A Policy Conversation on Family Caregiving for Older Adults

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Sierra Health Foundation
Kathleen Kelly, MPA
Executive Director
Family Caregiver Alliance
kkelly@caregiver.org
caregiver.org
Who Are Family Caregivers in California?

• California has 4.5 million caregivers to adults aged 18 and older.
  – 60% of caregivers are women
  – On average, caregivers are 49 years old.
    • 1 in 4 caregivers are Millennials
  – 56% of caregivers are employed
  – 1 in 4 assist a person with dementia
  – The average time in this role is 4 years.

• Caregivers in the state provide an estimated $57 billion dollars of care, surpassing Medi-Cal in terms of economic value.

CA Task Force on Family Caregiving, USC 2018.
What do family caregivers provide?

- Health insurance advocate
- Financial management
- Household tasks
- Medication management
- Medical equipment operations
- Medical tasks
- Family member coordination
- Health decisions assistance
- Transportation
- Personal Care
- Social activities organizing
- Emotional support
- Food for special diets preparation
- Care coordination
Most are women (75%), average age 58, 57% are employed
Very diverse: 31% API; 29% Caucasian; 18% Latinx; 13% African American
Majority are the primary caregiver (85%) with 82% getting no or less help than they need
42% caring for 2 years or less; 60% caring for 2 years or more (33% have been caregivers for 5 years or more)
Majority are caring for an adult with a cognitive impairment – 76% have dementia, 9% had a stroke with multiple other health impairments
Caregivers report:
  Stress: 92% report more than they can handle
  Anxiety: 66% report feelings of sadness, depression or anxiety
  Depression: 39% mild to moderate; 12% moderate to severe
  Social Isolation: 67% indicate social isolation
What Challenges Do Caregivers Face?

• Health impacts of caregiving:
  – Musculoskeletal injury
  – Cardiovascular disease
  – Poor immune functioning
  – Depression
  – Possible increased mortality

• Financial impacts of caregiving:
  – High out-of-pocket costs (e.g., home modification)
  – Negative impact on employment (e.g., reduced work hours)
  – Reduced savings opportunities
  – Increased risk of poverty
Blue Sky Statement

All California family caregivers deserve a range of high quality services and supports and policies that promote their physical, emotional and financial wellbeing at home and in the workplace.
What Programs Directly Support Family Caregivers in CA?

• National Family Caregiver Support Program Title III(E) (established 2000)
  - Funding from ACL-AoA to CA Dept. of Aging to 33 Area Agencies on Aging for service delivery – most typically through contracts with CBO’s but also at the AAA organization level
  - Services include including caregiver information, referral assistance, counseling and training support, temporary respite
  - Targets caregivers of adults over 60 except for dementia (any age qualifies)

• California network of 11 Caregiver Resource Centers (established 1984)
  - Provides information, assessment, educational programs, skill training, psychoeducational interventions, counseling, support groups, consumer-directed respite, legal consultation
  - Targets caregivers of adult-onset cognitive impairments (18 and up) such as stroke, Parkinson’s, head injury, dementia
  - General fund budget through the CA Dept. of Health Care Services. The budget for the CRC’s cut by 74% in 2010. CRC’s assess and address caregiver concerns through CRC-delivered services with respite typically through vouchers.

CA Task Force on Family Caregiving, USC 2018.
What Policies Directly Support Family Caregivers in CA?

California has a history of “firsts” related to family caregivers:
First in the country to pass legislation to recognize and address family caregivers with the Caregiver Resource Centers (1980)
First in the country to pass Paid Family Leave that covered family caregivers (2002)
Championed consumer choice in HCBS
And have passed other supportive policies, such as:
CARE Act to identify a family caregiver during hospitalization and discharge
And did have a small state tax credit for caregiver expenses that was allowed to sunset.
Made numerous refinements to the Paid Family Leave Program
The CATFFC was created under ACR 38 (Brown):

- This measure would establish the California Task Force on Family Caregiving, to meet, if a nonstate organization agrees to provide administrative support to the task force, to examine issues relative to the challenges faced by family caregivers and opportunities to improve caregiver support, review the current network and the services and supports available to caregivers, and make policy recommendations to the Legislature.
Recommendation 1

• Support the financial wellbeing of family caregivers, and limit the extent to which this role contributes to an increased risk of poverty and long-term financial insecurity.

  • Tax credits for the high out-of-pocket costs of caregiving

  • Stipend or similar program to support caregivers with the costs of community-based services

  • Build on Family Medical Leave Act and Paid Family Leave laws
    • Increase awareness of existing programs

CA Task Force on Family Caregiving, USC 2018.
Recommendation 2

• Modernize and standardize caregiver assessments across the state to support individualization of services, reduce service fragmentation, and increase knowledge of who among caregivers in the state uses services.

  • Develop and implement a standardized assessment tool
  • Increase funding for caregiver assessments
  • Collect representative survey data on caregivers in California
  • Remove barriers across agencies that inhibit safe return of people with an intellectual disability or cognitive impairment
Recommendation 3

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

  • Increase access to tailored education and training materials and programs
  • Provide culturally competent education and training
  • Increase funding to California’s Caregiver Resource Centers to provide information, education, and training
Recommendation 4

• Increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.

  • Grow the number of respite care providers in the state
  • Expand access to affordable respite services
Recommendation 5

• Integrate family caregivers into hospital processes, support them in navigating care transitions and with providing complex care tasks, and increase caregiver choice in whether to complete complex care tasks.

• Allow nurses to delegate some tasks (e.g., administering medication) to qualified home health providers

• Standardize the hospital discharge process to better support caregivers

• Assist with implementation of the California Hospital and Family Caregiver Act

• Ensure access to telehealth for caregivers and recipients
Recommendation 6

• Increase funding to California’s Caregiver Resource Centers to expand services, including respite care and educational programs, and support innovative programs.

CA Task Force on Family Caregiving, USC 2018.
Recommendation 7

• Create a statewide advisory council on matters affecting family caregivers that provides advice on integrating caregiver issues across state departments, services, initiatives, and programs, and provides policy expertise to the Legislature.
Can We Talk About Caregiving?

We need to accelerate the public dialogue about caregiving and advocate for changes in policies that better support the financial, health and social well-being of caregiving families.
Family Caregiver Alliance offers education, services, research, and advocacy based on the real needs of family and informal caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

National Center on Caregiving (NCC) was established by FCA to advance the development of high-quality, cost-effective programs and policies for caregivers in every state. NCC sponsors the Family Care Navigator, a state-by-state resource locator designed to help caregivers find support services in their communities.

Bay Area Caregiver Resource Center — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA’s staff of family consultants, through education programs and direct support, offer effective tools to manage the complex and demanding tasks of caregiving.

FCA CareJourney is a secure online solution for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer’s, stroke, Parkinson’s, and other illnesses.

FCA Learning Center is the place for caregiver education where you can read, watch, listen, and learn online from FCA’s vast library of caregiving knowledge.
Website:  
http://tffc.usc.edu

- Email: tffc@usc.edu
- Facebook:  
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