Challenges encountered by family caregivers

Existing policies in California to support caregivers have not kept pace with changing needs. Although many caregivers describe the help they provide in positive terms, the social and political environment in which caregiving occurs makes some aspects of caregiving difficult.

Caregiving is expensive for many families. This is often due to high out-of-pocket costs related to caregiving and income lost from taking time off from or leaving paid employment prematurely. An AARP study released in 2016 showed that more than 3 out of 4 caregivers absorb out-of-pocket costs related to caregiving, at an average of nearly $7,000 per year.

Some family caregivers are vulnerable to worsening health and wellbeing. Caregivers who provide high intensity care or more hours of care are at increased risk. Caregivers endure higher rates of cardiovascular risk factors, poorer immune functioning, and higher levels of depression than noncaregivers.

The policy recommendations from the California Task Force on Family Caregiving are intended to address some of these challenges and help caregivers continue in their roles without harm to themselves.

During meetings from October 2016 to June 2018, Task Force members reviewed up-to-date research focused on priority areas and shared their respective areas of expertise, discussed policy solutions to problems experienced by caregivers, and carefully considered the implications of each solution. Recommendations in the final report of the Task Force have been reviewed and refined on multiple occasions by members of the Task Force.

Supporting caregivers to remain in this role, if desired, can help older adults and people with disabilities live safely in their communities and avoid expensive institutionalization. If Californians are willing to take on a caregiving role, they should be supported while doing so. Key recommendations are described here. See detailed recommendations at tffc@usc.edu.
Recommendation 1:
Given the high costs of caregiving and the detrimental impact of this role on employment in the current policy context, the California Task Force on Family Caregiving recommends the legislature 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.

Recommendation 2:
There is little data available on family caregivers in California to guide service providers. To remedy this, the California Task Force on Family Caregiving recommends legislation to modernize and standardize caregiver assessments across the state to increase knowledge of who among caregivers in the state uses services, support individualization of services, and reduce service fragmentation. This should be accompanied by survey data to understand which caregivers are not being reached by services.

Recommendation 3:
Over 80% of caregivers indicate they need more information on caregiving-related topics. This can be stressful, and can make it difficult to provide the high quality care families want to provide. The California Task Force on Family Caregiving recommends legislation to equip caregivers with easily accessible information, education, and training that is specific to their situation, provided in culturally competent and relevant ways.

Edie Yau, Task Force member, Santa Clara

There needs to be better data on family caregiving in order to understand the diverse needs and gaps in services in order for California to plan for the future.
Recommendation 4: Respite care supports caregiver health and wellbeing, and may delay nursing home placement. Current respite options, however, do not support caregiver choice and preferences and are prohibitively expensive. The Task Force recommends the legislature increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.

Recommendation 5: Caregivers are key members of the health care team, but they are often under-recognized. Once a care recipient is discharged from a hospital, caregivers are often left to complete complex care tasks with little support, training, or even choice. The Task Force recommends legislation to 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.

Recommendation 6: California has a service infrastructure ready to support family caregivers across the state through the California Caregiver Resource Centers. With decades of experience on caregiver needs, in-depth knowledge of the populations in their service areas, and connections to community partners, the CRCs are uniquely placed to serve family caregivers throughout the state. Demand for CRC services will only grow in coming decades. The Task Force recommends the legislature increase funding to California’s Caregiver Resource Centers to expand services.

Additional funding will expand existing services provided by the CRCs, including administering high-quality caregiver assessments by trained professionals, providing information and referral services using up-to-date resource lists, providing evidence-based education and training programs, and raising caregiver awareness. Additional funding would also support innovative programs to meet the evolving needs of family caregivers, including digital and online programs.
Recommendation 7:
The population of caregivers will continue to evolve, as well as the types of challenges they encounter in this role. To ensure that policies continue to keep pace, the Task Force recommends the legislature support 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. An ongoing advisory council focused on family caregivers is needed given the evolving needs of family caregivers and changing health and social service policies and infrastructures. California needs statewide leadership in this area given how many different agencies caregiving issues impact. The advisory council should have the capacity to work across state and local agencies to identify issues caregivers are facing, as well as best and promising practices to resolve these.

References


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See the final report at: http://ttfc.usc.edu