SUMMARY: This policy brief profiles California’s informal caregivers—adults who provide care to a family member or friend coping with an illness or disability. Although caregivers appear to be as healthy as non-caregivers of the same age, they report higher levels of psychological distress and engagement in poor health-related behaviors, such as smoking. Middle-aged caregivers may be at greatest risk for poor health outcomes such as high blood pressure, diabetes and heart disease. Few caregivers are paid for their work or use state services that might help alleviate both financial and psychological burdens. Caregivers should foresee difficult times ahead, given recent state budget cuts to programs that support caregivers, and older and disabled adults.

The number of informal caregivers is growing as California’s population ages.

This policy brief examines the health status of California’s informal caregivers using data from the 2009 California Health Interview Survey, the largest state-specific health survey containing one of the few sources of population-based information on California caregivers.

More than six million Californians age 18 and older have provided informal care for a family member or friend with a long-term illness or disability during the past year. This care can involve helping individuals with things they can no longer do for themselves, such as bathing, shopping, managing medications or paying bills. In 2009, California caregivers provided an estimated 3.9 billion hours of care at an estimated value of $47 billion.¹

The magnitude of largely uncompensated care by family and friends will rapidly increase as the U.S. Census projects a more than doubling of the age 65 and older population in the next 30 years.

California’s Caregivers

Caregiving crosses racial boundaries in California. Among adults age 18 and older, approximately one in four white adults (24.8%), one in four African-American adults (26.3%), one in five Hispanic adults (19.8%) and one in six Asian, Hawaiian or Pacific Islander adults (15.9%) is a caregiver.

Compared to non-caregivers, the average caregiver is female, middle-aged and relatively well educated (Exhibit 1). Most caregivers have attended at least some college and have incomes at or above 300% of the Federal Poverty Level (FPL), which in 2009 was $10,830 for an individual and $22,050 for a family of four. Besides their caregiving responsibilities, 52% of caregivers work full-time and around 11% work part-time, similar to the rates of non-caregivers.

Support for this policy brief was provided by a grant from The SCAN Foundation.
What the Caregiving Situation Looks Like for California’s Caregivers

The majority of informal caregivers in California care for a family member and provide long-term assistance—on average, caregivers have been providing care for just over three years. Caregivers provide over 21 hours of care per week. For the approximately one-third of caregivers who live with care recipients, the number of caregiving hours per week increases to 36 hours—almost as much as a full-time job.

California’s informal caregivers may experience financial pressures associated with caregiving, as only 7.4% are paid for their help. Moreover, nearly 20% of caregivers spent more than $250 of their own money on caregiving in the past month. The strains of caregiving may be alleviated by respite services (short-term temporary relief from caregiving), yet only 13.5% of caregivers report ever using any respite care.
A closer look at caregiving by age group reveals notable differences in the caregiving situation. Compared to younger and middle-aged caregivers, older caregivers are more likely to be caring for a spouse or partner (29.8%); living with the person they are caring for (45.2%); providing more hours of care per week (32.2 hrs); and caregiving for a longer period of time (61.8 months; Exhibits 2 and 3).

The Effects of Caregiving on Caregivers’ Health

Although caregivers may appear to be at least as healthy as non-caregivers of the same age, caregivers report having higher levels of psychological distress and engagement in poor health-related behaviors, compared to their non-caregiving counterparts (Exhibit 4). Over one million caregivers report moderate or serious distress levels, with almost one-third of them reporting that their emotions interfere a lot with their household chores (29.9%) or their social lives (32.9%).

Obesity rates as well as binge drinking and current smoking rates are also higher among caregivers compared to non-caregivers. Moreover, among all caregivers, the likelihood of smoking increases by about 208% for caregivers with serious distress compared to those with low distress levels, after controlling for age, race, gender, education and income levels (Exhibit 5).
Caregivers Who May Be Most Vulnerable to Poor Health

Although it may seem that older caregivers would exhibit worse health associated with caregiving since they have been in the caregiver role for longer periods of time and report providing more care hours per week than other caregivers, middle-aged caregivers may actually be at greatest risk for poor health. Compared to both older caregivers and to non-caregivers of the same age, middle-aged caregivers are more likely to binge drink (25.2%), smoke (15.9%), and/or be obese (30.1%; Exhibit 6).

We also found that compared to younger caregivers, middle-aged caregivers are more likely to exhibit poorer health status. Among middle-aged caregivers, 9.8% report having diabetes, 6.6% report having heart disease and 34.3% report having high blood pressure, significantly higher rates compared to those of younger caregivers.

Middle-aged caregivers may provide care with little outside support, as 29% are single, divorced or widowed, and many hold down full-time jobs (58.1%) and part-time jobs (9%). Moreover, 22.5% of middle-aged...
Conclusions

Our study suggests that a support system is critically needed to shore up stressed and strapped caregivers in California. Yet recent cuts to the In-Home Supportive Services program and the scheduled elimination of the Adult Day Health Care program will undoubtedly place greater burdens on informal caregivers to fill the gap left in the wake of these programs.

Provisions of the recent Affordable Care Act (ACA) may provide opportunities to fill the gaps in the wake of program cuts at the state level, although realization of these provisions’ objectives is not certain for the near future. One of the provisions, the CLASS Act, provides a cash benefit to purchase supports and services that could be used to compensate

The CLASS Act could provide significant support to caregivers and their families.
The existing patchwork of elder care programs could be better coordinated.

Caregivers for needed respite or mental health services. The ACA also provides states with more flexibility to offer home and community-based services to low-income, elderly individuals. The Community First Choice Option provides community-based attendant supports and services to disabled individuals requiring an institutional level of care, encouraging Medicaid beneficiaries to remain in their homes. Other Medicaid provisions of the ACA include new funding for Aging and Disability Resource Centers (ADRC) that provide assistance to caregivers and persons with long-term care needs.

Nevertheless, new policies should be considered that coordinate and integrate the patchwork of programs run by the State’s Departments of Aging, Health Care Services and Public Health to give caregivers streamlined and comprehensive access to needed support services. Expanding paid family leave policies to include all types of familial relationships can also protect caregivers’ jobs and keep caregivers in the workforce rather than having them rely on the dwindling public safety net after losing or leaving their jobs because of caregiving.

Given the reduced funding for community-based programs and the uncertain effects of ACA provisions, caregivers should foresee difficult times ahead. The current long-term care system—with its heavy reliance on unpaid, informal care—will likely be unsustainable in the long run.
Health-Related Behaviors by Caregiver Age Group

Exhibit 6

<table>
<thead>
<tr>
<th>Moderate or Severe Social Impairment in Past 12 Months</th>
<th>Moderate or Severe Chore Impairment in Past 12 Months</th>
<th>Current Smoker</th>
<th>Binge Drinking in Past 12 Months</th>
<th>Obese</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 45-64 Caregiver</td>
<td>Ages 45-64 Non-Caregiver</td>
<td>Age 65+ Caregiver</td>
<td>Age 65+ Non-Caregiver</td>
<td></td>
</tr>
<tr>
<td>77.2%</td>
<td>67.2%</td>
<td>15.9%</td>
<td>25.2%</td>
<td>30.1%</td>
</tr>
<tr>
<td>69.5%</td>
<td>61.3%</td>
<td>12.9%</td>
<td>24.5%</td>
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</tr>
<tr>
<td>68.4%</td>
<td>66.6%</td>
<td>7.2%</td>
<td>7.7%</td>
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</tr>
<tr>
<td>66.6%</td>
<td>59.9%</td>
<td></td>
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</tr>
</tbody>
</table>
| Source: 2009 California Health Interview Survey

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Endnotes
1 AARP Public Policy Institute 2011. See http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf
2 Binge drinking for males is defined as having five or more alcoholic drinks in a day and for females as having four or more alcoholic drinks in a day.

“The current system of informal, unpaid care is unsustainable.”