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

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SCAN Foundation LTSS Summit
September 27, 2018
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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

- Administrative & Research Team at USC

- Convened in October 2016, will end in July 2018
  - Bi-monthly meetings, alternating by phone and in-person
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
Administration of the Task Force was made possible by a grant from AARP California and Archstone Foundation
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
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
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
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.
Rec. 1 sub-recommendations

- 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 with Leave Laws

- 40% workers not eligible
- Lack of awareness
- HR professionals
- Employers
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.
Rec. 2 sub-recommendations

- 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
Equip caregivers with easily accessible information, education, and training that is specific to their situation, and is provided in culturally competent and relevant ways.
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.
Rec. 3 sub-recommendations

• 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
Increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.
Rec. 4 sub-recommendations

- Grow the number of respite care providers in the state
- Expand access to affordable respite services
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.
Rec. 5 sub-recommendations

• 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
What Programs Directly Support Family Caregivers in CA?

- **National Family Caregiver Support Program Title IIIE** (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.
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.
Recommendation topics areas

- **Topic 1: Financial wellbeing, employment, and costs of caregiving**
  - Recommendation 1; Recommendation 4

- **Topic 2: Service infrastructure, assessment, and Caregiver Resource Centers**
  - Recommendations 2; Recommendation 6

- **Topic 3: Education and training, culturally competent services**

- **Topic 4: Integrating caregivers in health settings, nurse delegation, telehealth**

- **Topic 5: Ongoing caregiver advisory council**
Work Group Tasks
30 min. + 15 min. break

1) Select a topic area/recommendation to focus on and join a work group
   - Welcome others once you find a group to work with!

2) Select a note taker AND a group speaker to present at the end of the session

3) In your group, identify:
   - 2 ways to advance this recommendation ("action items")
   - The timing of your suggested action items (e.g., 1 year? 3 months?)
   - Who is expected to take action

4) Give your 2 concisely written recommendations to Kylie before breaking
   - OR email to kyliemey@usc.edu
    - Include your topic area and name of your selected speaker

5) During your break, identify what YOU or YOUR organization is going to do to support recommendations and post this on the sticky board
   - Please add contact information if you’d like to stay in the loop!
Learn more and pick up materials at:

- [http://tffc.usc.edu](http://tffc.usc.edu)
- Facebook: [https://www.facebook.com/CAtfffc/](https://www.facebook.com/CAtfffc/)
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