

Health Policy Brief

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Who Is Caring for the Caregivers? The Financial, Physical, and Mental Health Costs of Caregiving in California

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SUMMARY: Data from the 2020 California Health Interview Survey indicate that a sizable proportion of family and friend caregivers in California are struggling financially, experiencing physical or mental health problems, and receiving little if any financial support for their caregiving responsibilities. In 2020, 1 in 4 California caregivers provided 20 or more hours of care to a family member or friend in a typical week, yet only around 1 in 11 received payment for any of the hours spent providing care. More than 20% reported that caring for

a family member or friend was “somewhat” to “extremely” financially stressful, with Black or African American (28%), Asian (23.4%), and Latinx adult caregivers (21.9%) more likely than white adult caregivers (17.7%) to report this experience. In addition to financial concerns, about 1 in 7 caregivers (13.5%) reported a physical or mental health problem within the past 12 months due to caregiving. Fewer than 1% of California caregivers reported using employment-based leave benefits to support their caregiving responsibilities in 2020.

Family and friend caregivers are the backbone of our long-term care system, providing the lion’s share of home and community-based care for people with chronic care needs and disabilities.¹ Most people who provide care do so because caregiving is perceived as a familial responsibility. Those providing care seek to avoid the emotional and financial costs associated with care in institutional settings, such as nursing homes, and instead choose to keep their family member or friend at home, where they prefer to be.

There are both challenges and opportunities associated with caregiving. Numerous studies have documented the many adverse consequences of caregiving to the caregiver, including decreased use of preventive health services, increased risk for negative

physical and/or mental health outcomes, and missed opportunities that result from the reduced time spent nurturing other important relationships and responsibilities, both at home and in the workplace.² At the same time, personal rewards have also been associated with caregiving, as family members and friends experience the gratification of “giving back” to someone who has supported them in the past.³

The nature and intensity of caregiving fall along a broad continuum. While some caregivers provide limited hours of instrumental support (e.g., helping with shopping or getting to medical appointments), others provide significant hours of hands-on assistance with personal care needs (e.g., bathing and dressing).²



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“Only about 1 in 11 reported having been paid for their caregiving hours.”

Many caregivers are engaged in a role that is all-encompassing, providing both instrumental and personal care, while also serving as care coordinators who must navigate a highly complex and fragmented system of health and social services.¹

Using the first California Health Interview Survey (CHIS) data about caregivers available in more than a decade, this policy brief presents a current profile of caregivers in California. We describe who these family and friend caregivers are; whom they care for; and how they are faring financially, physically, and mentally.

A Demographic Profile of California Caregivers

An estimated 6.7 million people were caregivers in California in 2020. In this brief, caregivers are defined as adults who reported providing help in the last 12 months to a family member or friend with a serious or chronic illness or disability. The racial and ethnic identity of caregivers in California closely reflects their representation in the general population: 40.7% identify as white, 37.4% as Latinx, 11% as Asian, 6.3% as Black or African American, 3.4% as two or more races, and fewer than 1% as Native Hawaiian or Pacific Islander (0.5%) or as American Indian or Alaska Native (0.7%). About 1 in 10 caregivers (11.4%) have incomes between 0% and 99% of the federal poverty level (FPL). Around a third (31%) have incomes of 100%–299% FPL, and a majority have incomes of 300% FPL and above (see Appendix Exhibit 1).

Caregivers in California are predominantly women (57.7%). Caregivers in the state represent every adult age group; 1 in 8 (12.6%) are young adults (ages 18 to 25), and 1 in 5 are older adults (ages 65 and over). More than two-thirds (67.5%) of caregivers fall into the middle age range, with the largest proportion (38.9%) between the ages of 45 and 64 (see Appendix Exhibit 1).

Characteristics of Care Recipients

In 2020, about two-thirds (64.7%) of caregivers provided care to older adults (ages 65+), with about 1 in 5 (21.9%) providing care to those among the “oldest old” (ages 85+) (see Appendix Exhibit 2a). Caregivers increasingly care for much older individuals, who are more prone to frailty, at higher risk for falls, and more likely to develop Alzheimer’s disease or other dementias, all of which intensify the demands of caregiving.⁴ About 1 in 5 caregivers reported that the person they were caring for had Alzheimer’s, dementia, confusion, or forgetfulness. A majority of caregivers (57.3%) took care of someone who did not live with them, and about one-quarter of caregivers reported that the person they care for lived alone, which put them at greater risk for falls or other unattended health events.

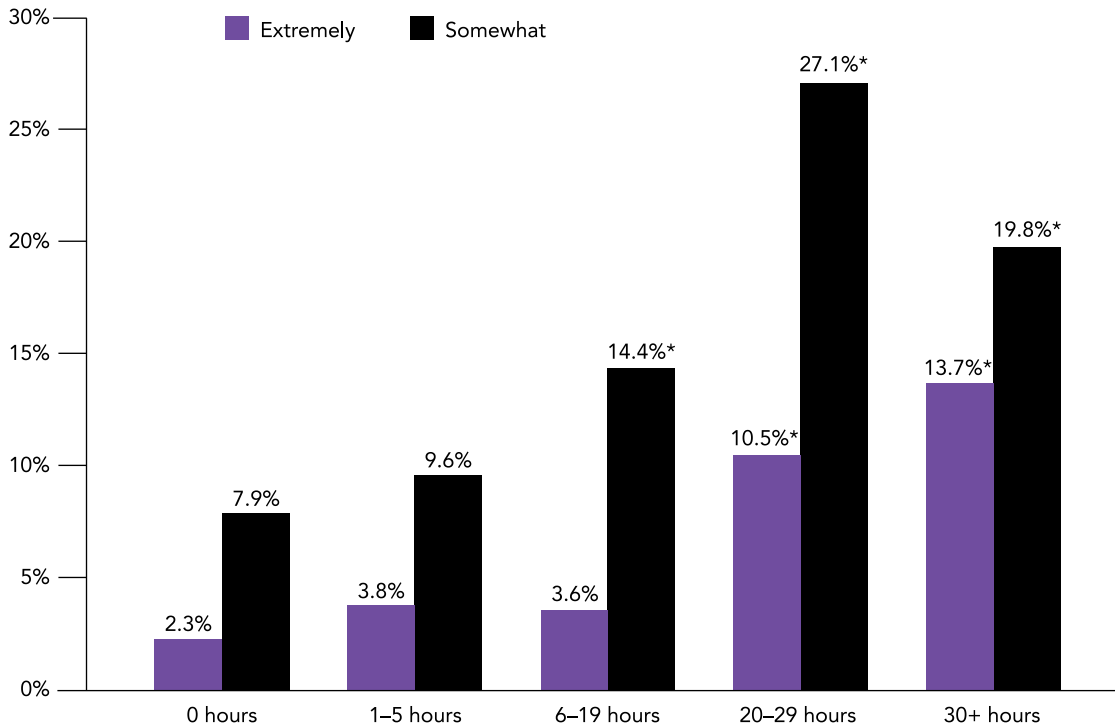
Hidden Costs of Caregiving in California

Caregivers provide essential care to family members or friends with an illness or disability, with care having differing degrees of intensity, depending on the recipient’s level of disability and related care needs. In 2020, close to half of caregivers provided 1 to 5 hours of care during a typical week, while about one-quarter provided 6 to 19 hours of care (similar to a part-time job). Although 1 in 4 caregivers provided 20 or more hours of care per week, and 1 in 8 provided 30 or more hours (similar to a full-time job), only about 1 in 11 (8.8%) reported having been paid for any of these caregiving hours (see Appendix Exhibit 3a-b). The value of these unpaid contributions is enormous, and in 2017 it was estimated at around \$470 billion nationwide and \$63 billion in California.⁵

In addition to the substantial number of hours given to providing uncompensated care, time spent on caregiving often results in “opportunity costs” (e.g., missed opportunities for educational or career advancement, and less time spent on self care and social needs).⁶ While a majority of caregivers reported that they also work a full-time (53.4%) or part-time (9.7%) job, many may be missing out on income-earning opportunities as a result

Financial Stress Due to Caregiving in Past Year, by Number of Care Hours Provided in a Typical Week, 2020

Exhibit 1



Source: 2020 California Health Interview Survey

*Statistically significant at $p < .05$, all groups compared to 1–5 hours

of their caregiving activities. Furthermore, many family caregivers also assume out-of-pocket costs for care-related household and medical expenses, estimated at an average of \$7,242 per year nationally.⁷ Ultimately, these caregivers are juggling multiple responsibilities that contribute to financial, physical, and/or mental strain.

Caregiver Experience of Financial Stress

Nearly half of caregivers (44.4%) report experiencing some level of financial stress due to caregiving, with about 1 in 5 (20.5%) reporting that caring for their relative or friend was “somewhat” to “extremely” financially stressful (see Appendix Exhibit 4a). In general, as the number of care hours provided per week increases, more caregivers report having greater financial stress. For example, around 13% of caregivers who provided 1 to 5 hours of care per week reported that caring for their relative or friend was somewhat to extremely stressful financially, compared with 37.6% of caregivers who provided 20 to 29 hours of

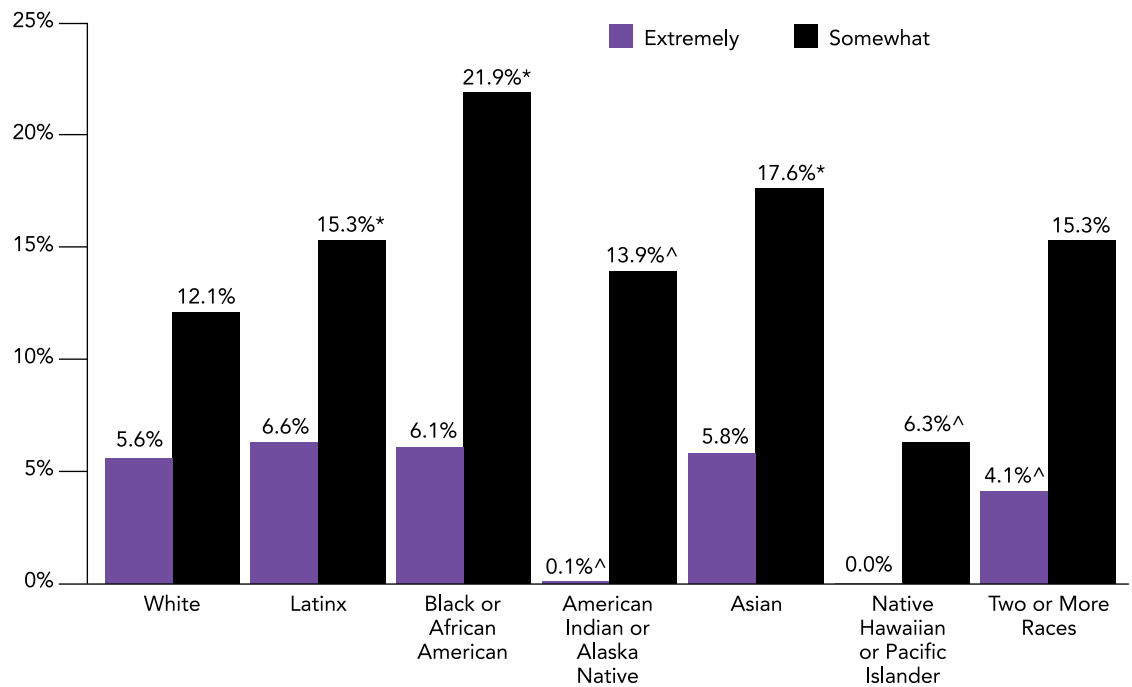
care and 33.5% of those who provided 30 or more hours of care in a typical week. The figures for both of the latter groups were statistically significantly higher compared to the figure for caregivers providing 1 to 5 hours of care (Exhibit 1).

Increased levels of financial stress from caregiving were also associated with a caregiver’s socioeconomic status, measured as a percentage of the federal poverty level (FPL). Notably, the proportion of caregivers with incomes of 0%–99% FPL who experienced “extreme” financial stress was double that of those with incomes of 100%–299% FPL, and three times that of caregivers with incomes of 300%+ FPL, a statistically significant difference. Similarly, twice as many caregivers with incomes of 100%–199% FPL felt “somewhat” financially stressed due to caregiving compared to caregivers with incomes of 300%+ FPL, also a statistically significant difference (see Appendix Exhibit 4b).

“Nearly half of caregivers reported experiencing some level of financial stress due to caregiving.”

Exhibit 2

Financial Stress Due to Caregiving in Past Year, by Race or Ethnicity, 2020



Source: 2020 California Health Interview Survey

*Statistically significant at $p < .05$, all groups compared to white adults

^Statistically unstable estimate

“13.5% of all caregivers reported suffering a physical or mental health problem due to caregiving in the past 12 months.”

Comparing racial or ethnic groups, Black or African American (28%), Asian (23.4%), and Latinx (21.9%) caregivers were more likely than those who were white (17.7%) to report that caregiving was “somewhat” to “extremely” financially stressful (Exhibit 2).

Among caregivers, women (46.4%) were more likely than men (41.7%) to report financial stress across all levels (i.e., “extremely,” “somewhat,” or “a little”) (see Appendix Exhibit 4c). Because women are paid less than men on average across

occupations and industries, this may partially explain why more women than men feel financially stressed as caregivers.⁸

Caregivers’ Physical and Mental Health Problems

CHIS also assessed the extent to which caregiving contributed to caregivers’ physical or mental health problems. In 2020, 13.5% of all caregivers reported suffering a physical or mental health problem due to caregiving in the past 12 months (see Appendix Exhibit 5a).

When accounting for racial or ethnic differences, the proportion of Native Hawaiian or Pacific Islander (NHPI) caregivers (25.3%) reporting physical or mental health problems due to caregiving was nearly double that of the overall caregiver population, although this estimate was statistically unstable (Exhibit 3).

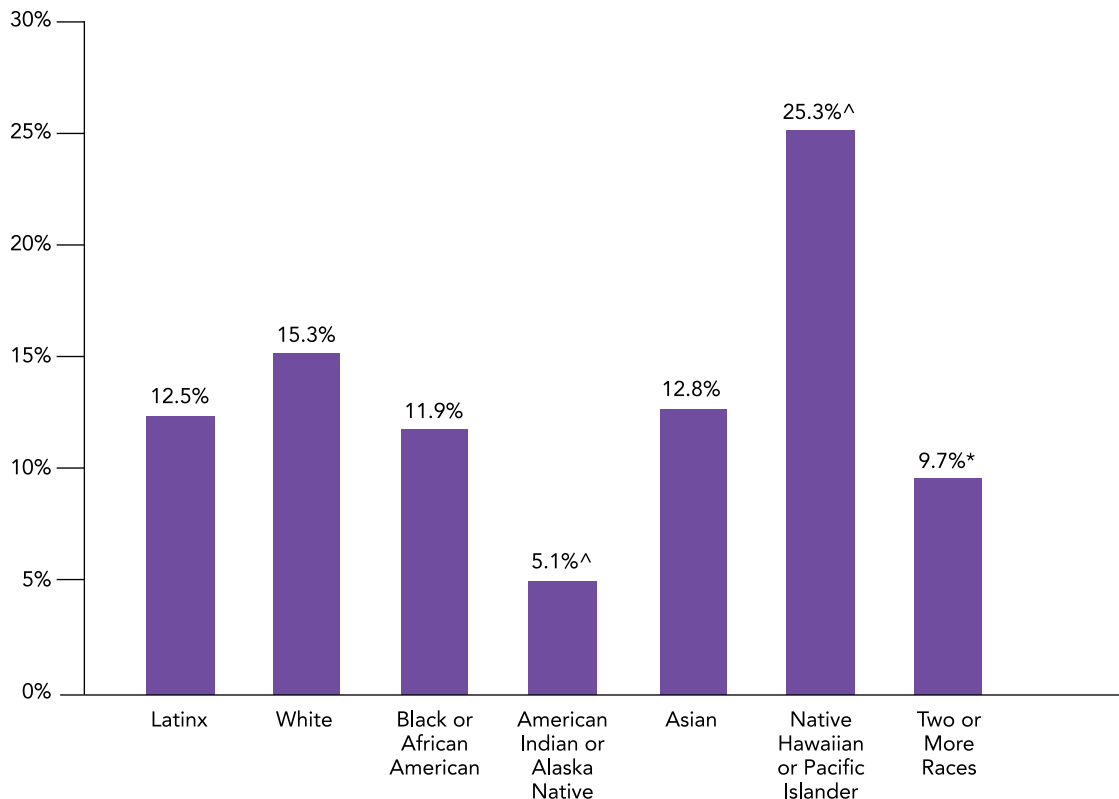
When considering gender differences among caregivers, we found that women were about 50% more likely than men to report physical or mental health problems. Regarding age differences, caregivers ages 18–44 (17.2%) were significantly more likely than middle-aged (45–64 years of age; 11.1%) and older adult caregivers (65+ years of age; 10.5%) to report the same (see Appendix Exhibit 5a-b).

We also found that increased hours of caregiving were associated with an increase in the proportion of caregivers reporting a physical or mental health problem related to caregiving. This finding is similar to the positive association we found between the average amount of caregiving hours provided weekly and reported levels of financial stress. As mentioned previously, the largest proportion of caregivers (47.8%) provide about 1 to 5 hours of care during a typical week. Among these caregivers, about 1 in 10 (11.8%) report having had a physical or mental health problem in the past year due to caregiving. For caregivers who provide 30 or more hours of care (or the equivalent of a full-time job), the percentage reporting a physical

“Among caregivers, women were about 50% more likely than men to report physical or mental health problems.”

Physical and Mental Health Problems Due to Caregiving in Past Year, by Race or Ethnicity, 2020

Exhibit 3



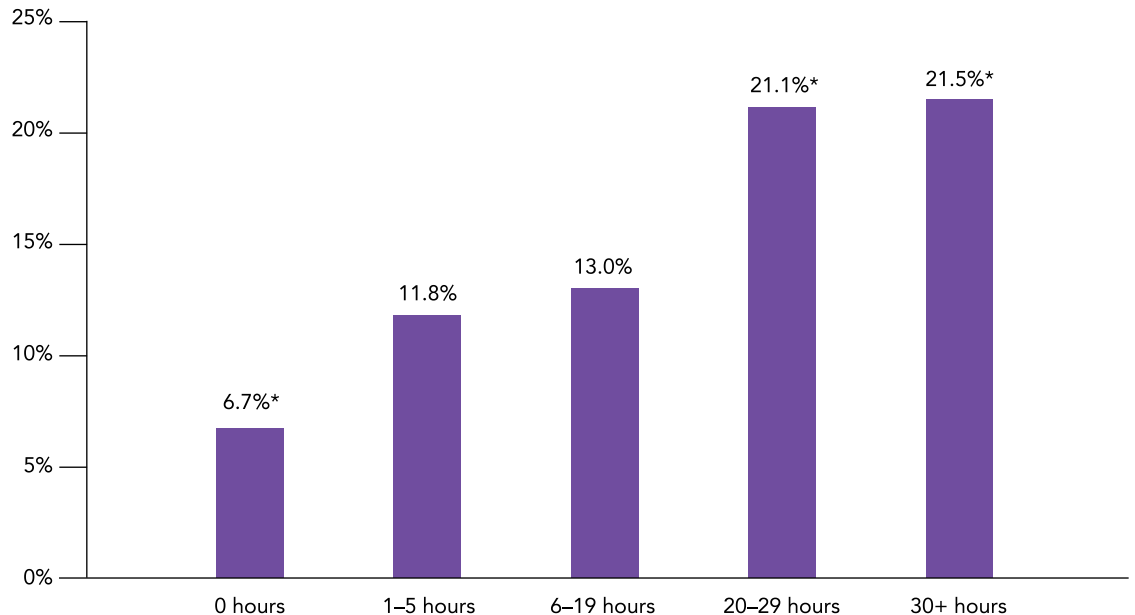
Source: 2020 California Health Interview Survey

*Statistically significant at $p < .05$, all groups compared to white adults

^Statistically unstable estimate

Exhibit 4

Physical or Mental Health Problem Due to Caregiving in Past 12 Months, by Care Hours Provided in a Typical Week, 2020



Source: 2020 California Health Interview Survey

*Statistically significant at $p < .05$, all groups compared to 1-5 hours

“Only a tiny fraction of caregivers reported using employment-based benefits, such as temporary, sick, or vacation leave or paid family leave.”

or mental health problem due to caregiving nearly doubles, to around 1 in 5 (21.5%), a statistically significant difference (Exhibit 4).

Caregiver Utilization of Employment-Based Benefits

As noted earlier, the majority of caregivers (64.4%) were employed. However, only a tiny fraction of caregivers reported using employment-based benefits, such as temporary, sick, or vacation leave (2.8%) or paid family leave (0.7%), which in California is provided primarily through a state benefit program.⁹ Among those who were working full time (53.4%), only 1.3% reported using paid family leave. Even smaller rates of uptake were reported by those who were working part time (0.2%) or who were employed but had not been at work in the past week (0.6%) (data not shown).

Discussion

Since 2002, California has been a leader in spearheading policies that support family caregivers, beginning with the passage of the California Paid Family Leave Act (PFL), which provides eligible caregivers with benefit payments for up to eight weeks in a 12-month period, with income replacement of between 60% and 70% of their weekly wages.

Financial needs of caregivers. Two major limitations of California’s PFL are that it currently does not provide either sufficient income replacement or job protection. The CHIS 2020 data presented in this brief indicate that little of this public benefit is being accessed or used by family caregivers, many of whom have reduced their hours of work, retired early, or quit their jobs.

Only 1.3% of caregivers who also worked full time utilized the PFL program in 2020, despite the fact that most employers are required to collect employee contributions to the California State Disability Insurance program, which funds PFL. Additionally, those providing care to a friend or other non-relative are unable to receive benefits from the program. In 2020, 13.4% of caregivers in California reported that they had provided care to a friend or another individual who was not related to them (see Appendix Exhibit 2e).

Although limitations remain, there is hope on the horizon for enhanced caregiving supports. In recent years, California has passed a series of laws that build on the PFL and aim to alleviate the financial stress that many caregivers experience.

- California Paid Sick Leave, passed in 2015, allows employed individuals a minimum of three job-protected and paid sick days per year.
- Since July 2020, the California Family Rights Act (CFRA) has required employers with 50 or more employees to grant caregivers up to 12 weeks of unpaid time off at any point within a year.
- Senate Bill (SB) 1383 (Jackson), which went into effect on January 1, 2021, broadens eligibility for the CFRA by lowering the employer threshold to five or more employees.

The CFRA and PFL can be applied simultaneously to provide both job protection and income replacement. While SB 1383 and the CFRA help caregivers by expanding access to job protections, they fall short of providing the greater income replacement that many caregivers need in order to use and benefit from these enhancements.

California's Master Plan for Aging (MPA), established through executive order by Governor Gavin Newsom in June 2019, provides an important window of opportunity to advance caregiving policy in California.¹⁰ The plan strives to establish greater resources for paid caregivers through the creation of more caregiving jobs, job placement support, livable wages, and improved job quality.

Importantly, several recent legislative proposals align with—and would expand—MPA caregiving goals by also addressing the financial needs of family and friend caregivers. For example:

- Assembly Bill (AB) 123 (Gonzalez) would have increased the paid family leave benefit to 90% of weekly wages starting in January 2022, but it was vetoed by Governor Newsom.¹¹
- AB 995 (Gonzalez) would extend California's Paid Sick Leave Law from three days to five days, allowing working caregivers to use their paid sick days to care for a family member.
- AB 1041 (Wicks) would expand the definition of "family member" to any "designated person" by an employee, so that caregivers who were once excluded from PFL can now be included.

“In 2020, 13.4% of caregivers in California reported that they had provided care to a friend or individual not related to them.”

“More financial and supportive resources need to be dedicated to bolstering these efforts to assist caregivers.”

These and other proposed bills (see sidebar), if passed into law, would represent tremendous progress in the state’s response to the financial needs of employed family and friend caregivers.

Physical and mental health needs of caregivers. While there is a lack of widely available programs to address the physical and mental health needs of caregivers in California, there are long-standing state-funded programs—such as the Caregiver Resource Centers (CRCs)—that provide a comprehensive set of support services to caregivers at little to no cost.¹² The federally funded VA Program of Comprehensive Assistance for Family Caregivers, which provides supports for family caregivers of post-9/11 veterans, is an exemplary model that addresses both caregiver and care recipient needs.¹³

Policy Recommendations

To better respond to the financial, physical, and mental health needs of California’s caregivers, we recommend the following policy actions:

- Increase awareness, make access easier for family caregivers, and encourage uptake of the paid family leave benefit in California—for example, by promoting it through the Employment Development Department, employers and human resource administrators, aging and disability resource centers, and community/local media efforts.
- Include a mandatory caregiver assessment as part of all health and social services intake processes. Engage health and social services providers to systematically identify and assess caregivers’ financial, health, and social care needs and connect them to appropriate benefits and resources.
- Enhance and expand the reach of existing caregiver support programs—and introduce new ones—that help reduce caregiver financial stress and prevent or address their emergent physical and mental health care needs.

OTHER PROPOSED LEGISLATION

AB 1119 (Wicks) would protect California employees from discrimination for family responsibilities and would require employers to provide reasonable accommodations when an employee’s minor child’s or care recipient’s school or place of care is closed due to an unforeseen need.

AB 84 (Ting) and SB 95 (Skinner) would extend the COVID-19 supplemental paid sick leave and expand the definition of a covered worker. SB95 went into effect earlier this year, but it expired on Sept. 30.

AB 95 (Low) would require California employers with 25 or more employees to provide 10 days of unpaid, job-protected bereavement leave. Employers with fewer than 25 employees would be required to provide 3 days of unpaid, job-protected bereavement leave.

AB 401 (Wicks) would require the Employment Development Department to update its language assistance to better help caregivers who don’t speak English with their PFL claim.

Conclusion

With 1 in 4 California adults providing care to a family member or friend with a serious or chronic illness or disability, more financial and supportive resources need to be dedicated to bolstering these efforts to assist caregivers. Supporting the needs of family and friend caregivers is critically important to ensure that they can continue to provide essential care to their family member or friend, while not compromising their own health and well-being.

Data Sources and Methods

This policy brief presents data from the 2020 CHIS, conducted by the UCLA Center for Health Policy Research (CHPR). In this brief, a caregiver is defined as an individual who provided care to a family member or a friend with a serious or chronic illness or disability in the past year. Data and information on care recipients such as age, relationship with caregiver, illness or disability, and living situation are derived from caregiver responses to questions regarding the person they are caring for.

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The California Health Interview Survey covers a wide array of health-related topics, including health insurance coverage, health status and behaviors, and access to health care. It is based on interviews conducted continuously throughout the year with respondents from more than 20,000 California households. CHIS interviews were offered in English, Spanish, Chinese (both Mandarin and Cantonese), Vietnamese, Korean, and Tagalog. CHIS is designed with complex survey methods requiring analysts to use complex survey weights in order to provide accurate variance estimates and statistical testing. CHIS is a collaboration of the UCLA Center for Health Policy Research, the California Department of Public Health, the California Department of Health Care Services, and the Public Health Institute. For funders and other information on CHIS, visit chis.ucla.edu.

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