregiver count totals do not reflect the sum of all unique caregivers across quarters – this would result in duplicate counting. The Fiscal Year and total counts are deduplicated for the entire year whereas each quarter count is deduplicated by that specific quarter. This means that the same caregiver can appear across multiple quarter counts but will only be counted once for the annual total.
* Definitions - refer to Appendix A: Glossary
* Inclusion Criteria – refer to Appendix C: Technical Specifications
* Activity reporting dates by quarter: Q1 = 7/1/2022-9/30/2022; Q2 = 10/1/2022 - 12/31/2022; Q3 = 1/1/2023-3/31/2023; Q4 = 4/1/2023-6/30/2023
* Data extraction dates: 08/15/2023

Table C3: CRC Counseling Services Summary by Quarter and CRC Fiscal Year 2022-2023

	In-House	Vouchered Service			
Quarter 1	Clients	Clients	Transactions	Hours	Amount ($)
Bay Area	0	30	39	83	8,300
Coast	0	26	46	80	5,310
Del Mar	8	0	0	0	0
Del Oro	0	3	4	6	600
Inland	29	0	0	0	0
Los Angeles	0	0	1	0	0
Orange	3	0	0	0	0
Passages	0	8	11	28	3,700
Redwood	0	2	5	5	500
Southern	14	0	0	0	0
Valley	0	4	4	24	1,860
Total	**54**	**73**	**110**	**226**	**20,270**
Quarter 2	Clients	Clients	Transactions	Hours	Amount ($)
Bay Area	0	19	26	49	4,900
Coast	4	26	42	62	5,735
Del Mar	9	0	0	0	0
Del Oro	5	16	35	46	4,600
Inland	28	0	0	0	0
Los Angeles	0	0	0	0	0
Orange	6	0	0	0	0
Passages	0	9	16	32	4,150
Redwood	2	4	7	18	1,770
Southern	6	0	0	0	0
Valley	0	5	5	21	1,740
Total	**60**	**79**	**131**	**228**	**22,895**
Quarter 3	Clients	Clients	Transactions	Hours	Amount ($)
Bay Area	0	18	24	41	4,100
Coast	0	27	44	70	5,315
Del Mar	12	0	0	0	0
Del Oro	11	15	28	34	3,400
Inland	17	0	0	0	0
Los Angeles	0	10	16	38	3,800
Orange	24	0	0	0	0
Passages	0	15	25	38	5,000
Redwood	3	5	8	20	2,000
Southern	13	0	0	0	0
Valley	0	4	4	11	1,385
Total	**80**	**94**	**149**	**252**	**25,000**

	In-House	Vouchered Service			
Quarter 4	**Clients**	**Clients**	**Transactions**	**Hours**	**Amount ($)**
Bay Area	0	31	57	114	11,400
Coast	1	22	38	71	4,178
Del Mar	11	0	0	0	0
Del Oro	8	5	6	13	1,300
Inland	19	0	0	0	0
Los Angeles	0	12	26	56	5,600
Orange	17	0	0	0	0
Passages	0	12	21	32	4,075
Redwood	1	8	17	39	3,870
Southern	19	0	0	0	0
Valley	0	5	5	20	1,750
Total	**76**	**95**	**170**	**345**	**32,173**
Fiscal Year	**Clients**	**Clients**	**Transactions**	**Hours**	**Amount ($)**
Bay Area	0	66	146	287	28,700
Coast	5	60	170	283	20,538
Del Mar	26	0	0	0	0
Del Oro	12	19	73	99	9,900
Inland	69	0	0	0	0
Los Angeles	0	16	43	94	9,400
Orange	44	0	0	0	0
Passages	0	27	73	130	16,925
Redwood	6	14	37	82	8,140
Southern	42	0	0	0	0
Valley	0	15	18	76	6,735
Total	**204**	**217**	**560**	**1,051**	**100,338**

* Unique caregiver count totals do not reflect the sum of all unique caregivers across quarters – this would result in duplicate counting. The Fiscal Year and total counts are deduplicated for the entire year whereas each quarter count is deduplicated by that specific quarter. This means that the same caregiver can appear across multiple quarter counts but will only be counted once for the annual total.
* Definitions - refer to Appendix A: Glossary
* Inclusion Criteria – refer to Appendix C: Technical Specifications
* Activity reporting dates by quarter: Q1 = 7/1/2022-9/30/2022; Q2 = 10/1/2022 - 12/31/2022; Q3 = 1/1/2023-3/31/2023; Q4 = 4/1/2023-6/30/2023
* Data extraction dates: 08/15/2023 – 09/18/2023

Table C4: Service Grant Vouchers by Quarter and CRC - Fiscal Year 2022 - 2023

	Legal Consultation				Respite				Supplemental		
Quarter 1	Transactions	Clients	Hours	Amount ($)	Transaction	Clients	Hours	Amount ($)	Transaction	Clients	Amount ($)
Bay Area	6	6	9	1,350	32	20	1,060	26,518	2	2	193
Coast	0	0	0	0	157	89	2,159	75,339	0	0	0
Del Mar	3	3	2	300	53	30	1,979	48,990	0	0	0
Del Oro	2	2	4	350	12	11	168	5,224	0	0	0
Inland	0	0	0	0	14	12	883	13,635	11	11	3,095
LA	0	0	0	0	11	8	316	7,930	1	1	82
Orange	2	2	2	500	443	141	4,737	155,793	74	33	26,032
Passages	3	3	3	525	49	28	531	16,276	0	0	0
Redwood	6	6	6	570	56	34	1,933	53,239	0	0	0
Southern	8	8	8	820	68	41	695	20,655	0	0	0
Valley	2	2	2	350	302	164	4,127	108,757	1	1	20
Total	**32**	**32**	**36**	**4,765**	**1,197**	**578**	**18,589**	**532,357**	**89**	**48**	**29,422**
Quarter 2	Transactions	Clients	Hours	Amount ($)	Transaction	Clients	Hours	Amount ($)	Transaction	Clients	Amount ($)
Bay Area	6	6	9	1,275	34	24	1,062	29,757	0	0	0
Coast	0	0	0	0	206	103	2,539	91,534	0	0	0
Del Mar	6	6	6	600	109	50	3,029	87,178	0	0	0
Del Oro	14	13	21	2,110	133	62	2,180	70,453	0	0	0
Inland	0	0	0	0	42	28	2,101	32,681	24	20	7,010
LA	0	0	0	0	17	12	433	9,510	0	0	0
Orange	1	1	10	2,691	511	164	6,387	182,710	52	24	23,790
Passages	3	3	3	525	86	43	934	29,461	0	0	0
Redwood	4	4	4	380	144	67	4,528	124,028	0	0	0
Southern	12	11	12	1,230	127	63	1,318	37,624	0	0	0
Valley	2	2	2	350	300	166	4,188	111,399	0	0	0
Total	**48**	**46**	**67**	**9,161**	**1,709**	**782**	**28,699**	**806,336**	**76**	**44**	**30,800**

	Legal Consultation				Respite				Supplemental		
Quarter 3	Transactions	Clients	Hours	Amount ($)	Transaction	Clients	Hours	Amount ($)	Transaction	Clients	Amount ($)
Bay Area	2	2	3	450	38	30	1,279	37,309	0	0	0
Coast	0	0	0	0	125	70	1,358	49,570	0	0	0
Del Mar	11	11	11	1,200	89	53	2,536	65,556	0	0	0
Del Oro	1	1	1	100	272	97	3,018	101,906	0	0	0
Inland	0	0	0	0	32	27	1,553	24,795	20	18	5,122
LA	4	4	4	400	57	44	1,689	41,283	31	17	2,911
Orange	0	0	0	0	624	171	6,817	221,850	114	42	47,926
Passages	4	4	4	700	95	46	1,023	31,445	0	0	0
Redwood	5	5	5	475	137	71	3,436	94,259	0	0	0
Southern	5	5	5	550	163	75	1,922	50,809	0	0	0
Valley	0	0	0	0	325	176	4,510	114,797	0	0	0
Total	**32**	**32**	**33**	**3,875**	**1,957**	**860**	**29,141**	**833,579**	**165**	**77**	**55,959**
Quarter 4	Transactions	Clients	Hours	Amount ($)	Transaction	Clients	Hours	Amount ($)	Transaction	Clients	Amount ($)
Bay Area	5	5	5	660	54	39	1,828	60,121	0	0	0
Coast	0	0	0	0	80	48	1,141	41,135	0	0	0
Del Mar	10	10	10	1,000	98	60	2,536	63,375	0	0	0
Del Oro	1	1	1	100	212	104	2,245	75,919	0	0	0
Inland	0	0	0	0	60	43	3,246	51,240	90	79	26,187
LA	0	0	0	0	98	66	3,808	102,473	2	1	190
Orange	2	2	2	500	444	136	8,658	198,142	69	28	31,058
Passages	6	6	6	1,050	178	81	2,563	78,314	0	0	0
Redwood	6	6	6	570	169	102	4,681	124,378	0	0	0
Southern	3	3	3	345	112	86	1,271	37,577	0	0	0
Valley	4	4	4	700	258	161	4,576	119,308	0	0	0
Total	**37**	**37**	**37**	**4,925**	**1,763**	**926**	**36,553**	**951,982**	**161**	**108**	**57,435**

Fiscal Year	Legal Consultation				Respite				Supplemental		
	Transactions	Clients	Hours	Amount ($)	Transaction	Clients	Hours	Amount ($)	Transaction	Clients	Amount ($)
Bay Area	19	19	26	3,735	158	87	5,229	153,704	2	2	193
Coast	0	0	0	0	568	168	7,196	257,579	0	0	0
Del Mar	30	30	29	3,100	349	128	10,081	265,099	0	0	0
Del Oro	18	17	27	2,660	629	153	7,611	253,503	0	0	0
Inland	0	0	0	0	148	80	7,783	122,351	145	106	41,413
LA	4	4	4	400	183	116	6,246	161,196	34	19	3,182
Orange	5	5	14	3,691	2,022	331	26,600	758,495	309	102	128,806
Passages	16	16	16	2,800	408	115	5,050	155,496	0	0	0
Redwood	21	21	21	1,995	506	170	14,578	395,904	0	0	0
Southern	28	27	28	2,945	470	148	5,206	146,665	0	0	0
Valley	8	8	8	1,400	1,185	352	17,401	454,261	1	1	20
Total	149	147	172	22,726	6,626	1,848	112,982	3,124,253	491	230	173,615

* Definitions - refer to Appendix A: Glossary
* Activity reporting dates by quarter: Q1 = 7/1/2022-9/30/2022; Q2 = 10/1/2022 - 12/31/2022; Q3 = 1/1/2023-3/31/2023; Q4 = 4/1/2023-6/30/2023
* Data extraction date: 09/18/2023

Table C5: Count of Client Satisfaction Surveys Submitted

Bay Area	390
Coast	103
Del Mar	74
Del Oro	387
Inland	456
LA	60
Orange	256
Passages	71
Redwood	77
Southern	185
Valley	195
Total Surveys	**2,254**

Count of all survey entries emailed to HS-FCI and affiliates. This includes survey entries with at least one recorded response from Question 2 and beyond.

Table C6: Overall Service Satisfaction Scores Summary

Extremely Dissatisfied	50 2.2%
Dissatisifed	30 1.3%
Neutral	87 3.9%
Somewhat Satisfied	303 13.6%
Extremely Satisfied	1,759 78.9%
Total Responses	**2,229**

Each row presents the tally of responses on the top and the corresponding percentage on the bottom. The Total Responses row only shows the aggregate tally of all valid responses. For this table, all survey entries are valid.

Table C7: Recommend CRC to Friend or Family Member Scores Summary

Will Definitely Not Recommend	20 0.9%
Probably Will Not Recommend	18 0.8%
Neutral	89 4.1%
Will Probably Recommend	216 10.0%
Will Definitely Recommend	1,809 84.1%
Total Responses	**2,152**

Each row presents the tally of responses on the top and the corresponding percentage on the bottom. The Total Responses row only shows the aggregate tally of all valid responses. For this table, all survey entries are valid.

Table C8: Overall Service Satisfaction, Service Recommendation Willingness, and Impact of Services Score Means

	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley	All CRCs
Service Satisfaction	4.60	4.64	4.74	4.71	4.61	4.61	4.85	4.85	4.60	4.51	4.59	4.66
Recommend CRC to Friend or Family Memberx	4.71	4.69	4.89	4.72	4.76	4.79	4.93	4.83	4.71	4.68	4.75	4.75
More Confident as Caregiver	4.12	4.06	4.19	4.13	4.26	4.15	4.34	4.09	4.09	4.13	4.14	4.18
Better Able to Manage Care	4.14	4.08	4.22	4.12	4.26	4.09	4.30	4.06	4.11	4.18	4.22	4.19
More Knowledge and Awareness	4.23	4.25	4.38	4.31	4.37	4.41	4.39	4.22	4.36	4.16	4.35	4.31
Understand the Disease/Disability/Problem Better	4.02	4.02	4.06	4.03	4.24	4.06	4.29	3.79	4.11	4.05	4.11	4.10
Taking Better Care of Self	3.99	4.00	4.13	3.97	4.15	4.06	4.17	4.01	3.99	4.00	4.11	4.06
Less Stressed	3.80	3.88	4.06	3.85	4.03	3.89	4.07	3.81	3.73	3.93	3.96	3.92

Overall Service Satisfaction: Scores range from 1 (Extremely Dissatisfied) to 5 (Extremely Satisfied). Recommend CRC to Friend or Family Member: Scores range from 1 (Will Definitely Not Recommend) to 5 (Will Definitely Recommend). All other categories: Scores range from 1 (Strongly Disagree) to 5 (Strongly Agree). All entries valid.

Table C9: Offered Telehealth, Online Class, or Online Support Group

	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley	All CRCs
Yes	304	75	58	302	327	50	212	52	66	133	155	1,734
	79.4%	72.8%	82.9%	81.0%	85.4%	92.6%	89.1%	76.5%	85.7%	71.9%	81.2%	81.6%
No	31	10	4	33	31	2	15	6	5	26	19	182
	8.1%	9.7%	5.7%	8.8%	8.1%	3.7%	6.3%	8.8%	6.5%	14.1%	9.9%	8.6%
I Don't Know	48	18	8	38	25	2	11	10	6	26	17	209
	12.5%	17.5%	11.4%	10.2%	6.5%	3.7%	4.6%	14.7%	7.8%	14.1%	8.9%	9.8%

Response percentages may not add to 100 due to rounding. For this table, all survey entries are valid.

Table C10: Has Used CareNavTM

	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley	All CRCs
Yes	133	45	9	119	79	10	68	5	15	31	19	533
	34.6%	44.1%	12.5%	31.7%	20.4%	18.5%	27.4%	7.2%	19.5%	16.8%	9.9%	24.9%
No	205	50	57	218	262	40	153	58	51	139	157	1,390
	53.4%	49.0%	79.2%	58.1%	67.7%	74.1%	61.7%	84.1%	66.2%	75.5%	81.8%	64.8%
I Don't Know	46	7	6	38	46	4	27	6	11	14	16	221
	12.0%	6.9%	8.3%	10.1%	11.9%	7.4%	10.9%	8.7%	14.3%	7.6%	8.3%	10.3%

Response percentages may not add to 100 due to rounding. For this table, all survey entries are valid.

Table C11: Online Experience Satisfaction Scores Summary

Extremely Dissatisfied	7
	1.4%
Somewhat Dissatisfied	14
	2.7%
Neutral	67
	13.1%
Somewhat Satisfied	170
	33.1%
Extremely Satisfied	255
	49.7%
Total	513

Each row presents the tally of responses on the top and the corresponding percentage on the bottom. The Total Responses row only shows the aggregate tally of all valid responses. For this table, only survey entries that scored a "Yes" (1) for the "Has Used CareNav" item are considered valid. Scores range from 1 (Extremely Dissatisfied) to 5 (Extremely Satisfied). Response percentages may not add to 100 due to rounding.

Table C12: Reasons for Not Using CareNav Percentages

Did Not Know About it	31.6%
No Internet	4.0%
Did Not Need it	19.1%
No Technical Experience	13.8%
Too Confusing	1.5%
Other Reason	11.9%

Response percentages do not add to 100 as multiple responses can be selected per survey entry. For this table, only survey entries that scored a "No" (0) for the "Has Used CareNav" item and did not respond to the "Online Experience Satisfaction" item are considered valid.

Table C13: No Response Percentages Across Survey Questions

	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley	All CRCs
Overall Satisfaction	1.5%	0.0%	2.7%	1.0%	0.7%	5.0%	0.8%	0.0%	2.6%	0.5%	1.0%	1.1%
Recommend CRC	0.8%	0.0%	5.4%	2.6%	2.4%	13.3%	17.6%	7.0%	1.3%	2.7%	5.1%	4.5%
Confident as Caregiver	2.3%	1.0%	2.7%	3.1%	2.6%	10.0%	2.3%	7.0%	3.9%	0.5%	3.6%	2.8%
Better Able to Manage	1.8%	1.0%	2.7%	3.6%	2.9%	10.0%	2.0%	2.8%	2.6%	0.5%	3.6%	2.7%
More Knowledge/Awareness	1.5%	1.0%	2.7%	2.6%	1.8%	10.0%	1.6%	2.8%	1.3%	0.5%	4.1%	2.2%
Understand Issue Better	2.3%	1.0%	4.1%	4.1%	8.1%	10.0%	2.7%	5.6%	2.6%	0.5%	6.7%	4.4%
Better Self Care	1.5%	1.0%	5.4%	2.8%	7.0%	10.0%	1.6%	5.6%	3.9%	0.5%	5.1%	3.6%
Reduced Stress	2.8%	1.0%	6.8%	4.4%	7.9%	10.0%	2.4%	4.2%	3.9%	0.5%	5.6%	4.4%
Virtual Services Offered	1.8%	0.0%	5.4%	3.6%	16.0%	10.0%	7.0%	4.2%	0.0%	0.0%	2.1%	5.7%
Used CareNav	1.5%	1.0%	2.7%	3.1%	15.1%	10.0%	3.1%	2.8%	0.0%	0.5%	1.5%	4.9%
Satisfaction with CareNav	2.3%	2.2%	11.1%	1.7%	1.3%	30.0%	11.8%	20.0%	0.0%	0.0%	0.0%	3.8%
Reasons for no CareNav Use	0.0%	4.0%	5.3%	6.0%	2.3%	27.5%	37.9%	20.7%	9.8%	2.2%	8.3%	9.1%

No response percentages are the percentage of absent responses among all valid responders. All surveys regardless of responses are valid for the majority of questions. Only Satisfaction with CareNav and Reasons for no CareNav Use have more restrictive validity criteria. Please see Table 7 and Table 8 for criteria.

Table C14: Counts of Surveys Sent and Response Rates

	Bay Area	Coast	Del Mar	Del Oro	Inland	LA	Orange	Passages	Redwood	Southern	Valley
Online Sent	1,112	498	0	1,864	1,227	345	0	0	232	2,055	0
Online Completed	360	92	0	331	88	60	0	0	0	139	0
Online Response Rate	32.4%	18.5%		17.8%	7.2%	17.4%			0.0%	6.8%	
Online Undeliverable	25	6	0	0	33	3	0	0	0	8	0
Paper Sent	121	103	183	250	1,804	20	500	164	292	329	484
Paper Completed	31	11	77	56	445	0	198	68	78	46	227
Paper Response Rate	25.6%	10.7%	42.1%	22.4%	24.7%	0.0%	39.6%	41.5%	26.7%	14.0%	46.9%
Paper Undeliverable	0	1	0	0	0	0	0	0	0	13	0

Response rates are the proportion of sent surveys that were completed. Undeliverable surveys are not included in the response rate. Blanks represent unreported data or response rates that cannot be calculated.
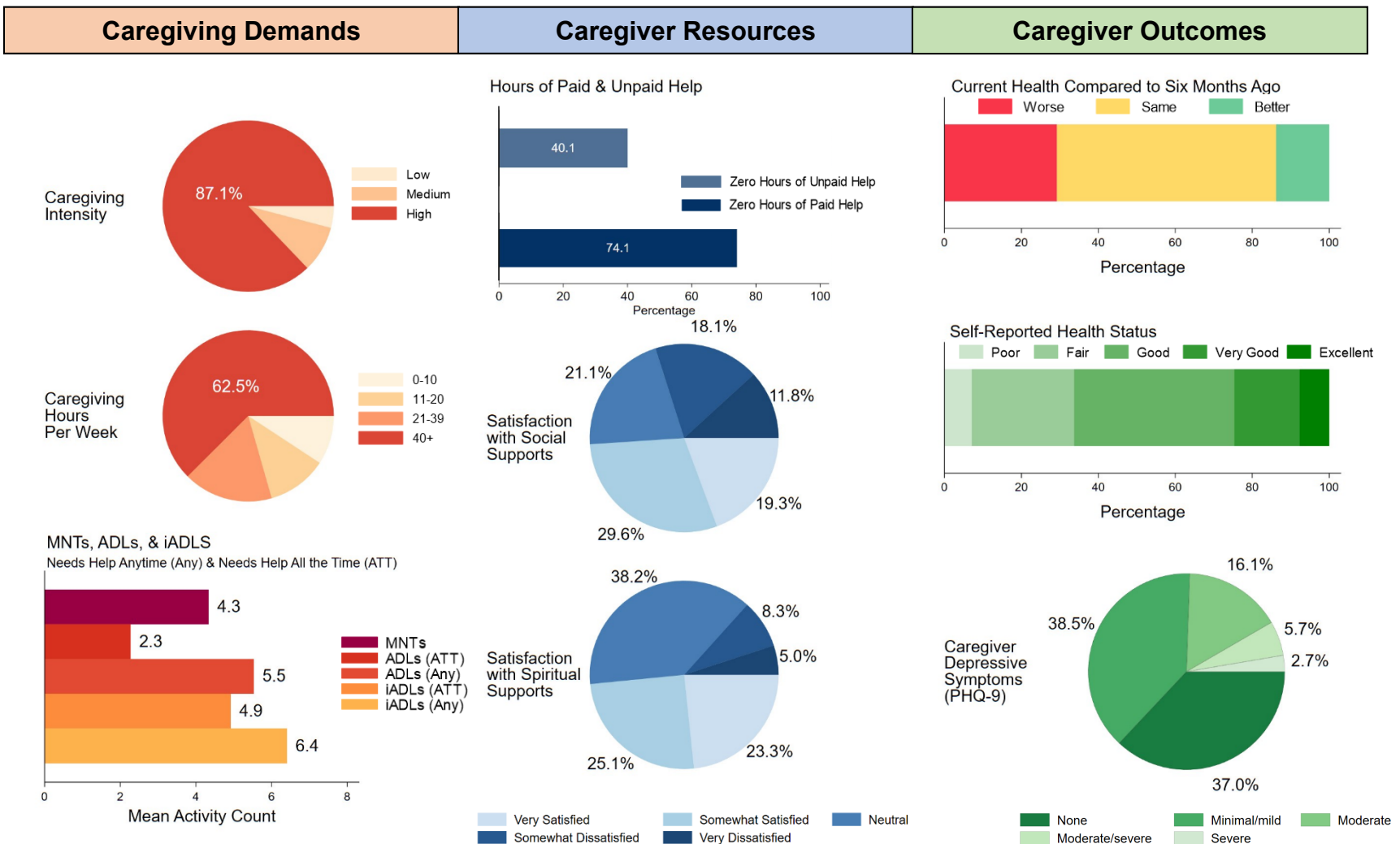
D. Caregiver Subgroup Snapshots

Appendix D presents the subgroup breakdowns of the figures in Chapter VI: Special Populations Caregiver Demands, Resources, and Outcomes by Socio-demographic Characteristics section.

Caregivers Aged 18-44

n = 1,132-1,447
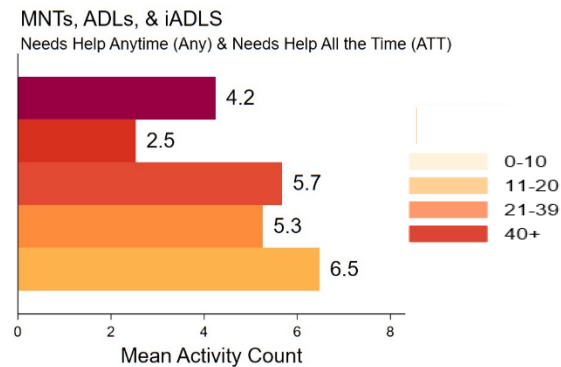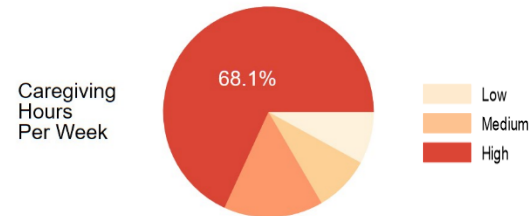Data Extracted from CareNav™: 01/01/2019 –

Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Demands

Caregiving Intensity
- Low
- Medium
- High: 87.1%

Caregiving Hours Per Week
- 0-10
- 11-20
- 21-39
- 40+: 62.5%

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)
- MNTs: 4.3
- ADLs (ATT): 2.3
- ADLs (Any): 5.5
- iADLs (ATT): 4.9
- iADLs (Any): 6.4

Mean Activity Count

Caregiver Resources

Hours of Paid & Unpaid Help
- Zero Hours of Unpaid Help: 40.1
- Zero Hours of Paid Help: 74.1

Percentage

Satisfaction with Social Supports
- 18.1%
- 11.8%
- 19.3%
- 29.6%
- 21.1%

Satisfaction with Spiritual Supports
- 38.2%
- 8.3%
- 5.0%
- 23.3%
- 25.1%

Very Satisfied / Somewhat Satisfied / Neutral / Somewhat Dissatisfied / Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago
- Worse
- Same
- Better

Percentage

Self-Reported Health Status
- Poor
- Fair
- Good
- Very Good
- Excellent

Percentage

Caregiver Depressive Symptoms (PHQ-9)
- 16.1%
- 5.7%
- 2.7%
- 37.0%
- 38.5%

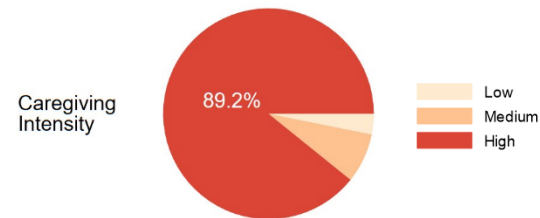None / Minimal/mild / Moderate / Moderate/severe / Severe
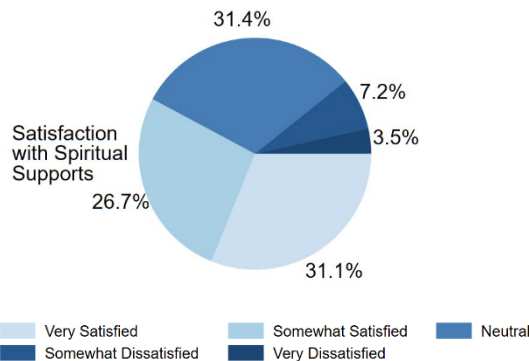
Caregivers Aged 45-64

n = 5,142-6,509
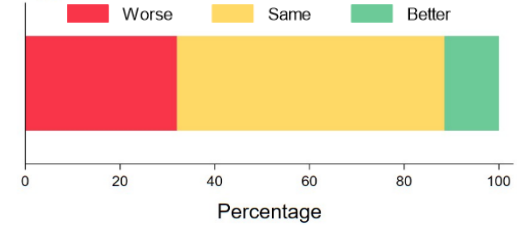Data Extracted from CareNav™: 01/01/2019 –

Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Demands

Caregiving Intensity

89.2%
- Low
- Medium
- High

Caregiving Hours Per Week

68.1%
- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 4.2
- 2.5
- 5.7
- 5.3
- 6.5

Legend:
- 0-10
- 11-20
- 21-39
- 40+

Mean Activity Count

Caregiver Resources

Hours of Paid & Unpaid Help

41.7 — Zero Hours of Unpaid Help
65.4 — Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports

- 16.5%
- 20.8%
- 12.1%
- 20.6%
- 30.0%

Satisfaction with Spiritual Supports

- 31.4%
- 7.2%
- 3.5%
- 31.1%
- 26.7%

- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago
- Worse
- Same
- Better

Percentage

Self-Reported Health Status
- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)

- 13.0%
- 42.0%
- 6.1%
- 2.0%
- 36.8%

- Worse
- Same
- Better

Caregiving Demands

Caregiving Intensity

91.8%

- Low
- Medium
- High

Caregiving Hours Per Week

80.6%

- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 4.0
- 2.6
- 5.7
- 5.4
- 6.5

- Low
- Medium
- High

Mean Activity Count

Caregiver Resources

Hours of Paid & Unpaid Help

- 52.2 — Zero Hours of Unpaid Help
- 64.8 — Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports

- 14.5%
- 8.3%
- 20.5%
- 25.1%
- 31.7%

Satisfaction with Spiritual Supports

- 29.4%
- 5.3%
- 2.0%
- 28.1%
- 35.2%

- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago

- Worse
- Same
- Better

Percentage

Self-Reported Health Status

- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)

- 43.8%
- 11.6%
- 4.5%
- 1.2%
- 38.8%

- Worse
- Same
- Better

Caregivers Aged 85 and Older

n = 564-757

Data Extracted from CareNav™: 01/01/2019 –
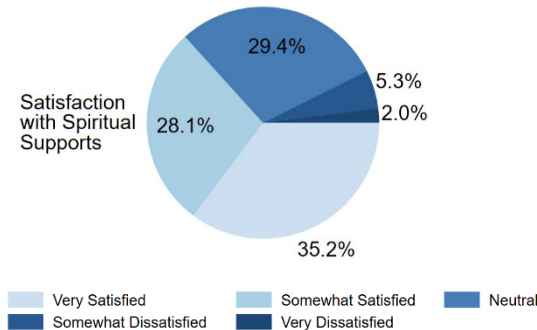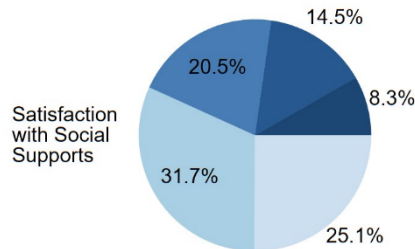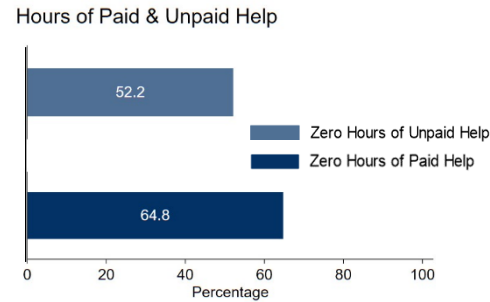
Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Demands

Caregiving Intensity

94.5% High

- Low
- Medium
- High

Caregiving Hours Per Week

86.9% High

- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 3.7
- 2.5
- 5.7
- 5.3
- 6.6

Mean Activity Count

- Low
- Medium
- High

Caregiver Resources

Hours of Paid & Unpaid Help

- 45.7 — Zero Hours of Unpaid Help
- 59.0 — Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports

- 19.5%
- 7.6%
- 5.1%
- 35.4%
- 32.4%

Satisfaction with Spiritual Supports

- 32.7%
- 5.0%
- 1.4%
- 34.3%
- 26.6%

Legend:
- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago

- Worse
- Same
- Better

Percentage

Self-Reported Health Status

- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)

- 44.0%
- 11.1%
- 1.9%
- 0.3%
- 42.7%

Legend:
- Worse
- Same
- Better

Asian American & Pacific Islander Caregivers
n = 1,197-1,516
Data Extracted from CareNav™: 01/01/2019 –
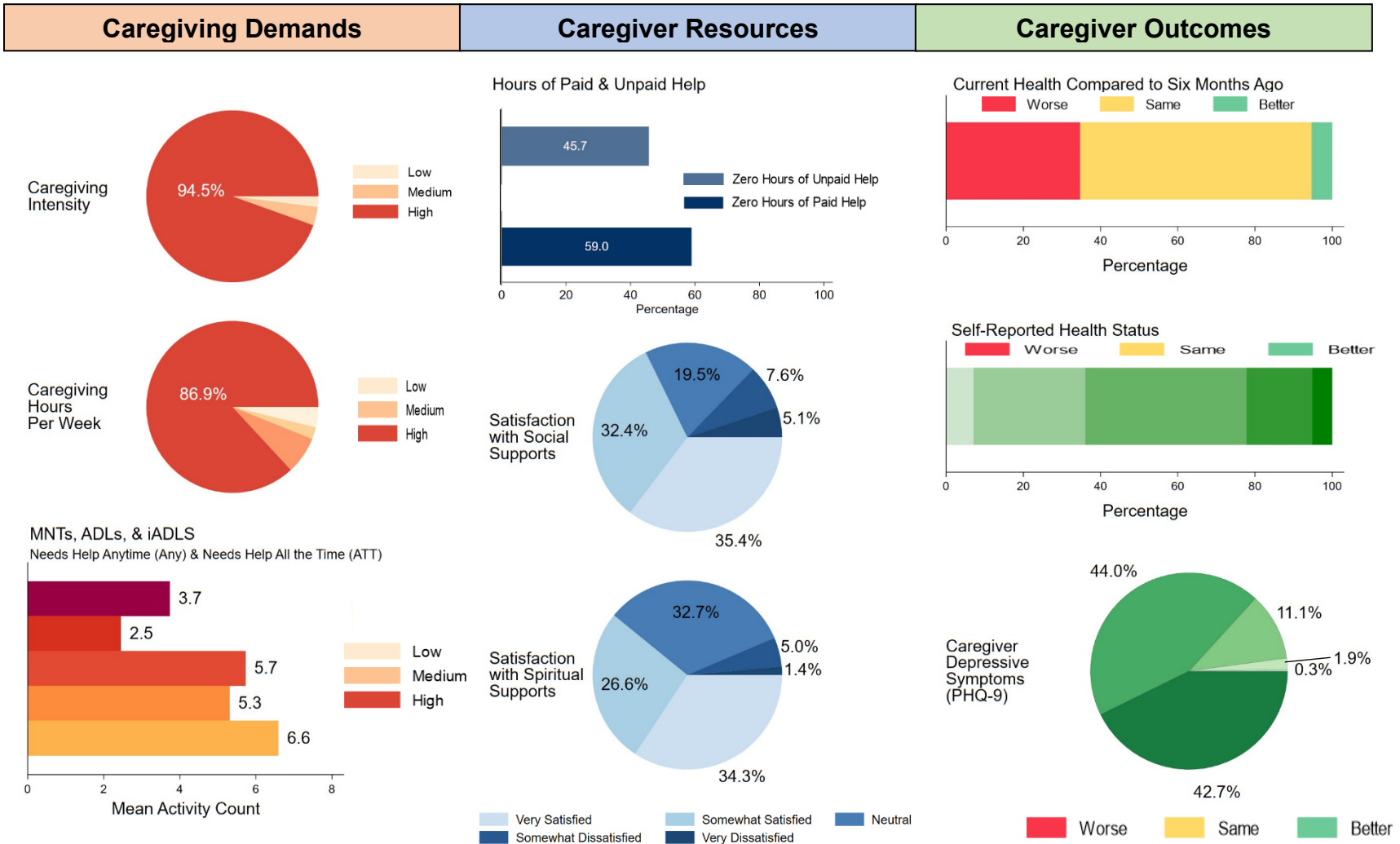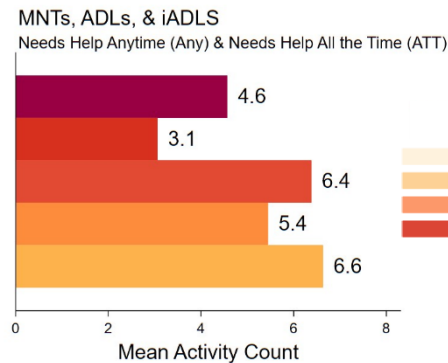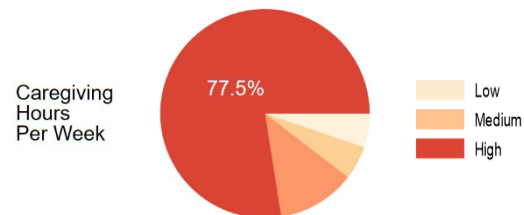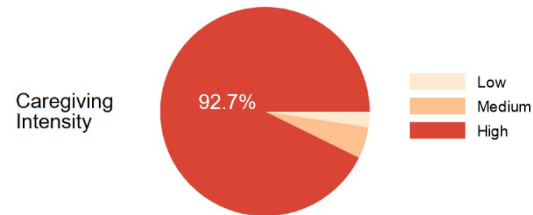
Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Demands

Caregiving Intensity
- 92.7% High
- Low
- Medium
- High

Caregiving Hours Per Week
- 77.5% High
- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 4.6
- 3.1
- 6.4
- 5.4
- 6.6

Legend:
- 0-10
- 11-20
- 21-39
- 40+

Mean Activity Count

Caregiver Resources

Hours of Paid & Unpaid Help
- 41.6 — Zero Hours of Unpaid Help
- 63.0 — Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports
- 15.2%
- 26.7%
- 7.3%
- 16.6%
- 34.1%

Satisfaction with Spiritual Supports
- 38.4%
- 6.5%
- 2.1%
- 23.1%
- 29.8%

Legend:
- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago
- Worse
- Same
- Better

Percentage

Self-Reported Health Status
- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)
- 14.3%
- 5.5%
- 2.5%
- 36.9%
- 40.8%

Legend:
- Worse
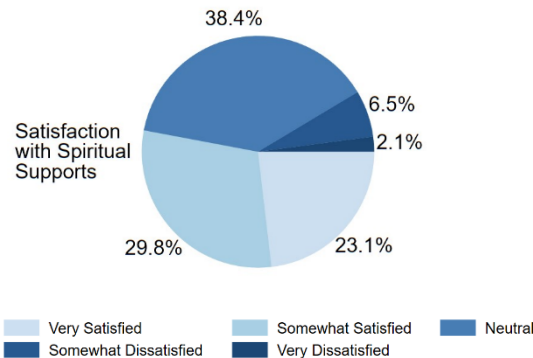- Same
- Better

Black non-Hispanic Caregivers
n = 1,001-1,271
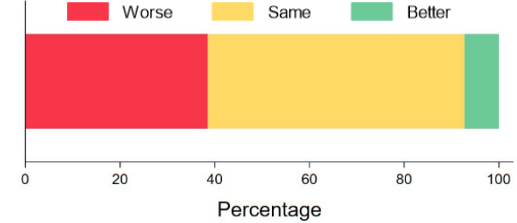Data Extracted from CareNav™: 01/01/2019 –

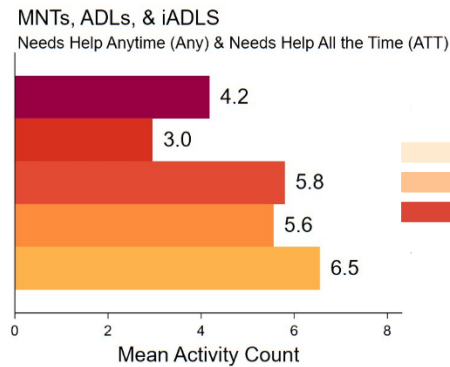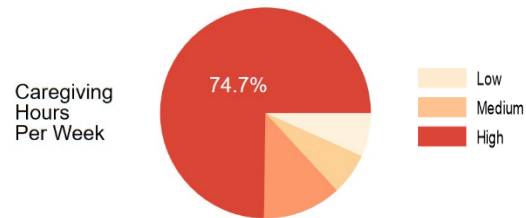| Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Intensity

91.4% High

Legend: Low, Medium, High

Caregiving Hours Per Week

74.7% High

Legend: Low, Medium, High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 4.2
- 3.0
- 5.8
- 5.6
- 6.5

Mean Activity Count

Legend: Low, Medium, High

Hours of Paid & Unpaid Help

- Zero Hours of Unpaid Help: 44.2
- Zero Hours of Paid Help: 68.2

Percentage

Satisfaction with Social Supports

- 17.3%
- 14.9%
- 17.2%
- 19.0%
- 31.6%

Satisfaction with Spiritual Supports

- 19.9%
- 6.9%
- 2.7%
- 27.1%
- 43.4%

Legend: Very Satisfied, Somewhat Satisfied, Neutral, Somewhat Dissatisfied, Very Dissatisfied

Current Health Compared to Six Months Ago

Legend: Worse, Same, Better

Percentage

Self-Reported Health Status

Legend: Worse, Same, Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)

- 40.6%
- 11.4%
- 6.0%
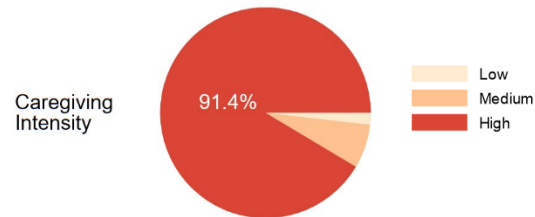- 1.1%
- 40.9%

Legend: Worse, Same, Better
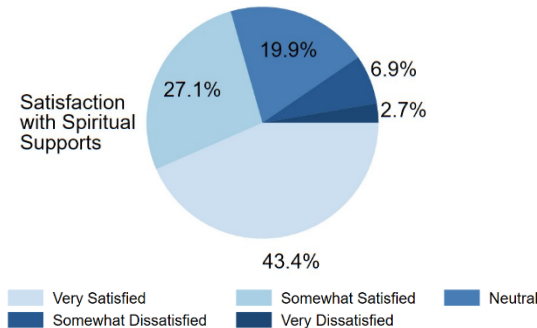
Latino and Hispanic Caregivers

n = 3,126-3,890

Data Extracted from CareNav™: 01/01/2019 –

Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Demands

Caregiving Intensity

90.1% High
- Low
- Medium
- High

Caregiving Hours Per Week

72.6% High
- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 4.4
- 2.6
- 5.7
- 5.4
- 6.5

Legend:
- 0-10
- 11-20
- 21-39
- 40+

Mean Activity Count

Caregiver Resources

Hours of Paid & Unpaid Help

- 39.4 Zero Hours of Unpaid Help
- 70.4 Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports
- 16.7%
- 10.9%
- 22.5%
- 30.4%
- 19.5%

Satisfaction with Spiritual Supports
- 25.0%
- 6.7%
- 2.9%
- 39.5%
- 25.9%
- 25.9%

Legend:
- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Caregiver Outcomes

Current Health Compared to Six Months Ago
- Worse
- Same
- Better

Percentage

Self-Reported Health Status
- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)
- 45.2%
- 11.6%
- 5.1%
- 1.5%
- 36.6%

Legend:
- Worse
- Same
- Better

White non-Hispanic Caregivers

n = 6,077-7,849

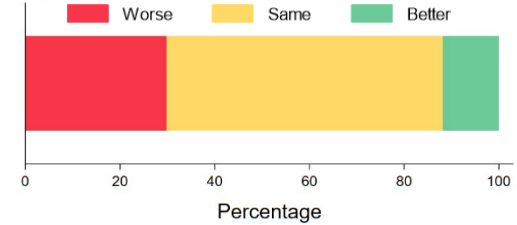Data Extracted from CareNav™: 01/01/2019 –

Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Intensity

89.9% High
- Low
- Medium
- High

Caregiving Hours Per Week

73.8% High
- Low
- Medium
- High

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

- 3.9
- 2.3
- 5.5
- 5.1
- 6.5

Legend:
- Low
- Medium
- High

Mean Activity Count

Hours of Paid & Unpaid Help

- Zero Hours of Unpaid Help: 51.1
- Zero Hours of Paid Help: 63.5

Percentage

Satisfaction with Social Supports
- 14.5%
- 9.2%
- 25.4%
- 30.1%
- 20.8%

Satisfaction with Spiritual Supports
- 34.2%
- 6.0%
- 3.0%
- 29.6%
- 27.2%

Legend:
- Very Satisfied
- Somewhat Satisfied
- Neutral
- Somewhat Dissatisfied
- Very Dissatisfied

Current Health Compared to Six Months Ago
- Worse
- Same
- Better

Percentage

Self-Reported Health Status
- Worse
- Same
- Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)
- 42.2%
- 12.7%
- 5.1%
- 1.6%
- 38.5%

Legend:
- Worse
- Same
- Better

California caregiver Resource Centers — Educate, Connect, Support.

UC DAVIS HEALTH | **BETTY IRENE MOORE SCHOOL OF NURSING** — Family Caregiving Institute

Caregivers at or Above the Federal Poverty Level
n = 9,493-12,055
Data Extracted from CareNav™: 01/01/2019 –

| Caregiving Demands | Caregiver Resources | Caregiver Outcomes |

Caregiving Intensity
90.1%
Low / Medium / High

Hours of Paid & Unpaid Help
46.4 — Zero Hours of Unpaid Help
63.9 — Zero Hours of Paid Help

Current Health Compared to Six Months Ago
Worse / Same / Better

Caregiving Hours Per Week
72.8%
Low / Medium / High

Satisfaction with Social Supports
15.1%
9.2%
24.1%
31.3%
20.2%

Self-Reported Health Status
Worse / Same / Better

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)
4.1
2.6
5.7
5.3
6.5
Low / Medium / High
Mean Activity Count

Satisfaction with Spiritual Supports
32.0%
6.2%
2.6%
27.9%
31.3%

Very Satisfied / Somewhat Satisfied / Neutral
Somewhat Dissatisfied / Very Dissatisfied

Caregiver Depressive Symptoms (PHQ-9)
42.4%
12.1%
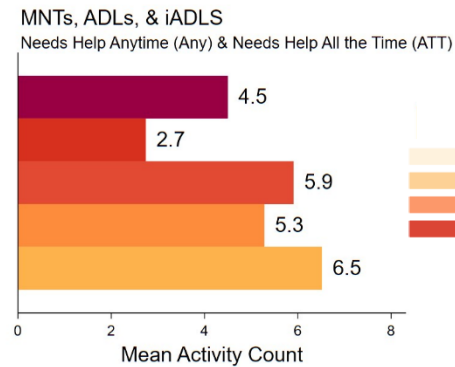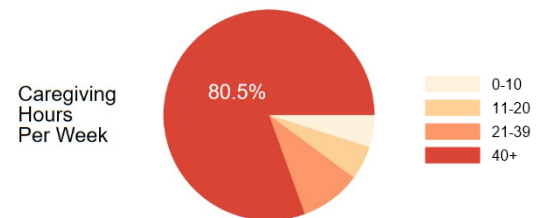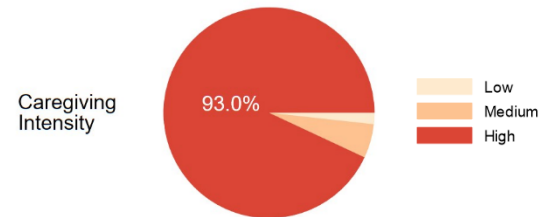4.8%
1.3%
39.3%

Worse / Same / Better

Caregivers Below the Federal Poverty Level

n = 2,074-2,547

Data Extracted from CareNav™: 01/01/2019 –

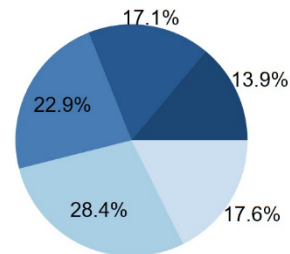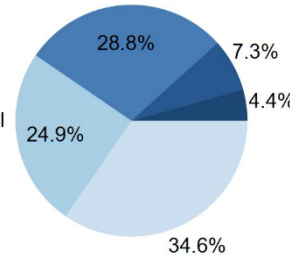| Caregiving Demands	Caregiver Resources	Caregiver Outcomes

Caregiving Intensity

93.0%

Low
Medium
High

Caregiving Hours Per Week

80.5%

0-10
11-20
21-39
40+

MNTs, ADLs, & iADLS
Needs Help Anytime (Any) & Needs Help All the Time (ATT)

4.5
2.7
5.9
5.3
6.5

Mean Activity Count

0-10
11-20
21-39
40+

Hours of Paid & Unpaid Help

48.6
73.5

Zero Hours of Unpaid Help
Zero Hours of Paid Help

Percentage

Satisfaction with Social Supports

17.1%
13.9%
22.9%
28.4%
17.6%

Satisfaction with Spiritual Supports

28.8%
7.3%
4.4%
24.9%
34.6%

Very Satisfied
Somewhat Dissatisfied
Somewhat Satisfied
Very Dissatisfied
Neutral

Current Health Compared to Six Months Ago

Worse   Same   Better

Percentage

Self-Reported Health Status

Worse   Same   Better

Percentage

Caregiver Depressive Symptoms (PHQ-9)

14.6%
7.2%
3.0%
44.3%
30.9%

Worse   Same   Better
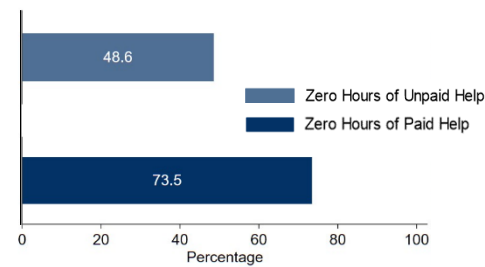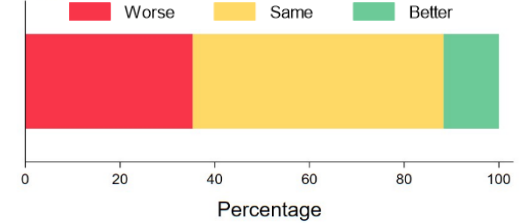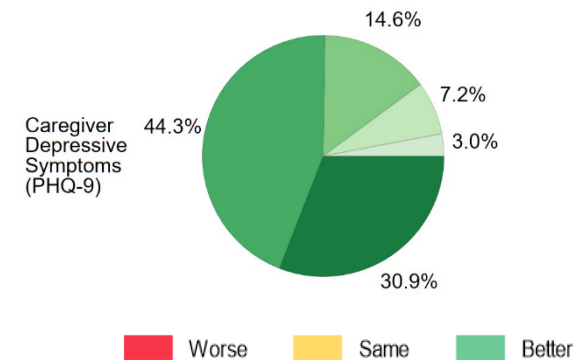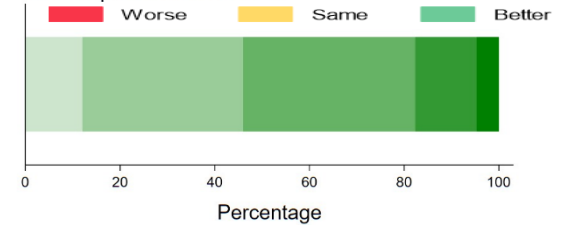
E. Outreach and Education Narrative

Appendix E contains CCRC site-specific narratives about their outreach and education efforts. These were collected to better capture the various programs sites manage and lead across the year. Terms and definitions are included at the bottom of this section.

Table E1: Site Outreach and Education Overview

CCRC	Outreach and Education Overview
Del Mar	Our Caregiver Resource Center is nestled in the breathtaking Central Coast of California. Our cities are home to a vibrant Latino community that has historically been difficult to engage for many organizations. To better serve this community, our CRC is part of a collaborative effort with other agencies that serve older adults. This effort focuses on expanding outreach to Latinos living in rural areas that are difficult to access. As members of this collaborative, we keep each other informed of relevant community events and opportunities for outreach. Our organization has also begun participating in weekend events to reach more people that may only be available on those days. Despite the significant impact of COVID-19 on our region, we are pleased to see a sense of normalcy returning with more in-person events resuming. Our Communications and Development Manager has created social media accounts on various channels to reach people of all ages. Our social channels have been gaining popularity and provide educational material and community resources. Beyond our social reach, we have created many culturally appropriate advertisements to ensure we reach everyone.
Del Oro	Our biggest strength is a full-time Education and Outreach Coordinator who works to implement our rigorous plan, which includes: internet-based marketing and social media; developing training and community outreach activities to market Del Oro services and form collaborative partnerships; targeted mailings to professionals, service organizations, and associations about educational offerings; engaging in traditional media publicity through television and radio and newspapers and publications; participation in community planning and service coordination committees and planning bodies; displaying tables of information at health fairs, senior fairs, conferences, community forums; presenting to professional groups to provide an overview of our philosophy and services; and participating in community groups and attending meetings for the purpose of professional outreach. Care and attention are given to equity and inclusion through understanding the unique needs of underserved individuals and best practices to effectively communicate considering their cultural and linguistic differences; however, our biggest challenge is our 13-County region as each area has distinct needs. We look for community partners we can work with to reach specific groups and build rapport. In our plan, we look to places of work, faith-based institutions, libraries, community clubs, community health centers, Indian Health Services, schools, and local newspapers to target our efforts. For example, we are working with the Alzheimer's Association to plan an African American Forum in March 2023 at the church of our Education and Outreach Coordinator. We do rely on the Statewide system and the vast offerings available throughout the State.
Inland	ICRC conducts outreach in a variety of ways to reach the diverse population and geographic areas it serves. Below is a description of each: **Outreach Events**: ICRC Education/Outreach staff participate in over 100 outreach activities each month in collaboration with family resource centers, senior centers, churches, assisted living facilities, libraries, community centers, medical clinics, independent living centers and disease specific organizations. It does this through outreach visits, community presentations, and participation in health fairs.

	Education: The agency hosts 10 educational workshops each month in English and 8 in Spanish. Presenters are professionals from collaborating agencies who discuss topics affecting caregivers, seniors, and persons with disabilities. ICRC will enhance these efforts in the above-named service areas to increase agency referrals by hiring an additional Education/Outreach Coordinator if granted funds. **Participation in Collaboratives:** ICRC's clinical and outreach staff participate in over 40 collaborative meetings each month across San Bernardino and Riverside Counties, engaging social service providers in the region. **Focus Groups and Listening Sessions:** ICRC is consistently working on closing the gap of unmet needs in the community. The agency is currently involved in coordinating and facilitating focus groups for the development of an Inland Empire Master Plan on Aging. It also collaborates with agencies to host listening sessions about challenging topics such as end of life planning, mental health services, and grief and loss. Through these groups the agency has been able to learn how clients want to be reached and how they want information presented which assists in our outreach efforts. **Collaborations with Community Organizations:** The agency collaborates with organizations when needed to reach mutual clients and also to create innovative programming. **Social Media:** ICRC regularly posts on Instagram and Facebook. It does 8 Facebook Lives in English and 4 in Spanish each month. **E-mail blasts and Robo-Calls:** ICRC invites current clients to participate in support groups and classes through e-mail blasts using constant contact. It follows up these efforts with robo-calls to remind those who registered. **Mailings:** ICRC does mailings to clients who prefer to be reached by mail and also does targeted mailings depending on the event that is being held. **Diverse Populations:** In addition to the above, ICRC will conduct outreach events/activities tailored to reach specific demographic groups. For example, it has held "Loteria" events where perspective clients play and win prizes to reach Spanish Speakers. It is currently developing outreach videos targeting the AAPI, LGTBQ, Veterans, Hispanic/Latinx, African American, and Deaf and Hard of Hearing communities to expand mental health awareness.
LA	The Los Angeles Caregiver Resource Center (LACRC) employs a multifaceted approach to communication, utilizing diverse channels to reach a wider audience. This includes leveraging social media platforms, hosting webinars, and producing engaging video content. By employing a variety of mediums, LACRC ensures that its message resonates with various ethnic and cultural groups. LACRC also recognizes that different communities have unique needs and interests. As a result, we have developed targeted outreach campaigns to effectively engage with these groups. For example, we have developed the CONFIDENCE/CONFIANZA program which helps Latinx caregivers of persons living with dementia reduce financial strain. LACRC is always actively collaborating with community leaders and organizations to gain insights and build relationships, enhancing outreach effectiveness. Some organizations LACRC has developed community partnerships with are 211 LA, Independence at Home, First African Methodist Episcopal Church (FAME), City of West Hollywood, and Farsi speaking communities. We use available data to create educational programs, develop focus groups, and find resources that tailor to each and every one of these groups. With this data, we have been able to create additional support groups at First AME and facilitate educational programs in different languages with Independence at Home.

Orange	Caregiver Resource Center OC is capitalizing on various sources to help support our efforts of outreach and education programs provided by our organization. Our community liaisons are active in attending health fairs, conferences, and other events to increase awareness and knowledge of all our program has to offer. Further, our Education Coordinator regularly connects with other providers in the community to provide in-services on our programs, and educational classes to help improve services provided to caregivers served by other providers. Our program offers educational classes created and facilitated internally, as well as collaborations with other service providers, and hosting of experts in their own field with topics of relevance to the caregiving community. We offer classes in person and virtually, in multiple languages, live and recorded, in hopes of meeting the communities need.
Southern	Southern Caregiver Resource Center relies heavily on digital outreach, especially social media (Facebook, Instagram, LinkedIn, and YouTube) and email marketing. SCRC tasks our Education and Outreach staff with creating content relevant to our client base and maintaining our well-established posting schedule across platforms. SCRC also makes use of virtual platforms for our educational events, incorporating content hosted via Podomatic, Instagram Live, and YouTube Live into our training calendar and caregiver resource library. Large-scale media campaigns, including the use of billboards, bus benches, commercials broadcast over radio and TV, and ads in printed media also support SCRC's outreach efforts. Our in-person outreach strategy is unique: SCRC employs a team of Community Outreach Workers (colloquially referred to as Promotoras) dedicated to in-person outreach full-time. Our Promotoras participate in health and resource fairs and community networking meetings, as well as tabling, brochure placement, and flyer distribution at publicly accessible locations seven days a week. The majority of SCRC's outreach workers are bilingual, fluent in English and Spanish; this allows us to properly serve the substantial Spanish-speaking communities in San Diego and Imperial Counties. Our outreach workers also facilitate partnerships with local clinics, resource centers, and other nonprofit organizations in order to increase our prospective client base. SCRC's most significant regional challenge is appealing to individuals from cultures that, typically, do not identify with the "caregiver" label or seek professional help with caregiving. Our Education and Outreach team actively promotes evidence-based and culturally appropriate programming, emphasizing the proven benefits to counseling, practicing self-care as a caregiver, and caregiving-related education and training. We also distribute printed materials and host events in both English and Spanish, so potential clients can communicate in the language they are most comfortable with anytime they interact with SCRC. Many of our Education and Outreach staff are or have been caregivers themselves; this unique experience allows our team to connect with potential clients and address their hesitations on a deeper level. A combination of digital and in-person methods, along with SCRC's unique employee structure, allows us to create and maintain successful outreach campaigns.
Valley	VCRC continues to be intentionally focused on reaching out to the underserved communities in our community. These efforts are easily identified as we continue to narrow our contact goals toward segments of our community with socioeconomic hinderances to receiving adequate support in their caregiving journey. Our recent activities include intentional connection with the LGTBQ+ Community by attending a senior group called Gray Alliance, where we presented our program information. From that connection this group started a text chat line to support each other by implementing wellness checks, rides, light housekeeping, groceries, light yard work, cooking pet care. We have stretched our reach into the outlying areas of our nine different counties that we serve. These efforts have renewed our collaboration with the Community Action Agency for Tulare County's C-Set organization whose focus is to assist individuals and communities to achieve self-reliance. Partnering with C-Set has allowed us to share our program information to more than 400 families through their Meals on Wheels program and by working together with the smaller senior centers in the rural communities.

	We have also increased our collaboration with a local Memory Care facility in Los Banos and started a monthly general Caregiver support group. This has given a needed opportunity to an area that previously were required to drive 30-45 minutes to the nearest support group.
FCA Bay Area	As the "parent" brand for the CRC network, the goal of the Statewide outreach efforts is to develop brand awareness. Our marketing primarily directs people to the statewide website, which has on average 6,000 visitors each month. Through these efforts, we have not only increased traffic to the statewide website but have also driven outbound traffic to the local CRC's websites and CareNav. Blog content on the statewide website ranks high on Google searches, which leads to greater brand awareness and caregiver education. Our outreach also includes connecting with other content creators in the caregiving industry to ensure they are familiar with the CRCs and informing their audiences of CRC services. This results in podcast guesting opportunities and guest content contributions. Collectively, our digital marketing efforts increase the familiarity with the CRC brand and direct users to their local CRC.

Table E2: Outreach and Education Terms

Term	Definition
Diverse or Underserved Audiences (D or U)	Communities or individuals "at a higher risk for health disparities by virtue of their race or ethnicity, socioeconomic status, geography, gender, age, disability status, or other risk factors associated with sex and gender"[5]. Sites included activities for specific populations (e.g., Hmong Health Alliance, Asian Community Health Center) as well as those that include a D or U audience.
Education	Education/training sessions for members of the community. These sessions are open to the community and are not limited to CRC clients.
Health or Resource Fairs	Health, senior or resource fairs conducted in person or virtually.
Meetings | Presentations	In-person or virtual meetings to members of the public (potential clients), community groups and/or providers with the goal of generating awareness of CRC services.
Public Information Sharing | Outreach	Outreach with the purpose of building name recognition, community building, and encouraging use of / referral to services through email blasts, newsletters, social media posts, etc.