

**Draft Recommendations for the California Task Force on Family Caregiving
12.21.2017**

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.

Recommendation 1a: The California Task Force on Family Caregiving recommends that the Legislature pass a tax credit for the out-of-pocket costs of family caregiving. Out-of-pocket costs include payment for housing costs, home modifications, respite, medical costs, and other household expenses incurred from providing care to the recipient. Eligibility criteria for this credit should be limited so that it may serve prevent middle-income caregivers from descending into poverty. This credit should be no less than \$5,000 per year.

Recommendation 1b: It is recommended that California implement a program similar to Hawaii's Kupuna Care program, wherein caregivers who are employed for at least 30 hours per week receive up to \$70 per day for services to care recipients who are not eligible for Medicaid. Services can include adult day care, chore services, home-delivered meals, personal care, respite care, or transportation.

Recommendation 1c: The Task Force calls upon the Legislature to increase access to current programs that support employed caregivers, particularly job protections. This should be accomplished through both expanding eligibility criteria so these policies apply to more family caregivers, and awareness-raising so caregivers know these programs exist.

The following steps are recommended to implement this recommendation:

- i. Reduce the number of employees required for a private sector employer to comply with the federal Family Medical Leave Act (FMLA) in California.
- ii. Extend job protections found in the FMLA to those participating in the state's Paid Family Leave program (PFL).
- iii. Expand PFL to automatically apply to public sector employees instead of the current opt-in program.
- iv. Increase the number of weeks over which PFL is Provided from 6 weeks to 12 weeks per year.
- v. Increase awareness and knowledge about the FMLA and PFL programs and their eligibility criteria among employees and employers. Specifically, employers who must comply with FMLA and PFL laws should be required to provide information annually about these programs to employees.
- vi. Require agencies overseeing implementation of awareness campaigns to consult with local community leaders from underserved groups to ensure culturally-appropriate awareness campaigns.

Recommendation 2:

Modernize and standardize caregiver assessments provided to family caregivers across the state so as to support individualization of services, reduced service fragmentation, and increased knowledge of who among caregivers in the state uses services.

Recommendation 2a: Develop and implement a standardized caregiver assessment to be delivered universally by programs 1) delivering services to older adults which rely on the contributions of family caregivers and/or 2) serve family caregivers directly. This assessment should be delivered on a secure, digitalized platform where information can be shared across agencies, including healthcare agencies, to minimize unnecessary duplication and reduce fragmentation of services. De-identified data should be available and utilized to learn about which caregivers are accessing services in California.

With regards to the design the of assessment instrument, the assessment should be comprised of validated measures that can be implemented in a clinical setting with minimal provider burden. Programs should have the option of further tailoring assessment items to meet their specific program needs. The platform should further support regular reassessment for those programs where this is appropriate. In all cases, the assessment and, where applicable, reassessments, should be delivered by providers trained on proper administration.

Recommendation 2b: Increase reimbursement rates for caregiver assessments completed by agencies providing services under The Older Americans Act IIIIE program, including Area Agencies on Aging, Caregiver Resource Centers, and others with IIIIE contracts so more caregivers can be reached.

Recommendation 2c: Regularly collect data on California’s caregiver population, including information on the demographics of the caregiver and recipient, as well as the caregiver’s health and financial wellbeing. This recommendation can be accomplished through the inclusion of the caregiver module in the California Health Interview Survey. A caregiver-specific module should be included no less than once every 3 years to provide up-to-date information on this evolving population. Further, this data should be utilized to find out which caregivers are not receiving services throughout the state, and other unmet needs in this population.

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.

Recommendation 3a: Increase access to tailored or individualized education and training materials for family caregivers. Tailoring should be based on the disease or condition of the care recipient, the stage of the disease or condition, the caregiver’s current level of knowledge and ability to consume the information, and the preferences of the caregiver in terms of both the amount of information and how to access this information. Further, provision of education and training should be provided at critical points by relevant health and social services organizations, such as during care transitions and at the time of diagnoses.

Recommendation 3b: Increase access to information, education, and training for family caregivers through culturally-relevant awareness-raising and service provision.

The following steps are recommended to implement this recommendation:

- I. Funding an ongoing awareness campaign that targets individuals who provide care but do not necessarily call themselves “caregivers,” caregivers who do not approach services because they believe they are ineligible for assistance, and underserved caregivers who typically hesitate to approach formal services.

- II. Funding the translation and adaptation of informational materials and programs, including videos, brochures, classes, and events into multiple languages and for caregivers from a variety of backgrounds.
- III. Evaluate the effectiveness of cultural competence and sensitivity training among organizations which serve family caregivers, including implementation of the Older California Equality and Protection Act that requires providers to receive training on working with LGBT clients. Based on this assessment, the state should provide up-to-date guidance on cultural competence and sensitivity training among service providers to be provided on a regular basis.

Recommendation 3c: Increase funding for California’s Caregiver Resource Centers to provide information, education, and training. Funds should be allocated to allow CRCs to regularly update resource lists given changing service networks and new programs. Funding should also be marked to provide additional educational events, classes and resources to meet the evolving needs of caregivers, including how to provide complex care tasks.

Recommendation 4:

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

Recommendation 4a: Grow the number of respite care providers in the state so that family caregivers can take a break when they need one. Specifically, the state should recruit additional providers to assist caregivers in rural areas, those who speak the same language as the care recipient, and those who can work flexible hours, including during evenings and weekends. Opportunities for job advancement should be one component to enhance provider recruitment.

Recommendation 4b: Expand access to affordable respite services to family caregivers so that they can take a break without harming their financial wellbeing.

The following steps are recommended to implement this recommendation:

- I. Increase respite funding for California’s Caregiver Resource Centers, Area Agencies on Aging, and other organizations who currently distribute state funds for respite to family caregivers.
- II. Expand opportunities to obtain respite, either in the home or outside of the home, for caregivers seeking to participate in caregiver services such as educational events, counseling, and support groups.
- III. Create an infrastructure and standardized training for volunteer respite provider programs. Volunteers should be trained or otherwise supported to the extent that caregivers still have the ability to leave the home during this respite.
- IV. Provide respite to caregivers on sliding scale basis, similar to that used for families caring for children with developmental disabilities.

Recommendation 4c: Provide culturally specific awareness and outreach to caregivers about currently available programs, including respite and support groups. Awareness-raising should target individuals who provide care but do not necessarily call themselves “caregivers,” caregivers who do not approach services because they believe they are ineligible for assistance, and underserved caregivers who typically hesitate to approach formal services. Awareness-raising for these programs should also occur online, and include the option to access support groups and educational services online for those caregivers who would find this useful.

Recommendation 4d: Provide reliable funding for caregivers to access affordable home modifications or assistive devices that allow caregivers to safely and more easily provide care in the community. Further, future housing stock should be developed based on principals of universal design so older adults may age in place in these units.

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.

Recommendation 5a: Allow nurses to delegate additional nursing and complex care tasks to qualified home health care providers. Tasks for which delegation is appropriate include but are not limited to regular oral medication administration, administration of insulin in pre-filled instruments or pens, administering intramuscular injection medications, administering glucometer tests, and administering ear/eye drops.

Recommendation 5b: Standardize protocols and procedures at hospital discharge that recognize family caregivers once the caregiver is identified.

Specific steps for implementation of this recommendation include:

- Require the caregiver be notified about caregivers' rights at hospital discharge, including the right to say the discharge is unsafe, the right to refuse to provide care, rights regarding the sharing of information, and the ability to talk to a social worker when this is offered at the facility.
- Require caregivers be provided with information on "red flags" to be aware of once the care recipient has been discharged and which indicate a need for the care recipient to return to the hospital.

Recommendation 5c: Expand access to home care referrals following hospital discharge by lowering eligibility requirements so that more care recipients receive formal services and the caregiver has time to adjust to the new role.

Recommendation 5d: Enhance current provisions of the Caregiver Advise, Recognize, and Education Act (CARE Act) to improve recognition and education of family caregivers.

Steps for enhancing the CARE Act include:

- Require hospitals to enable recipients to list multiple caregivers in their electronic health records.
- Require hospitals to provide educational materials that families can take home and review after discharge, in addition to education provided in the hospital.
- 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.
- Provide funding to expand access to translated materials and trainings provided to caregivers at discharge as a part of CARE Act requirements

Recommendation 6:

Remove barriers and encourage collaboration across agencies for the safe return of individuals with intellectual disabilities and cognitive impairments.

Recommendation 6a: Remove barriers to data sharing across agencies that inhibit the investigation of missing persons who have an intellectual disability or cognitive impairment. Once removed, an education effort should take place to review what information can be shared across agencies, as well as how to best collaborate with other departments to locate individuals.

Overarching recommendations:

The Task Force urges the Legislature to increase funding to the California Caregiver Resource Centers. The Task Force urges the Legislature to increase funding to the California Caregiver Resource Centers. Additional funding would increase CRCs' ability to administer high quality caregiver assessments by trained professionals, provide information and referral services using up-to-date resource lists, provide education and training programs, and conduct awareness-raising to reach caregivers. CRCs also facilitate respite services by distributing respite funds. Additional funding for respite care would be used to allow caregiver to leave the home and take a break to address their own needs, including attendance at educational events and support groups.

Support an ongoing task force on family caregiving to provide policy expertise to the legislature and state agencies, identify solutions that support caregivers across agencies and organizations, and provide bi-annually updated recommendations and assessment of progress. An ongoing task force 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 task force 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. The task force should be responsible for bi-annually updated reports on policy recommendations that support the state's caregivers, including updates on the progress of previous recommendations.