



November 1, 2020

Dear Alameda County Caregiver Advocate,

With an estimated 239,000 family caregivers living in Alameda 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 Alameda 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 Alameda Co., the estimated annual economic value of the county's 239,000 family caregivers in unpaid contributions is approximately \$1.96 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 Alameda have worked tirelessly to keep their doors open since the start of the pandemic, with limited resources 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.

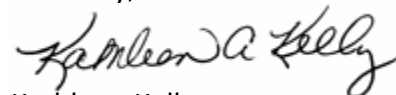
As the state with the most adults age 65 or older in the US, California's imperative is to act now to address family caregiver needs. This urgency is underscored in the 2018 report *Picking Up the Pace of Change in California: A Report from the California Task Force on Family Caregiving* (USC Leonard 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 Alameda 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 2020 with over 120 Alameda caregivers and providers in a day long listening and learning session.

This *State of Caregiving in Alameda 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 Alameda 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,



Kathleen Kelly
Executive Director
Family Caregiver Alliance

State of Caregiving in Alameda 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 Alameda County family caregivers. The study objectives were 1) to identify family caregiver needs, available services, and gaps in services in Alameda 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 City/County agency leaders, health care and community service providers, and advocates; and, an online survey of family 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 January 24, 2020 in Oakland, California. The conveying was hosted by FCA in partnership with a broad and diverse group of community organizations. The study and convening offered important opportunities to listen to, speak with, and learn from over 120 family caregivers and professionals in Alameda County.

Alameda County

Alameda County is one of the most diverse counties in America. As a multiracial, multiethnic multicultural, multilingual county, Alameda County civic and community leaders are committed to ensuring health equity and equal access to critically needed community services and supports for all residents. To achieve this aim, a number of cross-agency and organization partnerships have formed to reduce health disparities in the county, which disproportionately

impact socioeconomically disadvantaged individuals and communities of color.¹ The urgency of addressing these issues has been further highlighted with the recent Coronavirus (COVID-19) pandemic, which is casting an important light on health care disparities and the associated imperative to promote health equity in communities of color through structural change.

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 struggle to cover out-of-pocket health care expenses) and who live in geographically distant communities with few social and health care resources can also experience these disparities.² ^F

The need to address health equity and equal access to services and supports is underscored by the county's growing older adult population. The California Department of Finance forecasts that Alameda County's population of adults age 65 and older will grow from approximately 169,000 in 2010 to 605,000 in 2060. By 2060, older adults will comprise more than 23% of the total county population.^{3,4} This demographic trend data coupled with statistics that show that cancer, heart disease, and Alzheimer's disease and other dementias cause more than half of all deaths in the county for individuals age 65 and older (58.6), support an urgent call to action to respond to the needs of adults living with complex illness and their caregivers today.

Added to the county's changing aging demographics, in 2060, approximately 89,792 residents age 65 and older will have Alzheimer's disease or related dementias, a threefold increase from 2020 (26,480).³ Individuals age 85 and older and African Americans will be impacted the most—African Americans have the highest rate of death due to Alzheimer's disease and dementia in the county.

“People don't know where to go for help or information, and information is limited and does not always clarify how to access services.”

—Alameda County Caregiver

The emotional, financial, and physical costs of caring for family members or friends with Alzheimer's disease or other cognitive impairment is substantial. In 2019, the estimated direct costs to American society of caring for those with Alzheimer's and other dementias was \$290 billion.⁵ Countering this cost in Alameda County, will require increasing the availability and accessibility of services and supports for all residents living with Alzheimer's and related dementias and their caregivers, especially African American residents.

^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).

Alameda Family Caregivers

The needs and struggles of Alameda County family caregivers are similar to family caregivers across the United States. Many face financial, physical, and emotional difficulties providing day-to-day care for family members and friends. Despite these challenges, the care these caregivers provide contributes significantly to society. In 2017, an estimated 41 million family caregivers in the United States provided 34 billion hours of unpaid care. The economic value of this care was approximately \$470 billion.⁶ In Alameda County, the economic value of unpaid care provided by the county's estimated 239,000 family caregivers in 2019 was approximately \$2.74 billion.

A core goal in Alameda County's most recent Countywide Area Plan for Older Adults (CWAP) 2020-2024, is to "Enhance the healthy, safety, and well-being of older adults and caregivers by providing an array of coordinated services and developing the County of Alameda Aging and Disability Resource Connection as a platform for seamless access to those services." To reach this goal, the County plans to continue funding caregiver information, access assistance, support services, and respite under the Older Americans Act Title III-E National Family Caregiver Support Program (NFCSP).⁷ Despite the County's deep commitment to serving older adults and family caregivers, because of limited federal, state, and local funding for caregiver services, fewer than 5% of family caregivers in the county receive services and supports each year.[€]

Study Findings

Key findings from the Alameda County caregiver study and the January 2020 caregiver convening, "Caregiver Conversations: A Day of Learning, Support, and Information Exchange," frame the state of caregiving in Alameda County today.

- ▶ In response to the survey question, "How much support do you have as a caregiver from family members, friends, community-based organizations (CBOs), paid staff?" caregivers reported the following (N=59):
 - Help from family: 67% said "not enough" or "not at all"
 - Help from friends: 80% said "not enough" or "not at all"
 - Help from CBO's: 66% said "not enough" or "not at all"
 - Help from paid staff: 82% said "not enough" or "not at all"
- ▶ When asked what kind of care caregivers provided for a family member or friend, 92% of survey respondents reported providing health care assistance (N=59). Tasks associated with this assistance range from attending medical visits, to managing medication, to helping with medical tasks and equipment.

"To meet the needs of caregivers and care recipients, a caregiving system today must address multiple levels of care and increase caregiver skill levels as care recipient needs become more challenging."

—Key Informant



Supervisor Nate Miley presenting opening remarks at the January 2020 Alameda County caregiving convening.

- ▶ In a county with 239,000 family caregivers, in 2019, Alameda County had only 12 adult day services programs—two Adult Day Programs, four Adult Day Health Care (ADHC)/Community-Based Adult Services (CBAS), and, five Programs for All-Inclusive Care of the Elderly (PACE). Participant attendance varies by program and licensed slots. Despite this variation, the total number of care recipients served through these programs compared to the need is modest. In 2019 the average daily attendance for participants attending the four ADHC programs combined was between 250-300.⁸
- ▶ Throughout the San Francisco Bay Area, service providers receiving NFCSP funds (contractors) report valuing 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.
- ▶ Key informants who participated in the study interviews underscored that there is a lack of caregiver services supply and demand data for Alameda County. They recommended that the County implement a unified data collection system for caregiver services.
- ▶ Family caregivers who participated in AAA focus groups to inform the 2020-2014 CWAP, reported the need for reasonably priced respite care, adult day care, and overnight home care. They and other support group participants additionally highlighted the need for increased resources and resource information and education in all forms for older adults and their caregivers living in Alameda County.⁷

Recommendations

Analysis of the Alameda 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: Ensure that family caregivers in the county are routinely identified and that the diversity of their needs are assessed and supported in health care and community services—this includes identifying and addressing systemic barriers to equity and inclusion for diverse family caregivers throughout Alameda 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
- **Action Item:** Use information collected from outreach efforts, surveys, interviews, public forums, and focus groups to summarize opportunities to remove service barriers and respond to diverse caregivers and their needs.

Recommendation 2: Advocate for and provide an array of quality-driven, 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 Alameda 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.

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

Recommendation 4: Equip caregivers with easily accessible information, education, training, and support that is specific to their situation, and is provided in culturally competent, inclusive, 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:** Build on Alameda County’s Healthy Brain Initiative—continue educating 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 Alameda 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 Alameda 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 Alameda family caregivers today and tomorrow. The recommendations and action items presented in this report provide a framework to begin this process.

One Size DOES NOT Fit All: The Diversity of Family Caregivers

Rita B. Choula
AARP Public Policy Institute
January 24, 2019



Rita B. Choula, AARP Director – Caregiving. Keynote speaker at the January 2020 Alameda County caregiving convening.

Funding and Acknowledgments

Funding for the Alameda County caregiver study was made possible by the Thomas J. Long Foundation. The Long Foundation also funded the Alameda County caregiving convening. Special thanks go to the Stupski Foundation for hosting the convening breakfast and to the California Endowment for providing the event meeting space. We are profoundly grateful to the family caregivers and service professionals who participated in the caregiver survey and key informant interviews, and who attended the caregiving convening. They are the voices behind the “State of Caregiving in Alameda County” recommendations and action items.

Finally, we would like to thank the following caregiving convening planning committee members: Marilyn Ababio, Comfort Homesake; Erich Bagan, Stupski Foundation; Andrea Dodge, Alameda County Health Care Services Agency; Cynthia Carter Perrilliat, Alameda County Care Alliance; Leah Eskenazi, Family Caregiver Alliance; Rezsín Gonzalez, Alameda County Department of Adult and Aging Services; Grace Liu, Alzheimer’s Association; Monique Parrish, LifeCourse Strategies; Bill Pelter, Ability Now Bay Area; Micheal Pope, Alzheimer’s Services of the East Bay; Frishta Sharif, Caregiver Support Program, City of Fremont.

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€ Calculation estimates performed by Susan Poor Consulting.