Picking Up the Pace of Change in California:

A Report From the California Task Force on Family Caregiving

USC Leonard Davis School of Gerontology
California Task Force on Family Caregiving (TTFC)

AARP Real Possibilities California

ARCHSTONE FOUNDATION

Letter from the California Task Force on Family Caregiving

Dear California Caregivers,

Caregiving is a journey unlike any other. To those who have not yet traveled this road—and most of us will, eventually— it is difficult to describe the multitude of situations that evolve to create the experience of providing care for a family member. Caregivers are often rewarded with great satisfaction and appreciation that comes from providing assistance to a family member who needs help. At the same time, the caregiving role comes with formidable challenges.

The challenge before us is three-fold. First, the older adult population in California is increasing at a rapid rate. By 2030 nearly one-fifth of California's population will be over age 65. Consequently, it is projected that a higher proportion of Californians will be family caregivers than are in this role today. Second, the population is becoming more diverse, driving demand for culturally competent services and programs. Finally, family structures are changing, impacting the number of available caregivers to those who need assistance. Families have fewer children, and there is an increase in long-distance caregiving and diverse family ties of choice.

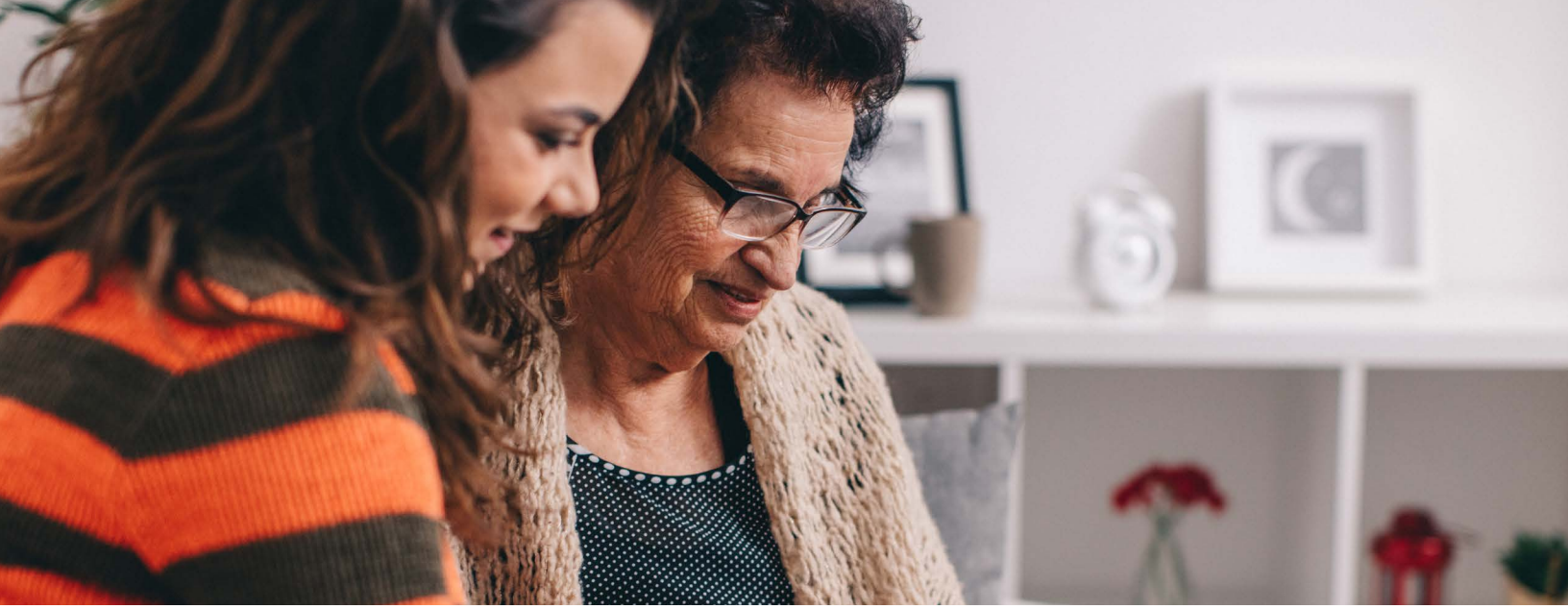
After evaluating these issues, as well as existing policies and supports, we as a Task Force believe the road traveled by caregivers could be smoother. Resources and information are difficult to navigate. Family members are faced with difficult choices between caring for a family member and risking financial harm. Few caregivers are afforded the opportunity to take a break when they need it.

Responsive policymaking can pave the way for a better caregiving journey for families. This report is intended to offer recommendations that will enhance existing policies and provide better support to California's 4.5 million family caregivers. We believe these recommendations will help families adopt a caregiving role by reducing the enormous sacrifices to their health as well as their financial, social, and emotional wellbeing.

We have entitled this report "Picking Up the Pace of Change" to urge our representatives to respond with urgency to help the millions of family caregivers in the state today. We hope you will join us in asking the Legislature to construct a better way forward for caregivers by adopting the recommendations described in this report.

Sincerely,

The California Task Force on Family Caregiving



Executive Summary

The California Task Force on Family Caregiving (the Task Force) was established through Assembly Concurrent Resolution 38 (ACR 38-Brown) to address the challenges encountered by California's 4.5 million family caregivers who care for individuals ages 18 and older.[1,2] Family caregivers are foundational to California's long-term services and supports infrastructure, surpassing Medi-Cal in terms of the economic value of their unpaid caregiving contributions.[2] However, family caregivers face many challenges in this role, including balancing employment and caregiving, accessing culturally relevant and competent services, paying for supportive services, and attending to their own health and wellbeing.

Existing policies in California to support caregivers have not kept pace with changing needs. The recommendations described in this report are intended to bridge the gap between existing policies and the challenges faced by California's caregivers. After a two-year process and careful consideration, the Task Force is submitting the following recommendations to the legislature.

- 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 2: 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.
- 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 4: Increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.
- 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 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.

The California Task Force on Family Caregiving urges the legislature to act on these recommendations and sub-recommendations as soon as possible to better support the state's family caregivers. Gradual and incremental change will result in missed opportunities to help caregivers preserve their health and financial wellbeing.

Funding and Acknowledgments

The Task Force was authorized by California Assembly Concurrent Resolution (ACR) 38. Administrative support, including convening the Task Force, is funded by grants from AARP California and Archstone Foundation to the University of Southern California's Leonard Davis School of Gerontology.

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Photo Credit: Family Caregiver Alliance

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Introduction

The California Task Force on Family Caregiving (the Task Force) was established through Assembly Concurrent Resolution 38 (ACR 38-Brown) to address the challenges encountered by California's 4.5 million family caregivers.[1,2] Family caregivers are foundational to California's long-term services and supports infrastructure, surpassing Medi-Cal in terms of the economic value of their unpaid caregiving contributions.[2] However, family caregivers face many challenges in this role, including balancing employment and caregiving, accessing culturally relevant and competent services, paying for supportive services, and attending to their own health and wellbeing.

Existing policies in California to support caregivers have not kept pace with changing needs. Below are some examples of lag between existing needs and available support for California's caregivers.

- Medical technologies and public health advancements that have added years to life are re-shaping the trajectory of caregiving, such that older adults survive for many years with multiple chronic conditions.[3] Consequently, caregivers who are employed often need flexible leave options to accommodate the changing support needs of the person they assist.[4]

- Caregivers today are often asked to do complex care tasks (e.g., wound care).[5] Often they are underprepared to complete these tasks or uncomfortable doing so at all.

- Demand for home care providers, who often provide respite, is growing while the supply of workers has not kept pace.[6] Affordable respite services are increasingly difficult to find, making it challenging for caregivers to take a break.[7, 8]

- Services and supports are needed for a population of caregivers and receivers that is more diverse than ever,[3] but many organizations lack the resources to meet diverse needs.[9]

These are just some examples of how the changing needs of caregivers have outpaced the progress of existing policies in California.

The recommendations described in this report are intended to bridge the gap between existing policies and emerging challenges faced by California's caregivers. However, the Task Force also recognizes there are many unknown factors affecting caregivers. Federal-level events in recent months, such as tax reforms, have demonstrated the potential for major changes to quickly occur in policy and funding priorities. Technologies, including telehealth options, continue to be developed and are becoming more accessible. California policies should adapt to support these options that help caregivers access services for themselves and recipients, and reduce healthcare costs. Collecting up-to-date data and creating an ongoing caregiver advisory council will ensure policies remain current, so the state remains responsive to the evolving needs of family caregivers and changing contexts.

Demographics information on family caregivers

There are currently an estimated 4.5 million family caregivers to adults over the age of 18 in California.[2] Family caregivers are the spouses, partners, adult children, other relatives, friends, or neighbors who provide care and support to adults with disabilities and/or older adults.[1] Notably, the definition of "family caregivers" includes "families of choice," not just families people are born into. Researchers expect the ranks of family caregivers will grow due to population aging, increasing longevity, the growing number of individuals with chronic conditions associated with an aging population such as Alzheimer's Disease and related dementias (ADRDs), and the increasing cost of long-term services and supports (LTSS).[3]

It is challenging to describe who family caregivers are, given variation among this population's survey reports. Definitions of "caregiver" vary. Drawing from multiple data sources can help provide an inclusive picture. Most reports indicate that the number of women who are caregivers is disproportionate to their percentage of the population; 53–60% of caregivers are women.[3, 12, 13] Caregivers are generally "middle aged."[3,12] On average, caregivers are 49 years old.[13] Notably, there is a growing

WHO ARE FAMILY CAREGIVERS?

THE CAREGIVER

There are currently an estimated 4.5 million family caregivers adults over the age of **18** in California

35-60% of caregivers are women

On average, caregivers are **49 years old**

Notably, there is a growing population of young caregivers; **1 in 4 caregivers are Millennials**

Targeting adults who are providing care and assistance is a challenge for service providers. You have to market the identity of being a family caregiver . . . across generations, diverse populations, and urban, suburban, and rural communities in the state. One-size-fits-all outreach tactics do not work in a state the size of California.

Kathy Kelly
Task Force member,
San Francisco

CAREGIVING CIRCUMSTANCES

Between **34% and 47% of caregivers live with the person for whom they care**

The majority of caregivers are employed (56%), although one estimate puts the rate as low as 38%

Approximately **¼ of caregivers assist a person with dementia**

The average length of time in the role is 4 years, but this varies considerably

population of young caregivers; 1 in 4 caregivers are millennials; 1 in 6 Millennial caregivers assists someone with dementia.[13, 14] There is discrepancy in terms of the racial and ethnic composition of caregivers. In one study, just 17% of caregivers reported being non-Hispanic White/Caucasian, 20% African American/Black, 20% Asian American, and 21% Hispanic.[13] In another study, 72% of caregivers reported being White/Caucasian.[12] The majority of caregivers are employed (56%),[13] although one estimate puts the rate as low as 38%.[12] Between 34% and 47% of caregivers live with the person for whom they care.[3,12,13] The average length of time in the role is 4 years, but this varies considerably.[13] Approximately one-quarter of caregivers assist a person with dementia.[12,13]

While averages like those described above are informative, caregivers are a diverse group in terms of culture, background, capacity, need for support, and desire to provide care. When making policies, it is important to keep these differences in mind to address the needs of all family caregivers.

Challenges encountered by family caregivers

Family caregiving itself is not a policy problem. Many caregivers describe the help they provide in positive terms, and find the role rewarding.[15] However, the social and political environment in which caregiving occurs makes some aspects of caregiving difficult. Some of these challenges are described in-depth in their corresponding sections of this report. Specific negative outcomes are briefly considered below.

Health and wellbeing.

Some family caregivers are vulnerable to worsening health and wellbeing. Caregivers who provide higher intensity care or more hours of care are at increased risk.[16] Declining health may be due to engaging in negative health behaviors and neglecting positive ones,[17] distress from caregiving tasks,[18] and injury as a result of care duties.[19] As a result, caregivers endure higher rates of cardiovascular risk factors, poorer immune functioning, and higher levels of depression than noncaregivers. [20]

Financial security and employment.

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.[21] An AARP study released in 2016 showed that more than 3 out of 4 caregivers absorb out-of-pocket costs, at an average of nearly $7,000 per year.[8] Costs for caring for a loved one with Alzheimer's Disease or a related dementia average well over $10,000 a year in out-of-pocket costs. Although California has family leave benefits to provide eligible workers,[22] few caregivers know about this.[23]

California has long had a network of supports and services available to assist caregivers. Of note are the California Caregiver Resource Centers, which were established in law in 1984. At the 11 CRCs throughout the state, caregiver needs can be assessed so that tools like support groups, counselling, and educational programming can be identified. However, despite a peak budget of $10.5 million to serve the millions of caregivers across the state, funds to the CRCs were cut by 74% in 2010. This curtailed the amount of services the CRCs could provide to caregivers. Other barriers to accessing supports and services include high costs,[8,24] services that are not tailored to individual needs, lack of culturally relevant options,[9] and even difficulty among caregivers in identifying what kinds of support are available.[26,27]

> "When looking across race/ethnicity, out-of-pocket spending is highest among Hispanic/Latino caregivers ($9,022 per year; on average, 44% of their income)."
>
> *AARP*
> Costs of Caregiving 2016[8]

> The cost of caregiving is expensive, whether it's hiring help in the home or assisted living. Kim was caring for her husband with Alzheimer's and years into caring for him at home she asked herself, "Do I pay for nursing care for my husband or college for my two daughters?" This is the kind of dilemma family caregivers face.
>
> *Edie Yau*
> Task Force member, Santa Clara

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. 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.

The California Task Force on Family Caregiving

Appointed members

Task Force members were appointed by California's Senate and Assembly leadership (six members per house). Appointments were completed in August 2016. Members come from the non-profit, public, and private sectors. In addition to a wealth of professional expertise, several members have extensive personal experience as family caregivers. Below is a roster of Task Force members, whose complete bios can be found in Appendix A.

- **Mary Ball**, former President/CEO at Alzheimer's San Diego
- **Donna Benton**, PhD, Research Associate Professor of Gerontology, University of Southern California
- **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

University of Southern California Administrative and Research Staff

ACR 38 requires the support of a non-state organization.[1] This entity, the Administrative and Research Support Team, is led by Kathleen Wilber, PhD at the University of Southern California's Leonard Davis School of Gerontology.[28] The USC Team convened and provided support for Task Force member meetings every other month, researched promising practices in family caregiving, conducted a survey of caregiver services in the state, drafted reports to funding organizations, and maintains a web presence for the Task Force.

Policy priorities and the process of making recommendations

On October 20, 2016, the Task Force met for its inaugural meeting. At this meeting, Task Force members used

a consensus process to identify key priority issues. Members agreed upon six priority areas to guide their work. These are listed below. Additional information about the priority-setting process and descriptions of each priority area can be found in the Interim Report.[29]

- 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

Recommendations

Recommendations by the California Task Force on Family Caregiving came out of an intensive two-year process. 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 have been reviewed and refined on multiple occasions by members of the Task Force. Overarching recommendations from this process are listed below.

- **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 2**: 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.

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

KEY VALUES TO GUIDE CAREGIVING POLICIES

In addition to priority areas, Task Force members identified several underlying values to consider as they developed recommendations. These values run throughout the Task Force recommendations.

Key values include:

- Supporting diverse caregiver needs, including cultural awareness, cultural competency, and sensitivity
- Person- & family-centered care
- Work-life balance
- Choice & options for caregivers (e.g., capacity to be a caregiver)
- Supporting paid caregivers.

- **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 6**: Increase funding to California's Caregiver Resource Centers to expand services, including respite 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.

The sections of this report discuss each recommendation area in-depth, and describe why the Task Force is making each recommendation. Recommendations include sub-recommendations describing specific policies to achieve the overarching recommendation.

> 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, Santa Clara

Members of the California Task Force on Family Caregiving at the first meeting

Recommendation 1:
Support the financial wellbeing of family caregivers

The economic impact of caregiving is extensive. Family caregivers in California provide approximately $58 billion worth of care and assistance each year.[2] Assistance provided by caregivers often comes at a cost to their own financial wellbeing. Thirty-six percent of family caregivers to adults above the age of 50 report feeling financial strain from their caregiving duties.[13] By providing for today's older and disabled adults, caregivers may risk their own financial security both in the present and in later life. A 2016 study on attitudes of California residents ages 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."[30]

The high out-of-pocket costs of caregiving

Caregiving is expensive. 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).[8] 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. Caregivers to persons who are eligible for Medicaid services receive some protection from these costs through home- and community-based services. However, when home- and community-based service hours are inadequate or the caregiver assists someone who is not eligible for Medicaid, they may have pay $25 per hour for a home care provider for when they cannot provide care themselves.[31] 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.[13] Many states have looked into creating long-term care insurance programs to cover some of the out-of-pocket costs of caregiving.[32,33]

Tax credits do exist at the federal level to cover out-of-pocket costs related to care, but eligibility criteria are so strict that few caregivers can use credits. To qualify for federal tax credits, the relative receiving care must have an income of less than $4,050.51 per year, the family member must provide 50% of the older adult's expenses, and either the caregiver must cohabitate with the receiver or meet certain relationship criteria.[34] Still tax credits in such cases only go up to $4,050 and may not cover all costs. Out-of-pocket costs of caregiving beyond 10% of a family's income may also be deducted from income tax only if the care receiver's impairment meets certain criteria. Under these provisions, there are many ways in which a family member can be considered ineligible for federal tax credits. A 2016 survey among Californians ages 40 and older found that 82% would support a proposal to provide tax breaks to those providing care to a family member.[30] California previously offered a tax credit for caregiving. New legislation for a tax credit to cover some of the out-of-pocket costs of caregiving has been introduced at both the state (AB 806, Kalra) and federal levels.[36,37,38]

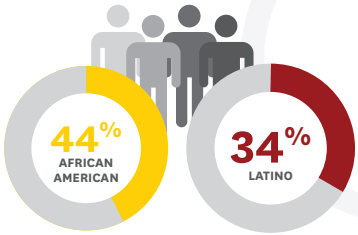
Negative impacts of caregiving on employment and long-term financial wellbeing

While 56% of family caregivers work full time, caregiving can considerably impact employment.[13] Sixty-one percent of caregivers report caregiving had impacted their work, causing them to lower work hours, turn down promotions, and make similar accommodations.[13] Among those providing substantial healthcare assistance to a recipient, 20% reported missing work due to caregiving in the past month and 8% reported reduced productivity at work attributable caregiving (i.e., "presenteeism").[39]

Approximately 10% of caregivers leave the workforce prematurely to provide care.[23] A Metlife survey estimates that women who leave the labor force to provide care lose $142,693 in wages and $131,351 in Social Security benefits. The difference in wages and income lost is even higher among men, likely due to a wage gap; men who leave the labor force to provide care stand to lose an average of $89,107 in wages but $144,609 in Social Security benefits.[21] Further, caregiving magnifies the impact of stopping work on risk of poverty; women who are caregivers who stopped working were 4.3 times more likely to experience poverty than non-caregivers who did so. There is evidence to suggest that women, who are more likely than men to be become caregivers in the first place, become caught in a "vicious cycle of poverty" from caregiving.[40] Reduced attachment to the workforce because of child care and traditional male "breadwinner" dynamics within families can mean that women are more likely to become caregivers when a need arises. This undermines women's ability to accumulate Social Security credits, savings, and may result in reduced income earnings.

HIGH COSTS OF CAREGIVING

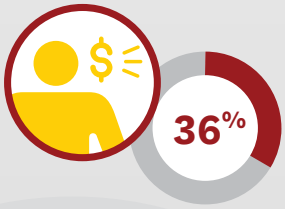
Family caregivers in California provide approximately **$58 billion worth of care and assistance** each year



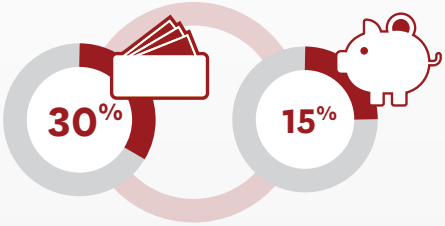
African-American/Black and Hispanic caregivers spend a higher proportion of their income on out-of-pocket costs to provide care than Caucasian/White and Asian caregivers, averaging **44%** and **34%** of annual incomes, respectively, compared to **14%** among Caucasian/White and **9%** among Asian caregivers.

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

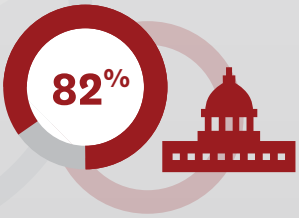


36% percent of family caregivers to adults above the age of 50 **report feeling financial strain from their caregiving duties**



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**

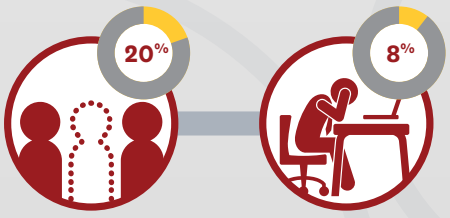
IMPACT OF CAREGIVING ON EMPLOYMENT

While 56% of family caregivers work full time, caregiving can considerably impact employment

Approximately **10% of caregivers leave the workforce prematurely to provide care**

61% of caregivers report caregiving had impacted their work, causing them to lower work hours, turn down promotions, and make similar accommodations

A Metlife survey estimates that women who leave the labor force to provide care lose $142,693 in wages and $131,351 in Social Security benefits. The difference in wages and income lost is even higher among men, likely due to a wage gap, who stand to lose an average of $89,107 is wages but $144,609 is Social Security benefits.



Among those providing substantial healthcare assistance to a recipient, **20% reported missing work due to caregiving in the past month and 8% reported reduced productivity at work attributable caregiving** (i.e., “presenteeism”)

Caregiving magnifies the impact of stopping work on risk of poverty; **women who are caregivers who stopped working were 4.3 times more likely to experience poverty than non-caregivers who did so**

> Seventy-two percent of Americans ages 40 or older say letting a family member take time away from work or adjust their work schedule to provide ongoing living assistance without penalties from their employer would be helpful in improving the quality of care.
>
> *Associated Press-NORC Center for Public Affairs Research* [30]

In California, family caregivers who receive payments to provide care for their family members working in the In Home Supportive Services (IHSS) Home and Community Based Services (HCBS) program are denied access to state-level unemployment insurance, though they may elect to contribute towards disability insurance. Additionally, their wages as IHSS employment do not count towards the federal Medicare and Social Security programs. These exclusions make financial wellbeing particularly difficult for family caregivers who leave other employment to care for family members. IHSS caregivers comprise approximately 73% of providers serving an estimated 492,542 IHSS recipients in California per month.[41]

Family leave

Some workers who need to take time away from their employment to provide care have access to job protections through the federal Family Medical Leave Act (1993) (FMLA).[42] Under FMLA, eligible workers are provided 12 weeks of unpaid leave to provide care to certain dependent or seriously ill family members and for their own medical needs.[43] Strict eligibility criteria, however, limit the reach of this policy. 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 worked 1,250 hours in the last year, and been on payroll for the past 20 weeks. Consequently, the law only covers only 55–60% of workers due to limitations in eligibility.[43] Many states have altered eligibility criteria so that employers with fewer than 50 employees are eligible for 12 weeks of job protection. California is not one of these states. [44]

In addition to job protection, since 2004 most California employees are eligible for 6 weeks of paid family leave (PFL), where payment is funded by payroll taxes through the State Disability Insurance (SDI) program. [45] Notably, PFL does not entail job protection, although many caregivers who are eligible for PFL are eligible for FMLA. In 2012 workers paid an average of $428.81 to be eligible PFL. In April 2016 California Governor Jerry Brown signed SB 908 amending the current PFL compensation system, which provided 55% weekly wage replacement up to $1,067 in 2016.[46] The new law requires those with earnings near minimum wage to receive 70% of their usual pay and workers earning up to $108,000 per year to earn 60% of their usual pay starting in 2018. Unlike federal legislation, this law applies to all private and non-profit sector employers, not just those with over 50 employees. Public sector employees are eligible if their employer opts into the program.

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 (See up-to-date figures: https://data.edd.ca.gov/Disability-Insurance/Paid-Family-Leave-PFL-Monthly-Data/r95e-fvkm). In contrast, in Rhode Island over a quarter of PFL claims were for caregiving for an older adult. An evaluation prepared for the California Employment Department sheds light on several causes for this low take-up rate.[23] The primary reason workers do not use PFL is that they do not know this program exists. In 2015, just 36% of California's voters were aware of the program, a rate that dropped 7% from a 2011 poll.[47] Awareness among some racial/ethnic minority populations is even lower, in part due to poorly translated awareness-raising materials. Employees are not the only ones who could learn more about PFL. Human resource departments and professionals are among the most likely to advise employees on access to PFL, but 78% of human resource professionals indicate additional PFL training is needed.[23] Misconceptions surrounding eligibility criteria also contribute to low uptake; many employees assume they are not eligible, believing PFL is a public assistance rather than an insurance program they have paid into. Finally, low wage replacement is another key reason for not using PFL. One study suggests that one-third of those who were aware of the program did not make use of it because the of inadequate level of wage replacement. (Notably, this evaluation was completed prior to an increase in the rate.)

Although when the PFL program began there was concern it would negatively impact businesses, this has not been

found to happen. A 2011 evaluation of California's paid leave law indicates that 89% of 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.[48] Further, while PFL has been found to increase the length of leave taken, nine months after the leave is taken researchers found an increase in work hours and reduction in unemployment. Among workers in low-quality jobs (e.g., jobs that do not require a degree, pay little, and are more likely to be part-time), retention rates for those who took paid leave were 10% higher than those who did not.[23] Some estimates indicate this retention can yield cost savings for employers.[50] Private sector businesses, eager to offer competitive benefits to workers, have turned to paid family leave policies. In 2016, Deloitte, a consulting firm with 78,000 employees based in New York, began offering 16 weeks of fully paid leave to employees.[51,52] However, new policies for family leave among California's tech giants appear to focus on parental leave without additions for family caregivers for aging and disabled adults.[53] Breaking from this trend, in early 2017 Facebook announced six weeks of paid caregiving leave to employees. [54]

Policies and programs besides FMLA and PFL to support employed caregivers

There are other policies that can support caregivers' continued employment in addition to leave. These include legislation against family responsibility discrimination, flexible hours, and paid sick leave.

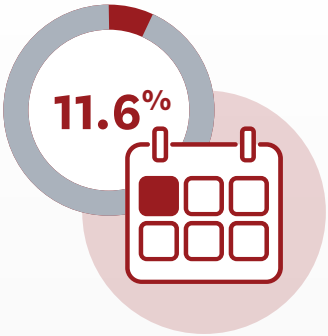
Family responsibility discrimination protections. Family caregivers are often subject to Family Responsibility Discrimination (FRD), whereby employers negatively assess caregivers' performance as employees, excessively scrutinize, make unwarranted assumptions, or openly treat these employees unfairly because of their caregiving role.[4] An employer who denies a family caregiver access to family leave when they are eligible is an example of FRD. According to a recent survey, two-thirds of caregivers support laws banning workplace discrimination based on caregiving responsibilities.[13] In 2013 Senate Bill 404 (Jackson) was introduced in California to bar employers from discriminating against "familial status."[55] However, this bill did not make it out of the Senate. In contrast, in 2016 New York successfully passed legislation to expand job protections to family caregivers, disallowing employment discrimination based on caregiving status.[56]

Flexible work schedules. Flexible work schedules allow caregivers to more easily meet the demands of caregiving, such as being able to leave the office to take the care recipient to a doctor's appointment in the middle of the day. Just a third of full-time workers have access to flexible hours, with workers in less skilled positions less likely to have access to flexible work hours.[57] However, many family caregivers are reluctant to request flexible hours given concerns about discrimination.[23] In 2013 San Francisco passed the Family Friendly Workplace Ordinance allowing employees to request flexible working schedules to provide care to a child, family member with a persistent health condition, or a parent aged 65 and older.[58] Eligible employees must provide at least eight hours of work a week and must have been with the employer for six months. The law does allow employers to turn down requests for flexible work, predictable hours, and work setting. Related, caregivers also struggle to access partial work days to accommodate the unique needs of their families. The current process is onerous for caregivers, where recorded conditions need to be continuously updated for caregivers to access partial days of work.

Paid sick leave. Paid sick leave policies enable family caregivers to be compensated when they must provide care for a short period. Of the approximately 52% of American employers providing paid sick leave, the average allotted time for leave is around 5 days.[59] In 2016, 68% of all workers were eligible for paid sick leave in the U.S.[60] San Francisco has been described as an exemplar for its 2007 Paid Sick Leave Ordinance, which allows employees to earn paid sick days after working three months with an employer.[61] Evaluations of this program have been positive. A 2011 survey suggests that 6 out of 7 employers report no negative impact on profitability, while more than half of employees reported experiencing a benefit from the program.[62] Given its success, other cities in California, including Los Angeles, have passed similar policies.[63] In 2014, California passed a statewide paid sick leave law, Healthy Workplaces, Healthy Families Act, such that employees working with the same employer for 30 or more days will, beginning in July 2015, accrue paid sick days.[64] Although there is minimal information on the effectiveness of this policy, there is likely to be similar issues as those observed for PFL: confusion among employees and employers, fear of being negatively appraised as an employee for taking sick leave, and lack of awareness of the new law.

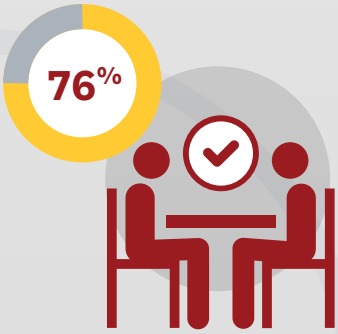
LIMITATIONS OF CURRENT LEAVE LAWS IN THE STATE

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.*

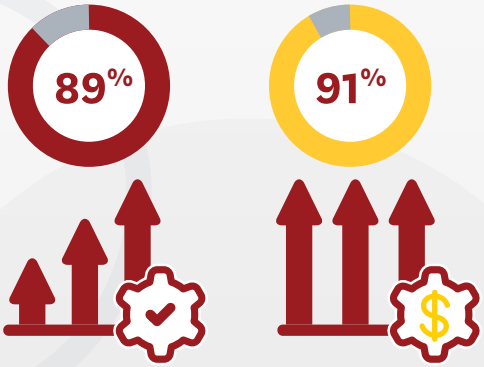


Despite having the oldest paid family leave law in the nation, just **11.6% of paid leave claims in California were taken by family caregivers from March 2017 to April 2018**

The primary reason workers do not use PFL is that they do not know this program exists. In 2015, just 36% of California's voters were aware of the program, a rate that dropped seven percentage points from a 2011 poll.



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**



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.

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 1a: Family caregivers spend an average of $7,000 per year on out-of-pocket costs related to caregiving and often draw on their own savings to cover these costs. Federal tax credits for out-of-pocket costs exclude many caregivers. The Task Force recommends that the legislature pass a statewide 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. This credit should be no less than $5,000 per year. Eligibility criteria for this credit should be limited to prevent middle-income caregivers from descending into poverty.

Recommendation 1b: Caregivers may struggle to cover the costs of home care that can allow them to continue in their employment and attend to other responsibilities. The Task Force recommends that the legislature implement a long-term care insurance program to cover the costs of community-based services. Services can include adult day care, chore services, home-delivered meals, personal care, respite care, and transportation.

Recommendation 1c: Caregivers often struggle to balance employment with caregiving. Existing protections have considerable gaps that leave caregivers vulnerable to employment insecurity. The Task Force recommends legislation 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 raising awareness so caregivers know these programs exist.

The following steps are recommended to implement this recommendation:

1. Reduce the number of employees required for a private sector employer to comply with the federal Family Medical Leave Act (FMLA) in California.
2. Extend job protections found in the FMLA to those participating in the state's Paid Family Leave program (PFL).
3. Expand PFL to automatically apply to public sector employees instead of the current opt-in program.
4. Increase the number of weeks over which PFL is provided from 6 weeks to 12 weeks per year.
5. 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.
6. Require agencies overseeing implementation of awareness campaigns to consult with local community leaders from underserved groups to ensure culturally-appropriate awareness campaigns.

Recommendation 1d: Study the issue of family caregiver retirement with a focus on caregivers who provide care for family members as employees (e.g., In Home Supports and Services providers). Specifically, a study should consider the impact of access to unemployment insurance on caregivers whose family members passed away, and access to state and federal retirement programs by caregivers who have left the workforce to care for family members.

Recommendation 2:
Learn about caregivers and their needs to improve services

Data on family caregivers specific to California is difficult to come by. Such data is important to know the characteristics of caregivers, what kinds of challenges they face, and to anticipate future needs in this population. Data can also be used to understand which caregivers are using supports and services, such as those provided by California's Caregiver Resource Centers, Area Agencies on Aging, and other non-profit organizations. More importantly, data can be used to identify which caregivers are under-served so steps can be taken to remedy this.

Large survey data on family caregivers

Survey data can be used to understand who among Californians provides care or assistance to a friend or family member. Survey data with many observations and a sample that represents the population is best suited for this. Representative samples increase the chances that research findings will apply to the actual population of caregivers, since it would be expensive to survey every caregiver in California. Surveys with many observations allow researchers to achieve reliable results, particularly when studying relatively uncommon events (e.g., job loss) and subpopulations of caregivers (e.g., caregivers to people with dementia). Datasets with a lot of observations also allow researchers to use sophisticated research methods, such as those that attempt to decipher predictors of a phenomenon.[65]

There are few datasets available that provide rich information on caregivers at the state level. The California Health Interview Study (CHIS) is a large representative dataset that is regularly collected. CHIS last asked about family caregiving in a 2009 module.[66] Inclusion of this module in the survey resulted in information on the demographics, health, and wellbeing of family caregivers.[66,67,68] However, this information is nearly a decade old and no longer reflects California's population of caregivers.[66] Routine collection and utilization of data on caregivers would provide up-to-date information on caregivers in California to inform policies.

Caregiver assessments and administrative data on caregivers

Individual programs serving caregivers often learn about the clients through caregiver assessments. An assessment is "a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver's perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants, and seeks to maintain the caregiver's own health and well-being."[69] Caregiver assessments are an important service tool, as well as a potential source of data on caregivers using services.

In clinical settings, assessments can help caregivers and service providers identify individual caregivers' specific needs. Some caregivers need assistance navigating complex webs of medical and community care, while others may have access to all the services the care recipient needs but lack emotional support for themselves. Few caregivers can identify these needs alone or are able to articulate what it is they could use assistance with.[70] Some organizations, such as the California Caregiver Resource Centers (CRCs), maintain files on clients and update them with regular reassessments.[71] This enables organizations to keep track of changes in the caregiving situation (e.g., Does the care recipient still live in the community?), caregiver health (e.g., Is the caregiver at a higher risk of depression than last year?), and eligibility for services (e.g., Is the care recipient now eligible for Medi-Cal?). In doing so, programs can remain responsive to the needs of the caregiver. A survey of organizations providing services to caregivers in California found that 60% routinely provided a caregiver assessment.[72]

> 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. The number of family caregivers will only continue to grow as the population ages.
>
> *Edie Yau*
> Task Force member, Santa Clara

In addition to opportunities to improve services to individual caregivers, assessments can be used as a source of data for organizations to better understand who they serve and how to improve services. Organizations serving caregivers have limited resources, and thus must decide how to distribute these. Typically, level of need is a key determining factor for resource distribution, although eligibility criteria like income, as well as other target characteristics, can impact distribution.[73] Caregiver assessments can help to determine level of need, eligibility criteria, and whether clients fit within target populations. Further, by looking at scores from measures included in the assessment like self-rated health and depression, service providers can decide how to invest resources for programming.

Caregiver assessments need to be carefully planned to achieve the benefits described above. At the National Consensus Development Conference for Caregiver Assessment held in San Francisco by the Family Caregiver Alliance in 2006, participants came up with seven principles for caregiver assessments.[69] Despite this conference occurring more than a decade ago, recommendations largely have not been implemented across organizations providing caregiver assessments in California.

In addition, caregiver assessments can be designed in a way that supports statewide data collection on caregivers using services. This was previously done by the Family Caregiver Alliance prior to funding cuts to the CRC program.[74] If data compiled from statewide assessments were compared to survey data of caregivers in California, it would be possible to know who among caregivers are not receiving services. This information could guide providers in their efforts to reach underserved populations. To accomplish this, assessments should be comprised of empirically-tested measures completed on a secure digital platform, and be consistently administered throughout the state.[75] Coordination of assessments could also reduce fragmentation if some information about caregivers could be securely shared across organizations, as is done with electronic health records. This could save caregivers and providers time, and reduce redundancies in services.

Currently there is no required caregiver assessment for major federal programs that serve or affect caregivers. Neither the Older Americans Act nor Medicaid waiver programs require caregiver assessments as defined, even when services going to the care recipient require a caregiver.[69] Although a recent evaluation found that 81% of Area Agencies on Aging offer a caregiver assessment, the meaning of "assessment" by these agencies varies considerably, and may only signify a very basic assessment of the caregiver.[76] Weaknesses appear to be recognized by agencies, many of whom requested additional guidance on caregiver assessments. California's CRCs have had a universal assessment since 1988, although administration has become less standardized over time and is typically not completed on a digital platform. California has an opportunity to considerably improve how caregivers are assessed and access services and supports.

RECOMMENDATIONS FOR CAREGIVER ASSESSMENTS FROM THE NATIONAL CONSENSUS DEVELOPMENT CONFERENCE FOR CAREGIVER ASSESSMENT[69]

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address their needs.
2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
3. Caregiver assessment should result in a plan of care (developed collaboratively with the caregiver), that indicates the provision of services and intended measurable outcomes.
4. Caregiver assessment should be multidimensional in approach and periodically updated.
5. Caregiver assessment should reflect culturally competent practice.
6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners' and service providers' education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.
7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

Approaches to critically missing incidents (i.e., at-risk missing persons) and agency fragmentation

For caregivers to individuals with an intellectual disability or cognitive impairment, symptoms like wandering can be a regular source of anxiety. Nearly half of those with dementia will wander at one point.[77] Many times when a care recipient with dementia goes missing, it is an isolated and unexpected incident.[78] Consequently, few caregivers are prepared when this occurs. When a person with an intellectual disability or cognitive impairment goes missing, it is essential to find them as soon as possible to reduce risk of harm. In a review of newspaper reports of people with dementia who were reported missing it was discovered that, of those not found the next day, only half were found alive.[78] To hasten safe returns of people with an intellectual disability or cognitive impairment, the Bringing Our Loved Ones Home task force was initiated in Los Angeles County.[79] To more efficiently identify those who go missing, they proposed increasing collaboration across agencies and an educational effort to reduce barriers to inter-agency collaboration, which can cause dangerous delays.

WHAT IS A "CRITICALLY MISSING INCIDENT"?

Missing persons incidents are referred to as "critical" when there is an added degree of risk. Situations where the missing individual has a mental or cognitive impairment are critical incidents that many caregivers worry about. In such cases, the individual is less likely to know where they are or how to seek help, and may shed items that could be used to identify them (e.g., identity cards, cell phone). Critical missing incidents also include those cases where the missing person requires medical attention (e.g., regular medication) or has no previous history of disappearing.

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 2a: Caregiver assessments need to be carefully designed to inform services for individual caregivers and programs, and standardized so information can be compared across organizations. The Task Force recommends the move to develop and implement a standardized caregiver assessment to be delivered universally by programs 1) that deliver services to older adults or anyone over the age of 18 with a disability who relies on the contributions of family caregivers or 2) that 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 comprise empirically-tested measures that can be implemented in a clinical setting with minimal provider burden. Domains should include information on the caregiving context, the health and functional status of the recipient, the caregiver's values and preferences, the wellbeing of the caregiver, consequences of caregiving, the caregiver's skills and knowledge on how to provide care, and resources available to the caregiver. Programs should have the option to further tailor 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: Assessments take time to complete and require trained assessors to do so properly. They are an integral and highly valuable component of service delivery. The Task Force recommends increasing funding for caregiver assessments completed by agencies providing services under The Older Americans Act IIIE program, including Area Agencies on Aging, California Caregiver Resource Centers, and others with IIIE contracts so more caregivers can be reached. The Task Force acknowledges that this recommendation would require action at the federal level.

Recommendation 2c: To understand which caregivers are not accessing services and to track evolving needs in this population, statewide survey data on caregivers is needed. The Task Force recommends regularly collecting 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 including the caregiver module in the California Health Interview Survey. A caregiver-specific module should be included no less than once every three years to provide up-to-date information on this 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 2d: 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.

Photo Credit: Family Caregiver Alliance

Recommendation 3:
Equip caregivers with education and training

Despite the ubiquity of caregiving, often caregivers are unprepared for this role. Over 80% of caregivers indicate they need more information on caregiving-related topics.[80] Lack of information can be stressful to caregivers striving to provide high-quality care. Even experts struggle to access the information they need as caregivers. As one veteran aging and long-term services researcher explained: "As [my husband's] sole caregiver, I found myself plunged into a confusing world of poorly coordinated care, confusing systems, and an expectation that the caregiver could take on full-time responsibilities."[81]

Barriers to accessing high-quality information, education, and training

A decentralized system to access information. A main barrier to accessing information on caregiving is that current resources are relatively decentralized.[26,82] Caregivers have an overwhelming number of options to choose from to access information, including non-profit, government, and commercial services, and may not know which services will best meet their needs. Some of these services are increasingly linked together and make referrals when another agency can better answer caregiver's questions. However, fluctuating funding levels can make an information infrastructure difficult to create and maintain.[72] Since 2000 the federal National Family Caregiver Support Program though the Older Americans Act has required State Units on Aging (SUAs) and local Area Agencies on Aging (AAAs) to provide information on services and supports, as well as education and training to family caregivers.[3] In California, statewide Caregiver Resource Centers (CRCs) also fulfill this role. Funding cuts, however, reduced the capacity of California's CRCs to provide information and education services, including outreach to new caregivers who do not know that services exist.

Inadequately tailored information.

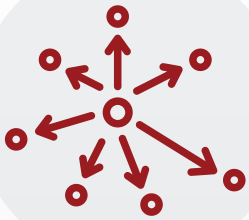
One of the challenges in accessing quality information as a caregiver is that a lot of information is not adequately tailored to meet individual needs. Caregiving requires a range of skills, knowledge, and abilities that evolve over time, and vary from family to family. Tailoring information pertains to the topics covered, timing, level of depth, how information is provided, language, and more.

Topics. Topics that caregivers often need information on include the care recipient's condition, the care recipient's prognosis, services and supports for caregivers and recipients, and financial supports.[27,83,84,85,86] Still, the information, education, and training needs of caregivers vary broadly. Caregivers providing more than 20 hours per week of care are more likely to report an interest in learning about stress management (51%, compared to 42% among caregivers in general), for example.[13] As the care recipient's condition progresses or the caregiver's needs change, new kinds of information are needed. Often caregivers need to learn how to complete complex care tasks, for example.[5] Seventy-two percent of organizations serving caregivers provide support for complex care tasks, although just half the organizations that do so provide education services on complex care.[72]

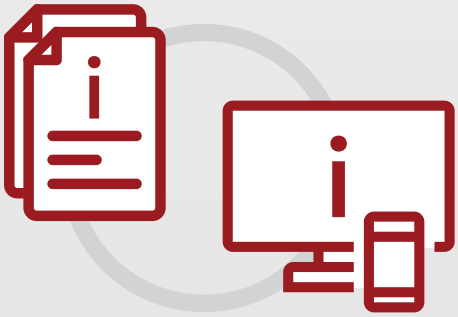
> A majority of family caregivers don't know how to navigate the long-term services and supports (LTSS) system. They don't know what services exist and what to look for.
>
> *Edie Yau*
> Task Force member, Santa Clara

MAIN REASONS CAREGIVERS STRUGGLE TO ACCESS INFORMATION

Over **80%** of caregivers indicate they need more information on caregiving-related topics



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**.

Timing and depth. The delivery of information, education, and training to caregivers also matters, including the timing, level, and depth. Too much information provided at once—such as at the time of diagnosis—can be overwhelming. Prioritizing some information is important. For example, caregivers to persons with dementia report wanting to know about services, prognosis, and how to handle crises following diagnosis; it is only later that most want to know more about support groups and financial issues. [88]

Means of accessing. Caregivers also vary in how they prefer to access information and education, both in terms of the source and how material is presented. One survey found that the most common means of accessing information among caregivers are family and friends (93%) and healthcare providers (84%). Increasingly caregivers go online to access information and advice. Most caregivers have used online resources to learn how to provide care (59%) and how to cope with stress from caregiving (52%).[83] Younger caregivers find online research more helpful than older caregivers.[89] Still, most caregivers would like to have a variety of ways to access information.[82,90]

Other barriers to accessing information. In addition to those barriers described above, other challenges caregivers face when trying to access information are listed below.

- Not thinking the caregiving situation is serious enough to merit learning about formal services [90,91]
- Fear that the care recipient would react poorly if he or she found out about the caregiver's information-seeking efforts [90,91]
- Poor understanding of service systems, making it difficult to find relevant information [82,92]
- Not having enough time to gather information, such as when the caregiver needs to make decisions under pressure [3,90,91]
- Not identifying with the term "caregiver," and thus not utilizing information services marketed towards caregivers [90,93]
- Receiving printed information, especially resource lists, that are out of date [94]
- Receiving unreliable or poor quality information [82]
- Information, education, and training materials that are difficult to understand, such as when technical language and jargon is used [27,81,82]

Targeted outreach and provision of culturally relevant and appropriate information

Some caregivers may be uniquely disadvantaged when seeking relevant information, education, and training. Caregivers from racial/ethnic, cultural minority groups, and people with limited English proficiency do not access information services to the same extent as other caregivers. Targeted outreach and tailored services and materials are needed to best serve these caregivers. Lesbian, gay, bisexual, or transgender (LGBT) caregivers should also be considered here, given the overlap between some of the challenges these caregivers face when seeking information.

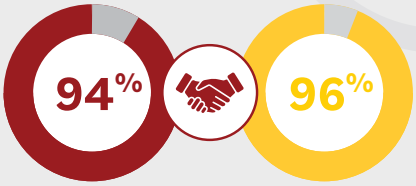
Targeted outreach. In focus groups with caregivers in California, it was discovered that Native American, Filipino, and Russian participants did not know about available services to caregivers.[9] Hispanic survey participants, by comparison, knew that programs existed, but not how to access to them. Lack of awareness among some groups may indicate poor targeted outreach by providers. In some cases, caregivers from racial/ethnic minority groups may be reluctant to approach services, due to lack of trust in government services and the belief that information would not be useful.[9,95] Likewise, caregivers who are LGBT or caring for someone who is LGBT have unique experiences that providers need to consider. LGBT caregivers and recipients are sometimes hesitant to approach formal services given the relatively recent laws, policies, and social norms that treated this group unjustly, and persisting prejudicial attitudes. Of organizations serving caregivers in California, nearly half indicate there is little or no targeting for LGBT caregivers.[72]

Culturally tailored information and programming. Even when caregivers are aware of available services, they often assume that these services do not provide culturally relevant programming.[9,95] In many cases, this is true. Of organizations providing services to caregivers in California, just 67% indicated their organizations strive to provide culturally relevant and competent services.[72] Nineteen percent indicated their organization did little or no targeting of caregivers from racial/ethnic minority groups. Some educational interventions have been adapted and have been demonstrated to benefit multiple racial/ethnic and cultural groups, but not many.[3] Interventions adapted to meet the unique needs of LGBT caregivers are virtually non-existent.[3]

GETTING TO KNOW
California's Caregiver Resource Centers

At the 11 CRCs throughout the state, caregiver needs can be assessed so that tools like support groups, counseling, and educational programming can be identified

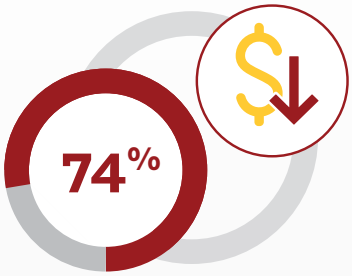
Caregivers expressed high satisfaction with these services, with



94% of caregivers reporting that CRC staff provided them with information and resources to best manage their caregiving situation

96% finding the educational programs they attended helpful

California's Caregiver Resource Centers have been providing direct services, information services and evidence-based educational programs for decades, and are integral to California's Aging Network . . . California Caregiver Resource Centers that were established in law in 1984.



In 2009, **CRC funding was cut by 74%**, from $10.5 million. In 2015, a $2 million recovery restored some of these funds, but current levels of funding remain far below 2008 levels and are inadequate to meet demands

Although recent reports on CRC services are not available following severe funding cuts, the most recent report from 2008 indicates that **13,143 caregivers received family consultations** that year and **712 participated in psychoeducational support groups**

Additional funding for CRCs would expand the reach of programs and services and support innovative new programs, including digital and online services

> As a small, private non-profit, it is difficult to provide translations or find staff members who speak languages that we may need to serve families.
>
> *Service provider from the Best Practices Study of Caregiver Services and Supports in California, see Appendix E*

A national survey found that 22% of Hispanic caregivers and 19% of Asian caregivers expressed a need for non-English informational materials.[23] Of organizations providing services to caregivers in California, 83% indicated the provided services in languages other than English and 79% indicated they provided written materials to caregivers in a language other than English.[72] Still, some of these efforts have been marred by poor translation.[23]

Training for providers. In focus groups, caregivers from racial/ethnic minority groups in California expressed their desire for providers to better understand their culture by receiving training on cultural competence.[9] Cultural competence is "a set of congruent behaviors, attitudes, and policies that come together in a system or agency, or among professionals, that enables effective work in cross-cultural situations."[97] Such cross-cultural contexts are the norm in California, where healthcare professionals, social service providers, caregivers, and care recipients are likely to differ in cultural and linguistic background. Service providers must be adept in navigating cross-cultural encounters to effectively support the state's caregiver population.[98] At the same time, it is also important that providers do not make assumptions based on a caregiver's background, and respect individual differences.[99] Seventy-two percent of organizations serving caregivers in California provide training on cultural competence to staff.[72] However, among those organizations providing some form of training, the frequency of trainings varied considerably. Forty-nine percent indicate staff received training at least once a year, and another 28% indicate this occurred at least every two to five years. Considering the amount of staff turnover that can occur during this time, a frequency of less than once per year is likely inadequate.

Similar training is important to serve LGBT caregivers.[100] In one study, it was found that Area Agencies on Aging employees who received training on serving LGB individuals were twice as likely to receive requests for assistance from this population.[96] In 2006 the legislature passed the Older Californian Equality and Protection Act, requiring agencies to offer provider training on LGBT older adults, and to consider the specific needs of LGBT elders in area plans and assessments.[101] Given overlap in organizations serving older adults and caregivers, many of the same providers who assist caregivers receive training under this legislation. In 2008 legislation requiring health care staff in long-term care settings be trained in preventing discrimination based on sexual orientation and gender identity was passed.[102] Still, caregivers need to be wary, as there is some indication that in some areas training is completed merely to "check a box."[72,103]

> It's imperative to understand different cultures to best meet the needs of our participants.
>
> *Service provider from the Best Practices Study of Caregiver Services and Supports in California, see Appendix E*

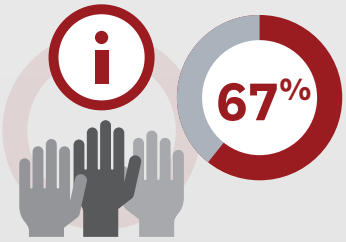
Evidence-based educational interventions for caregivers

There are a wide variety of evidence-based programs and interventions to equip caregivers for their role.[3,104] Evidence-based interventions are interventions that have been rigorously tested in multiple settings such that positive outcomes (e.g., improved health) can be attributed primarily to the intervention. Evidence-based interventions ensure that resources are well-spent

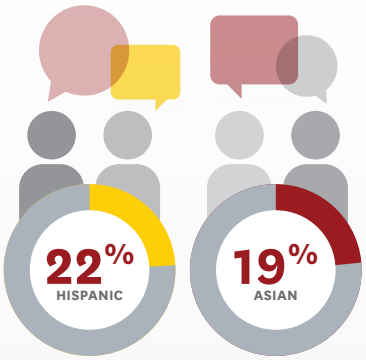
CULTURALLY TAILORED EDUCATIONAL MATERIALS AND SERVICES

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**

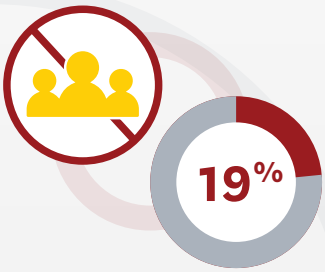
Some educational interventions have been adapted and demonstrated to benefit multiple racial, ethnic, and cultural groups, but not many



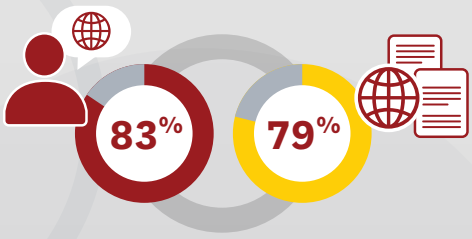
Of organizations providing services to caregivers in California, just **67% indicated their organizations strive to provide culturally relevant and competent services**



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



19% of organizations providing services to caregivers in indicated their organization did little or no targeting of racial/ethnic minority caregiver



Of organizations providing services to caregivers in California, **83%** indicated the provided services in languages other than English and **79%** indicated they provided written materials to caregivers in a language other than English

by raising the likelihood of positive outcomes.[105] One problem with these programs and other evidence-based interventions is that they are difficult to implement because they require organizations to purchase licensed materials and training. [3, 106]

Two of the most common evidence-based educational programs offered throughout California are 1) Savvy Caregiver and the Spanish-language version, Cuidano con Respeto, for caregivers to people with dementia and 2) Powerful Tools for Caregivers. Promising outcomes from Savvy Caregiver include improved caregiver competence,[94,107] improved reaction to disruptive behaviors, [94,107,108] reduced depression,[107] reduced burden,[107,108] reduced anxiety,[107] and reduced frequency of behavioral symptoms of dementia (e.g., wandering).[107] Powerful Tools is effective at improving self-efficacy,[109,110] enhancing self-care,[109,110] improving health,[109,110] and increasing knowledge of community resources.[109] Both programs have demonstrated effectiveness in racial/ethnic minority populations.[108,111] In 2014 the state reported 13,646 caregivers benefited from counseling, support groups, or training, including the Savvy Caregiver and Powerful Tools programs.[112] While impressive, this is a small fraction of all caregivers in the state.

The role of California's Caregiver Resource Centers in facilitating access to information, education, and training

California's Caregiver Resource Centers have been providing information services and evidence-based educational programs for decades, and are integral to California's Aging Network. Services provided by California's CRCs are available to caregivers to people with a range of degenerative conditions with different information needs, including Alzheimer's Disease, Parkinson's Disease, stroke, and others. The Family Caregiver Alliance, which hosts the Bay Area Caregiver Resource Center, previously managed information for and maintained a database on the CRCs. Although recent reports on CRC services are not available following severe funding cuts, the most recent report from 2008 indicates that 13,143 caregivers received family consultations that year and 712 participated in psychoeducational support groups.[112] Caregivers expressed high satisfaction with these services, with 94% of caregivers reporting that CRC staff provided them with information and resources to best manage their caregiving situation, and 96% finding the educational programs they attended helpful. In 2009 CRC funding was cut by 74%, from $10.5 million. In 2015 a $2 million recovery restored some of these funds, but current levels of funding remain far below 2008 levels and are inadequate to meet demands. In their 2014 report, the Senate Select Committee on Aging and Long-Term Care recommended re-investing in programs benefiting caregivers that were subject to severe funding cuts, including the California Caregiver Resource Centers. [113]

There is reason to believe that enhanced caregiver supports, such as those provided by California's CRCs, could reduce costly institutionalization. Researchers at the University of Washington compared service users of the Family Caregiver Support Program before and after additional funding was approved in 2012.[114] With the increased funding, providers could expand services to assist those with slightly lower measured need (e.g., burden) and services were provided at a higher intensity. Twelve months after being screened for FCSP services, 9% of care recipients under expanded services were enrolled in Medicaid-funded long-term supports and services compared to 11% under usual services. Further, at least one evidence-based intervention has found to reduce state Medicaid costs.[115] Although evaluation data is not available, it is possible similar programs delivered by the Aging Network and CRCs, could have a similar effect.

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.

Recommendation 3a: Caregiving requires a wide range of skills, knowledge, and abilities that evolve over time. There is considerable variation between caregivers in what kinds of information are needed, how information is presented, when information is given, and more. Caregivers often do not have a lot of time to search for information, and thus tailored information must be readily accessible. The Task Force recommends the legislature take steps to 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, relevant health and social services organizations should provide education and training at critical points, such as during care transitions and at the time of diagnoses.

Recommendation 3b: 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. Similar challenges exist for LGBT caregivers and those caring for LGBT older adults. The Task Force recommends legislation to increase access to information, education, and training for family caregivers through raising awareness and providing services in culturally-relevant ways.

The following steps are recommended to implement this recommendation:

1. Identify public and private funding services for 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 often hesitate to approach formal services.
2. Fund 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.
3. Evaluate the effectiveness of cultural competence and sensitivity training among organizations that serve family caregivers, including implementing the Older California Equality and Protection Act, which 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 on a regular basis.

Recommendation 3c: Caregivers provide an estimated $58 billion dollars in caregiving each year. Supporting caregivers in this role may lead to delays in care recipients using expensive Medicaid services. The Task Force recommends that legislature increase funding to California's Caregiver Resource Centers (CRCs) for essential services, including information, education, and training to caregivers. 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 innovative program options such as on how to provide complex care tasks.

Recommendation 4:
Increase access to affordable and accessible services

Respite care

Respite care services provide caregivers with a break from caregiving, and may be either planned or provided in an emergency.[116] Respite care is based on the needs of the caregiver, unlike the home- and community-based services that some care recipients receive through Medicaid. Caregivers use respite services so they can go to work or for recreation. Respite often occurs in the care receiver's home, but can be provided in an institution or with a host family.[117] How respite is received—in-home through an agency or friend, at an institution, or at an adult day program—should be up to the family caregiver and recipient. Generally "respite" refers to paid services (e.g., home care provider, adult day services, short-term stay in a facility), but family and friends can be considered informal sources of respite.

Respite is one of the most sought out services for caregivers.[13] Respite services are particularly important to caregivers reporting high burden: 42% of highly burdened caregivers express an interest in respite care compared to 24% of caregivers with low levels of burden.[13] Those who live with the person they care for, attend to a person with Alzheimer's Disease, or care for someone with a mental health issue also show higher levels of interest in respite services.

Respite services positively impact caregivers' health and wellbeing. Using adult day services, a form of respite, lowers caregivers' exposure to stress by approximately an hour per day and dampens the care recipient's reactivity to problem behaviors.[118] Dysregulated cortisol levels—an indication of chronic stress—can be restored in family caregivers to persons with dementia who use an adult day service, even on days when this service is not being provided.[119] This can reduce risk of illness and poor mental health among caregivers.

Barriers to using respite

Despite high interest among caregivers in access to respite services and the measured benefits of these services, just 15% of caregivers reported ever using respite.[13] One of the challenges is finding services, a struggle that resonates with the challenges caregivers face in accessing information, education, and training described above.[120] In addition, lack of available providers and the high costs of respite are key to explaining low rates of respite utilization.

Availability of respite providers. One difficulty caregivers face in scheduling respite services is a shortage in the number of qualified providers. Home care providers, who often provide respite, are one of the fastest growing jobs in the US, and turnover is high.[6, 121] One estimate suggests a 32% per year turnover rate among home care providers.[139] Those in rural areas are particularly likely to struggle with accessing a home care provider, as are caregivers seeking to schedule respite last-minute or for evening hours.[122] 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.

Even where a respite care provider is available, caregivers seeking in-home respite may be reluctant to schedule services because of perceptions about skill level. This is merited to some extent. In-home providers often are left to face a wide range of challenges on their own with little support and minimal training.[6] When respite is scheduled as a one-off occurrence, in-home respite providers are even

> I would like to establish an affordable respite program so the caregivers could get away for a few weekends. For many caregivers who provide around-the-clock care, the cost of around $500 per day to get away is prohibitive.
>
> *Bob Lesh*
> Task Force member, Mountain View

RESPITE IS IMPORTANT TO CAREGIVERS

Respite is one of the most sought out service for caregivers

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Respite services positively impact caregivers' health and wellbeing

Using adult day services, a form of respite, **lowers exposure to stress for caregivers by approximately an hour per day** and dampens reactivity to problem behaviors by the care recipient

more likely to encounter unfamiliar demands. Job retention also contributes to challenges in maintaining a trained workforce.[6,139] Job advancement opportunities, including additional training as recommended by California's Senate Select Committee on Aging and Long-Term Care,[113] could help to address the shortage of trained respite providers by promoting retention and creating a better trained workforce for recipients with complex care needs.

High costs of respite. A major barrier to accessing respite is the high cost. Respite care is expensive. Many caregivers must rely on costly home-care agencies for respite at a median rate of over $25 per hour in California.[123] This exceeds what caregivers are willing and able to pay in many cases, especially when respite care is limited to low-intensity duties like companionship.[124] The average out-of-pocket cost for respite is $587 per year for caregivers.[8] Importantly, this figure excludes caregivers who cannot afford to purchase any respite. For caregivers seeking respite for multiple days, this can be prohibitively expensive. One Task Force member reported that he used to be able to arrange a per diem rate with home care agencies to schedule respite, but recently found he could not find an agency offering a per diem rate anymore even after calling 14 agencies.

Respite through the Older Americans Act and California's Caregiver Resource Centers. For caregivers who are eligible, some publically-available programs provide respite, including some through the Older American's Act. The National Family Caregiver Support Program provides some funding for respite care as a part of Title IIIE services, largely to low-income caregivers. However, since passing, funding for IIIE programs has only reached a maximum of $156.2 million for all services, far below the level of need expressed among caregivers.[116] Although other federal support has been approved in the past through the Lifespan Respite Care Act, the most ever appropriated to the program was $2.5 million per year despite approval for up to $94.8 million.

The California Caregiver Resource Centers distribute some of the state's respite funding to clients from the Older Americans Act, although demand typically outstrips availability of respite scholarships. Respite for clients at the state's Caregiver Resource Centers is not only important in that it allows caregivers to take a break; respite can allow caregivers to participate in other caregiver support services, including in-person support groups, educational events, and conferences. When caregivers have more support options available, they are more likely to participate in support groups that can benefit mental health. [125]

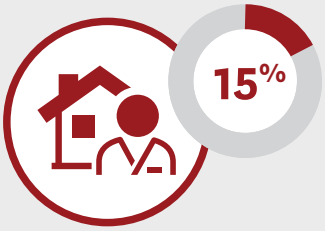
Other means of accessing affordable respite. Caregivers to older adults are not the only group of caregivers who rely on respite. Family caregivers to people with developmental disabilities also use respite services. Regional Centers throughout the state distribute respite services to these caregivers on a sliding-scale basis through the Family Cost Participation Program.[126] This scale is such that middle-income families are able to use respite services without risking financial devastation.[127]

Volunteer pools of respite providers could also help address the high cost of services and could assist with shortages in the number of providers. This is the approach taken by the CareCorps Demonstration Act (H.R. 3493 and H.R. 3494) proposed at the federal level.[128,129] This program would support local programs in matching qualified volunteers with older adults in need of support. Volunteer providers also could be readily found at universities. An exploratory study of a respite care program delivered by social work students found that caregivers were largely satisfied with the student-provided service and appreciated having students engage with the care receiver.[130] Still, many caregivers expressed initial discomfort with leaving an older family members with a student volunteer, limiting the benefits of this approach to respite.

Importantly, respite may support caregivers' continued engagement in the care role, and delay downstream costs including institutionalization in an skilled nursing facility. Residence in a skilled nursing facility, in addition to being undesirable for many people requiring care,[131] is a service frequently paid for by Medicaid after individuals "spend down" savings to be eligible for the program. At least one study demonstrated a delay in institutionalization among caregivers who received respite early in their care journey. [132] Given potential cost savings, state and federal governments have an incentive to help caregivers attain respite.

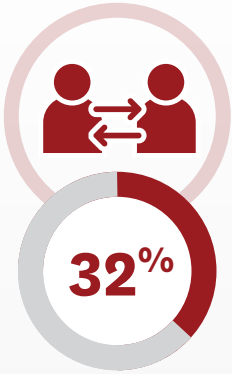
CAREGIVERS STRUGGLE TO ACCESS RESPITE SERVICES

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

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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 4a: There is a shortage of quality respite care providers in the state that meet the needs and preferences of caregivers. The legislature should 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 available to enhance provider recruitment.

Recommendation 4b: Respite care is prohibitively expensive to many caregivers and difficult to access. Demand is expected to grow in coming years given California's aging population. The legislature should expand access to affordable respite services to family caregivers so that they can take a break without harming their financial wellbeing.

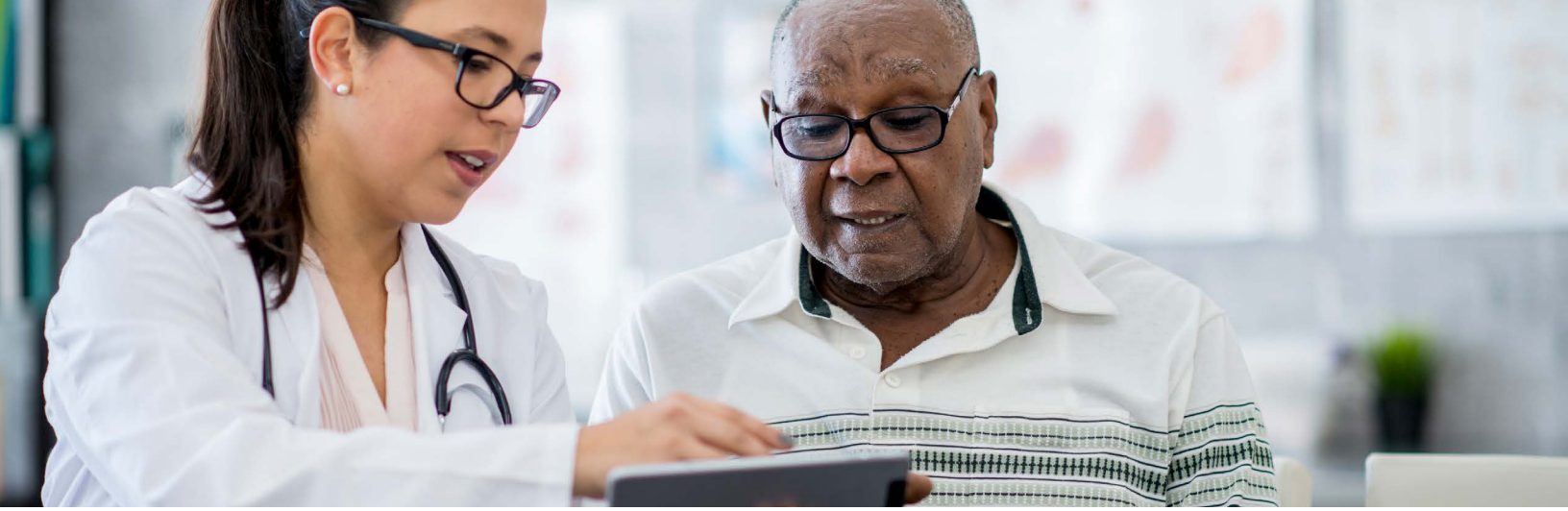
The following steps are recommended to implement this recommendation:

1. Increase respite funding for California's Caregiver Resource Centers, Area Agencies on Aging, and other organizations that currently distribute state funds for respite to family caregivers.

2. 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.

3. Develop an infrastructure and standardized training for volunteer respite provider programs and evaluate its impact on caregiver wellbeing. Volunteers should be trained or otherwise supported to the extent that caregivers still have the ability to leave the home during this respite.

4. Provide respite to caregivers on sliding scale basis, similar to that used for families caring for children with developmental disabilities.



Recommendation 5:
Integrate caregivers into healthcare settings and provide support with complex care

Complex care tasks completed by family caregivers

Forty-six percent of caregivers to those with multiple chronic physical and cognitive conditions report assisting with medical tasks.[5] The most common tasks include medication management (78%), help with assistive devices (43%), preparation of food for special diets (41%), and wound care (35%).[5] Many family caregivers are unprepared to provide complex care and report feeling pressured to do so. For example, of caregivers who manage medication (e.g., administering, monitoring side effects and dosage), 66% found this to be challenging. Approximately 29% reported this task to be challenging due to fear of causing harm, and 24% reported an additional need for training. Most family caregivers (61%) reported learning how to do this task on their own. Of caregivers who provide complex care, more than half indicated they felt they had no choice in the matter. There are several reasons why complex care tasks are increasingly done by family caregivers. Some are demographic; rising life expectancies have not been accompanied by decreases in comorbidities, leading to longer lives in poor health or with a disability.[133,134] Business and policy factors also contribute. Shortening hospital stays and rising home care costs make family caregivers the default choice to provide complex care.[135]

Nurse delegation of complex care tasks

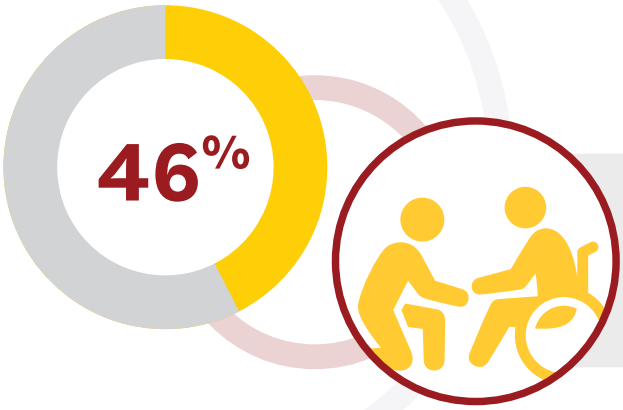
Another reason caregivers take on complex care tasks, despite discomfort and lack of preparation, is that home care providers in California are not allowed to do most complex care tasks. Of 16 suggested tasks, just 2 (administering glucometer test and administer an enema) can be delegated by a nurse to home care providers in California.[136] Oral medication administration, administration of insulin in pre-filled instruments or pens, and administering ear/eye drops are among the tasks that cannot be delegated to a home care aid in California. Most states allow more tasks to be delegated. When ranked against other states on the ability to delegate complex care tasks, California ranked 45th.[136] In states where statutory guidelines were reformed to support delegation, such as Washington and New Jersey, evaluations have shown positive results.[137,138] For example, in New Jersey families reported increased peace of mind and improved timeliness in having tasks completed.[138] Nurses, too, were satisfied with results. Evaluations of this policy change showed no adverse impact of the change. Further, delegation may alleviate anticipated shortages in nurses with the aging population.[139] Training in complex tasks is also an avenue for job advancement for home care retention, supporting retention of these workers.[6,139]

Recognition of caregivers during discharge and support during care transitions

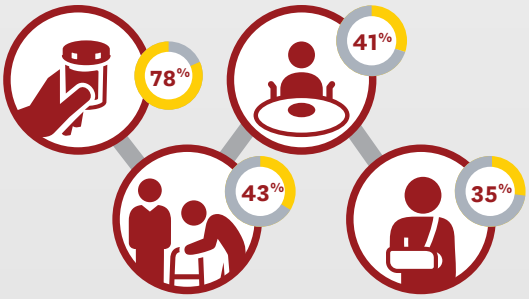
Novel complex care needs often arise following a hospitalization, creating new demands on caregivers. Fifty-three percent of caregivers report the person they cared for visited a hospital in the past year.[13] Despite being an integral member of the care team, the role of family caregivers in healthcare processes is often unrecognized.[140] However, the healthcare system relies on family caregivers to complete many tasks stemming from injuries, illnesses, and disabling conditions after care recipients use medical services.

Discharge processes. "Discharge planning" is defined by Medicare as "a process used to decide what a patient needs for a smooth move from one level of care to another."[141,142] It is a Condition of Participation (CoP)—that is, a funding requirement—for any healthcare

MEDICAL TASKS BY CAREGIVERS



46% percent of caregivers report assisting with medical tasks



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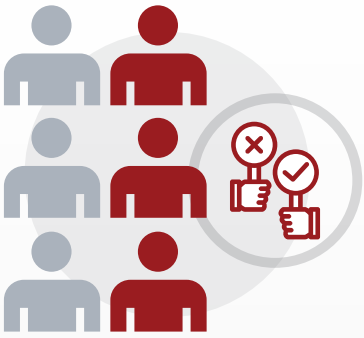
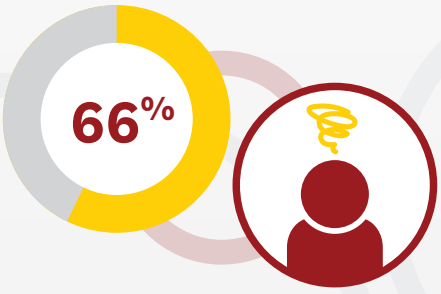


Of caregivers who provide complex care, **more than half indicated they felt they had no choice in the matter**



Many family caregivers are unprepared to provide complex care, and report feeling pressured to do so. For example, of caregivers who manage medication (e.g., administering, monitoring side effects and dosage), **66% found this to be challenging**.

Business and policy factors also contribute. **Shortening hospital stays and rising home care costs make family caregivers the default choice** to provide complex care

facility receiving Medicare reimbursement through Medicare. Although the federal Medicare program has requirements for what actions hospitals must perform as a part of discharge planning, these requirements do little to acknowledge the caregiver where one is identified. Caregivers are discussed as extensions of the care recipient, not individuals who have distinct support needs to fulfill the discharge plan. Given the lack of strict discharge planning requirements through Medicare, patients and family caregivers have vastly different experiences depending on the hospital where services are received. Discharge evaluation questions, staff, the type and extent of education provided, and referrals to outside sources all vary from facility to facility. However, there is growing interest among hospitals in improving discharge processes. The 2009 Patient Protection and Affordable Care Act (ACA) implemented new Medicare value-based payment structures for common conditions associated with high rates of hospital re-admission.[143] Under this reform, hospitals are not reimbursed for the care received by a Medicare patient when they are re-admitted to the same hospital within 30 days of discharge due to the same condition they were originally admitted for. Consequently, many hospitals are reviewing and investing in the discharge planning process to avoid potential loss of financial reimbursement.[144] Support for caregivers at discharge before the care recipient transitions to a new care setting is one way to prevent re-admission.

Care transitions. Support to caregivers during care transitions has been explored to prevent re-admissions. The term "care transition" refers to the movement of the care recipient from one setting to another or to another level of care (e.g., intensive care unit to inpatient rehabilitation), or from formal healthcare facilities to independent living at home.[140] Caregivers report feeling high levels of stress and inconsistencies in the acknowledgement, training, and expectations they receive from healthcare practitioners during transitions. This can cause problems since caregivers' "buy-in" to the care plan and understanding of discharge and at-home tasks are key to care plans being followed.[140,144]

The first month after discharge from a hospital is a time when family caregivers are adapting to changes in psychosocial status and daily functionality. Care that is considered normal in the hospital (e.g., feeding tubes) can be overwhelming for family caregivers, causing many caregivers to report feeling "terrified" when left alone with the patient.[135] This is a time when recipients are most vulnerable to dangerous medication errors, missed care tasks, and lack of support from community-based resources.[141] Patients and their caregivers from racial/ethnic minority groups and people with limited English proficiency may be at an additional disadvantage. Failure to provide culturally relevant education and training during care transitions, as well as lack of translated materials, results in these caregivers not scheduling follow-up appointments.[145] This increases the likelihood of emergency room visits when problems occur.

Access to temporary assistance in scheduling follow-up medical appointments, and arranging medical equipment, home modification, and connection with community resources can remedy caregiver burden and ease the transition to the home environment.[146] The Care Transition Intervention is an evidence-based intervention where caregivers receive training on medication management from a nurse/coach after discharge and are given instructions on responding to health situations (e.g., a list of "red flags" and what to do if one occurs).[147] The program demonstrated a 5% reduction in re-admission rates at 90 days since discharge. At 180 days since discharge, hospital costs for intervention patients was an average of $488 less than for non-intervention patients.

The California Hospital and Family Caregiver Law (Caregiver Advise Recognize and Enable Act)

In response to unmet caregiver training needs at hospital discharge, 40 states have signed into law versions of the Caregiver Advise Recode and Enable (CARE) Act.[148] In October 2015 California passed Senate Bill Number 675 (Lui) known as The California Hospital and Family Caregiver Law, the state's version of the CARE Act.[149] This bill requires hospitals to allow patients to identify a family caregiver upon admission, notify family caregivers of a patient's discharge or transfer to another facility, and provide education on the patient's care needs after discharge, if the patient provides consent to do so. Due to the law's recent passage, little is known about how it is being implemented and its impact. However, there is reason to believe compliance is likely low given that hospitals have little guidance on how to implement the legislation.[150]

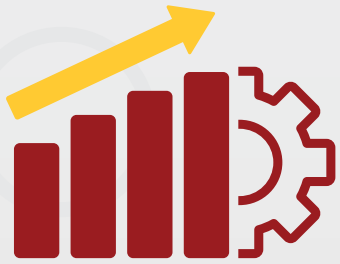
Identifying caregivers in electronic health records

One challenge to implementing the California Hospital and Family Caregiver Law is identifying caregivers in the first place. "Caregiver" is a term used by service providers, but

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 identity 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

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 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

not necessarily adopted by family caregivers.[151] Caregivers often more readily (and understandably) use terms like "spouse," "daughter," or "friend." Some experts advise clinical staff to ask other questions when a patient is admitted, such as "Who assists you at home? Who do you call in case of an emergency? Who helps with medications or doctors' appointments?"[135] Another challenge is with adding caregivers to the medical record; there is often more than one caregiver, a factor which is under-recognized.[3]

Assessing caregivers on their capacity and willingness to provide care

Once identified, the California Hospital and Family Caregiver Law does not require family caregivers to be assessed on either their own needs as a caregiver or their capacity to provide care. This may be a missed opportunity to protect the health and wellbeing of the caregiver and the care recipient. A caregiver assessment prior to discharge can reveal caregiver needs regarding information on medication routines to reduce the risk of dangerous medication errors, and potential issues a caregiver is not anticipating like home modification. It can also help hospital staff with matching the patient and caregiver to the proper resources and/or program in the community.[135] Failure to provide these services can cause emotional distress and anxiety for family caregivers who feel unprepared for their sudden or considerably changed caregiving role.[152]

Training caregivers to provide complex care at home

Hospitals have discretion over what it means to provide education and training to caregivers. Anecdotal evidence suggests this lack of specificity in the legislation has led to an environment where, even when identified, caregivers often receive only minimal information and education. But there is opportunity for innovation. Some health systems in California are using technology to meet California Hospital and Family Caregiver Law requirements, such as video trainings based on specific needs.[153] However, this raises the concern of whether tailored information specific to patients and caregivers is provided. In addition, anecdotal evidence suggests more needs to be done to provide translated informational materials and instruction to caregivers at discharge, as well as materials the caregiver can view at home (e.g., educational videos).

Using telehealth to assist caregivers with accessing services and support

Telehealth is "the use of electronic information and telecommunications technologies to support and promote long distance clinical health care, patient and professional health-related education, public health, and health administration."[154] Telehealth can increase access to services and may reduce the need for caregivers to miss work when they or the person they assist need to attend an appointment. It can also be used to provide education at any time, and has particular value for caregivers who have difficulty leaving the home. Existing telehealth interventions and services for caregivers have included education, consultation, therapy, social support, monitoring, and clinical care.[155] These have shown remarkably positive results in terms of psychological health, knowledge, coping, social support, quality of life, and even cost savings.[155] California's Kaiser Permanente was an early adopter of telehealth services, and has found innovative ways to integrate telehealth into client care plans with relatively high satisfaction.[156] Expanding on initial legislation from 1996, since 2011 California has allowed telehealth to be used to provide Medi-Cal services.[157] Still, some populations struggle to access telehealth services and may be left behind as these services continue to grow and evolve.[158] Federal-level policies for Medicare also make it difficult for providers to be reimbursed for telehealth services, as do private health insurance policies following fee-for-service models.[158] Although some barriers to expanding access to telehealth services are due to federal policies, access within the state could be expanded through provision of equipment, information about existing programs, and training on how to use telehealth services. It is critical that caregivers be supported in accessing telehealth services to address their own health and the recipient's.

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 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: California lags far behind other states in allowing home care providers to do complex care tasks, even tasks as basic as administering medications. As a result, family members must hire a nurse to do these tasks

or complete these themselves. The Task Force recommends that the legislature pass statutory changes that would 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, and administering ear/eye drops.

Recommendation 5b: Discharge processes are often missed opportunities to provide support for family caregivers. Legislation should be submitted to standardize protocols and procedures at hospital discharge that recognize family caregivers once the caregiver is identified.

Specific steps for implementing this recommendation include the following:

- 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: Passing the California Hospital and Family Caregiver Law was an important step to better supporting caregivers with complex care. However, there is little guidance on how to implement provisions of the California Hospital and Family Caregiver Law. The Task Force recommends that legislature enhance current provisions of the California Hospital and Family Caregiver Law to improve recognition and education of family caregivers.

Steps for enhancing the California Hospital and Family Caregiver Law include the following:

- Work with the stakeholders like the California Hospital Association to identity opportunities to improve implementation.
- 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 hospitals provide education to caregivers prior to discharge, require that they 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 California Hospital and Family Caregiver requirements.

Recommendation 5d: Use of telehealth to provide more timely access to care can help both patients and their family caregivers by decreasing the burden and cost of transportation, and lessening travel to and from a provider's office. Telehealth may also help patients remain in their homes longer. While California has a strong telehealth law, the state should ensure telehealth services are available to all persons, regardless of insurer. Furthermore, the state should create greater transparency around telehealth by requiring that in-network provider directories include information about the availability of telehealth-delivered services. ■

Conclusion

Caregivers provide billions of dollars in care each year, care that allows individuals with a disability and older adults to remain in the community, often at a personal cost. They are the cornerstone of California's long-term supports and services system. Policies have not kept pace with the changing circumstances in which caregivers find themselves, leaving many family members and friends who provide help worse off from doing so. The recommendations submitted to the legislature by the California Task Force on Family Caregiving are necessary to address the gap between the needs of family caregivers and existing policies. Recommendations support caregivers' financial security and mental and physical health, and can help families provide high-quality care.

In addition to those recommendations described above, the Task Force has two additional recommendations for the legislature.

Recommendation 6: Increase funding to the California Caregiver Resource Centers to expand services and support innovative programs

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, California's 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 California's 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: Support an ongoing advisory council on family caregiving

The population of caregivers will continue to evolve, as well the types of challenges they encounter in this role. *To ensure that policies continue to keep pace, the Task Force recommends creating 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. Although there are multiple ways this recommendation could accomplished, one option is to enact legislation to put the proposed advisory council under the California Health and Human Services Agency.

The California Task Force on Family Caregiving urges the legislature to act on these recommendations as soon as possible to begin better supporting the state's family caregivers. Gradual and incremental change will result in missed opportunities to help caregivers preserve their health and financial wellbeing.

Appendix A:
Summary of Recommendations from the California Task Force on Family Caregiving

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 1a: Family caregivers spend an average of $7,000 per year on out-of-pocket costs related to caregiving and often draw on their own savings to cover these costs. Federal tax credits for out-of-pocket costs exclude many caregivers. The Task Force recommends that the legislature pass a statewide 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. This credit should be no less than $5,000 per year. Eligibility criteria for this credit should be limited to prevent middle-income caregivers from descending into poverty.

Recommendation 1b: Caregivers may struggle to cover the costs of home care that can allow them to continue in their employment and attend to other responsibilities. The Task Force recommends the legislature implement a long-term insurance program to cover the costs of community-based services where the care recipient is not eligible for Medicaid. Services can include adult day care, chore services, home-delivered meals, personal care, respite care, and transportation.

Recommendation 1c: Caregivers often struggle to balance employment with caregiving. Existing protections have considerable gaps that leave caregivers vulnerable to employment insecurity. The Task Force recommends legislation 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:

1. Reduce the number of employees required for a private sector employer to comply with the federal Family Medical Leave Act (FMLA) in California.
2. Extend job protections found in the FMLA to those participating in the state's Paid Family Leave program (PFL).
3. Expand PFL to automatically apply to public sector employees instead of the current opt-in program.
4. Increase the number of weeks over which PFL is provided from 6 weeks to 12 weeks per year.
5. 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.
6. Require agencies overseeing implementation of awareness campaigns to consult with local community leaders from underserved groups to ensure culturally-appropriate awareness campaigns.

Recommendation 1d: Study the issue of family caregiver retirement with a focus on caregivers who provide care for family members as employees (e.g., In Home Supports and Services providers). Specifically, a study should consider the impact of access to unemployment insurance on caregivers whose family members passed away, and access to state and federal retirement programs by caregivers who have left the workforce to care for family members.

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 2a: Caregiver assessments need to be carefully designed to inform services for individual caregivers and programs, and standardized so information can be compared across organizations. The Task Force recommends the legislature move to develop and implement a standardized caregiver assessment to be delivered universally by programs 1) that deliver services to older adults or anyone over the age of 18 with a disability who relies on the contributions of family caregivers or 2) that 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 comprise empirically-tested measures that can be implemented in a clinical setting with minimal provider burden. Domains should include information on the caregiving context, the health and functional status of the recipient, the caregiver's values and preferences, the wellbeing of the caregiver, consequences of caregiving, the caregiver's skills and knowledge on how to provide care, and resources available to the caregiver. Programs should have the option to further tailor 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: Assessments take time to complete and require trained assessors to do so properly. They are an integral and highly valuable component of service delivery. The Task Force recommends increasing funding for caregiver assessments completed by agencies providing services under The Older Americans Act IIIE program, including Area Agencies on Aging, California Caregiver Resource Centers, and others with IIIE contracts so more caregivers can be reached. The Task Force acknowledges that this recommendation would require action at the federal level.

Recommendation 2c: To understand which caregivers are not accessing services and to track evolving needs in this population, statewide survey data on caregivers is needed. The Task Force recommends regularly collecting 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 including the caregiver module in the California Health Interview Survey. A caregiver-specific module should be included no less than once every three years to provide up-to-date information on this 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 2d: 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.

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 equip caregivers with easily accessible information, education, and training that is specific to their situation, provided in culturally competent and relevant ways.

Recommendation 3a: Caregiving requires a wide range of skills, knowledge, and abilities that evolve over time. There is considerable variation between caregivers in what kinds of information are needed, how information is presented, when information is given, and more. Caregivers often do not have a lot of time to search for information, and thus tailored information must be readily accessible. The Task Force recommends the legislature take steps to 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, relevant health and social services organizations should provide education and training at critical points, such as during care transitions and at the time of diagnoses.

Recommendation 3b: 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. Similar challenges exist for LGBT caregivers and those caring for LGBT older adults. The Task Force recommends legislation to increase access to information, education, and training for family caregivers through raising awareness and providing services in culturally-relevant ways.

The following steps are recommended to implement this recommendation:

1. Identify public and private funding services for 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 often hesitate to approach formal services.

2. Fund 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.

3. Evaluate the effectiveness of cultural competence and sensitivity training among organizations that serve family caregivers, including implementing the Older California Equality and Protection Act, which 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 on a regular basis.

Recommendation 3c: Caregivers provide an estimated $58 billion dollars in caregiving each year. Supporting caregivers in this role may lead to delays in care recipients using expensive Medicaid services. The Task Force recommends that legislatures increase funding to California's Caregiver Resource Centers (CRCs) for essential services, including information, education, and training to caregivers. 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 innovative program options such as how to provide complex care tasks.

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 4a: There is a shortage of quality respite care providers in the state that meet the needs and preferences of caregivers. The legislature should 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 available to enhance provider recruitment.

Recommendation 4b: Respite care is prohibitively expensive to many caregivers and difficult to access. Demand is expected to grow in coming years given California's aging population. The legislature should 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:

1. Increase respite funding for California's Caregiver Resource Centers, Area Agencies on Aging, and other organizations that currently distribute state funds for respite to family caregivers.

2. 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.

3. Develop an infrastructure and standardized training for volunteer respite provider programs and evaluate its impact on caregiver wellbeing. Volunteers should be trained or otherwise supported to the extent that caregivers still have the ability to leave the home during this respite.

4. Provide respite to caregivers on sliding scale basis, similar to that used for families caring for children with developmental disabilities.

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 5a: California lags far behind other states in allowing home care providers to do complex care tasks, even tasks as basic as administering medications. As a result, family members must hire a nurse to do these tasks or complete these themselves. The Task Force recommends that the legislature pass statutory changes that would 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, and administering ear/eye drops.

Recommendation 5b: Discharge processes are often missed opportunities to provide support for family caregivers. Legislation should be submitted to standardize protocols and procedures at hospital discharge that recognize family caregivers once the caregiver is identified.

Specific steps for implementing this recommendation include the following:

1. 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.

2. 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: Passing the California Hospital and Family Caregiver Law was an important step to better supporting caregivers with complex care. However, there is little guidance on how to implement provisions of the California Hospital and Family Caregiver Law . The Task Force recommends that legislature enhance current provisions of the California Hospital and Family Caregiver Law to improve recognition and education of family caregivers.

Steps for enhancing the California Hospital and Family Caregiver Law include the following:

1. Work with the stakeholders like the California Hospital Association to identity opportunities to improve implementation.

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

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

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

5. 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.

Recommendation 5d: The use of telehealth to provide more timely access to care can help both patients and their family caregivers by decreasing the burden and cost of transportation, and lessening travel to and from a provider's office. Telehealth may also help patients remain in their homes longer. While California has a strong telehealth law, the state should ensure telehealth services are available to all persons, regardless of insurer. Furthermore, the state should create greater transparency around telehealth by requiring that in-network provider directories include information about the availability of telehealth-delivered services.

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 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.

Appendix B:
Table of Recommendations

RECOMMENDATION	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
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.	Caregivers face high out-of-pocket costs related to caregiving (e.g., housing costs, home modifications, respite, medical costs).	1a. Pass a statewide tax credit for the out-of-pocket costs of family caregiving. This credit should be no less than $5,000 per year. Eligibility criteria for this credit should be limited to prevent middle-income caregivers from descending into poverty.
	Caregivers to those who are not eligible for Medicaid home- and community-based services struggle to cover the costs of home care that can allow them to continue in their employment and attend to other responsibilities.	1b. The Task Force recommends that the legislature implement a long-term care insurance program to cover the costs of community-based services.
	Caregivers often struggle to balance employment with caregiving. Existing protections have considerable gaps that leave caregivers vulnerable to employment insecurity.	1c. The Task Force recommends legislation 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 raising awareness so caregivers know these programs exist. The following steps are recommended to implement this recommendation: 1. Reduce the number of employees required for a private sector employer to comply with the federal Family Medical Leave Act (FMLA) in California. 2. Extend job protections found in the FMLA to those participating in the state's Paid Family Leave (PFL) program. 3. Expand PFL to automatically apply to public sector employees instead of the current opt-in program. 4. Increase the number of weeks over which PFL is provided from 6 weeks to 12 weeks per year. 5. 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. 6. Require agencies overseeing implementation of awareness campaigns to consult with local community leaders from underserved groups to ensure culturally-appropriate awareness campaigns.
	Little is known about caregivers who provide care for family members as employees, and the long-term financial consequences of this role.	1d: Study the issue of family caregiver retirement with a focus on caregivers who provide care for family members as employees (e.g., In Home Supports and Services providers). Specifically, a study should consider the impact of access to unemployment insurance on caregivers whose family members passed away, and access to state and federal retirement programs by caregivers who have left the workforce to care for family members.

RECOMMENDATION	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
RECOMMENDATION 2: 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.	California does not have a standardized caregiver assessment. A carefully designed standardized assessment would inform services for individual caregivers and programs, and allow information to be compared across organizations.	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. The assessment should be comprised of empirically-tested measures that can be implemented in a clinical setting with minimal provider burden. The platform should further support regular reassessment for those programs where this is appropriate. The assessment and, where applicable, reassessments, should be delivered by providers trained on proper administration.
	Caregiver assessments are an important part of the service delivery process to provide efficient and tailored services to caregivers. Higher reimbursement would support providers in completing high quality assessments.	2b. Advocate for increased funding to provide caregiver assessments completed by agencies providing services under The Older Americans Act IIIE program, including Area Agencies on Aging, California Caregiver Resource Centers, and others with IIIE contracts, so more caregivers can be reached. The Task Force acknowledges that this recommendation would require action at the federal level.
	It is not known who among caregivers are not accessing services and supports, nor is there up-to-date information on the characteristics of this population to inform supportive services.	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. To accomplish this, consider including a caregiver module in the California Health Interview Survey. A caregiver-specific module should be included no less than once every three years to provide up-to-date information on this population. Survey data should be utilized to find out which caregivers are not receiving services throughout the state, and other unmet needs in this population.
	Caregivers often worry about family members with a developmental disability or cognitive impairment wandering and getting lost. It is essential that those who wander be found as soon as possible to prevent their harm. However, agencies in some communities are not adequately equipped to work together to do this.	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.

RECOMMENDATION	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
RECOMMENDATION 3: Equip caregivers with easily accessible information, education, and training specific to their situation, provided in culturally competent and relevant ways.	Caregiving requires a wide range of skills, knowledge, and abilities that evolve over time. There is considerable variation between caregivers in what kinds of information is needed, how information is presented, when information is given, and more. Caregivers often do not have a lot of time to search for information, and thus tailored information must be readily accessible.	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, relevant health and social services organizations should provide education and training at critical points, such as during care transitions and at the time of diagnoses.
	Caregivers from some racial/ethnic, cultural, and linguistic groups 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. Similar challenges exist for LGBT caregivers and those caring for LGBT older adults.	3b. Increase access to information, education, and training for family caregivers through raising awareness and providing services in culturally-relevant ways. The following steps are recommended to implement this recommendation: 1. 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 often hesitate to approach formal services. 2. 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. 3. Evaluate the effectiveness of cultural competence and sensitivity training among organizations that serve family caregivers, including implementing the Older California Equality and Protection Act, which 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.
	California's Caregiver Resource Centers provide essential services, including information, education, and training to caregivers across the state. Current funding levels are inadequate to meet the needs of family caregivers.	Allocated funds to allow California's Caregiver Resource Centers to regularly update resource lists to reflect changing service networks and new programs. 3c. 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	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
	There is a shortage of quality respite care providers in the state that meet the needs and preferences of caregivers.	4a. Recruit additional providers to assist caregivers, especially those 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 4: Increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.	Respite care is prohibitively expensive to many caregivers and difficult to access. Demand is expected to grow in coming years given California's aging population.	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: 1. Increase respite funding for California's Caregiver Resource Centers, Area Agencies on Aging, and other organizations that currently distribute state funds for respite to family caregivers. 2. 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. 3. Develop an infrastructure and standardized training for volunteer respite provider programs and evaluate its impact on caregiver wellbeing. Volunteers should be trained or otherwise supported to the extent that caregivers still have the ability to leave the home during this respite. 4. Provide respite to caregivers on sliding scale basis, similar to that used for families caring for children with developmental disabilities.

RECOMMENDATION	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
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.	California lags far behind other states in allowing home care providers to do complex care tasks, even tasks as basic as administering medications. As a result, family members must hire a nurse to do these tasks or complete these themselves.	5a. Pass statutory changes that would 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, and administering ear/eye drops.
	Discharge are often missed opportunities to provide support for family caregivers. Discharge generally precedes a care transition, a time when risk of harm to older adults is high.	5b. Standardize protocols and procedures at hospital discharge that recognizes family caregivers once the caregiver is identified. Specific steps for implementing this recommendation include: 1. 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. 2. 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.
	There is little guidance on how to implement provisions of the California Hospital and Family Caregiver Law , which may undermine its effectiveness.	5c. Enhance current provisions of the California Hospital and Family Caregiver Law to improve recognition and education of family caregivers. Steps for enhancing the California Hospital and Family Caregiver Law include: 1. Work with stakeholders like the California Hospital Association to identity opportunities to improve implementation. 2. Require hospitals to enable recipients to list multiple caregivers in their electronic health records. 3. Require hospitals to provide educational materials that families can take home and review after discharge, in addition to education provided in the hospital. 4. 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. 5. 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.
	The use of telehealth to provide more timely access to care can help both patients and their family caregivers by decreasing the burden and cost of transportation, and lessening travel to and from a provider's office. Teleheath may also help patients remain in their homes longer.	5d. Ensure telehealth services are available to all persons, regardless of insurer. Create greater transparency around telehealth by requiring that in-network provider directories include information about the availability of telehealth-delivered services.

RECOMMENDATION	REASONS FOR THE RECOMMENDATION	COMPONENTS OF RECOMMENDATION
RECOMMENDATION 6: Increase funding to California's Caregiver Resource Centers to expand services, including respite and educational programs, and support innovative programs.	California has a ready service infrastructure 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 with an aging population.	The Task Force recommends the legislature increase funding to the California Caregiver Resource Centers. 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: 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.	The population of caregivers will continue to evolve, as well the types of challenges they encounter in this role.	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. 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.

Appendix C:
Appointed members of the California Task Force on Family Caregiving

Mary Ball, Former President / CEO at Alzheimer's San Diego, Assembly Appointee

Mary Ball, Former President & Chief Executive Officer of Alzheimer's San Diego, brings versatile experience from leadership roles in business, government, and nonprofit sectors to an organization that serves the more than 60,000 individuals and their families who are battling the disease today in San Diego. Ball has played a crucial role in the incredible progress San Diego has made to advance care and cure in our community. Through her innate ability to inspire key community leaders to join the effort, and to lead a team rooted in their commitment to serving families, Ball has helped build an incredible local momentum for addressing the Alzheimer's epidemic in San Diego.

Donna Benton (Chair), PhD, Research Associate Professor of Gerontology at, University of Southern California, Senate Appointee

Donna Benton, PhD, is a Research Associate Professor of Gerontology at the USC Leonard Davis School of Gerontology. She received her graduate training in clinical psychology from the California School of Professional Psychology and was a Gero-psychological postdoctoral fellow at USC/Rancho Los Amigos Medical Center. Dr. Benton is the Director of the USC Family Caregiver Support Center /Los Angeles Caregiver Resource Center. She has over 30 years of experience in working with families and the community, to help improve services and support to persons with dementia. She has served as a commissioner on the California Commission on Aging (CCOA) and served as chair of the legislative sub-committee for many years.

Les Cohen, Legislative Advocate Emeritus, atnd Orange County Ombudsman, Senate Appointee

Les had a 40 year long and successful history as an accomplished legislative advocate emeritus walking the Halls of the State Capitol on behalf of a diverse group of public and private clients. He has spent the last 12 years a volunteer Ombudsman, with 4 years in Sacramento and currently 8 years with the Council on Aging-OC. Les was honored by the legislature when he retired in 2000.

Carmen Estrada, Executive Director of Inland Caregiver Resource Center, Assembly Appointee

In addition to serving as the Executive Director of the Inland Caregiver Resource Center, Carmen Estrada is a member of the Association of California Caregiver Resource Centers, Inland Empire Disabilities Collaborative, San Bernardino County Intergenerational Committee, and San Bernardino County Senior Affairs Commission.

Sandra Fitzpatrick (Co-Chair) Executive Director of the California Commission on Aging, Assembly Appointee

Sandra Fitzpatrick has over 35 years of experience in development and evaluation of senior and volunteer services, with an expertise in rural service delivery. Since 2004, Ms. Fitzpatrick has been the Executive Director of the California Commission on Aging, which serves as the principal advocate for 6+ million older Californians. She launched several Commission-led efforts, including the Senior Center Initiative, Elder Justice Initiative and Aging Women & Poverty Collaborative. In 2005, she worked with the Governor's office to coordinate California's White House Conference on Aging delegation and attended the Conference as a national policy committee voting delegate. She is a member of the California Elder Justice Coalition and an honorary Board Member of the California Foundation on Aging. Formerly, she was the Executive Director of the Area Agency on Aging in northern California and a member of the Executive Committee of the California Association of Area Agencies on Aging.

Kathleen Kelly, MPA, Executive Director of the Family Caregiver Alliance, Senate Appointee

Kathleen Kelly is Executive Director of Family Caregiver Alliance, a national nonprofit organization that provides direct caregiver support services, public policy development, research and public awareness regarding family caregivers. As Director, she oversees programs of the Bay Area Caregiver Resource Center providing direct services to families in the San Francisco Bay Area, California policy collaborations and the National Center on Caregiving. During her tenure the organization has grown from a grassroots program to a national organization that provides leadership on supporting family caregivers with best practice interventions, public policy, state system development and leading edge research.

Ms. Kelly represents the agency on a variety of national coalitions and partnerships that are working towards coordinated care with the inclusion of family caregivers as

part of the care team, better training for health and social service professionals and increasing training and support for family caregivers. In her current project portfolio, Ms. Kelly is heading a team that developed FCA CareJourney, a system approach that combines data and services together to deliver tailored supports over the long term using secure mobile ready technologies. She has written and lectured about caregiving, public policy, program and system development and use of consumer technology. Ms. Kelly lives with her family in San Francisco, CA.

Robert Lesh, Consumer, Mountain View, Assembly Appointee

Mr. Robert Lesh was chosen to join the Task Force on Family Caregiving based on his forty-two years of personal experience in family caregiving, having submitted his name at the behest of the Northern California Chapter of the Mutiple Sclerosis Society. Prior to his appointment on the task force, Mr. Lesh worked for forty years as a sales representative and sales manager in the medical industry; during that time, he sold both capital and disposable products. Additionally, for the past forty-two years he has acted as a primary caregiver for his wife, who was diagnosed with multiple sclerosis shortly before the two married. Mr. Lesh hopes to bring his personal experience as a full-time family caregiver and active MS support group leader to the task force in order to provide a consumer-driven view of caregivers' most significant needs.

Karen Lincoln, PhD, Associate Professor and Director of, USC Hartford Center of Excellence in Geriatric Social Work at the University of Southern California, Senate Appointee

Dr. Karen D. Lincoln is an Associate Professor in the USC School of Social Work, Director of the USC Hartford Center of Excellence in Geriatric Social Work, Co-director at the Southern California Clinical and Translational Science Institute, Community Engagement Core, and Founder and Chair of Advocates for African American Elders at the University of Southern California. Dr. Lincoln has published over 50 articles and book chapters in the areas of stress, aging and mental health disparities. She has been published in The New York Times and The Wall Street Journal and has contributed to articles published in The Washington Post, US News & World Report, Los Angeles Magazine, Los Angeles Daily News, and the St. Louis Post-Dispatch. Dr. Lincoln has received more than $2 million in grant funding to support her research which focuses on improving clinical and community-based treatment of African Americans with mental health disorders and chronic health conditions. She also contributes to a blog where she fuses social commentary with her vast knowledge of health and mental health of African American communities; posing questions such as "Is Being Black Bad for Your Health?," disseminating information about how the Affordable Care Act will impact African Americans, and sharing her inspiration for a "Healthy Black America."

Dr. Lincoln is a Fellow of the Gerontological Society of America, a Hartford Faculty Scholar, and a member of the California Task Force for Family Caregiving. She is also Owner and CEO of Karen D. Lincoln Consulting Services. Her company provides a full range of applied research and evaluation services and cultural competency training to nonprofits, community-based organizations, government agencies and major universities.

Dr. Lincoln is an honors graduate from UC Berkeley where she received a B.A. in Sociology with a minor in African American studies and a graduate from the University of Michigan where she earned a MSW, a M.A. in Sociology and a Ph.D. in Social Work and Sociology. In 2014, Dr. Lincoln was ranked third among the most influential African American social work scholars in the United States. In 2015, she was ranked twelfth among all female social work scholars in the United States.

Anat Louis, PsyD, Director Direct Services at the , Department of Aging for the, City of Los Angeles, Assembly Appointee

Dr. Louis oversees Core Programs at the City of Los Angeles Department of Aging, including Information & Assistance, Program Development, the Emergency Alert Response System program, and Emergency Assistance Program. She is the Program lead in the LA City and County Adult & Disability Resource Connection (ADRC). Dr. Louis serves as the department's expert on family caregiving by developing training and community outreach, and serves as a committee member of various networks and community-based programs. Presently, she sits on several committees, including: USC Alzheimer's Disease Research Center; Fall Prevention Coalition Steering Committee; UCLA SPIRP (Stroke Prevention Intervention Research Project) committee; UCLA Healthy Aging Partnership in Prevention Initiative (HAPPI); LA County Older Adult System of Care committee and City Attorney Late in Life Advocacy Counsel (LILAC).

Eric Mercado, Research Editor at, Los Angeles Magazine, Senate Appointee

Eric Mercado has been research editor at Los Angeles Magazine since 1995, where he oversees the research department and manages the editorial interns. His primary job, however, is making sure no mistakes creep into the magazine. Mercado, a former reporter at Eastern Group Publications in East L.A., served as associate research editor at the L.A. Weekly before coming to Los Angeles.

Douglas (Doug) Moore, Executive Director of the UDW Homecare Providers Union and International Vice President of the American Federation of State, County, and Municipal Employees, Assembly Appointee

Doug Moore is the Executive Director of the United Domestic Workers of America, a homecare union made up of over 66,000 in-home care providers across the state of California. He is also an International Vice President of AFSCME, and has an outstanding record of success building and energizing member-driven unions spanning more than 30 years. Moore began his career in 1980 as a rank-and-file member of CWA and has since worked for SEIU, AFL-CIO, and AFSCME. In 2005 Moore was appointed the Deputy Administrator of UDW and rebuilt the struggling union from the ground up. Today, thanks in large part to Moore's fearless leadership, UDW is the largest and most innovative AFSCME local in California.

Edie Yau, Director of Diversity and Inclusion for the Alzheimer's Association, Senate Appointee

Edie Yau is from Santa Clara and is the Director of Diversity and Inclusion for the Alzheimer's Association, Northern California and Northern Nevada Chapter. She has led the chapter to develop and implement culturally relevant programs for families. She also serves on the Latino Health Advisory Board for the UC Davis School of Medicine Latino Aging Research Resource Center. Ms. Yau has been in the field of aging for over 20 years and has an MA in Gerontology.

Appendix D:
Glossary

1115 WAIVER
The Medicaid program provides the opportunity for states to apply for waivers that allow them alter their program. There are multiple types of Medicaid waivers states can apply for. Section 1115 waivers allow states to pilot and evaluate new policies and approaches, and are often limited to specific demographic regions.[159]

ALZHEIMER'S DISEASE AND RELATED DEMENTIA (ADRD)
Dementia, a symptom of Alzheimer's Disease and other neurodegenerative conditions, denotes memory and other forms of cognitive decline impacting one's ability to function independently. Alzheimer's Disease (AD) is the most common cause of dementia. In most cases, dementia is not reversible and often triggers a need for care and supportive services.

THE CALIFORNIA HOSPITAL AND FAMILY CAREGIVER LAW
This legislation provides additional support to caregivers during hospital transitions by requiring hospitals to attempt to record the name of the family caregiver at admission, notify the caregiver when the recipient/patient is discharged, provide instructions to family caregivers to meet recipient needs (e.g., how to administer medications), and provide information in a culturally appropriate manner.[160] California passed this law in October 2015 in SB 675.[149] In other states, similar legislation is called the Caregiver Advice, Recognize, and Enable Act (CARE Act).

CAREGIVER
Any relative, spouse, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance to, an older person or an adult with a chronic or disabling condition.[1]

CARE MANAGEMENT
Caring for an older adult with a disability often requires support from a network of multiple agents, including primary and secondary family caregivers, LTSS, and legal, medical, and other community services. Care management helps those needing support and their caregivers identify and access appropriate services.[161] *Care coordination*, a related term, refers the actual arrangement of supportive services. During care coordination, key goals include providing continuum of services.

CARE TRANSITION
When a patient requiring support due to physical or functional limitations moves from one setting to another, such as a hospital back to the community. During transitions, caregivers often must take on new caregiving tasks with little experience, such as providing wound care after a fall. Care transitions are associated with increased health risk for patients primarily attributable to a fragmented health care system and poor communication.[162]

COMPLEX MEDICAL TASKS
Care duties that go beyond assistance with activities of daily living or instrumental activities of daily living and include medical/nursing tasks. In a recent report by the AARP and United Hospital Fund, medical/nursing tasks included medication management, wound care, equipment monitoring, preparing food for special diets, and incontinence management.[2]

CULTURAL COMPETENCY
The capacity to effectively provide a service within the context of a social group's beliefs, behaviors, and needs, while recognizing and respecting diverse values, needs, and understandings.[163] Services that should display cultural competency include medical services (such as a visit to a primary care provider) and social support services (including-home assistance). Failure to provide culturally competent services can lead to unmet needs for caregivers and care recipients.

CULTURALLY RELEVANT SERVICES
Services that are responsive to clients' cultural backgrounds, beliefs, and values. Examples of culturally relevant services include providing services in the appropriate language and including programming relevant to client populations.

FAMILY MEDICAL LEAVE ACT
Federal legislation requiring private employers with over 50 employees to provide 12 weeks of unpaid leave to eligible employees providing care to certain dependent or seriously ill family members or for their own medical needs. Certain states have additional regulations. In California, certain employees are also eligible for up to 6 weeks of paid leave.

HOME AND COMMUNITY BASED SERVICES (HCBS)

Services provided to Medi-Cal (Medicaid) beneficiaries with a functional and/or cognitive impairment. Services are provided to assist older adults and people with disabilities to remain in the community rather than institutions, and may include homemaker services, home health care, and home modification.

IN-HOME SUPPORTIVE AND SERVICES (IHSS)

IHSS assists with paying for for community-based support for low-income older adults and people with disabilities. Once determined eligible, the care recipient employs the IHSS service provider. Often IHSS providers are family members, who sometimes have little experience providing care.

LONG-TERM SUPPORTS AND SERVICES (LTSS)

LTSS are services provided to individuals with physical and/or functional disabilities to assist with activities of daily living (eating, bathing, dressing, transferring [e.g., getting in and out of bed], and toileting) and instrumental activities of daily living (e.g., preparing meals, shopping, using a telephone, managing medications, managing money, accessing transportation, and housework). LTSS is a broad term, encompassing both institutional and community-based services.

MEDI-CAL

California's Medicaid program, which provides health insurance for certain Americans (e.g., older adults) living at or near poverty. Medi-Cal is the primary payer of long-term care in the US, including nursing home and home- and community-based services.[164] Medi-Cal costs are shared by states and the federal government.

MEDICARE

A federal health insurance provided to nearly all Americans over the age of 65 and some younger people with specific healthcare needs. Medicare has multiple components to it, including acute care, rehabilitation, prevention, and prescription drug coverage. Like Medi-Cal, Medicare is primarily funded by payroll taxes of current working Americans.

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Added to the Oder Americans Act in 2000, the National Family Caregiver Support Program provides services to caregivers of older adults through State Units on Aging, Area Agencies on Aging, and local providers. Services include information and assistance, counseling, respite care, support groups, education, and more.

PAID FAMILY LEAVE

Since 2004 most California employees are eligible for 6 weeks of paid family leave (PFL) when they need to take time out of paid employment to provide care. Payment is funded by payroll taxes through the State Disability Insurance (SDI) program. Notably, PFL does not entail job protection, although many caregivers who are eligible for PFL are eligible for FMLA.

PERSON-CENTERED CARE

Described by experts as care where "individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires."[165]

RESPITE CARE

Care provided by an individual or organization other than the caregiver so that the caregiver can take a break. Respite is provided in a number of ways—regularly each week for a few hours, or for several days at a time. Respite care is known to improve caregiver health and wellbeing.[166] However, respite can be difficult to access, in part because of the high costs.

SOCIAL SECURITY

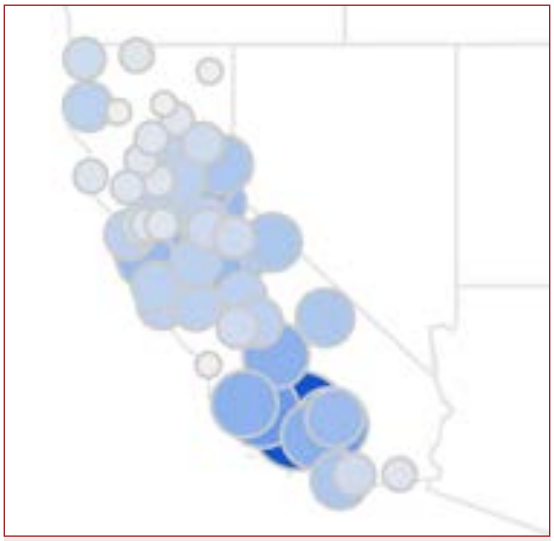
Funded by payroll taxes of current workers, Social Security is a monthly payment provided to eligible older adults to supplement income and lower the risk of poverty in old age. Eligibility is based both on age (age 67 for those born in 1960 and after) and credits. Credits are collected by working in the paid labor force. One can earn up to 4 credits per year, with earning of $1,260 of more counting towards a credit.[167] Workers must earn 40 credits to be eligible for payments. Family caregivers do not receive credits.

Appendix E:

Summary results from the *Best Practices Study of Caregiver Services and Supports in California*

In preparation for making recommendations to the state's legislature in July 2018, the California Task Force on Family Caregiving designed a survey to understand the current state of caregiver services in the state. The Research and Administrative Team at the University of Southern California (USC) prepared, distributed, and analyzed this survey on the Task Force's behalf and with their input.

Collected from August to December 2017, responses to the online survey came from 75 organizations across California that provide direct services to caregivers. Respondents included disease-specific organizations (e.g., Alzheimer's Association) (23%; 17), Area Agencies on Aging (13%; 10), Caregiver Resource Centers (12%; 9), and others. The most frequent services provided by these organizations included education on self-care (80%; 59), communication skills (73%;54), legal issues (72%; 53), and support groups (72%; 53).



Survey responses across California

Key findings:

- Most organizations offered at least one type of caregiver intervention (65%; 45). The most common evidence-based interventions were Powerful Tools for Caregivers (20%; 9) and Savvy Caregiver/Cuidando con Respeto (16%; 7). Many other interventions described in write-in responses were not evidence-based.
- Most programs had eligibility criteria for services (69%; 51), but changes in funding sources led to often-changing criteria.
- Sixty percent (44) of organizations routinely offered a caregiver assessment, although items included on assessments varied considerably.
- Eighty-eight percent (54) of organizations indicated they tailored services to meet specific cultural needs. Write-in responses revealed organizations employed innovative ways to do so, including consulting with partner organizations, assessing cultural competency of organizations receiving referrals, and hiring diverse staff.
- Most organizations (79%; 49) provided support to caregivers juggling competing roles, such as being an employee. The most frequent approaches to support employed caregivers included education (40%; 18) and emotional support and counseling (27%; 12).

Overall, findings suggest that California has a flexible and dedicated network of caregiver support services, but there are considerable holes and weak spots to address. Strengthening this network could prevent caregivers from slipping past services without getting support that could make their role more manageable.

For detailed findings and methodology, please see: http://tffc.usc.edu/wp-content/uploads/2018/01/Best-Practices-in-Serving-California's-Caregivers-1.4.pdf

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