



California Task Force on Family Caregiving Picking Up the Pace of Change for California's Caregivers

Assembly Aging & Long-Term Care Committee
Informational Hearing
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Donna Benton

Chair CTFFC

Research Associate Professor

USC Leonard Davis School of

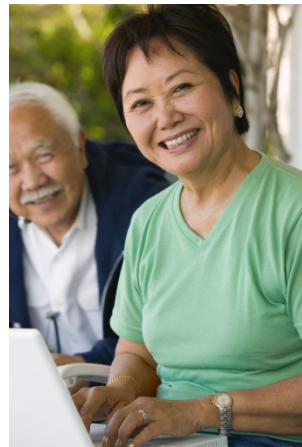
Gerontology

Benton@usc.edu



Who are family caregivers in California?

- California has 4.5 million caregivers to adults aged 18 and older¹
 - 60% of caregivers are women²
 - On average, caregivers are 49 years old²
 - 1 in 4 caregivers are Millennials³
 - 56% of caregivers are employed²
 - 1 in 4 assist a person with dementia²
 - The average time in this role is 4 years²
- Caregivers in the state provide an estimated \$57 billion dollars of care,
 - surpassing Medi-Cal in terms of economic value¹





What challenges do caregivers face?

- Health impacts of caregiving:⁴
 - Musculoskeletal injury
 - Cardiovascular disease
 - Poor immune functioning
 - Depression
 - Possible increased mortality
- Financial impacts of caregiving:
 - High out-of-pocket costs (e.g., home modification)⁵
 - Negative impact on employment (e.g., reduced work hours)²
 - Reduced savings opportunities⁶
 - Increased risk of poverty⁷





Process of developing recommendations

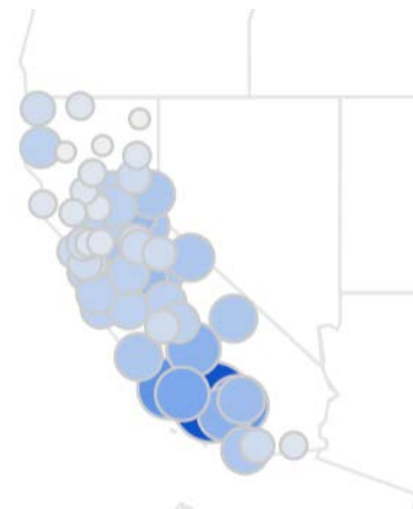
- Priority areas reported in Interim Report to the Legislature in January 2017:
 - Integrated approach to care management
 - Comprehensive array & continuum of services
 - Caregiver compensation
 - Data on caregivers and services
 - Access to affordable & accessible services
 - Education and training





Process of developing recommendations

- Research-driven reviews on each priority area at each meeting
- A compilation of work by other state task forces
 - http://tffc.usc.edu/wp-content/uploads/2017/08/task_force_comparisons.pdf
- Survey of agencies serving caregivers across California (Best Practices)
 - <http://tffc.usc.edu/wp-content/uploads/2018/01/Best-Practices-in-Serving-California's-Caregivers-1.4.pdf>
- Best practices in policymaking brief:
 - <http://tffc.usc.edu/wp-content/uploads/2018/01/Strategies-to-Create-Policies-that-Support-Family-Caregivers-final.pdf>





Values to guide recommendations and legislation

- Support diverse caregiver needs, including cultural awareness, cultural competency, and sensitivity
- Person- & family-centered care
- Work-life balance
- Choice & options for caregivers



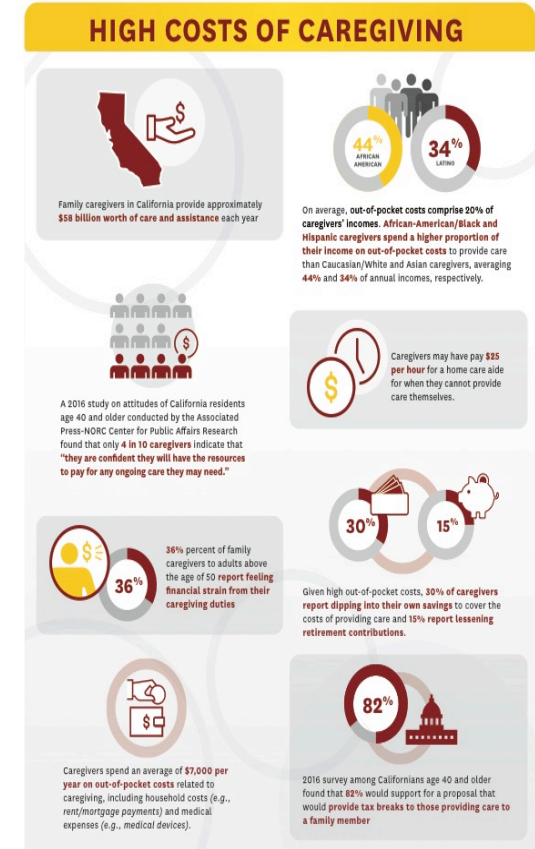


Recommendation 1

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





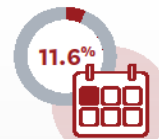
Challenges in Leave Laws

- 40% workers not eligible
- Lack of awareness
 - HR professionals
 - Employers

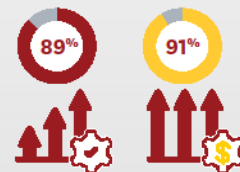
Did You Know?: LIMITATIONS OF CURRENT LEAVE LAWS IN THE STATE



FMLA applies only to employees at private companies with over 50 employees living within a 75-mile radius. To be eligible, employees must have worked at least 12 months with their employer, have provided 1,250 hours worked in the last year, and been on payroll for the past 20 weeks. Consequently, the law only covers only 55 to 60% of workers due to limitations in eligibility.¹



Despite having the oldest paid family leave law in the nation, just 11.6% of paid leave claims in California were taken by family caregivers from March 2017 to April 2018.²



A 2011 evaluation of California's paid leave law indicates that 89% employers found a positive or unnoticeable effect of PFL on productivity, and 91% reported the same outcomes for profitability/performance. Very few employers were aware of any abuses of the policy.³



Human resource departments and professionals are among the most likely to advise employees on access to PFL, but of 78% of human resource professionals indicate additional PFL training is needed.⁴

Learn more about ways to improve leave options by viewing the final report of the California Task Force on Family Caregiving: www.tffc.usc.edu

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School of Gerontology
Public Policy Institute



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 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.



Sandi Fitzpatrick, MA
Co-Chair CTFFC
Executive Director
California Commission on Aging
sfitzpatrick@ccoa.ca.gov



Creation of the CATFFC through ACR 38

- The CATFFC was created under ACR 38 (Brown)⁸:
 - *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.*
 - *The task force would be required to submit an interim report to the Legislature no later than January 1, 2017, and a final report no later than **July 1, 2018.***





Organization of the CA TFFC

- 12 members were appointed
 - 6 by the Assembly, 6 by the Senate
- Election of Chair, Dr. Donna Benton, and Co-Chair, Sandi Fitzpatrick
- Non-state funding through AARP and Archstone Foundation
- Administrative & Research Team at USC (led by Dr. Kathleen Wilber)
- Convened in October 2016, will end in July 2018
 - Bi-monthly meetings, alternating by phone and in-person





This is the first time California has a Task Force looking into caregiving. My hope is that we shine a spotlight on the millions of Californians providing unpaid care to recognize both the value and burden they take on.

-Edie Yau, Task Force member



Task Force members

- Mary Ball, former President/CEO at Alzheimer's San Diego
- Donna Benton, PhD, Research Associate Professor of Gerontology, USC
- Les Cohen, Legislative Advocate Emeritus, Orange County Ombudsman
- Carmen Estrada, Executive Director of Inland Caregiver Resource Center
- Sandra Fitzpatrick, Executive Director, California Commission on Aging
- Kathleen Kelly, MPA, Executive Director of the Family Caregiver Alliance
- Karen Lincoln, PhD, Associate Professor and Director, USC Hartford Center of Excellence in Geriatric Social Work University of Southern California
- Anat Louis, PsyD, Director Direct Services, Department of Aging, City of Los Angeles
- Eric Mercado, Research Editor, Los Angeles Magazine
- Douglas Moore, Executive Director of the UDW Homecare Providers Union and International Vice President of the American Federation of State, County, and Municipal Employees
- Edie Yau, Director of Diversity and Inclusion for the Alzheimer's Association



The role of an academic partner

- Logistical convenience
 - Experience managing grants, staff and resources to convene meetings
- Complimentary skill set
 - Researchers to compile up-to-date, high quality research
 - Ability to conduct new research, as needed
- Institutional recognition
 - “Brand” recognition to assist with reaching out to community partners
 - Trustworthy email handle, website, materials



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

MAIN REASONS CAREGIVERS STRUGGLE TO ACCESS INFORMATION



A main barrier to accessing information on caregiving is that **current resources are relatively decentralized**



Caregivers also vary in how they prefer to access information and education, both in terms of the source and how material is presented



One of the challenges in accessing quality information as a caregiver is that a lot of information is **not adequately tailored to meet unique needs** . . . The information, education, and training needs of caregivers vary broadly



Caregivers from some racial/ethnic and cultural groups and people with limited English proficiency face added difficulty when trying to access information, education, and training. **Materials are often not translated, and providers may not have training in cultural competence.**



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

CAREGIVERS STRUGGLE TO ACCESS RESPITE SERVICES

Despite high interest among caregivers to access respite services, just 15% of caregivers reported ever using respite services



Caregivers may also be reluctant to schedule formal respite if they cannot access **culturally-appropriate** services, such as a respite provider who speaks the same language as the care recipient



One of the challenges to accessing respite is finding services



Home care providers, who often provide respite, are one of the fastest growing jobs in the US, and turnover is high. One estimate suggests a 32% per year turnover rate among home care aids.

Job retention also contributes to challenges in maintaining a trained workforce

Those in rural areas are particularly likely to struggle with accessing a provider, as are caregivers seeking to schedule last-minute respite or during the evening



In addition, lack of available providers and the high costs of respite are key to low rates of respite utilization



Many caregivers must rely on expensive home-care agencies for respite at a median rate of over \$25 per hour in California

The average out-of-pocket cost for respite is \$587 per year for caregivers. Importantly, this figure excludes caregivers who cannot afford to purchase any respite.



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

ENHANCING THE CALIFORNIA HOSPITAL AND FAMILY CAREGIVER ACT

Passing the California Hospital and Family Caregiver Act was an important step to better supporting caregivers providing complex care. However, there is little guidance on how to implement provisions of the California Hospital and Family Caregiver Act.



HERE ARE SOME WAYS TO IMPROVE THIS LAW:



Work with the stakeholders like the California Hospital Association to identify opportunities to improve implementation



When providing education to caregivers prior to discharge, require hospitals to assess the caregiver's capacity to provide care and their capacity to understand education provided at discharge



Require hospitals to enable recipients to list multiple caregivers in their electronic health records



Provide funding to expand access to translated materials and trainings provided to caregivers at discharge as a part of California Hospital and Family Caregiver requirements



Require hospitals to provide educational materials that families can take home and review after discharge, in addition to education provided in the hospital



Recommendation 6

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





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.



Thank you!

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and Archstone Foundation



CULTURALLY TAILORED EDUCATIONAL MATERIALS AND SERVICES



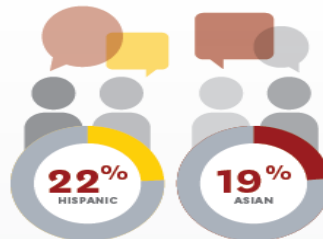
Even when caregivers from racial/ethnic minority groups are aware of available services, **it is often assumed that these services do not provide culturally relevant programming**



Some educational interventions have been adapted and demonstrated to benefit multiple racial, ethnic, and cultural groups, but not many



Of organizations providing services to caregivers in California, just **67% indicated their organizations strive to provide culturally relevant and competent services**



A national survey found that **22%** of Hispanic caregivers and **19%** of Asian caregivers **expressed a need for non-English informational materials**

