



March 15, 2021

Dear Contra Costa County Caregiver Advocate,

With an estimated 136,000 family caregivers living in Contra Costa County, action is required now to support and sustain this hardworking group of individuals who provide unpaid care for adult family members and friends. And for good reason. The number of family caregivers is increasing in every community across the country. In 2015, family caregivers comprised 16.6% of the adult population in the United States, today it is 19.2% (*Caregiving in the U.S., 2020 Report*, AARP, National Alliance for Caregiving). The sharpest increase has been among individuals caring for a family member or friend age 50 or older. Moreover, half of all caregivers perform a variety of complex medical/nursing tasks, such as administering multiple medications—including injections—changing wounds and managing medical equipment.

Each day people step into the caregiving role feeling unprepared or ill-informed about their care recipient's care needs, what they need to provide good care, and how they will provide it. Based on the national data, approximately 50% of Contra Costa County caregivers are performing medical/nursing tasks at home. They often provide this level of care with limited training and support. At the same time that more family caregivers in the county are providing complex care, a growing number (many of whom are Millennials) are also caring for Boomer generation parents, requiring them to juggle caregiving and work responsibilities.

It is time to fully recognize that family caregivers are the front line of defense in caring for the seriously ill in our communities. It is also time to recognize family caregivers' significant societal contributions, personal and financial. The annual economic value of the 41 million family caregivers in the United States who provide an estimated 34 billion hours of uncompensated care to an adult with function limitations is approximately \$470 billion (*Valuing the Invaluable: 2019 Update*, AARP). For Contra Costa, the estimated annual economic value of the county's 136,000 family caregivers in unpaid contributions is approximately \$1.56 billion.

While caregiving can be a deeply rich and meaningful experience, it can be emotionally, physically, and financially stressful. Unfortunately, adequate supports to address the range of needs for many caregivers remain elusive. They are often unavailable or unaffordable.

The COVID-19 pandemic has further illuminated the fragile nature of many community services and programs, especially for communities of color. While community service organizations throughout Contra Costa have worked tirelessly to keep their doors open since the start of the pandemic, many have struggled to transition to remote operations and respond to emerging caregiver challenges, e.g., financial instability due to working caregiver job loss, lack of access to needed supplies (wipes, cleaning supplies, adult diapers, pads), risk of infection from in-home care/respite providers, cessation of in-person adult day services, etc.

We can do better.

As the state with the most adults age 65 or older in the US, California's imperative is to act now to address family caregiver needs. This urgency is underscored in the 2018 report *Picking Up the Pace of Change in California: A Report from the California Task Force on Family Caregiving* (USC Leonard Davis School of Gerontology).

Building on the work of the California Task Force on Family Caregiving, in 2019, Family Caregiver Alliance (FCA) conducted a series of in-depth interviews with Contra Costa County service providers and subsequently a survey of caregivers and service providers, to better understand the needs of family caregivers in the county. FCA additionally hosted a convening in 2019 with over 140 Contra Costa caregivers and providers in a day long listening and learning session.

This *State of Caregiving in Contra Costa County* report summarizes key findings from these efforts. The report also presents key policy recommendations—including several Task Force recommendations—and corresponding action items for Contra Costa County that advocate for policy changes that support family caregiver health and well-being.

Our hope is that everyone who believes that family caregivers should no longer be overlooked will ask local and state public officials to adopt and implement these recommendations.

Sincerely,

A handwritten signature in black ink that reads "Kathleen Kelly". The signature is written in a cursive, flowing style.

Kathleen Kelly
Executive Director
Family Caregiver Alliance

State of Caregiving in Contra Costa County

Caring for family members with serious illness or disability is increasingly a mainstream phenomenon. But despite how common family caregiving is, the physical, social, financial, and educational resources required to meet the needs of this expanding group are inadequate.

In their 2018 report, *Picking Up the Pace of Change in California*, the California Task Force on Caregiving recognized that closing this service gap must be done through policy changes. They outlined seven recommendations for the California Legislature to adopt (report available at: <http://tffc.usc.edu/2018/07/02/final-report-from-the-california-task-force-on-family-caregiving-2/>). The recommendations respond to what California's 4.5 million family caregivers need most: financial support, coordinated and affordable culturally competent services, information and training, respite, and improved integration of family caregivers into hospital processes.

Building on the Task Force report and recommendations, in 2019 Family Caregiver Alliance (FCA) with funding from the Thomas J. Long Foundation conducted a study of Contra Costa County family caregivers. The study objectives were 1) to identify family caregiver needs, available services, and gaps in services in Contra Costa County; and 2) to identify actionable recommendations to improve county caregiver services and supports. Core study components included an analysis of county-level family caregiver data and reports; in-depth interviews with Contra Costa County Area Agency on Aging (AAA) staff, service providers and others; and, an online survey of Contra Costa caregivers and professionals providing services to caregivers.

The study was complemented by a daylong caregiving convening, "Caregiver Conversations: A Day of Learning, Support, and Information Exchange," held on June 25, 2019 in Pleasant Hill, California. The conveying was hosted by FCA in partnership with a diverse group of community organizations. The study and convening offered important opportunities to listen to, speak with, and learn from over 140 family caregivers and professionals in Contra Costa County.

Contra Costa County

Contra Costa County is aging like the rest of California. Currently, there are 283,000 individuals over the age of 60 (23.6% or nearly one in four residents).^{1€} In 2040, this percentage is expected to rise to 32.4% (one in three residents). The fastest growing age group in the county are those over age 85. This older age group, which has the highest risk for functional impairments requiring assistance, is expected to experience a 66.6% increase in population growth between 2010 and 2030, from 19,631 to 32,599.

The number of county residents age 65+ with Alzheimer’s disease and related dementias – one of the costliest diseases to provide care for—is expected to reach 35,735 in 2030, nearly twice the number with the disease in 2015.² Caring for an individual with Alzheimer’s disease or other cognitive impairment extracts an especially high financial and emotional cost on families as well as society (e.g., health insurance costs, missed work, etc.). In 2019, the estimated direct costs to American society of caring for those with Alzheimer’s and other dementias was \$290 billion.³

In addition to these aging and dementia statistics, Contra Costa’s general population—including family caregivers—is increasingly diverse. This demographic shift is important. Health and health care disparities, which reflect differences between groups in their health status and ability to obtain care and needed services, most directly impact persons of color; lesbian, gay, bisexual, and transgender individuals; and persons with limited English proficiency. Individuals who are low- to middle-income (the latter are ineligible for public programs and often struggle to cover out-of-pocket healthcare expenses) and who live in geographically distant communities with few social and health care resources can also experience these disparities.^{4F}

Unequal access to health and social service supports for both older adults and family caregivers is a paramount issue for Contra Costa County’s aging network—a collaboration of Ombudsman Services, the Contra Costa County Area Agency on Aging, and service providers and organizations whose purpose is to serve and advocate for older adults and family caregivers.

Contra Costa Family Caregivers

Contra Costa’s estimated 136,000 family caregivers face the same daunting challenges in arranging and providing care and support for aging family members as caregivers across the country. While the annual economic value of their unpaid care is approximately \$1.56 billion, less than 5% receive services and supports every year in the county (2019).^{5E} Annually, approximately 13,000 family caregivers receive education and public information, and 700 receive Older Americans Act Title III-E National Family Caregiver Support Program (NFCSP) funded individual supports (e.g., counseling, respite).⁶

Within this second group of caregivers receiving NFCSP funded supports, approximately 80% are women, primarily wives and daughters/daughters-in-law, forty-five% are White/Caucasian, 14% are Hispanic, 9% are Asian/Pacific Islander, and 9% are Black/African American.^{6,7} In 2017-18, eight contractors received NFCSP grants ranging from \$7,000 to \$125,000 (Contra Costa County AAA).⁸

“Despite the growing need, funding levels for aging services such as nutrition, support services, and caregiver supports have not kept pace with demand or with inflation.”

—Contra Costa County AAA
2017-2018 Area Plan Update

^F Health and health care disparities are intimately tied to socioeconomic and social determinants of health (i.e., the conditions in which people are born, grow, live, work, and age shaped by the distribution of money, power, and resources at the global, national, and local levels).

Study Findings

A lot has changed since the NFCSP was established in 2000. Family Caregivers in Contra Costa County today are increasingly younger, ethnically and racially more diverse, and provide complex care for loved ones for longer periods of time. The following major study findings frame the state of caregiving in Contra Costa County today.

- ▶ Caregivers appreciate the current services available to them but identify a variety of gaps and challenges including: service and information shortages (e.g., not enough adult day service programs and program options), inflexible service hours, the high cost of in-home care, finding reliable providers (particularly for people with dementia), long program wait lists, difficulty finding and accessing services, lack of telehealth options, not knowing how to connect with others for support (e.g., via support groups), and not qualifying for publicly funded programs but not being able to afford paying privately for services.
- ▶ Technology is of great interest to family caregivers. More than 75% of family caregiver survey respondents expressed interest in technology to help them check on or monitor a loved one, support medication refills and pick-ups, make and track medical appointments, assess health needs and conditions, ensure home safety, and monitor medication adherence. The most common technology applications currently used by caregivers are for scheduling and medication refill, and prescription medication delivery.



Reverend Keith Archuleta, Founder/Chief Executive Officer, Emerald HPC International, delivering the non-denominational invocation at the June 2019 Contra Costa County caregiving convening.

- ▶ In a county with 136,000 family caregivers, Contra Costa has a total of 11 adult day programs (includes a range of social, medical/health care, Alzheimer’s day care resource centers, and respite day programs). Average daily attendance for the 11 programs combined is approximately 500 participants, while average daily attendance for the two adult day health care (ADHC) programs combined is approximately 120 participants (ADHCs provide a full range of skilled health care and psychosocial services for frail elderly persons or adults with disabilities).

“Approximately 500 individuals are served each day through the county’s 11 adult day programs. That is a staggeringly low number compared to how many people need these services.”

—Caregiver Advocate

- ▶ Service providers receiving NFCSP funds (contractors) value the services they are able to provide under NFCSP, but many noted that the program is underfunded, outdated, and in need of new policy champions and leaders. NFCSP data reports were also cited as inadequate: they do not accurately capture caregiver unmet needs, the number of caregivers served and services provided, and reimbursements for services. Finally, collaboration across NFCSP-funded agencies was reported as challenging in terms of time and money.
- ▶ Both the 2012-2016 and 2017-2018 Contra Costa County Area Agency on Aging Area Plans ranked family caregiving as a priority, but underscored that current Older Americans Act funding for caregiver programs is insufficient to meet basic needs.^{9,10}

Recommendations

Analysis of the Contra Costa County family caregiver study key findings, convening outcomes, and California Caregiver Task Force recommendations, led to six primary recommendations for the county. They are presented below with corresponding county-specific action items.

Recommendation 1: Identify organizational barriers to diversity, equity and inclusion for family caregivers from throughout Contra Costa County; and, assess and respond to the information, education and support needs of diverse family caregivers in the county.

- **Action Item:** Conduct outreach efforts to diverse caregivers through a collaborative countywide effort, e.g., conduct town hall listening sessions by phone and video conference, to identify service barriers and gaps.^Ω

^Ω Collaborative to include representatives from City/County departments, faith groups, community-based organizations, disease-specific organizations, health care systems, advocacy groups, etc.

- **Action Item:** Use information collected from outreach efforts, surveys, interviews, public forums, and focus groups to summarize opportunities to remove service barriers for diverse caregivers and respond to their needs.

Recommendation 2: Advocate for and provide an array of quality and affordable community-based services for all caregivers, especially working caregivers who typically require full-day services to maintain their employment.

- **Action Item:** Map existing caregiver services, funding status, geographic reach, and service hours to 1) create a measure for assessing caregiver service needs (demand) with available resources (supply) in the county; and 2) advocate for expanded quality-driven affordable community-based services for all caregivers.
- **Action Item:** Conduct an inventory of caregiver-friendly workplace policies and practices; create a workgroup to identify best practices and disseminate to Contra Costa employers in partnership with employer advocacy groups.

Recommendation 3: Support the financial well-being of family caregivers and limit the extent to which this role contributes to an increased risk of poverty and long-term financial insecurity.

- **Action Item:** Explore developing a ballot measure to fund caregiver services through a sales tax increase—consider pairing early childhood education and senior services together on the measure to inspire broader constituent support.
- **Action Item:** Educate family caregivers about the availability of the federal Family Medical Leave Act (FMLA) and California Paid Family Leave and encourage them to access these resources when needed.

Recommendation 4: Equip caregivers with easily accessible information, education, and training that is specific to their situation, and is provided in culturally competent and relevant ways.

- **Action Item:** Ensure that **all** organizations that serve family caregivers provide culturally competent education and training tailored to individual caregiver needs, based on the disease or condition of the care recipient, the stage of the disease or condition, the caregiver’s level of knowledge and ability to consume information, and the information preferences of the caregiver.
- **Action Item:** Work to become a dementia capable Contra Costa County—educate the public about brain health, memory loss and associated behavior changes, and where to go for help and support.

Recommendation 5: Increase caregiver access to adult day and respite programs—includes increasing access for caregivers who are ineligible for Medi-Cal-funded programs.

- **Action Item:** Expand the number of affordable respite care programs—inside and outside the home.
- **Action Item:** Advocate for county subsidies to adult day programs to increase access to these services for care recipients and caregivers who lack the financial means to participate in these programs and cannot afford to pay privately.

Recommendation 6: Integrate family caregivers into hospital processes. Encourage hospital staff to help caregivers 1) evaluate whether they are able to perform complex care tasks (i.e., medication management, help with assistive devices, wound care, using monitors, operating durable medical equipment, etc.), and provide training to those who are; and 2) navigate hospital discharge and care transition processes (moving from one care setting to another).

- **Action Item:** Work with health care systems in Contra Costa County to recognize caregivers as vital members of the care recipient’s team by including the caregiver name on the care recipient’s electronic health record, and providing education, training, and support to family caregivers providing complex care tasks prior to the care recipient’s hospital discharge.

Conclusion

Given Contra Costa County’s diverse and growing caregiver population, current caregiver services and programs are critically underfunded at all levels. *All stakeholders should advocate for increased local, state, and federal funding of family caregiver services.*

Stakeholders should also work together to address the emotional, physical, employment, and financial needs of Contra Costa family caregivers today and tomorrow. The recommendations and action items presented in this report provide a framework to begin this process.



Caregiver panel and attendees at the June 2019 Contra Costa County caregiving convening.

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Kathleen Kelly, Executive Director, FCA at the June 2019 Contra Costa County caregiving convening

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€ Calculation estimates performed by Susan Poor Consulting.