





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 2021-June 2022

Submitted by the Family Caregiving Institute, November 1, 2022



Evaluation Team

Investigators:

Heather M. Young, PhD, RN, FAAN | Co-Principal Investigator

Janice Bell, MN, MPH, PhD, FAAN | Co-Principal Investigator

Jennifer Mongoven, MPH | Co-Investigator

Study team:

Benjamin Link, BS

Jessica Famula, MS, CCRP

Robin Whitney, PhD, RN

Orly Tonkikh, PhD, RN

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.

EXECUTIVE SUMMARY

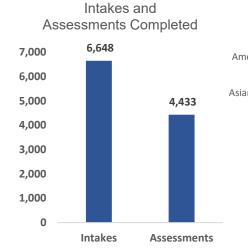
In 2019, the California Department of Health Care Services awarded the eleven nonprofit Caregiver Resource Centers (CRCs) \$30 million for the *Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile* project. The aim was to "expand and improve family caregiver services and enhance 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. During FY 2021-2022, CRCs advanced to using data from CareNav™ to inform decision making in program and outreach. Over the past year, the CRC Directors focused on the following overall goals for this project:

- 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

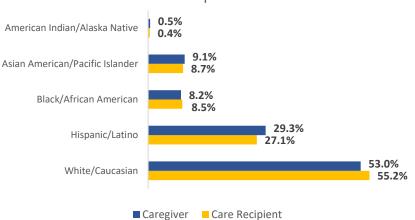
Across all CRCs, 14,670 unduplicated family caregivers received services from professional staff in FY 2021-2022. Of those 14,670 caregivers, 4,302 were first-time (new) CRC clients who went through intake on to full assessment and intensive services. Of all 6,648 caregivers who participated in intake screening, 4,433 (67%) completed at least one assessment. The CRCs provided one or more services such as family consultation, counseling, education, or vouchered services (counseling, legal, respite, supplemental) to 6,897 family caregivers. The total number of open cases (the sum of new and ongoing cases in the CareNav™ record) in FY 2021-2022 totaled 10,887 across the CRC system. Importantly, these counts underestimate the actual open caseload because they do not include family caregivers who entered before CareNav™ deployment. In FY 2021-2022, the CRCs provided family consultations (133,666 instances), reassessments (3,326), "in-house" counseling (174 caregivers), and vouchered services (counseling: 267 caregivers; legal: 165 caregivers; respite 2,080 caregivers; supplemental: 344 caregivers) as well as 9,884 outreach activities.

The CRCs serve diverse caregivers across the adult lifespan. Of the 4,433 caregivers who completed assessments, most were ages 45-64 years (47.6%) or 65-84 years (37.0%), and identified as female (75.8%), heterosexual (90.4%), and as married or partnered (67.9%). The CRCs serve a racially and ethnically diverse population, including white non-Hispanic (53.0%), Hispanic/Latino (29.3%), Asian American/Pacific Islander (9.1%), Black non-Hispanic (8.2%), and Native American/Alaska Native (0.5%) caregivers.

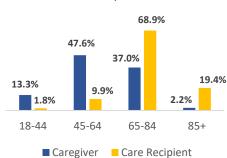
California Caregiver Resource Centers (CCRCs) July 2021 – June 2022 Dashboard | n = 4,433



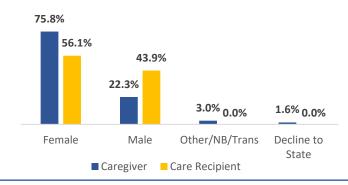
Racial & Ethnic Identity: Caregiver and Care Recipient



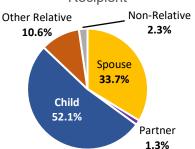
Age: Caregiver and Care Recipient



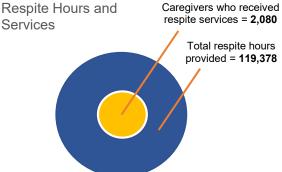
Gender: Caregiver and Care Recipient







Services



Outreach and Education Activities

Outreach = 9,884

Direct referrals, general public information/awareness activities, provider awareness.

Education = 1,039

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

Caregiver Supports



Support Groups = 1,054 clients

Individual Counseling Services = 441 clients

Legal and Financial Consultation = 165 clients

Supplemental Service Vouchers = 344 clients

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 ADL and IADL supports). Most (82%) assisted with at least one medical/nursing task, with 40.3% reporting that performing these tasks is difficult. Caregivers devote a great deal of time to their role, with 76.2% spending more than 40 hours per week caregiving. Despite these heavy demands, 70.6% received no paid help. Caregivers experienced health issues themselves, with only about one-quarter reporting being in excellent health (6.0%) or very good health (19.5%). Nearly one third (32.2%) reported worsening of health over the past year. Caregivers reported mental health concerns, with more than half experiencing strain (59.8%), 21.2% reporting moderate to severe depressive symptoms, 32.7% reporting sleep disturbances, and 22.8% experiencing significant loneliness. On a positive note, nearly half of caregivers report being satisfied with the spiritual support they receive (43.5%). Many caregivers made employment modifications as a result of caregiving responsibilities, with 7.1% reducing work hours, 5.2% quitting their current job, 3.4% taking early retirement, and 3.3% declining a promotion.

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

CRCs serve caregivers who are providing 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. They are paying the price with their own mental health, experiencing strain, worsening physical health and symptoms of depression and loneliness. The population served is in high need of services and supports. At the same time, this raises the question of how to bolster outreach to caregivers at lower risk, likely greater in number but not currently being served, who might benefit from CRC support and resources earlier in the caregiving trajectory.

Caregivers are highly satisfied with CRC services. Caregivers identify an array of benefits from their engagement with the CRCs, including tangible supports such as respite and legal assistance and emotional supports that improve confidence and capacity to care and reduce isolation. The CRCs have increased service and support during a time of significant need related to the pandemic, providing a lifeline to caregivers.

CareNav[™] implementation is advancing. Sites are benefiting from real-time accurate caregiver data and are using data for decision-making regarding programs, outreach, and equity.

The CRCs are functioning as a system. The sites have a shared commitment to supporting California's caregivers and are functioning as a collaborative network, sharing ideas and resources to improve equity, inclusion, and quality.

Fiscal Year 2022 was the third year of the augmentation cycle for the CRCs. In three years, the CRCs:

Adopted and mastered a variety of communication technologies

- Implemented a client-facing, interactive record platform to provide curated content to individual caregivers and real time data at the site level
- Participated in extensive retraining of staff on change management, how to use communication and client record technologies, retrained on service model definitions and practice issues, telehealth consults and service delivery, and increased use of social media
- Enhanced staff development in areas of diversity and clinical practice
- Expanded referral sources so that 60% of referrals come from social services or health care services
- Established statewide internal CRC committees on policy, clinical supervision, community education and staff education
- Worked with the Evaluation Team at UC Davis to submit information and data for annual reports and participated in process evaluation
- Responded to state and local requests for assistance during COVID-19
- Reorganized internally to respond to staff and caregiver service needs during the pandemic
- More than doubled all service numbers by Year 2 of the augmentation

RECOMMENDATIONS

The CRCs have expanded services and are using CareNavTM data in important ways to inform decisions and strategy. The Caregiver Resource programs could expand upon the following efforts:

- At the CRC site level:
 - Continue to review and address data quality and streamline work processes
 - 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
- Across all CRC sites, expand public outreach and information to increase awareness and support caregivers to use CareNavTM as a resource
- At the CRC system level:
 - Refine decision support to identify and target caregivers dealing with the most complexity and most challenging situations, so that CRC staff can be alerted more readily to prioritize these caregivers for services and more frequent reassessment
 - Collaborate to develop strategies to address priority health issues for caregivers, such as loneliness and sleep deprivation
 - Identify opportunities for collaboration that leverage strengths across the system, for example, sharing bilingual staff across regions.
 - Prioritize efforts to enhance equity and inclusion, identifying potential strategies
- At the state level (California Department on Aging):
 - Consider enhanced funding to enable further service expansion

- 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





