



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

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

Reporting Period: July 2022-June 2023

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

EXECUTIVE SUMMARY

In 2019, the California Department of Health Care Services awarded the eleven nonprofit Caregiver Resource Centers (CRCs) \$30 million for the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project. In Fiscal Year 2021, ongoing annual funding was established at \$15 million. The aim was to “expand and improve family caregiver services and enhance CRC information technology services” between 2019 and 2022. Early in Fiscal Year (FY) 2021, the CRCs accomplished full deployment of CareNav™, an online system that includes data collection using a uniform caregiver assessment, a record of CRC services provided, consumer information, care plans, CRC forms, and secure communications.

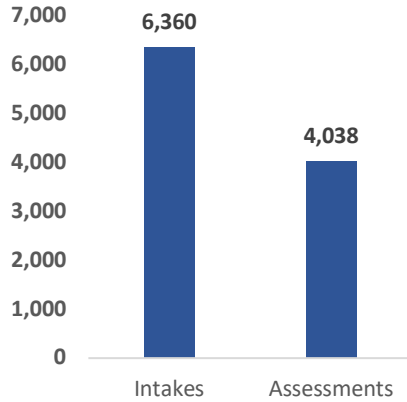
Across all CRCs, 13,904 unduplicated family caregivers received services from professional staff in FY 2022-2023. The CRCs provided one or more services such as family consultation, counseling, education, or vouchered services (counseling, legal, respite, supplemental) to 7,010 family caregivers. The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

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

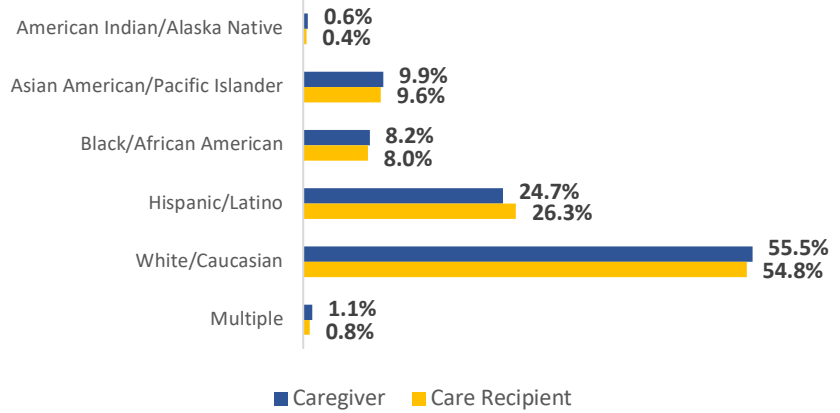
Caregivers support persons with a range of health conditions, with 68% having a diagnosis of Alzheimer’s Disease or a related disorder, followed by stroke (10.2%), “other” conditions (8.1%), Parkinson’s Disease (7.5%), cancer (3.5%), and brain injury (2.7%). Those served by the CRCs provide complex and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

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

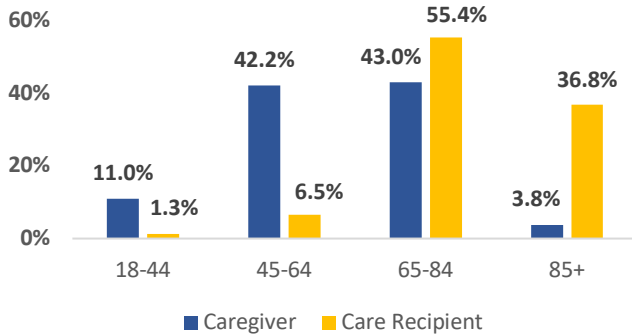
Intakes and Assessments Completed



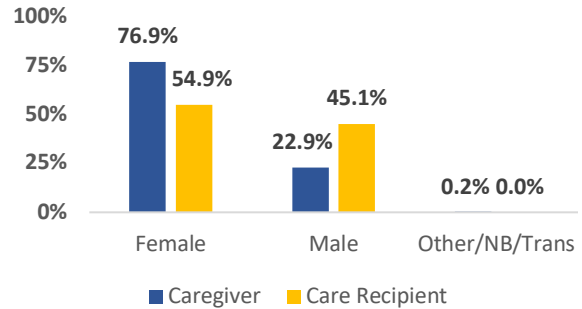
Racial & Ethnic Identity: Caregiver and Care Recipient



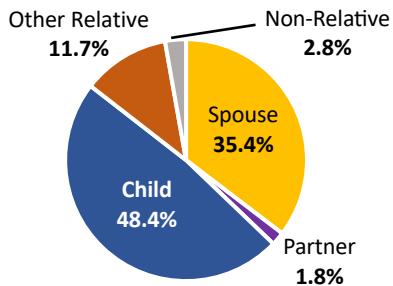
Age: Caregiver and Care Recipient



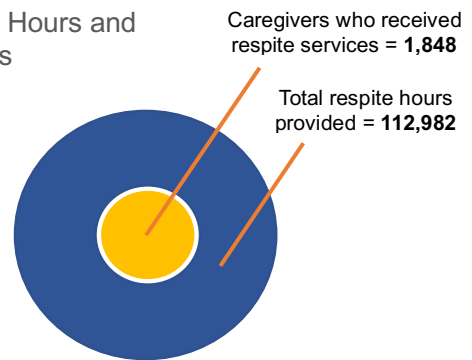
Gender: Caregiver and Care Recipient



Relationship of Caregiver and Care Recipient



Respite Hours and Services



Outreach and Education Activities

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

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

Caregiver Supports

Family Consultation = 158,177 consultations

Support Groups = 1,172 clients

Individual Counseling Services = 421 clients

Legal and Financial Consultation = 147 clients

Supplemental Service Vouchers = 230 clients

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

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

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

IMPACT

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


CRCs serve caregivers who provide complex, intense, and time-consuming care.

Caregivers are often the primary or only caregiver in the situation and commonly have little family or paid support.

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

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

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



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

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

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

RECOMMENDATIONS

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

At the CRC site level:

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

At the CRC system level:

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

At the state level (California Department on Aging):

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