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

Picking Up the Pace of Change:
Scaling Services for a Changing Caregiver Profile

Executive Summary
First Annual Report
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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 to "expand and improve family caregiver services and enhance CRC information technology services" between 2019 and 2022. Fiscal Year 2020 was the first year of implementation and was largely focused on the first three of four overall goals for this project:

1. Deployment of a statewide interactive caregiver client record (CareNav™) that includes data collection using a uniform caregiver assessment, CRC service services provided, consumer information, care plans, CRC forms, secure communications and other information;
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

History and Service Eligibility The expansion built upon 35 years of experience in the development and provision of services through the CA system of CRC's targeted to unpaid family caregivers of adults with Alzheimer's and related dementias, Parkinson's, head injury, stroke and other cognitive impairments with adult onset. The system is distinct in the breath of cognitive disorders in combination other chronic health conditions; the age of the family caregiver from age 18 up; ability to serve low to middle income family caregivers; the use of in-depth client data to shape planning, identification of diverse and employed family caregivers and to evaluate impact of services on caregiver health and well-being, acquisition of care and decision skills and decrease in social isolation. The system has used a uniform caregiver client assessment since 1987 with current updated version adopted in 2019.

Implementation Challenges The California CRCs had a vision to enhance access across the diverse communities of California and to meet growing service needs by modernizing their business practices using technology. This vision proved to be prescient as the COVID-19 pandemic gained momentum and the CRCs were able to respond quickly to provide services to their clients. The California CRCs took on an impressive goal – to harmonize their information technology platform and implement the new platform across the state in all eleven sites in six months. Early in the process there were delays related to state contracting and fully navigating local system barriers. Contracting delays had a ripple effect on ramping up both human resources and the deployment effort. Just as the implementation was launched and was gaining steam, the COVID-19 pandemic struck, accelerating new priorities and ways of working to assure that the CRCs could still serve their clients.

In addition to implementation activities, the CRC's responded to requests from state and county departments to make check-in calls to clients who had received services in the past 2+ years to determine unmet needs regarding: food security, assistance with care, mental health issues, financial strain, and need for CRC services. The pandemic brought new challenges and threats to caregivers, particularly those who already were at risk and struggling with their demands and resources. Sites demonstrated their deep commitment to caregivers by making a concerted effort to reach out to family caregivers

affected by the COVID-19 pandemic, making over 12,000 personal connections in the first month of the pandemic.

Implementation Activities Preparation activities for the install of CareNav™, communication technologies and staff training across the CRC took place in the first six months of the project. Activities included formalizing the CRC Expansion Project Team and expansion plan; assessing CRC's individual IT infrastructure, data importation, development of CRC data import templates, scheduling install dates at CRCs, staff technical capacities, internal workflow processes and development of statewide staff training including site install of CareNav™.

Staff Training and Preparation The goals for staff training were to increase skills for managing practice change, telehealth encounters and online service delivery, and to provide the context for uniform assessment and CRC service provision. The trainings also served a purpose in increasing CRC identity for staff and to encourage cross-CRC collaboration. Training sessions were offered as part of the kick-off conference and through single online programs for the balance of the fiscal year.

In January 2020, the official kick-off of implementation activities began with a two-day statewide training via interactive livestream and in person participation. Day one included a review of the expansion project vision and core goals, workshops on change management, nonprofit digital transformation, and an overview of the CareNav™ client record system. Day two included an overview of telehealth, a discussion of core CRC services, overview of CareNav™, sharing of unique CRC services and programs, and introductions to the project's statewide outreach initiative and formal evaluation strategy. As reported by interview participants, training was effective both in building skills and a shared commitment to enhancing and scaling services across the state.

CareNav™/Communication Technologies Install: Of the eleven sites, three were already using CareNav™: San Francisco Bay Area, Del Mar and Los Angeles CRCs. The remaining eight sites were scheduled for two-day installs and trainings at the CRC site with a completion date of June 30, 2020. The first two sites completed an onsite install in early March but COVID-19 shelter in place orders changed the plan. Staff pivoted to virtual training and installs for the balance of six other sites. The pandemic also brought opportunities, motivating the sites to quickly adopt new ways to connect to and support clients and accelerating demand for the technology deployment. ***Despite these significant and unexpected events, the process moved forward, and by the end of July, all sites had CareNav™ and related communication technologies installed.*** At that time, nine sites were using CareNav™ and two sites lagged in CareNav™ full use due to complications with reporting and data migration programs (since corrected).

CRC Services and Caregiver Profiles The data collected for the quantitative evaluation cover the service period from July 1, 2019 to June 30, 2020. A dashboard of the information is provided in Figure 1. During this start-up period, the 11 CRCs conducted nearly 5,000 initial caregiver screenings; of these, 3,321 (68%) received full assessment. Ethnicity of caregivers were White (55%), Hispanic/Latinx (19%), Asian/ Pacific Islander (8%) and African American (7%). More than half (52%) of the caregivers were under the age of 65:18-44 (7%); 45-64 (45%); 65-84 (42%); 85+ (4%). Approximately 83% of the care recipients were adults age 65 years or older, with more

than 30% age 85 years or older. Across the sites, the percentage of female caregivers averaged 73% and the percentage of female care recipients averaged 54%. Relationship to the care recipients were (43%) adult children, (45%) spouses/partners, other relative (9%) and other (3%).

Key Highlights from Assessment Data available in three CRC's who were using CareNav™ for FY 2020: Initial CareNav™ data provide a snapshot of 721 assessed caregivers from the San Francisco Bay Area, Del Mar (Monterey, Santa Cruz and San Benito) and Los Angeles. These caregivers were 75% women. In this sub-sample, almost 60% of caregivers were under the of 65: 18-44 (12%); 47% 45-64 (47%); 65-84 (38%); over age 85 (2%). Racial/ethnic backgrounds were African American (12%), Asian/Pacific Islander (17%), White (42%), Hispanic/Latinx (20%), Native American (0.6%). Most were married (63%) or a domestic partner (3%). Amount of time as a caregiver ranged from 38% less than two years, with 60% of caregivers providing assistance for longer periods: 27% two to five years; and 34% of caregiving for over five years. Almost half (46%) of the caregivers were employed with an addition19% identified as unemployed.

Caregiver tasks from these three sites provides an idea of the extent of assistance activities. Approximately 30% of caregivers report the person they care for "needs help all the time" with ADL/IADL tasks. Specifically, they help with the following: bathing (52%); dressing (42%); grooming (37%); toileting (36%); incontinence (38%); meal prep (80%); taking meds (74%); managing finances (86%); household chores (79%); using telephone (47%); mobility (32%); transferring (32%); shopping (87%); and transportation (91%). A new question in the updated assessment asks about medical tasks done by the caregiver. 41% of caregivers indicated that they provided one or more of the following tasks: skin/wound care; medication management; giving oral meds; giving medications by injections, IV, drops or other methods; special diet prep; operating medical equipment; operating durable medical equipment; using medical meters/monitors; and managing pain. *These three activity measures indicate a significant percent of caregivers are providing extensive personal care and medical tasks in addition to managing household and "life management" tasks for their relative or friend.*

CRC Services Provided CRC services received by family caregivers were: family consultation:13,070 caregivers; legal and financial consultation: 421 caregivers; support group participants: 2,626 caregivers; multi-session psycho-education groups: 873 caregivers; individual short-term counseling: 680 caregivers; respite services: 3095 caregivers (total of 149,184 hours); and community education and training programs: 107,620 participants (higher numbers than average due to partnered programming on COVID) and as mentioned, 12,000 family caregiver check-in calls during COVID shelter in place orders during March/April 2020.

Despite the challenges of California's wildfires and the COVID pandemic, delays in contracting and staffing shortages, installing and learning new technologies, the CRCs performed at service levels similar to those in the last published CRC Annual Report 2006-07 when the system was at a comparable level of funding.

Critical Issues for the Future Leadership and communication were critical elements throughout the process and remain paramount as the sites take the implementation to the next level, fully implementing CareNav™, bringing more clients onboard, using the

resources of CareNav™ to the fullest, and using the data to improve quality, inform strategy, and influence stakeholders. Going forward, the issue of the digital divide gains salience. As suggested by one participant, the CRCs might consider approaches to enhancing equity and inclusion by partnering with organizations that can assist individuals to access and use technology and to consider how to deliver linguistically congruent services in the online platform.

The next phase of implementation should involve developing a deeper understanding of the rich information available through CareNav™, determining both site-specific and state-wide reports that would be most helpful in evaluating adoption and dissemination of the programs into the community, effectiveness and gaps in service, quality of delivery, and the impact of the services and supports on caregiver outcomes. The CRCs recognize that during this implementation year, outreach and engagement to diverse communities was especially difficult. However, the CRC's are committed to increasing service levels, delivery options and engagement of family caregivers that reflect the ethnic and cultural identities of their communities.

The data holds power to drive individual and system changes. At the individual level, the assessment can be the basis for determining risk and matching services to caregiver needs. At the system level, the data can drive strategy for priority program development, funding and advocacy.

A determined and committed group of leaders and staff dedicated to improving the lives of caregivers began a journey together. They are well on their way to actualizing a vision for the future for California caregivers.

Notes:

The UC Davis Family Caregiver Institute, Betty Irene Moore School of Nursing was selected as the research team for the CRC expansion project (FY 20-22); oversight, Family Caregiver Alliance.

CareNav™ is an interactive caregiver client record system by Family Caregiver Alliance www.caregiver.org

Figure 1: CRC Data Dashboard

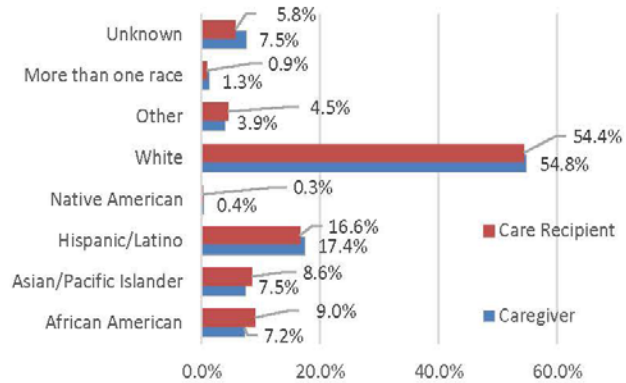**CALIFORNIA CAREGIVER RESOURCE CENTERS (CCRCs) JULY 2019 – JUNE 2020**
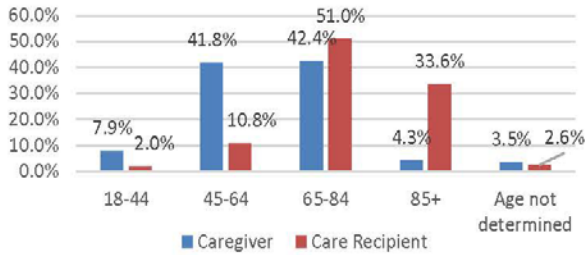
Intakes and Assessments Completed

- Intake: 4,876
- *Assessment: 3,321
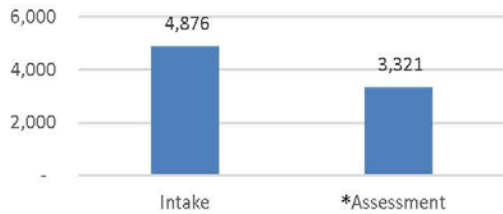
*Assessment excludes Orange (site assessment and reassessment data were submitted as a combined total)

Race / Ethnicity

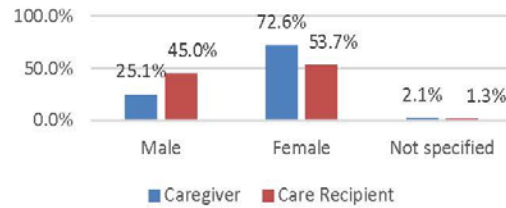|	Care Recipient	Caregiver
Unknown	5.8%	7.5%
More than one race	0.9%	1.3%
Other	4.5%	3.9%
White	54.4%	54.8%
Native American	0.3%	0.4%
Hispanic/Latino	16.6%	17.4%
Asian/Pacific Islander	8.6%	7.5%
African American	9.0%	7.2%

Age: Caregiver and Care Recipient*

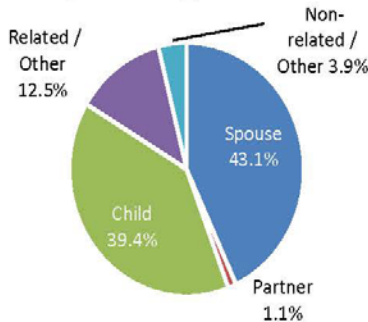|	Caregiver	Care Recipient
18-44	7.9%	2.0%
45-64	41.8%	10.8%
65-84	42.4%	51.0%
85+	4.3%	33.6%
Age not determined	3.5%	2.6%

*Excludes Coast (data provided in different categorical cut-offs)

Gender: Caregiver and Care Recipient

	Caregiver	Care Recipient
Male	25.1%	45.0%
Female	72.6%	53.7%
Not specified	2.1%	1.3%

Relationship of Caregiver and Care Recipient

- Spouse 43.1%
- Child 39.4%
- Related / Other 12.5%
- Non-related / Other 3.9%
- Partner 1.1%

Respite Hours and Services

Caregivers who received respite services = 3,095
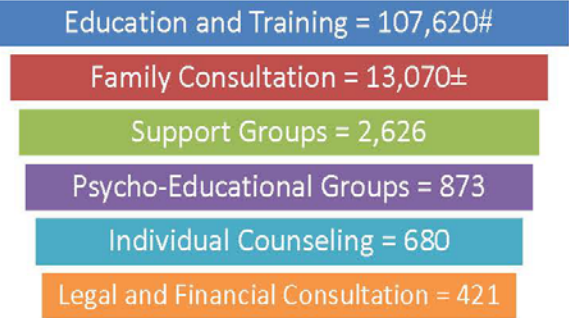
Total respite hours provided = 149,184
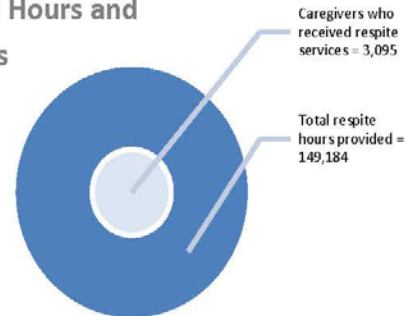
Outreach and Education Activities

Outreach = 2,229
Direct referrals, general public information/awareness activities, provider awareness.

Education = 641
Programs designed to help caregivers learn new skills or educate providers about the needs of family caregivers and available resources.

Total # of Caregiver Encounters*

- Education and Training = 107,620#
- Family Consultation = 13,070±
- Support Groups = 2,626
- Psycho-Educational Groups = 873
- Individual Counseling = 680
- Legal and Financial Consultation = 421

*Disclaimer: A difference in the definition of variables was noted during analysis; efforts are underway to standardize these definitions across sites.
#Excludes Inland (data not provided in same format
±Excludes Valley (data not provided in same format)

CCRCs: Bay Area, Coast, Del Mar, Del Oro, Inland, Los Angeles, Mountain, Orange, Redwood, Southern, and Valley

Recommendations

This report provides a summary of the process evaluation of implementation and the early results of a state-wide data collection effort. Recommendations are provided in three major areas: implementation, data integrity, and implications for service delivery.

Implementation:
1. Continue to engage in statewide communication and strategic planning to actualize the intention of this supplemental funding. As data become available, use the data to inform strategic decisions.
2. Continue efforts to address cross-site variation in data collection practices and communication with caregivers, learning from all sites and moving towards standardization where possible.
3. Engage in ongoing feedback about the usability and effectiveness of CareNav™.

Data Integrity:
1. The availability of data will facilitate review of the quality, accuracy and completeness of the data. Sites should engage in thoughtful review of summaries generated out of CareNav™, comparing and reconciling differences with their previous data reports.
2. Differences in variable definitions were noted across the sites; efforts are underway to standardize these definitions across all CRCs. Structured meetings with CRC front line providers will facilitate in-depth examination of variable definitions and data entry specifications. Further harmonization may be required across sites.

Implications for service delivery:
1. CRC directors across sites to explore with their staff:
   a. forecasting 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
   b. reasons for and need for further outreach to groups of caregivers served at lower rates than anticipated (e.g., low income, veterans, Latinx populations, rural residents)
   c. strategies to address high rates of caregiver mental health status and loneliness
2. Determine frequency of statewide evaluation of caregiver satisfaction with CRC services and implement regular and standardized satisfaction surveys across the state for review and incorporation of feedback at the sites.
3. Identify trends, gaps in service and outcomes to determine 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.
4. Consider translating CareNav™ into other languages to increase cultural and linguistic congruence across racial/ethnic groups.
5. Use data on caregivers and services to inform implementation of the California Master Plan on Aging and other statewide planning efforts.
6. Work closely with Department of Home and Community Services (DHCS) to further promote caregiving service standards and quality.