



California Task Force on Family Caregiving



Kathy Kelly
Executive Director
Family Caregiver Alliance
kkelly@caregiver.org

Sandi Fitzpatrick, MA
Executive Director
California Commission on Aging
sfitzpatrick@cco.ca.gov



Thank you!

This work was made possible by a grant from AARP California
and Archstone Foundation



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





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.



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



Process of developing recommendations

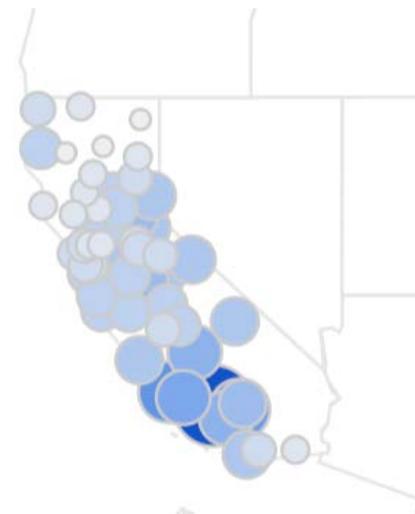
- Priority areas reported in Interim Report to the Legislature in January 2017:
 - Integrated approach to care management
 - Comprehensive array & continuum of services
 - Caregiver compensation
 - Data on caregivers and services
 - Access to affordable & accessible services
 - Education and training





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



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





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.



Draft of the final report and recommendations

- A draft of the final report can be found online:
 - <http://tffc.usc.edu/wp-content/uploads/2018/04/Task-Force-final-report-4.7.pdf>
- The final release of the report will be on July 1, 2018





Additional Information

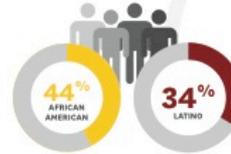
- Website: <http://tffc.usc.edu>
- Email: tffc@usc.edu
- Facebook:
<https://www.facebook.com/CAtffc/>
- Twitter: https://twitter.com/CA_tffc
 - @CA_tffc



HIGH COSTS OF CAREGIVING



Family caregivers in California provide approximately **\$58 billion** worth of care and assistance each year



On average, **out-of-pocket costs comprise 20% of caregivers' incomes. African-American/Black and Hispanic caregivers spend a higher proportion of their income on out-of-pocket costs** to provide care than Caucasian/White and Asian caregivers, averaging **44% and 34%** of annual incomes, respectively.



A 2016 study on attitudes of California residents age 40 and older conducted by the Associated Press-NORC Center for Public Affairs Research found that only **4 in 10** caregivers indicate that **"they are confident they will have the resources to pay for any ongoing care they may need."**



Caregivers may have pay **\$25 per hour** for a home care aide for when they cannot provide care themselves.

Copies available!



36% percent of family caregivers to adults above the age of 50 report feeling financial strain from their caregiving duties



Given high out-of-pocket costs, **30% of caregivers report dipping into their own savings** to cover the costs of providing care and **15% report lessening retirement contributions.**



Caregivers spend an average of **\$7,000 per year** on out-of-pocket costs related to caregiving, including household costs (e.g., rent/mortgage payments) and medical expenses (e.g., medical devices).



2016 survey among Californians age 40 and older found that **82%** would support for a proposal that would provide tax breaks to those providing care to a family member



References

1. Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the invaluable: 2015 update. *Insight on the Issues*, 104. Retrieved online at: <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>
2. National Alliance for Caregiving and AARP Public Policy Institute. (2015, June). Caregiving in the U.S. Retrieved online from: http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
3. Vega, W. A., Aranda, M. P., & Rodriguez, F. (2017). Millennials and Dementia Caregiving in the United States. USC Edward R. Roybal Institute on Aging and UsAgainstAlzheimer's. Retrieved online at: https://www.usagainstalzhaimers.org/sites/default/files/Dementia%20Caregiver%20Report_Final.pdf
4. Capistrant, B. D. (2016). Caregiving for older adults and the caregivers' health: an epidemiologic review. *Current Epidemiology Reports*, 3(1), 72-80.
5. Rainville, C., Skufca, L., & Mehegan, L. (2016, November). Family Caregiving and Out-of-Pocket Costs: 2016 Report. (Report for the AARP) Retrieved online from: http://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-cost-survey-res-ltc.pdf
6. MetLife Mature Market Institute, National Alliance for Caregiving, Center for Long-Term Care Research and Policy at New York Medical College. (2011, June). The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents. Retrieved online at: <https://www.metlife.com/mmi/research/caregiving-cost-working-caregivers.html#key%20findings>
7. Lee, Y., Tang, F., Kim, K. H., & Albert, S. M. (2015). The vicious cycle of parental caregiving and financial well-being: A longitudinal study of women. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 70(3), 425-431.
8. Assembly Concurrent Resolution, Cal. Assemb. B 38 (2014-2015), Chapter 200 (Cal. Stat. 2015)