5th Annual Report

Evaluation of the California Caregiver Resource Centers' Service Delivery and System Change

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“The support I have received has given me mental strength to step up and give the care that is needed! Knowing I am not alone in this journey and that there are people like [CRC Staff] that truly care about me has meant EVERYTHING to me!!”

– CRC Caregiver

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EXECUTIVE SUMMARY

In California, over 7 million family caregivers provide most of the long-term care, supporting older adults and persons with disabilities to remain in their environments of choice while supporting an array of physical, mental and functional needs. Family caregivers reflect the diverse population of California in age, race/ethnicity, gender, employment status and income. Eleven Caregiver Resource Center (CRC) sites serve family caregivers throughout California. Statewide implementation of CareNav^{TM} provides the nation's first comprehensive database of family caregivers, documenting who they are, the demands they face, the resources they need, and the outcomes of services and support. Caregivers represent diverse communities and circumstances. This report contains detailed analysis of data from fiscal year 2023-2024 (hereafter abbreviated FY23/24) and a look back to 2019, prior to CareNav^{TM} implementation. California State General Funds are allocated to CDA for the administration of CRC services through subcontracts with community-based providers, and the findings focus on these services. In addition, but not reported here, CRCs provide services to caregivers funded by federal, county and philanthropic sources.

The CRCs served over 12,217 unduplicated family caregivers in FY23/24. These diverse caregivers across the adult lifespan are caring for people with a range of health conditions and functional needs.

IMPACT

CRCs continue to serve caregivers who provide complex, intense, and time-consuming care. Caregivers 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 family consultants and respite care. Caregivers report important impacts on their physical and mental health and their ability to provide and sustain care because of the CRC programs.

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^{TM} implementation is advancing. Sites are using data for program decision-making. Caregiver use of CareNav^{TM} to enter data and initiate services is low at one in five caregivers served. This rate has remained stable for the last four years but conceals wide variability by CRC site. Those who use the online platform are very satisfied.

Overall, CRC caregiver services and issued service grants increased—in some cases considerably—since the year before the pandemic began. Family consultations increased the most, by over 1000%, and continue to increase year by year. This may reflect the CRC response to the increasing complexity of the caregiving role both during and after the pandemic.

Since the pandemic, CRC in-person services such as "in-house" counseling and support groups have declined, while these service activities have steadily increased overall. Taken together, this suggests a change in the mode of service delivery, from in-person to virtual, catalyzed by the pandemic. Further, this suggests the change in service delivery mode has been sustained and the CRCs are increasingly using technology to expand service delivery.

Service grant vouchers increased significantly from the pandemic with the new funding awarded to the CRCs. Thereafter, there have been small yet significant declines in these valuable caregiver resources—likely due to the unchanged level of state funding to the CRCs along with concomitant post-pandemic increases in the costs of the services themselves and in the costs of CRC operations (e.g., rent, salaries) without cost-of-living adjustments.

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:

- Use data on caregivers and services to inform implementation of the California Master Plan on Aging, the Equity Roadmap, and other statewide planning efforts

At the CRC site level:

- Use CareNav™ data to understand the needs and priorities of caregivers in each region, to identify gaps in services and communities who are not able to access resources
- Develop strategies to reach and engage sub-populations that have yet to benefit from the CRC services and supports
- Develop strategies to provide technical support to caregivers who could benefit from CareNav™ and associated resources
- Gather CRC site perspectives about reasons for low versus high CareNav™ use by caregivers and contextual factors that might explain site-specific variability in caregiver use rates

At the CRC system level:

- Collaborate across sites to identify programs and strategies that could be spread to other sites and provide support to leverage creative ideas
- Identify priority issues for additional programming and develop strategies to address these issues in culturally and linguistically appropriate ways
- Continue to identify opportunities for collaboration that leverage strengths across the system, for example, sharing bilingual staff across regions

- Continue analysis of caregiver, caregiving, and care recipient characteristics that predict caregiver use of CareNav™ to identify target groups for outreach to increase use of the platform
- Continue to engage in statewide CareNav™ data quality efforts toward standard service documentation to support future analysis of service impact on caregiver outcomes
- Consider a statewide tech support model to assist family caregivers as they navigate the CareNav™ platform
- Participate in reviewing the Equity Roadmap, prioritize potential actions, and develop plans to address disparities in caregiver experience, services and outcomes

At the state level (California Department on Aging):

- Increase awareness about caregiving, visibility of caregivers, and information about services
- Provide ongoing leadership for implementation of the Master Plan on Aging and the Equity Roadmap
- Consider enhanced funding to sustain current services and 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, the Equity Roadmap, and other statewide planning efforts

I. INTRODUCTION AND METHODS

In California, over 7 million family caregivers provide most of the long-term care, supporting older adults and persons with disabilities to remain in their environments of choice while supporting an array of physical, mental and functional needs. Family caregivers reflect the diverse population of California in age, race/ethnicity, gender, employment status and income. Caregivers provide regular personal and instrumental supports, complex and intense care, coordinate care, and assist with navigating acute health crises and hospitalizations across the trajectory of care. These individuals provide an estimated $81 billion worth of unpaid care each year in California.[1] Yet caregivers remain 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. Since that time, California reinvested in a statewide caregiver resource network supported by CareNav™, an online platform. In 2021, California again led the nation by establishing the Master Plan for Aging (https://mpa.aging.ca.gov/), with “Caregiving that Works” as one of the five bold goals for 2030. California’s investments and leadership align well with the 2022 National Strategy to Support Family Caregivers (https://acl.gov/CaregiverStrategy). The CRCs represent a national model for delivery of caregiver services and supports.

The UC Davis Family Caregiving Institute at the Betty Irene Moore School of Nursing is the evaluator of the implementation of the statewide online system and enhancements to the California Caregiver Resource Centers. In a related project, this team is leading the development of an Equity Roadmap, largely informed by the data collected through the CRC sites. The Equity Roadmap will serve as a basis for planning in the upcoming fiscal year.

This is the fifth annual report of this groundbreaking 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. All CRCs share values emphasizing choice, collaboration, innovation, quality, participation, respect, and diversity and 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. In addition, CRCs augment the core services with relevant programs and additional funding from federal, county and philanthropic sources. The state website provides on-line access to all CRCs with information about the services and programs they provide (https://www.caregivercalifornia.org/).

Evaluation of Program Expansion

This fifth annual report for fiscal year 2023-2024 (hereafter abbreviated FY23/24) summarizes CRC outcomes, including population served, services provided, CRC client and staff satisfaction and experience, and changes in service delivery over time. California State General Funds are allocated to CDA for the administration of CRC services through subcontracts with community-based providers, and the findings focus on these services.

Evaluation Design and Methods

The evaluation plan was developed by UC Davis researchers at the Betty Irene Moore School of Nursing Family Caregiving Institute in collaboration with the Family Caregiver Alliance (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 summarized in Table I-a. More information about data sources, methods, technical specifications and definitions is available in Appendix A and B.

Table I-a: Evaluation Data Sources for period July 2023 – June 2024

CareNav™: Activity (e.g., intake, assessment, family consultation) and Service Grant data
Outreach and Public Information Activities: CRC reports of public information and outreach activities
Education Activities: CRC reports of education activities
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: Comments collected on surveys

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. For the evaluation analysis, data were extracted from the CareNav™ platform for cases, activities, and service grants during the reporting period and transferred from Excel to Stata statistical software (version 16; College Station, TX) for analysis. The evaluation results include summary statistics (counts, mean, standard deviation, percentage) for the total of all cases combined across sites. A case status summary was compiled including counts of total cases and by type (new cases, and ongoing cases with/without activity during FY23/24 looking back within a two-year window).

Caregiver characteristics —including sociodemographic, health, and caregiving variables—are presented for the subset of caregivers who completed an assessment, since these cases had the most comprehensive data and least amount of missing data. Missing data were minimal.

CareNav^{TM} Analysis of Caregiver Status, Activities and Services Over Time

This analysis explores changes over time in caregiver status, activities and services. Data were drawn from CareNav^{TM} from 2019 through October 4, 2023. The purpose of this analysis was to determine the overall impact of the *Picking up the Pace of Change* funding intended to enhance and expand services. During the past five years, several important contextual factors influence interpretation of the findings, including the variable trajectories and timing of adoption of CareNav^{TM}, the effects of the pandemic, and the escalating costs of staff and services, without cost-of-living adjustments to reimbursement. Descriptive statistics were used to summarize the data, along with percentage of change.

Outreach, Public Information and Education Activities

Sites reported their 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. Data about strengths and challenges of the outreach campaigns, as well as about targeted efforts to reach diverse groups and underserved populations, were also collected through an annual survey of the sites. Qualitative data were analyzed using thematic analysis.

Caregiver Satisfaction Surveys

Caregiver satisfaction surveys, using a five-point scale, assessed satisfaction with services, confidence in caregiving, knowledge, caregiver stress, and experiences with the online platform and technology. Caregivers could also submit comments 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. Quantitative data were summarized using descriptive statistics and qualitative data were analyzed using thematic analysis.

> ***"You picked us up and got us on track to be successful caregivers."***
> ***– CRC Caregiver***

II. POPULATION SERVED

Caregiver and Care Recipient Sociodemographic Characteristics

There were a total of 5,855 new cases in FY23/24, representing 5,681 unique caregivers and 5,840 unique care recipients across the 11 CRCs. The following dashboard provides a snapshot of caregivers served by the CRCs during this fiscal year, including sociodemographic characteristics, caregiving activities, and outcomes. Detailed data on caregiver and care recipient sociodemographic and health characteristics can be found in Appendix C.

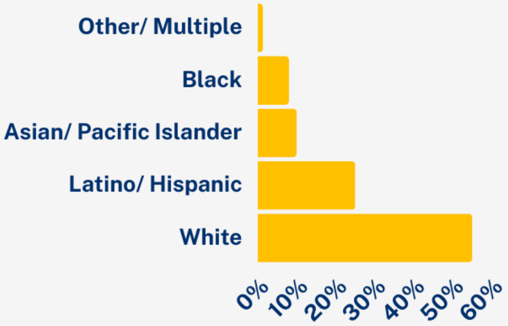
California Caregiver Resource Centers: Population Spotlight Fiscal Year 2023-2024

WHO ARE THE CAREGIVERS?

77%
identify as female

11%
earn income below the Federal Poverty Level

45%
report racial/ethnic identity other than White, non-Hispanic



73%
have a college degree or higher

4%
live in rural areas

WHAT ARE THE CAREGIVERS DOING?

85%
perform Medical or Nursing Tasks

73%
provide care >40hrs per week

38%
care for a spouse or partner

80%
assist with >10 personal care activities

WHAT ARE THEIR OUTCOMES?

34%
report their health has declined in the last 6 months

22%
experience clinically significant loneliness & isolation

24%
are somewhat or very dissatisfied with support from family & friends

64%
experience high caregiving strain

18%
experience moderate to severe depressive symptoms

Caregiver and Care Recipient Health

Caregivers provide care for persons with complex care needs, with multiple comorbid conditions and a high prevalence of memory loss. Most care recipients cannot be left alone for more than an hour, requiring constant vigilance and attention from the caregiver. Caregivers themselves report health challenges, most commonly anxiety, depression and problems with sleep. Tables II-a and II-b and Figure II-a provide details about caregiver and care recipient health and health service use.

Table II-a: Care Recipient Health

n= 5,840	%
Number of Medical Conditions	
0	2.11
1	7.67
2	20.70
3	22.04
4 or more	47.48
Medical Condition is Worsening	88.26
Experiences Memory Loss	91.82
Care Recipient Can Be Left Alone	
Always	7.79
Several Hours	30.35
<1 Hour	20.89
Never	40.97
Care Recipient Wanders	15.85
Documents in Place	
Advanced Health Care Directive	77.49
Durable Power of Attorney, Financial	56.59
Durable Power of Attorney, Healthcare	77.49
Guardianship/Conservatorship	4.25
Living Will	77.49
Physician Orders for Life-Sustaining Treatment (POLST) or Do Not Resuscitate (DNR)	37.64
Trust	43.70
Unsure of Documents in Place	10.94

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

Figure II-a: Care Recipient Health Service Use

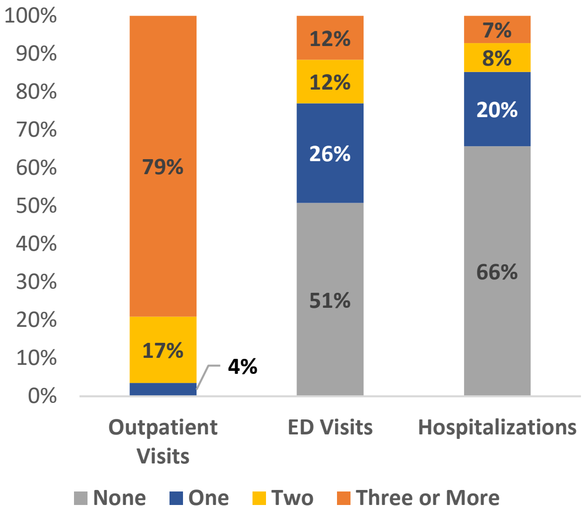


Table II-b: Caregiver Health

n= 5,681	%
Medical Conditions	
Anxiety	45.12
Arthritis	22.24
Cancer	4.97
Cardiovascular Disease	11.45
Depression	32.27
Diabetes	13.08
Gastrointestinal	10.33
Chronic Pain	23.93
HIV/AIDS	0.20
Kidney Disease	2.38
Liver Disease	1.85
Other Health Condition	56.31
Parkinson's Disease	0.26
Respiratory Condition	6.36
Sleep Disorder	33.93
Stroke	1.19
Mean Total Number of Medical Conditions *(SD)*	1.41 (1.80)
Number of Medical Conditions	
0	46.82
1	15.93
2	14.12
3	9.54
4 or more	13.59
Documents in Place	
Advanced Healthcare Directive	69.45
Durable Power of Attorney, Financial	45.68
Durable Power of Attorney, Healthcare	69.45
Living will	69.45
POLST/DNR	31.80
Trust	49.81
Unsure	17.08

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

Assistance with Personal Care Activities and Medical/ Nursing Tasks

Table II-c shows how frequently the care recipient required help with 15 direct care activities (no help, a little help, help most of the time, or help all the time). Table II-d and Figure II-b report the detailed experiences of caregivers who reported performing medical/nursing tasks (n= 3,142). These data highlight the intensity of supports that caregivers provide. On average, CRC caregivers support care recipients with seven different activities; 85% assist with medical/nursing tasks while 45% find the tasks difficult and 17% feel unprepared for the tasks.

Table II-c: Assistance with Activities

Activity (n = 5,840)	**Needs Any Help (%)**	**Needs Help All the Time (%)**
Bathing	82.13	45.79
Dressing	78.01	36.92
Eating	55.05	16.99
Grooming	74.04	31.19
Housekeeping	95.99	77.73
Incontinence	69.74	37.86
Managing Medications	93.00	70.16
Managing Money/Finances	95.76	84.00
Mobility	74.59	30.69
Preparing Meals	95.70	77.16
Shopping	96.90	87.49
Toileting	65.90	31.52
Transferring	68.49	30.36
Transportation	96.59	92.35
Using Telephone	76.11	43.38
Total Number *Mean (SD)*	12.05 (3.21)	7.83 (4.19)
Total Number *Median*	13	7

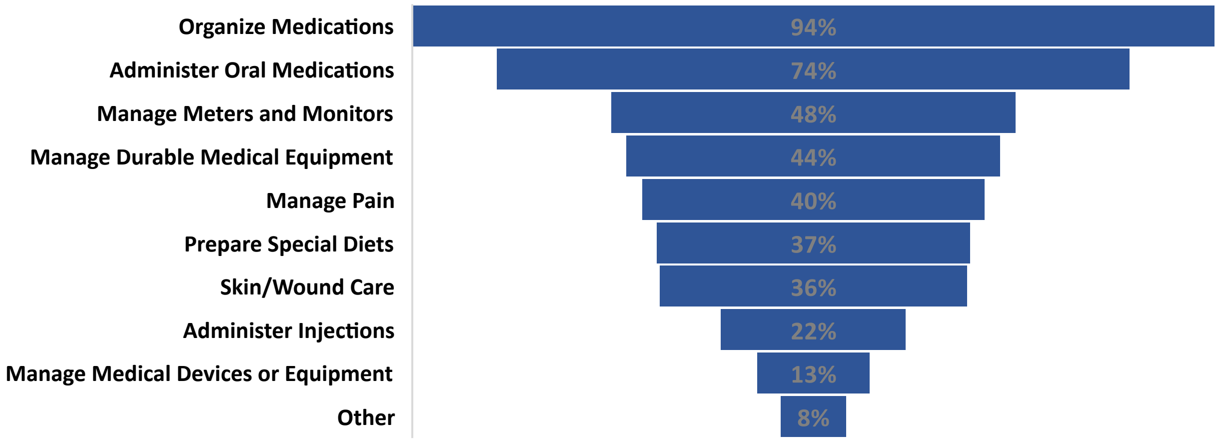
*Deduplicated by care recipient; percentages may not add to 100 due to rounding

Table II-d: Assistance with Medical/Nursing Tasks

n= 3,142	%
Mean Number of Tasks *(SD)*	4.15 (2.12)
Median Number of Tasks	4.00
Total Number of tasks	
1-3	42.87
4-6	40.76
7-10	16.36
Finds Medical/Nursing Tasks Difficult	
Strongly Disagree	19.01
Somewhat Disagree	14.61
Neutral	20.66
Somewhat Agree	33.60
Strongly Agree	12.12
Feels Prepared for Medical/Nursing Tasks	
Strongly Disagree	3.93
Somewhat Disagree	13.86
Neutral	22.29
Somewhat Agree	34.36
Strongly Agree	25.56

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

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



Behavior Problems Checklist

Caregivers who reported that the care recipient exhibited problems with memory or confusion-related behaviors (n= 3,305) completed a memory and behavior problems checklist, indicating which of 15 behaviors occurred and the degree to which it bothered them (Table II-e). The most upsetting behaviors include arguing, being aggressive to others verbally and threatening others.

Table II-e: Behavior Problems Checklist

n= 3,305	**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	69.17	18.01	48.35	33.65
Trouble remembering recent events	78.12	16.64	43.13	40.23
Trouble remembering significant past events	47.93	15.00	38.21	46.79
Losing or misplacing things	60.27	19.70	42.51	37.78
Forgetting what day it is	70.17	14.79	32.53	52.68
Starting, but not finishing, things	47.23	18.49	37.65	43.86
Difficulty concentrating on a task	55.25	17.15	40.04	42.81
Destroying property	6.93	11.74	13.13	75.13
Doing things that embarrass you	16.49	14.72	30.94	54.34
Waking you or others up at night	37.61	21.88	37.97	40.14
Talking loudly and rapidly	11.80	13.70	24.29	62.01
Engaging in dangerous behavior	14.74	23.61	23.47	52.92
Threats to hurt others	5.33	13.32	10.48	76.20
Aggressive to others verbally	21.60	23.88	31.50	44.62
Arguing, irritability/complaining	42.66	24.69	46.79	28.52

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

> ***"[I]t's extremely difficult and I don't think anyone really understands the level of commitment it takes. So I'm just so thankful and grateful that I found the [CRC site]. Every case manager I have had has been the epitome of professionalism, very caring and compassionate." – CRC Caregiver***

III. SERVICES PROVIDED

Together, the eleven CRCs provided services for 12,217 unduplicated family caregivers in FY23/24. The following dashboard provides a snapshot of services provided, including case status and outreach and education activities. Detailed data descriptions of the nature of services provided appear thereafter.

California Caregiver Resource Centers: Dashboard Fiscal Year 2023-2024

Case Status

Respite Hours and Services

Caregivers who received respite services = 1,734

Total respite hours provided = 103,554

Legal Consultation Hours and Services

Caregivers who received legal consultation = 137

Total legal hours provided = 157

Outreach and Education Activities

Outreach = 13,092
Direct referrals, general public information/awareness activities, provider awareness.

Education = 1,223
Program designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.

Caregiver Supports

Family Consultation = 41,422 hours

Support Groups = 1,194 clients

Individual Counseling Services = 436 clients

Supplemental Services Vouchers = 96 clients

> *"I would not have been able to navigate the challenges of caring for an aging parent alone - CRC saved me! I felt I had no where to turn, no support and very alone until CRC provided counseling, a support group and resources. THANK YOU!"*
>
> *-CRC Caregiver*

CRC Case Status Summary

The eleven CRCs opened 4,060 “new cases” (site mean: 369), defined as conducting a full assessment (i.e., risk assessment questions on intake indicated a need for more intensive services and the caregiver was interested in participating in this next level of engagement). The sites also followed an average of 7,085 “ongoing cases with activity” (site mean: 644), 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 the fiscal year. Another 11,180 cases were “open with no activity”, having an assessment in the last two years but no services in this fiscal year. “Open cases” (i.e., the sum of new and ongoing unique cases) in FY23/24 totaled 12,217 for all CRCs (site mean: 1,111) (Table III-a).

The CRCs conducted 6,546 intakes (caregiver screenings) in FY23/24 (site mean: 59) (Table III-b). Of these, approximately 20% were initiated by caregivers using the CareNav^{TM} portal. Of the caregivers completing intakes, 4,176 (64%) moved forward to full assessment (site mean: 380). Together the sites conducted 3,713 reassessments (site mean: 338), following up with caregivers who had a full initial assessment, typically within six months. In total, the CRCs completed 41,422 hours of family consultations (site mean: 3,766). 1,194 unique caregivers participated in professionally led support groups across all eleven sites (site mean: 109). These services are facilitated by licensed social workers and do not include peer-led support groups.

Table III-a: Case Status Summary: All California CRCs Combined, FY23/24

New Cases	4,060
Ongoing Cases with Activity	7,085
Ongoing Cases no Activity	11,180
Total Open Cases	12,217

Table III-b: Caregiver Activity Summary: All California CRCs Combined, FY23/24

Intake, n	6,546
Assessment, n	4,176
Reassessment, n	3,713
Family Consultation, hours	41,422
Support Group, unique caregivers	1,194

Note that the Intake screenings do not always move to full assessment; for instance, a case may be completed at intake if the staff is able to make a referral or provide advice during the screening and the caregiver does not desire further support.

“[The assessment by CRC Staff] was the first time I had an interview for personal care.” – CRC Caregiver

Service Grants

Overall, 436 unique caregivers were offered individual counseling sessions by all eleven CRCs through either “in-house” services or grant vouchers, with six CRCs (Coast, Del Mar, Inland, Orange, Redwood and Southern) providing “in-house” counseling sessions for 236 unique caregivers (site mean: 39) and seven (Bay Area, Coast, Del Oro, Los Angeles, Passages, Redwood, Valley) offering individual community counseling vouchers to 200 unique caregivers (site mean: 29) (Table III-c). Variability in the reported activities by site has several possible explanations: differences in overall site volume and caregivers eligible for CDA-contracted services: geographic distribution of resources within the state and CRC catchment areas, leading to some services being offered “in house” rather than by referral; and differences in site-specific workflow or understanding of definitions for entry into CareNav^{TM}.

Vouchered Services

The eleven CRCs together provided 514 vouchered transactions for counseling services totaling 865 hours ($81,465) to 236 unique caregivers; 140 vouchered transactions for legal services totaling 157 hours ($17,857) were provided to 137 unique caregivers; 5,737 vouchered transactions for respite care totaling 103,554 hours ($2,947,872) to 1,734 unique caregivers in FY23/24. Additionally, 275 vouchered transactions for supplemental grants ($74,153) were provided by six CRCs to 96 caregivers, typically for durable medical equipment or groceries (Table III-c).

Note, there have been no cost-of-living adjustments to the contracted services, reducing the relative value of every dollar spent. The CRCs continue to prioritize respite spending.

Table III-c: Service Grant Vouchers: All California CRCs Combined, FY23/24

Counseling	
Transactions	514
Caregivers	200
Hours	865
Amount	$81,465
Legal Consultation	
Transactions	140
Caregivers	137
Hours	157
Amount	$17,857
Respite	
Transactions	5,737
Caregivers	1,734
Hours	103,554
Amount	$2,947,872
Supplemental Grants	
Transactions	275
Caregivers	96
Amount	$74,153

> ***“The grant I received for extra respite caregiver hours… has made such a gigantic difference in my mental health, stress management and my capacity to continue as my mom's main caregiver in a joy-filled and patient manner!!!!!!! It's such a gift to be able to have something to look forward to for getting away for myself.” – CRC Caregiver***

Outreach and Education

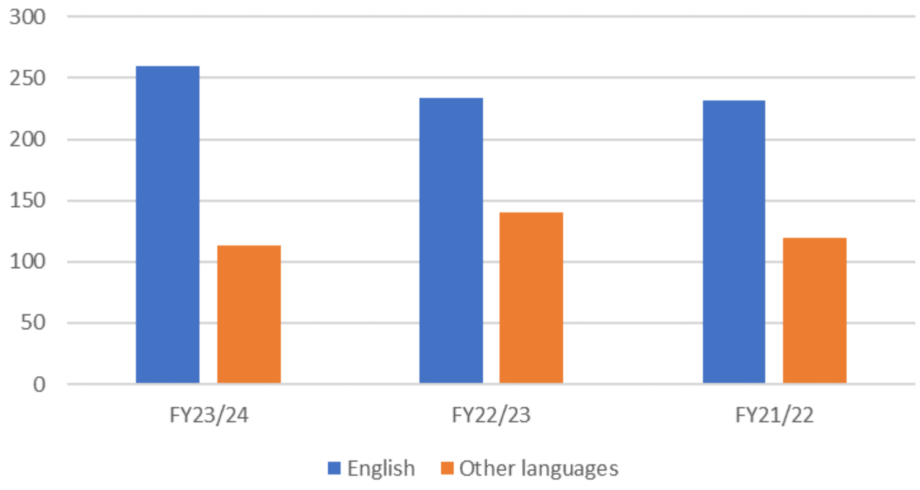
CRCs' outreach and marketing plans are tailored to their geographic catchment areas, populations served, and service needs of their region. This section includes activities conducted by an outside organization contracted to perform statewide outreach (hereafter referred to as "the Statewide Outreach Contractor"). In FY23/24, the eleven CRCs and the Statewide Outreach Contractor conducted a total of 13,092 outreach activities including health and resource fairs, meetings and presentations, public information and outreach as well as social media posts. CRCs also conducted 1,223 educational activities. The number of activities for education decreased by 693 (36%) in FY23/24 due to a significant drop in educational activities at one site. ***CRCs continue to target diverse and underrepresented groups in their outreach efforts.*** About 90% of the health or resource fair, 84% of education activities and 84% of meetings and presentations were targeted towards these groups (Table III-d). ***Classes offered statewide have plateaued from fiscal year to year*** (Figure III-a).

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

	Education		Health or Resource Fair		Meetings/ Presentations		Public Information/ Outreach	
	# Activities	# Reached	# Events	# Exposure	# Events	# Reached	# Distributions	# Contacts
All sites	1,223	29,951	687	60,889	2,389	43,684	1,104	36,582,775
Site mean	111	2,722	62	5,468	217	3,971	100	3,325,706
Site median	42	1,038	20	2,520	98	2046	58	43,039
Statewide Outreach	--	--	0	0	0	0	32	8,338
% D or U*	84.1	--	89.4	--	83.5	--	--	--

* D or U = Targeted to Diverse or underserved populations

Figure III-a: Statewide Classes Offered At All California CRCs Combined



Social media was utilized extensively by sites as part of CRC outreach campaigns (Table III-e). The CRC sites and the Statewide Outreach Contractor conducted 5,857 social media outreach activities in FY23/24, with 216,395 “subscribers” (also referred to as “followers”, “friends” or “contacts”) across six platforms. Additionally, sites used 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.

Table III-e: Social Media Use

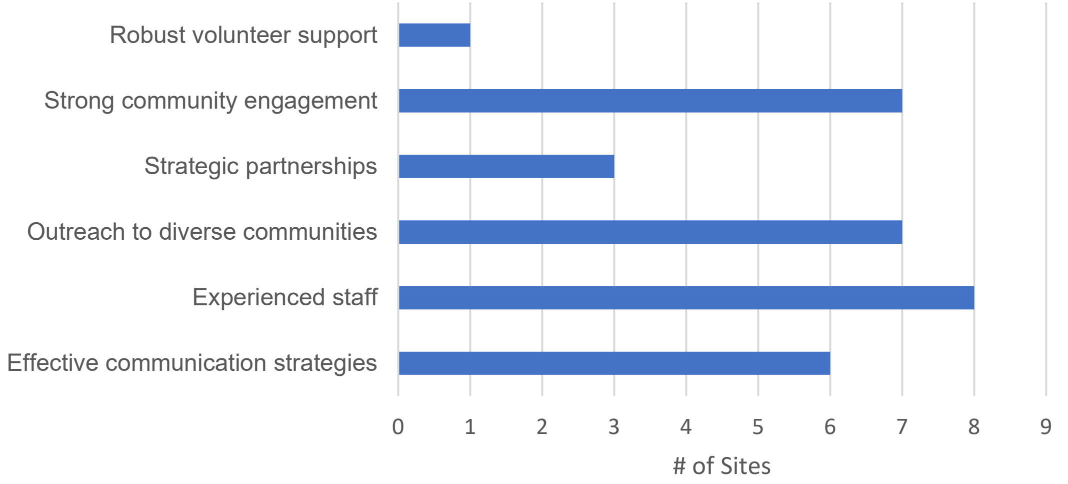
Social Media	Posts			Followers		
	Total	Mean	Range	Total	Mean	Range
Facebook	2013	183.0	2-401	61444	5585.8	434-20504
Twitter	305	27.7	28-127	20483	1862.1	143-17907
Instagram	1446	131.5	32-340	23207	2109.7	310-7647
YouTube	1469	133.5	1-1420	98174	8924.9	98-66500
TikTok	11	1.0	0-11	41	3.7	0-41
LinkedIn	584	53.1	0-213	13046	1186.0	176-7506
Other	29	2.6	0-29	n/a	n/a	n/a
Total	5,857			216,395		

CRC sites and the Statewide Outreach Contractor were invited to include an optional narrative describing their unique approaches to outreach and efforts to reach diverse groups and target subpopulations. The next sections include infrastructure, activities, and achievements reported by eight CRC sites and the Statewide Outreach Contractor.

Strength of outreach and education campaigns

The sites identified key strengths of their outreach and education campaigns, as shown in Figure III-b. *Experienced staff* emerged as the most common structure in promoting outreach and education. This expertise encompasses extensive experience in the health industry, particularly in aging and caregiving, as well as in creating strategies and dedicated content to increase visibility and recognition. Staff experience and expertise also contribute to creating stronger connections with potential clients and addressing their hesitations. Some sites improved customer service by promptly responding to comments and inquiries on the platforms. This skill set is leveraged for building brand awareness. *Strategic partnerships* and/or *strong community engagement* facilitated *outreach to diverse communities* using various virtual and in-person platforms, as further described below.

Figure III-b: Strength of outreach and education campaigns* | n=9



*None of the sites endorsed "Adequate funding and resources" as a strength

Using CareNav™ to inform outreach efforts

Four sites currently use, and one site plans to use, CareNav™ data to inform outreach efforts. They predominantly use client demographics to identify regions for promoting educational programs and addressing language needs, referral sources, and client portal utilization.

Regional challenges

The most frequently cited challenges were geographic, language and cultural barriers, and limited funding sources (Figure III-c). These challenges encompass barriers to access related to rurality, limited internet access, language barriers and limited culturally appropriate services. For sites with a large catchment area, it is challenging to extend outreach efforts to the entire region, leaving many areas and communities unaware of the CRC and the services offered. Geographic distances further complicate in-person attendance, particularly for those living in rural areas. Some rural areas lack adequate internet access, making virtual participation difficult. The relative cost of educational workshops appears high because of expected lower participation due to population density. Table III-f summarizes strategies to address challenges.

Figure III-c: Primary outreach and education regional challenges | n=9

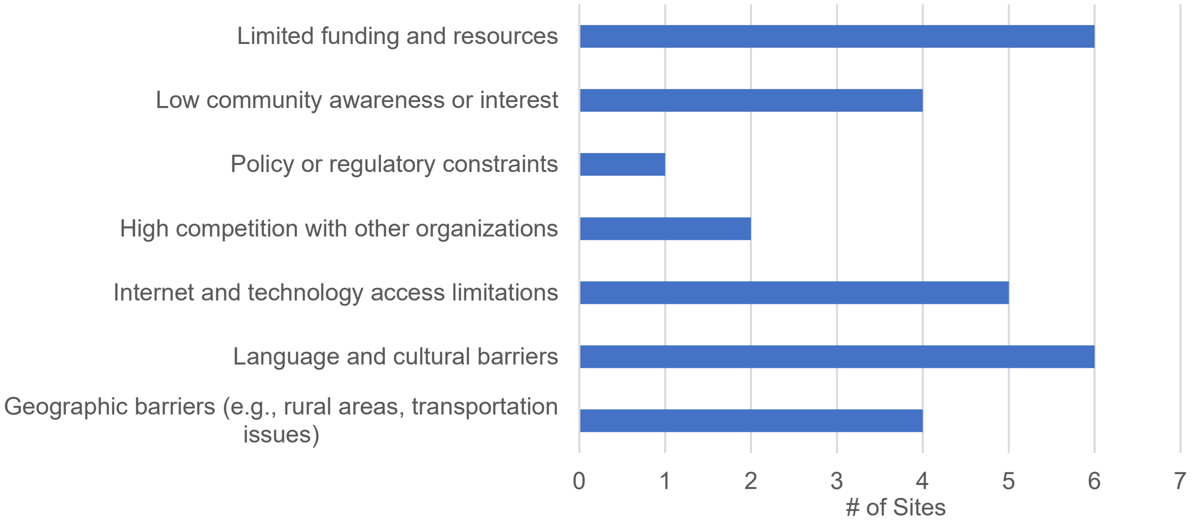


Table III-f: Primary outreach and education regional challenges and main strategies | n=9

Challenge	Featured strategies
Geographic barriers – particularly rural regions	Develop technology and resources to provide in-person and virtual hybrid events
Language and cultural barriers	Culturally appropriate programming Bilingual materials and events
Internet and technology access limitations	In-person education events and support groups Physical mailing
Limited funding and resources	Advocacy on behalf of the clients and educating the clients to communicate with legislators
Low community awareness or interest	Partnering with community-based organizations to raise awareness and educate
High competition with other organizations	Mapping high need demographics in counties and inform outreach efforts

Efforts to reach diverse groups and underserved populations

The sites made efforts to reach diverse groups and underserved populations, emphasizing partnerships with local organizations serving diverse communities, inclusive advertising and media campaigns, and providing linguistically and culturally tailored programs and materials (Figure III-d and Table III-g). Partnership with local organizations and participation in local community events enabled them to better understand needs and leverage resources, expertise, and networks to deliver linguistically and culturally tailored advertisements and resources. Some sites also enhanced their outreach to diverse communities by mapping high-need demographics to inform outreach efforts or employing bilingual community outreach workers ("Promotoras") focused on in-person outreach. Local efforts to incorporate multilingual resources are featured on the statewide website (www.caregivercalifornia.org).

Figure III-d: Outreach and education efforts made to reach diverse groups and underserved populations | n=9

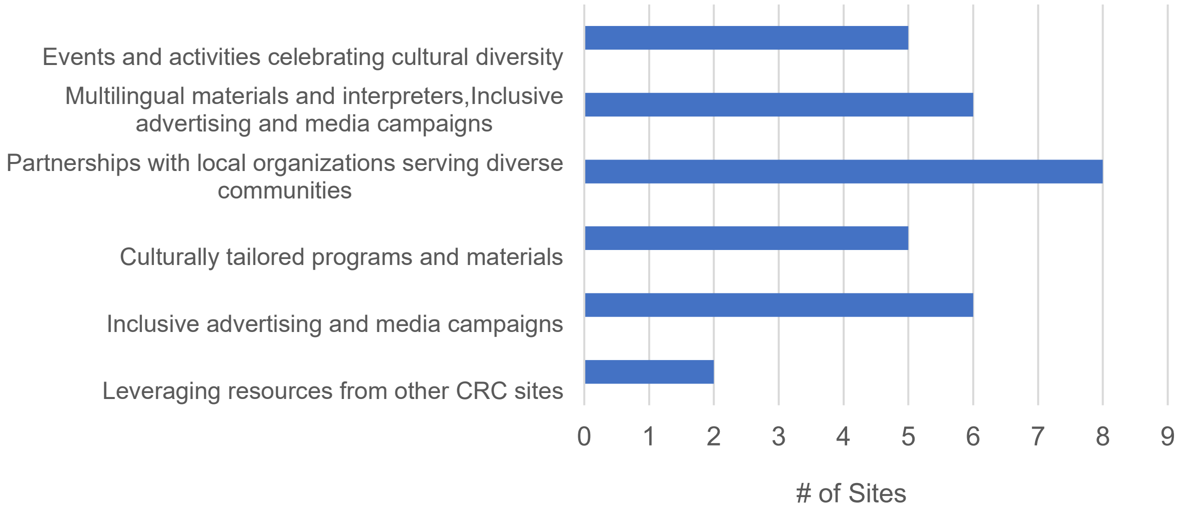


Table III-g: Outreach and education efforts made to reach diverse groups and underserved populations | n=9

Effort	Examples
Strategic partnerships with local organizations serving diverse communities	Reach specific groups, understand needs, provide education, tailor services, raise awareness, build rapport and reputation, host community events, and support non-profit organizations Types of organizations: non-profit organizations, research centers, faith- or culture-based organizations, governmental organizations, healthcare organizations and specialized healthcare programs, recreation centers, education and local media organizations
Events celebrating cultural diversity	Host community events Participate in local community events
Inclusive advertising and media campaigns	Targeted advertising campaigns on social media to ensure access for specific demographics Culturally appropriate social media posts with pictures
Culturally tailored programs and materials	Inclusive materials for several demographics, cultures and sensory needs Present information in context with community standards
Multilingual materials and interpreters	Promotional materials, website content, live and on-demand educational and support resources in multiple languages Schedule for uploading new and translated caregiving presentations in Spanish to YouTube channel
Leveraging resources from other CRC sites	Share resources in multiple languages from the local CRCs on the statewide website

Feedback received from diverse groups regarding outreach efforts

CRC sites received positive feedback from diverse clients, particularly emphasizing their appreciation for making services accessible to diverse communities, including LGBTQ+, as well as rural and isolated caregivers. The sites particularly highlighted client appreciation for having information and educational materials available in multiple languages, that align with preferred language. One site reported that clients shared their experience with learning about CRC through community partners or public/community spaces such as the library, local healthcare clinic, or community schools versus online outreach campaigns.

> *"Clients who were first introduced to [CRC site] at an in-person event have shared overwhelmingly positive feedback, with clients noting that their experience speaking with a [staff member] convinced them to reach out to [CRC site] for further support (many are able to recall the [staff member] who approached them by name)." – CRC Staff*

Highlighted achievements from outreach and education campaigns

The sites highlighted achievements from their outreach and education campaigns: Partnership with local organizations resulted in the creation of new multilingual information and education materials, caregiver conferences, and community events, that increased the number of people exposed to CRC services. For some sites, participation in local community activities contributed to building and expanding partnerships. There were distal outcomes, including trends indicating an increase in individuals learning about CRC services through the statewide educational calendar and through social media.

"He recibido información la cual he ido leyendo y aprendiendo un poco mejor las situaciones de mi esposo y poder entender su incapacidad." – CRC Caregiver

Translation: "I have received information which I have read and learned a little more about my husband's situation and to be able to understand his disability." – CRC Caregiver

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IV. CAREGIVER EXPERIENCE

Satisfaction Survey Participants

Caregiver satisfaction surveys were sent via mail or e-mail on a quarterly basis in multiple languages to all caregivers who had contact with the CRCs. In FY23/24, 2,780 caregivers participated in the survey. Note that demographic data are not collected in these surveys to preserve respondent anonymity. In addition to responding to the survey items, caregivers also provided comments on the services received, future topics of interest to them and their experience using the CareNav™ online platform.

Satisfaction Survey Scores

Caregivers are highly satisfied with their CRC experiences; about 79% report they are extremely satisfied and about 13% report they are somewhat satisfied (Table IV-a) with 83% "definitely recommending" the CRC to others. Results from this fiscal year are very similar to the previous two fiscal years.

Table IV-a: Satisfaction Surveys: Impact of Services

Overall Satisfaction (%)				Recommend CRC to Friend or Family Member (%)			
	FY23/24 *n* = 2,780	FY22/23 *n* = 2,229	FY21/22 *n* = 2,624		FY23/24 *n* = 2,615	FY22/23 *n* = 2,152	FY21/22 *n* = 2,624
Strongly Satisfied	78.8	78.9	78.6	Definitely Recommend	83.4	84.1	83.7
Somewhat Satisfied	12.8	13.6	13.5	Probably Recommend	9.4	10.0	10.1
Neutral	4.6	3.9	4.2	Neutral	4.9	4.1	3.7
Dissatisfied	1.7	1.3	1.6	Probably Not Recommend	1.2	0.8	1.3
Extremely Dissatisfied	2.1	2.2	2.2	Definitely Not Recommend	1.0	0.9	1.1

*Percentages may not add to 100 due to rounding

The impact of the CRCs' services is overwhelmingly positive in FY23/24, with caregivers feeling more confident, better able to manage care, better able to care for themselves, and becoming more knowledgeable. Table IV-b below shows the mean scores in each category. Scores have remained consistent across the last three fiscal years.

> ***"Supportive and knowledgeable staff... The respite grant has granted me a lifeline so I can breathe again." – CRC Caregiver***

Table IV-b: Satisfaction Surveys: Mean Scores*

Item	FY23/24 *n* = 2,809	FY22/23 *n* = 2,254	FY21/22 *n* = 2,624
More Confident as a Caregiver	4.2	4.2	4.2
Better Able to Manage Care	4.2	4.2	4.2
More Knowledge and Awareness	4.3	4.3	4.3
Understand the Disease/Disability/Problem Better	4.1	4.1	4.1
Taking Better Care of Self	4.0	4.1	4.0
Less Stressed	3.9	3.9	3.8

*Scored on a 1- 5 scale, where is 5 most positive

Caregiver Comments About Services

Caregivers provided 1,432 comments about services received or pending, ninety in Spanish. The comments address overall CRC services (449, 31%), interactions with staff (579, 40%), respite care (277, 19%), information and training and education (115, 8%), support groups (77, 5%), and counseling (48, 3%). Seventy nine percent of the comments (1,133) reflect benefits and impact of the services on caregiver and care recipient experiences. Sixteen percent of the comments (233) reflect challenges. Forty-one comments (3%) reflect mixed experiences. Forty-two comments (3%) include future suggestions for expansion or sustainment of services. An additional 274 comments address CareNav^{TM} use.

Caregivers emphasized the benefit of knowledgeable and caring providers, coupled with timely and sustained access to meet diverse caregiver needs. The CRC services had profound impacts by expanding caregiving and self-care capacity and improving physical and mental health. The valued attributes of the most-cited services and their impact are summarized in Table IV-c.

"…Sin su valioso apoyo este viaje y desafío de cuidar a mi ser amado no hubiera sido mejor. Agradezco a… mi consejera quien siempre me lleva de la mano y nunca me [ha] dejado sola en este camino…" – CRC caregiver

Translation: "…Without your valuable support, this journey and challenge of caring for my loved one would not have been better. I thank… my counselor, who always takes me by the hand and [has] never left me alone on this journey…" – CRC caregiver

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

Service	Caregiver Experience: Valuable Attributes	Impact
Family Consultation and interactions with staff	**Inclusive environment:** Caregivers felt heard, seen, understood, cared for, supported, valued, comforted, empowered, encouraged, welcomed **Assessment and reassessment:** understanding the needs and creating action plan with the caregiver; *Challenge*: complicated registration process **Assistance with navigation and coordination** of referrals service initiation and reimbursement **Proactive regular communication** focused on caregiver needs, self-care and well-being, updates, brainstorming ideas, getting feedback, tracking progress on goals, provision of relevant, tailored, and comprehensive information **Timely support**: the team was available and responsive, prompt problem solving; *Challenge*: waiting times, delay after completing intake **Professional and caring staff**: attentive, compassionate, empathetic, knowledgeable, skilled, reliable, patient, supportive, thoughtful, engaged, considerate, resourceful, finds solutions; *Challenge*: staff turnover	**Better mental health**: less isolated, less stressed, stronger, uplifted, hopeful, able to plan, enhanced self-worth **Enhanced caregiving capacity**: better understanding of care recipient feelings and needs, better informed and prepared to meet care recipient's needs, confidence to keep help at home, secured care recipient services **Better equipped to engage with self-care activities and other responsibilities**: feel more balanced, challenges easier to handle, resumed physical activity, implementing recommended changes to restore health, better prepared for future needs, know how to get support
Respite: home care, adult day services, help with chores	The most needed service, vital to fill the gap of IHSS services, "game changer" **Timely provision according to caregiver need**; *Challenges*: slow reimbursement, complex administrative process, shortages **Consistency**: having the same person *Challenges*: frequent turnover of workers, inconsistent funding: limited number of hours, inconsistent availability, sharing costs **Proficiency**: knowledgeable, skilled, efficient and experienced workers; *Challenges*: lack of competency in behavior management, or ADL support **Reliable**: *Challenge*: hard to find trusted person, scheduling issues, disagreements **Communication skills**: Kind, gentle, caring, compassionate, sympathetic, patient, attentive; *Challenge*: poor communication, limited linguistic diversity **Willing to help, enthusiastic:** *Challenges*: not proactive asking for additional tasks	**Better physical and mental health:** reduced stress and anxiety, relief, recharged, refreshed, peace of mind, lifted spirit, reduced burden, not alone, made life easier, stronger **Saved caregiver's employment:** enabled to keep working **Enhanced caregiving capacity**: more patient, avoided burnout, provided additional care **Allowed to engage in self-care activities**: Realized the need to accept help, time to rest, sleep and restore, adequate healthcare, engaged in psychosocial and educational activities, projects **Impact on the care recipient**: engaged in socialization and activities with the paid caregiver or adult day services, met needs

Education/ Training	**Wide variety of information sources, training formats and topics:** Learning from the program and other participants, new resources; *Challenge*: variable access to different topics **Variable settings**: Zoom classes to engage more people in the same situation; *Challenge*: Lack of in person classes in some areas, limited access to online seminars **Schedule accommodating various needs, including working caregivers:** *Challenge*: some classes offered at inconvenient times **Facilitator**: knowledgeable, well presented, professional, well planned	**Better mental health:** less stress, feel not alone **Enhanced caregiving capacity**: gained tools, better understanding of care recipient experience, how to manage needs, make home safe, better communication, more tolerant with the care recipient **Allowed to engage in self-care activities**: learned stress management techniques, prioritized self-care, built confidence to share
Support groups	**Inclusive environment, fit to caregiver characteristics**: feel heard, involved, comforted, sense of belonging, reassured, encouraged, ability to share experience and needs; *Challenge*: limited ability to relate when not matched to group demographic characteristics and caregiving trajectory **Timely**: *Challenge*: waitlist, group too small **Setting**: Variety of settings to meet various needs including online **Caring and supportive facilitator**: thoughtful, carefully listens	**Better mental health:** Less: depressive symptoms, feeling lost and stressed, feel not alone, better coping, acceptance **Enhanced caregiving capacity**: gained knowledge, wisdom, tips, better understanding of care recipient behavior
Counseling	**Timely and available at different stages along the caregiver journey including grief**: financial support; *Challenge:* limited number of sessions and limited eligibility, waiting time, impact is limited to the duration of the service **Acknowledging and processing caregiving experience**: clarified issues related to caregiving experience, acknowledged the work involved, reframed caregiver approach and dealt with frustration, understanding stressors **Provider**: professional, compassionate, sympathetic, developed trust	**Better mental health**: managed emotions, provided hope, less stress, feel not alone, encouraged **Enhanced caregiving capacity**: kept functioning in the caregiver role, developed ability to solve problems **Better self-care**: better understanding of importance of self-care, learned techniques and strategies to balance caregiving responsibilities and self-care

> ***"The respite was extremely helpful as this is a true 24 [hour]-a-day job. Getting out and knowing my husband was safe was amazing." – CRC Caregiver***

Caregiver Experience with CareNav^{TM} Online Platform

We also collected information about caregiver experiences with the online platform and the reasons given for not engaging with the online platform. Table IV-d indicates that most caregivers were offered online services (about 81%). About 27% of the survey respondents reported using the CareNav^{TM} system, a slight increase in usage since last year.

Table IV-d: Caregiver Engagement with Online Services and CareNav^{TM}

	Were Offered Online Services (%)*			Used CareNav^{TM} (%)*		
Response Categories	FY23/24 *n* = 2,651	FY22/23 *n* = 2,125	FY21/22 *n* = 2,624	FY23/24 *n* = 2,640	FY22/23 *n* = 2,144	FY21/22 *n* = 2,624
Yes	80.5	81.6	80.5	27.4	24.9	24.6
No	9.4	8.6	9.0	62.3	64.8	64.2
I Don't Know	10.1	9.8	10.4	10.3	10.3	11.2

*Percentages may not add to 100 due to rounding.

Figure IV-a shows that most caregivers who used CareNav^{TM} were satisfied with the experience (extremely satisfied, 53% and somewhat satisfied, 28%). Among those who did not use CareNav^{TM}, 31% indicated they did not know about the online options and about 18% indicated they do not need it. Lack of technical experience (13%), access to internet (4%) and finding the platform too confusing (3%) were other barriers (Figure IV-b).

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

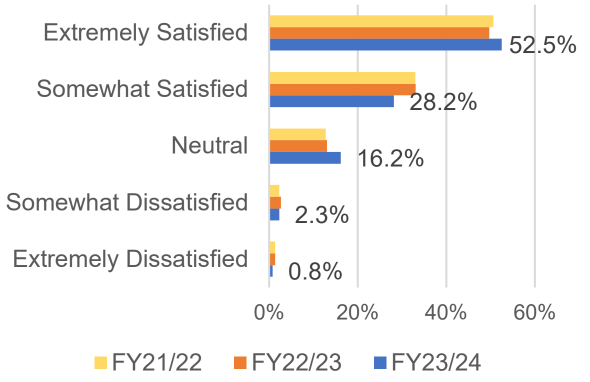
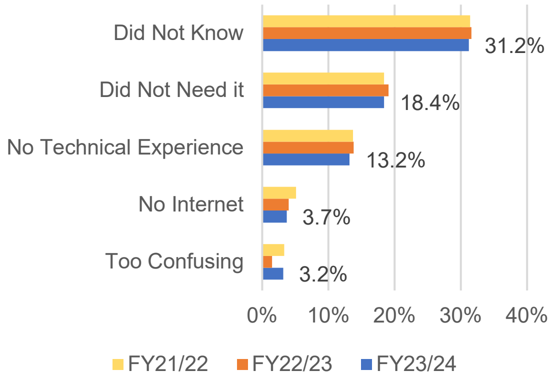


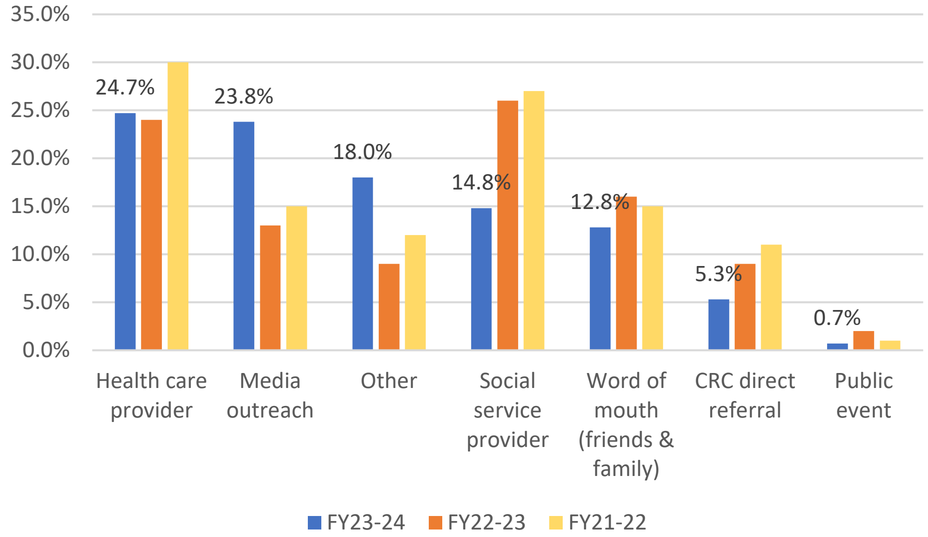
Figure IV-b: Reasons for not Using CareNav^{TM}



Referral Sources

During intake, care consultants ask caregivers how they heard about CRC services. Caregivers found the CRCs in a variety of ways (Figure IV-c) in FY23/24. Health care providers and media outreach were the leading sources of referral followed by social service providers and word of mouth. Referral via media outreach increased by almost 11% this year compared to last fiscal year, reflecting the impact of increased outreach efforts by CRCs. The category "other" included social media such as Facebook, TikTok, insurance brokers, senior centers, places of worship etc.

Figure IV-c: Referral Sources



Additionally, a variety of community agencies connected caregivers to the CRCs, including librarians, senior resource centers, meal programs, adult day care programs, AARP, Alzheimer's association, Council on Aging, the Social Security Office and many more. These referrals were particularly effective, reinforcing the importance of educating community agencies about the scope and services of the CRCs.

V. SCALING SERVICES THROUGH TECHNOLOGY USE

The *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project included goals for the CRCs to increase service delivery and to increase use of technologies to extend their services. By 2021, all eleven CRCs had fully deployed the CareNav^{TM} technology platform to track service delivery and support statewide uniform caregiver intake, assessment and reassessments. Using the data collected in the platform, this analysis examines changes over time in CRC service delivery for California caregivers.

Case Status Summary

CRC cases from FY21/22 through FY23/24 are summarized in Table V-a. FY21/22 is selected as the baseline for this analysis because it is the first year when all sites had fully deployed CareNav^{TM} and sites were no longer uploading batches of legacy data into the system. The number of "new cases" defined as conducting a full assessment declined by about 6% from FY21/22 to FY23/24. The number of new cases was lowest in FY22/23 and FY23/24 shows an increase since then. The number of "ongoing cases with activity", defined as caregivers having an assessment in the past two years and receiving one or more services (e.g., family consultation, reassessment, counseling, vouchered services) in the fiscal year of interest, increased by nearly 3%, with small increases each year. The number of "ongoing cases with no activity," defined as caregivers having an assessment in the last two years but no services in the fiscal year of interest increased by 13% from FY21/22 to FY23/24, reflecting an increase of 12% in "total open cases" (i.e., the sum of open cases with and without activity). Of note, FY22/23 was the first time that "ongoing case" tallies reflect full CareNav^{TM} implementation for the past two years and complete data from all sites. New cases have declined slightly since 2022. The number of open cases with no activity increased at a higher rate than the number of open cases with activity. While this might signal opportunities for outreach to caregivers previously engaged in the system, it may also indicate appropriate case triaging to those most in need of services.

Table V-a: Case Status Summary: All California CRCs Combined

	FY23/24	FY22/23	FY21/22	% Change since FY21/22*
New Cases, n	4,060	3,895	4,302	-5.63
Ongoing Cases with Activity, n	7,085	7,010	6,897	2.73
Ongoing Cases no Activity, n	11,180	11,162	9,883	13.12
Total Open Cases, n	12,217	12,278	10,887	12.22

*FY19/20 data unavailable for use as baseline. FY21/22 = full CareNav^{TM} deployment across sites as baseline

Caregiver Activity Summary

Two baselines are considered for this analysis, one using FY19/20 data, in consideration of pre- versus post-pandemic effects on service use; and one using FY21/22 which relies on the most complete data for comparison (Table V-b). From FY19/20 to FY23/24, intakes increased by 34%, assessments by 26% and family consultation increased by over 1000%. These increases approximate the net effect of the pandemic and CareNav^{TM} implementation on CRC services. The new technology supported virtual intake and assessment while the pandemic catalyzed the adoption of technology over in-person encounters. Across this period, “in-house” caregiver counseling (offered by some, but not all CRCs) and caregiver support groups declined by 65% and 55%, respectively. When the activity summary is examined using the FY21/22 baseline, a slightly different picture emerges. Intake and assessments declined slightly from FY21/22 to F 23/24, at 2% and 6% respectively, while reassessments, which could not be tracked from the FY19/20 baseline due to data issues, increased by 10%. From FY21/22 to FY23/24, family consultation increased by 19%, “in-house” counseling increased by 26% and unique caregivers served in support groups across the CRC system increased by 13%.

Table V-b: Caregiver Activity Summary: All California CRCs Combined

	FY23/24	FY22/23	FY21/22	FY20/21	FY19/20	% Change since FY19/20*	% Change since FY21/22**
Intake, n	6,533	6,360	6,648	6,126	4,876	33.98	-1.76
Assessment, n	4,176	4,038	4,433	4,299	3,321	25.75	-6.15
Reassessment, n	3,713	3,501	3,326	2,856	-----	-----	10.42
Family Consultation, n	165,686	158,177	133,666	25,546	13,070	1167.68	19.33
In-House Counseling	236	204	174	145	680	-65.29	26.27
Support Group, n unique caregivers	1,194	1,172	1,054	1,993	2,626	-54.53	13.28

*FY19/20 = pre-pandemic as baseline

**FY21/22 = full CareNav^{TM} deployment across sites as baseline

Service Grant Summary

The analysis of service grants used the same two baselines for comparison as the analysis of caregiver activities: first FY19/20 in consideration of pre- and post-pandemic effects on service use; and second FY21/22 for comparison with the most complete data in CareNav^{TM} (Table V-c). Using the FY19/20 baseline, counseling transactions increased by 268% and the number of unique caregivers served for counseling also nearly tripled. Legal consultations declined by 11% while the number of unique caregivers served increased by 43%. Respite transactions increased by 436%, but the number of unique caregivers served declined by 44% as did the number of hours of service (-31%).

From FY21/22 to FY23/24, service grant transactions declined in all categories. Counseling transactions declined by 28% with the number of unique caregivers served down 25%, the number of hours offered down 36% and the funded amount down 40%. Legal consultation declined by 17%, with the number of unique caregivers served down

17%, the number of service hours down 19% and the funded amount down 28%. Respite transactions declined 16%, with the number of caregivers served down 17%, the number of service hours down 13%, and the funded amount down 9%. Finally, supplemental grant transactions (usually for durable medical equipment), which could not be tracked from FY19/20, declined by 48% with the number of unique caregivers served down 72% and the funded amount down 43%.

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

	FY23/24	FY22/23	FY21/22	FY20/21	FY19/20	% Change since FY19/20*	% Change since FY21/22**
Counseling							
Transactions, n	514	572	716	714	140	267.14	-28.21
Unique Caregivers, n	200	217	267	404	51	292.16	-25.09
Hours, n	865	1,051	1,344	1,379	-----	-----	-35.64
Amount, $	$81,465	$100,338	$134,938	$131,451	-----	-----	-39.63
Legal Consultation							
Transactions, n	140	149	169	147	158	-11.39	-17.16
Unique Caregivers, n	137	147	165	147	96	42.71	-16.97
Hours, n	157	172	195	141	-----	-----	-19.49
Amount, $	$17,857	$22,726	$24,695	$16,140	-----	-----	-27.69
Respite							
Transactions, n	5,737	6,626	6,801	6,513	1,070	436.17	-15.64
Unique Caregivers, n	1,734	1,848	2,080	3,259	3,095	-43.97	-16.63
Hours, n	103,554	112,982	119,378	139,340	149,184	-30.59	-13.26
Amount, $	$2,947,872	$3,124,253	$3,223,778	$3,426,469	-----	-----	-8.56
Supplemental Grants							
Transactions, n	275	491	531	1492	-----	-----	-48.21
Unique Caregivers, n	96	230	344	649	-----	-----	-72.09
Amount, $	$74,153	$173,615	$130,765	$183,039	-----	-----	-43.29

*FY19/20 = pre-pandemic as baseline

*FY20/21 = full CareNav™ deployment across sites as baseline

Use of CareNav™ by Family Caregivers to Initiate Services

The rate of CareNav™ use by family caregivers to initiate services by entering intake data in the web portal remained stable at about 20% from 2021, when all CRC sites were fully onboard using the technology platform, to 2024 (Table V-d). It is important to note that this client adoption rate is comparable to patient portal use among older adults and underrepresented communities in health care systems, also around 20%.[2]

The overall rate of use at 1 in 5 caregivers, however, conceals large site-specific differences in caregiver CareNav™ uptake. In 2021, 56.8% was the highest rate of caregiver CareNav™ use at any site compared with the lowest rate of 1.4%. In 2024, this range was little changed at 55.8% (highest rate) 0.9% (lowest rate).

Table V-d: Intake Initiation in CareNav^{TM} by Caregivers 2021-2024 | n=22,665 intakes

Calendar Year	Rate for All Sites Combined*, %	Sites with High Rates**, n	Highest Site Rate, %	Sites with Low Rates†, n	Lowest Site Rate, %
2021	19.2	6	56.8	5	1.4
2022	20.7	4	40.6	7	1.8
2023	19.5	3	48.2	8	1.0
2024	20.7	5	55.8	4	0.9

* All Site rate: % caregivers initiating intake in CareNav^{TM} (vs. with Care Consultant) across n=11 Caregiver Resource Centers

** High Rate: % caregivers initiating intake in CareNav^{TM} is above rate for all sites combined

† Low Rate: % caregivers initiating intake in CareNav^{TM} (vs. with Care Consultant) at or below rate for all sites combined

In 2021, six CRC sites had “high rates” of caregiver CareNav^{TM} use, defined as use above the rate for all sites combined; in 2022 four sites had high rates, in 2023 three sites had high rates, and in 2024 four sites had high rates. In each year examined, the same CRC three sites had the lowest rates, and the same three sites had the highest rates. The site with the highest rate in all years combined had the highest rate in 2021 and 2022 but showed a decline in overall use from 57% in 2021 to 40% in 2024. In contrast, the site with the second highest rate, showed steady increases in caregiver CareNav^{TM} use in each year, from 23% in 2021 to 56% in 2024, and had the highest rate of all sites in the most recent two years.

Caregiver factors associated with CareNav^{TM} use are multifactorial. Preliminary analysis suggests these factors include younger age, white non-Hispanic race/ethnicity, caregiving duration less than two years and learning about CRC services via the internet rather than from health and social service providers.

Taken together, rates of caregiver CareNav^{TM} use are stable over time. Rates vary greatly by site with declines over time in some sites and increases over time in others. At the same time, the specific sites with high and low rates have remained the same. Rates of CareNav^{TM} use by caregivers are dependent on the CRC sites’ respective marketing and outreach programs including the search engine optimization (SEO) ranking of their respective websites. The statewide website may not be found by individual caregivers or may tend to direct them to their CRC website instead of to CareNav^{TM}.

“[I] don't know how I would have survived without services because most everything is focused on the patient not the caregiver. I am forever grateful.” – CRC Caregiver

Data Considerations for Interpretation of the Findings

Even with the data limitations outlined below, general conclusions can be drawn from this analysis and are summarized in the next section on impact. Two important caveats related to the data collected in CareNav^{TM} must be considered for interpreting the findings from this analysis:

1) Each data collection year, particularly 2019 through 2022, reflects very different circumstances for California caregivers, CRCs, and use of CareNav^{TM}. As examples:
    - **FY19/20:** During this year, wider CareNav^{TM} deployment began beyond the initial three pilot sites. Not all CRC sites were onboard with CareNav^{TM}. As sites deployed the technology, some opted to upload batches of earlier service data to the platform. This year also reflects pre-pandemic caregiver services.
    - **FY20/21:** This reflects the first year of the COVID-19 pandemic's impact on caregivers. The CareNav^{TM} technology platform allowed the CRCs to pivot quickly to continue uninterrupted services to California caregivers as restrictions were enacted on social interaction. Some CRC sites voluntarily uploaded batches of earlier service data into the platform during this year.
    - **FY21/22:** This is the first year that all CRCs had fully deployed CareNav^{TM}; no new batches of legacy data were uploaded. The COVID-19 pandemic continued to impact California's family caregivers.
    - **FY22/23:** This year reflected lessening of COVID-19 pandemic restrictions.
    - **FY23/24:** This is the first year that ongoing and open case tallies are complete for all sites as these tallies rely on the data in the previous two years for computation. In 2023, the tallies are complete for the sites that were later in adopting CareNav^{TM}.
2) Some differences in service delivery tallies by year may be driven by data quality issues. Since 2019, CRC representatives have engaged in regular data quality meetings with the UC Davis evaluation team focused on harmonizing site differences in service definitions and documentation uncovered since the evaluation shifted to the system level from the individual site level. As examples:
    - In 2019 and 2020, some sites reported Assessments and Reassessments as a combined service.
    - In FY19/20, some sites reported service units rather than the unique number of caregivers served.
    - Some legacy data includes the date of upload as the date of service thereby inflating the tallies in the year of upload. Accordingly, our estimates of change over time are conservative when using this period as the baseline.
    - Ongoing and open case tallies are based on site-specific timing of CareNav^{TM} adoption and are incomplete for some sites until 2023.
    - Site-specific rates of some services (e.g. Family Consultation) vary considerably raising ongoing questions about how these services are defined and documented by the sites.

VI. IMPACT AND RECOMMENDATIONS

Impact

Eleven CRC sites serve family caregivers throughout California. Statewide implementation of CareNav™ provides the nation's first comprehensive database of family caregivers, documenting who they are, the demands they face, the resources they need, and the outcomes of services and support. Caregivers represent diverse communities and circumstances. This report contains detailed analysis of data from FY23/24 and a look back to 2019, prior to CareNav™ implementation. Major findings include:

CRCs continue to serve caregivers who provide complex, intense, and time-consuming care. Caregivers 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 family consultants and respite care. Caregivers report important impacts on their physical and mental health and their ability to provide and sustain care because of the CRC programs.

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 using data for program decision-making. Caregiver use of CareNav™ to enter data and initiate services is low at one in five caregivers served. This rate has remained stable for the last four years but conceals wide variability by CRC site. Those who use the online platform are very satisfied.

Overall, CRC caregiver services and issued service grants increased—in some cases considerably—since the year before the pandemic began. Family consultations increased the most, by over 1000%, and continue to increase year by year. This may reflect the CRC response to the increasing complexity of the caregiving role both during and after the pandemic.

Since the pandemic, CRC in-person services such as "in-house" counseling and support groups have declined, while these service activities have steadily increased overall. Taken together, this suggests a change in the mode of service delivery, from in-person to virtual, catalyzed by the pandemic. Further, this suggests the change in service delivery mode has been sustained and the CRCs are increasingly using technology to expand service delivery.

Service grant vouchers increased significantly from the pandemic with the new funding awarded to the CRCs. Thereafter, the have been small yet significant

declines in these valuable caregiver resources—likely due to the unchanged level of state funding to the CRCs along with concomitant post-pandemic increases in the costs of the services themselves and in the costs of CRC operations (e.g., rent, salaries) without cost-of-living adjustments.

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:

- Use data on caregivers and services to inform implementation of the California Master Plan on Aging, the Equity Roadmap, and other statewide planning efforts

At the CRC site level:

- Use CareNav^{TM} data to understand the needs and priorities of caregivers in each region, to identify gaps in services and communities who are not able to access resources
- Develop strategies to reach and engage sub-populations that have yet to benefit from the CRC services and supports
- Develop strategies to provide technical support to caregivers who could benefit from CareNav^{TM} and associated resources.
- Gather CRC site perspectives about reasons for low versus high CareNav^{TM} use by caregivers and contextual factors that might explain site-specific variability in caregiver use rates

At the CRC system level:

- Collaborate across sites to identify programs and strategies that could be spread to other sites and provide support to leverage creative ideas
- Identify priority issues for additional programming and develop strategies to address these issues in culturally and linguistically appropriate ways
- Continue to identify opportunities for collaboration that leverage strengths across the system, for example, sharing bilingual staff across regions.
- Continue analysis of caregiver, caregiving, and care recipient characteristics that predict caregiver use of CareNav^{TM} to identify target groups for outreach to increase use of the platform
- Continue to engage in statewide CareNav^{TM} data quality efforts toward standard service documentation to support future analysis of service impact on caregiver outcomes
- Consider a statewide tech support model to assist family caregivers as they navigate the CareNav^{TM} platform
- Participate in reviewing the Equity Roadmap, prioritize potential actions, and develop plans to address disparities in caregiver experience, services and outcomes

At the state level (California Department on Aging):

- Increase awareness about caregiving, visibility of caregivers, and information about services
- Provide ongoing leadership for implementation of the Master Plan on Aging and the Equity Roadmap

- Consider enhanced funding to sustain current services and 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, the Equity Roadmap, and other statewide planning efforts

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"I have been impressed by the information, compassion and care given by [CRC Site]... [CRC Staff] were extremely supportive at a moment where I was losing hope for myself and finding the best care for [my relative]… Thank you for providing such an invaluable service. You are all incredible." – CRC Caregiver

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REFERENCES

1. Reinhard, SC, Caldera, S, Houser, A, and Choula, RB. (2023). Valuing the Invaluable: 2023 Update, Strengthening Supports for Family Caregivers. Washington DC: AARP. https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf

2. Sakaguchi-Tang, DK, Bosold, AL, Choi, YK, and Turner, AM. (2017). Patient portal use and experience among older adults: systematic review. *JMIR Med Inform.*;*5*(4):e38. DOI: 10.2196/medinform.8092

APPENDICES

A. Glossary
B. Technical Specifications
C. Appendix Tables

A. Glossary

The Appendix A glossary is an evolving list of definitions and terminology to help clarify CRC 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.
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.
Reporting Period	FY19/20: Fiscal Year 2019-2020 (7/1/2019-6/30/2020) FY20/21: Fiscal Year 2020-2021 (7/1/2020-6/30/2021) FY21/22: Fiscal Year 2021-2022 (7/1/2021-6/30/2022) FY22/23: Fiscal Year 2022-2023 (7/1/2022-6/30/2023) FY23/24: Fiscal Year 2023-2024 (7/1/2023-6/30/2024)

Terms	Definitions
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
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.
Outreach 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.

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

Service Grant Voucher Totals

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

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^{TM}. Specifically, we found that the “online” status of caregivers who initiate or complete forms through the online CareNav^{TM} 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 = 4,176). 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^{TM} 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^{TM}, caregivers were asked about a total of fifteen different activities and how much help the care recipient needed with each. For the purposes of calculating the level of care and care intensity, we selected the 6 activities that aligned most with the ADLs and 7 activities that aligned best with the IADLs assessed in the AARP survey. See Tables B2 and B3 below for ADLs and IADLs in AARP and equivalent activities in CareNav^{TM}. 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: Activities of Daily Living (ADL) Variables in AARP and Equivalent Activity Variables in CareNav^{TM}

AARP	CareNav^{TM}
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 Activities of Daily Living (IADL) Variables in AARP and Equivalent Activity Variables in CareNav^{TM}

AARP	CareNav^{TM}
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 (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^{TM}, 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^{TM} and Points Assigned for Level of Care/Care Intensity Calculation

AARP	CareNav^{TM}	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 (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^{TM} and were mapped to categories used in other data sources in the report (e.g., state and national datasets, US Census files) with only minor modifications.

C. Appendix Tables

Appendix C, Chapter II Population Served: Detailed Intake and Assessment Variables

Figure C1: Caregiver and Care Recipient Racial & Ethnic Identity

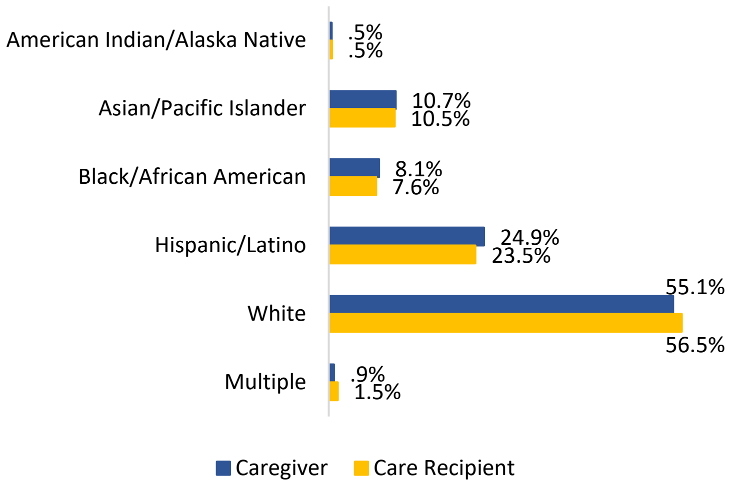

Figure C2: Caregiver and Care Recipient Gender Identity

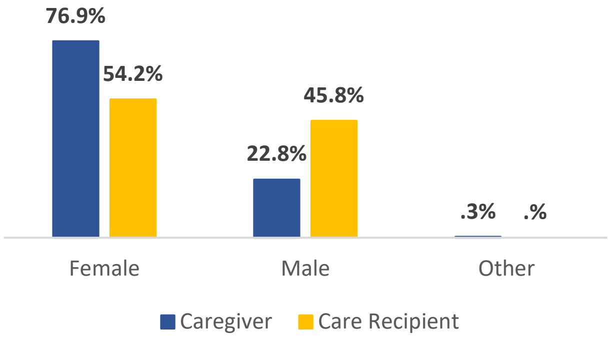

Figure C3: Caregiver and Care Recipient Age

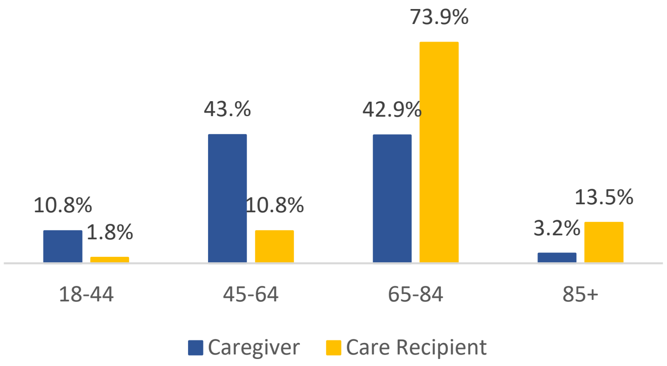

Table C1: Caregiver Sociodemographic Characteristics

n= 5,681	%
Primary Language	
English	92.10
Spanish	5.56
Other	2.34
Highest Level of Education	
Below High School	2.05
Some High School	1.91
High School Graduate	12.19
Some College	37.26
College Graduate	33.28
Post Graduate Degree	25.49
Declined to State	14.34
Marital Status	
Married/Partnered	70.75
Separated/Divorced	9.10
Single	17.10
Widowed	3.05
Employment Status	
Full Time	29.09
Part Time	10.96
Retired	42.05
Unemployed	14.09
Leave of Absence	2.10
Caregiver Lives Alone	6.79
Caregiver Lives in Rural Area	3.66
Identifies as Primary Caregiver	95.85
Other Caregiving Responsibilities	
Care for a child	6.42
Care for a child with a disability	1.23
Care for an adult with a disability	2.97
Other	3.10

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

Table C2: Care Recipient Sociodemographic Characteristics

n= 5,840	%
Care Recipient Marital Status	
Married/Partnered	55.18
Separated or Divorced	9.99
Single	7.53
Widowed	27.30
Care Recipient Lives in Rural Area	3.83
Care Recipient Lives Alone	9.54
Care Recipient is a Veteran	14.35
Care Recipient is Medicaid Eligible	
Yes	26.50
No	63.91
Unsure	9.60
Insurance Type	
Employer Insurance	1.88
Medicare	0
Medicaid/MediCal	24.4
VA Insurance	2.77
Uninsured	0.48
Other/Self-Pay	1.30
Long Term Care Insurance	4.74
Income Below FPL	18.88

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

Figure C4: Relationship of Caregiver and Care Recipient

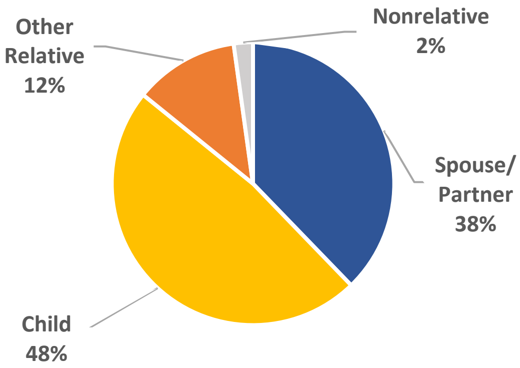

Table C3: Caregiver Sociodemographic Characteristics

n= 5,681	%
Household Income	
under $13,200	6.30
$13,200-$20,000	5.07
$20,000-$30,000	11.00
$30,000-$40,000	12.87
$40,000-$55,000	15.60
$55,000-$70,000	13.89
$70,000-$80,000	8.71
$80,000-$90,000	5.61
$95,000-$110,000	7.32
$110,000-$120,000	3.31
$120,000-$135,000	10.31
Employment Change Due to Caregiving	
No Change	73.66
Decreased Hours	6.88
Other	5.84
Quit Job	4.70
Family Leave	3.10
Early Retirement	2.82
Began Working	0.25
Increased Hours	0.57
Laid Off	1.25
Changed Jobs	0.78
Declined Promotion	0.14
Income Below FPL	11.3
Insurance Type	
Medicare	62.73
Medicaid/MediCal	22.55
VA Insurance	8.15
Uninsured	3.33
Other/Self-Pay	9.79
Long Term Care Insurance	12.04

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

Table C4: Caregiver Health and Caregiving Outcomes

n= 5,681	**%**
Self-Reported Health Status	
Excellent	5.42
Very Good	19.60
Good	42.30
Fair	26.68
Poor	6.00
Current Health Compared to Six Months Ago	
Better	8.70
Same	57.24
Worse	34.06
PHQ-9 (Depressive Symptoms)	
None	40.71
Minimal/Mild	40.82
Moderate	12.14
Moderate/Severe	5.00
Severe	1.32
UCLA-3 Loneliness Scale	
Not Lonely	77.66
Lonely	22.34
Zarit Burden Interview	
<8 (low strain)	36.20
8+ (high strain)	63.80
Satisfaction with Support from Family and Friends	
Very Satisfied	23.29
Somewhat Satisfied	28.52
Neutral	23.94
Somewhat Dissatisfied	15.51
Very Dissatisfied	8.74
Satisfaction with Spiritual Support	
Very Satisfied	32.78
Somewhat Satisfied	26.14
Neutral	31.82
Somewhat Dissatisfied	6.90
Very Dissatisfied	2.35

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

Table C5: Characteristics of Caregiving

n= 5,840	%
Duration of Caregiving	
<2 Years	41.50
2-5 Years	29.38
>5 Years	29.12
Caregiver Performs Medical/ Nursing Tasks	84.69
Level of Care (AARP)*	
1-3	9.90
4	23.78
5	66.32
Care Intensity (AARP)*	
Low Intensity	3.46
Medium Intensity	6.44
High Intensity	90.10
Caregiving Hours Per Week	
0-10	7.12
11-20	6.80
21-39	12.20
40+	73.42
Paid Help Hours Per Week	
0	69.11
1-10	12.56
11-20	6.57
21-30	4.54
31-40	2.82
40+	4.41
Unpaid Help Hours Per Week	
0	48.79
1-10	29.71
11-20	8.27
21-30	3.63
31-40	2.52
40+	7.08
Perceived Help from Family & Friends	
Amount Needed	19.02
Don't Need Help	1.68
Less Than Needed	51.21
No Help	28.10

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