



Association of California Caregiver Resource Centers

California System of Caregiver Resource Centers (CRC) Expansion Plans 2019-2022

Background California is set to see a rapid increase in older adults over the next decade when 20 percent of the population will be over age 65. This population – and their family caregivers - will be more diverse than at any other time in CA history. The estimated 4.7 million *unpaid* family members are the largest long-term workforce caring for older and disabled adults. Today’s caregiver profile is changing. Family caregivers are younger (80% are under the age of 65), they are more diverse, and the majority are employed. Almost all use the internet and social media daily to find information, transact business, schedule healthcare encounters and keep in touch with friends and family.

For many, providing care and support to family members with adult-onset cognitive impairment has severe consequences on the caregivers’ health and well-being. Evidence shows that most family caregivers are not prepared for their caregiver role and provide care with little or no support. Without proper comprehensive caregiver support, family caregivers suffer from stress, social isolation, and clinical depression; chronic illnesses (e.g. diabetes, heart disease, hypertension) are exacerbated due to caregiver burnout. Caregivers report deficits in feelings of competency to handle physical and behavioral tasks for the care recipient. Approximately 50% of caregivers help with medical tasks in the home.

Legislative Action CRCs, in partnership with members of the CA Task Force on Family Caregiving, AARP, service provider and consumer coalitions, family caregivers, statewide provider associations and organizations, advocated for a significant increase in funding for the CRCs in the FY 2019-20 budget process. This three-year award of \$30M (\$10M/year over 3 years) increases the total annual appropriation for support for caregiving families to \$15M/year. The CRCs are under the CA Department of Health Care Services. The three years are: FY 2019-20 to FY 2021-22.

Expansion Goals:

- Increase the numbers of family caregivers served annually to 30,000 individuals receiving one or more information or training services and to 8,000+ family caregivers who receive a more intensive level of services that require a full caregiver assessment, care plan and package of services.
- Deploy statewide interactive client record that captures demographic information and direct care needs of care recipient(s), provide financial, legal and health care planning and address self-care needs of the family caregiver (social, health and mental health); combine data with CRC service usage and analyze for quality of life, competence and reduced stress/burden on the primary family caregiver. The record is available to the caregiver via a dashboard incorporating consumer content, CRC service authorizations, care/action plan, CRC staff identification and HIPPA secure messaging. Parts of the intake and assessment process may be self-administered by the caregiver.
- Increase use of technologies by the CRCs to scale services, to provide options for families to receive services most convenient for their schedules and to test service options that utilize technologies for caregivers.
- Provide quality practice and adherence to the service model to provide consistent services across the state and assure that CRC staff have the skill sets required for implementation and expansion.

Included in this expansion are three statewide projects: 1. Start-up activities to install uniform client record system, train staff on use of technologies for data collection and service delivery and on the CRC service model (Yr. 1); 2. Statewide marketing of CRC system with emphasis on social media (Yrs. 1-3); 3. Statewide evaluation of expansion goals (Yrs. 1-3).

Caregiver Resource Centers The eleven nonprofit Caregiver Resource Centers (CRCs) throughout the state serve families and caregivers of adults affected by chronic health conditions such as: Alzheimer's or other dementias; other degenerative diseases which cause both physical and cognitive impairment such as Parkinson's, Huntington's, multiple sclerosis & amyotrophic lateral sclerosis; cerebrovascular diseases such as stroke, aneurysm and multi-infarct disease; brain injury due to trauma or infection; brain tumor and other brain impairing conditions. Each CRC serves as a point of entry to services available to caregiving families in every county of California. While each center tailors its services to its geographic area, all CRCs have a core component of 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 for whom few services are targeted. The CRCs are united by shared values emphasizing choice, collaboration, innovation, quality, participation, respect and diversity.

As family caregiving is a dynamic process, the CRCs expect that an additional 30% of clients from prior years will re-contact the CRC for information, consultation, and services to meet their changing needs. Services are free or low cost and include:

- **Specialized Information** – advice and assistance on caregiving issues including stress, diagnoses and community resources.
- **Uniform Caregiver 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.
- **Family Consultation & Care Navigation** - 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.
- **Respite Care** – 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.
- **Short-term Counseling** – family, individual and group sessions with licensed counselors to offer emotional support and help caregivers cope with the strain of the caregiving role.
- **Support Groups** – Monthly meetings in a supportive atmosphere where caregivers share experiences and exchange ideas to ease the stress of caregiving.
- **Professional Training** – Individually tailored workshops on long-term care, patient management, public policy issues, and legal/financial issues.
- **Legal & Financial Consultation** – Personal consultations with experienced attorneys regarding powers of attorney, estate and financial planning, conservatorships, community property laws and other complex matters.
- **Education** – Special workshops on topics such as diagnosis, treatment, long-term care planning, direct care skills and stress management to help caregivers cope with day-to-day concerns.

Description of Services and Service Model Unpaid family caregivers who contact a CRC receive a uniform intake and, if needing additional services, a uniform assessment that includes demographic information about the caregiver and care recipient, care recipient functioning (ADL's, IADL's, medical task assistance, behavioral issues if present), care planning (legal planning, advanced directives, durable powers), financial status, additional paid and unpaid support for the caregiver and care recipient, caregiver self-care (health, stress, depression, social isolation). At the completion of the assessment, a care plan is developed based on the preferences of the caregiver. For intensive clients, the service period is approximately 6 months with an open-ended invite to recontact the CRC as their needs change over time. A reassessment may take place on key measures at the end of the service period as well as a uniform client survey to determine satisfaction with services. A range of interventions and services are determined during the care planning process. All encounters with the family caregiver are tracked as units of service and entered into the client record. Also tracked are the format in which the services were delivered: in-person, telephone, telehealth, online support/classes. De-identified data containing intake, assessment, reassessment, units of services and service delivery format can be exported for analysis.

For further information regarding Evaluation of CRC Expansion, contact Kathy Kelly (kkelly@caregiver.org);

For further information regarding technology used in Expansion, contact Kathy Kelly (kkelly@caregiver.org);

For information about Statewide Marketing/Media, contact Roberto Velasquez (rvelasquez@caregivercenter.org)

Association of California Caregiver Resource Centers (ACCRC):

Executive Director: Mary Sheridan (marysherida@verizon.net); President: Donna Benton, PhD (benton@usc.edu)