

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

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

Executive Summary

Reporting period: July 2020-June 2021

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EXECUTIVE SUMMARY

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

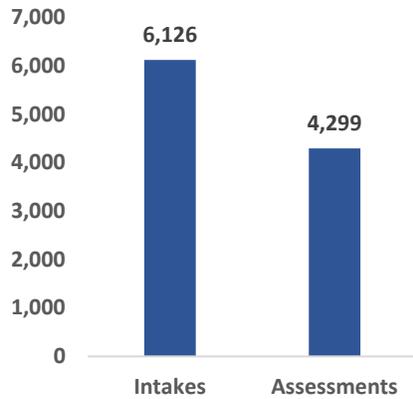
1. Monitor and optimize data quality in CareNav™, including harmonizing data definitions and reporting
2. Increase CRC staff technical capacity and technology acquisition to scale services
3. Promote uniform quality practice and availability of core CRC services statewide
4. Increase number of family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

Across all CRCs, approximately 33,000 caregivers received support in the past fiscal year, with a total of 6,126 contacting a CRC and 4,299 unduplicated caregivers completing assessments for 4,385 unduplicated care recipients. The CRCs followed an additional 28,817 ongoing cases during the year. Importantly, these counts underestimate the actual CRC open caseload because they are based on definitions that encompass a two-year window during which not all CRCs were fully up and running with complete CareNav™ data. Of the ongoing cases, 34% had some activity during this fiscal year, receiving one or more services such as family consultation (25,546 consultations), reassessment (2,856), counseling (1,369 hours) or vouchered services (legal: 134 hours; respite 135,656 hours). The CRC conducted 3,731 outreach activities, reaching over 500,000 Californians in the past year.

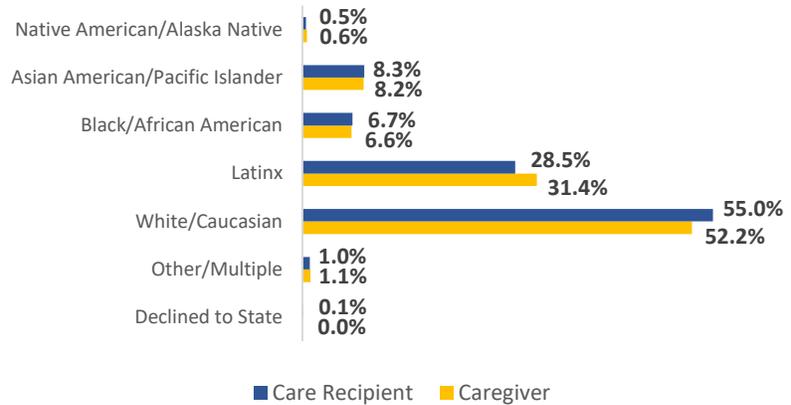
The CRCs serve diverse caregivers across the adult lifespan. Of the 4,299 caregivers who completed assessments, most were ages 45-64 years (47.7%) or 65-84 years (36.0%), and identified as female (74.9%), heterosexual (89.9%), and as married or partnered (65.4%). The CRCs serve a racially and ethnically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

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

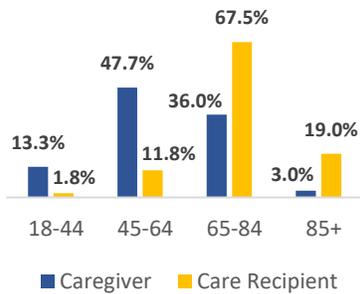
Intakes and Assessments Completed



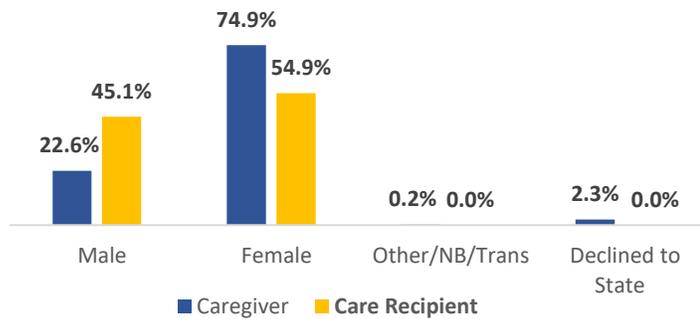
Racial & Ethnic Identity: Caregiver and Care Recipient



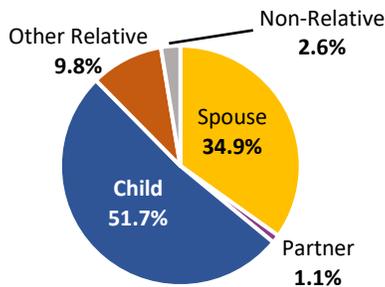
Age: Caregiver and Care Recipient



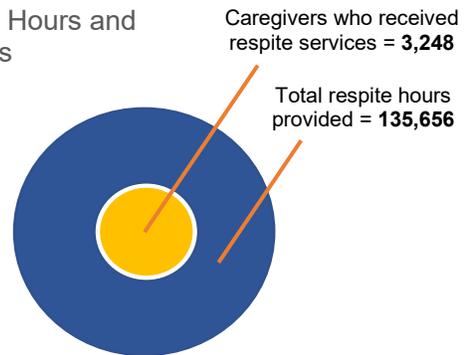
Gender: Caregiver and Care Recipient



Relationship of Caregiver and Care Recipient



Respite Hours and Services



Outreach and Education Activities

Outreach = 3,731
 Direct referrals, general public information/awareness activities, provider awareness.

Education = 1,163
 Programs designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.

Caregiver Supports

Family Consultation = 25,546 consultations

Support Groups = 1,993 clients

Individual Counseling = 1,369 hours

Psycho-Educational Groups = 264 clients

Legal and Financial Consultation = 134 hours

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

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

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

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

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

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

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

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

CRCs provided access to respite services exceeding 20% of the annual budget. Taken together, the eleven CRCs spent \$3,335,026 on respite services in this fiscal year, comprising 22% of the \$15,000,000 budget and exceeding the 10% threshold specified in the contract.

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

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

RECOMMENDATIONS

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

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

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

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

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

ACKNOWLEDGEMENTS

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