FAMILY CAREGIVING IN CALIFORNIA: 
A SURVEY OF REGISTERED VOTERS 
AGE 40 AND OLDER

July 2019 
Prepared by Terri Guengerich

https://doi.org/10.26419/res.00259.077
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KEY FINDINGS
Key Findings

Forty-four percent of voters age 40-plus in California, have experience as family caregivers, either by currently caring for an adult loved one (14%) or previously doing so (30%).

About nine in ten help their loved ones by providing companionship (94%), transportation (90%), and shopping (90%). Others provide more complex care by managing medications (74%), medical or nursing tasks (65%), or bathing and dressing (63%).

Six in ten (60%) current and former caregivers have worked while they provided care, and two in three (67%) have used their own money to provide care – most commonly on transportation, assistive technology, or home modifications.

Two in three (68%) current and former caregivers say they feel stressed emotionally due to their caregiving responsibilities. African-American/Black caregivers are less likely to report emotional stress (55%).

While most caregivers say that they feel they are helping their loved one (73%) or their family (70%) by providing care, under half say that such caregiving always provides them with a sense of accomplishment (43%).
Key Findings (Cont.)

Voters 40-plus in California overwhelmingly support workplace flexibility for working family caregivers in terms of ensuring employers cannot fire an employee for taking time off for caregiving (83%) and paid leave that allows employees to earn all of their wages while caregiving (70%).

The majority of voters (88%) support the provision of respite care to give family caregivers a break.

The majority of voters (89%) support the provision of a tax credit for family caregivers who incur expenses while providing care.

The majority of voters (85%) support allowing nurses to delegate more of their responsibilities to other trained health care workers, and 89% support allowing nurse practitioners to serve as the primary care provider for patients.

While most voters are not generally aware of telehealth, they overwhelmingly support policies that increase access to telehealth services and insurance coverage of telehealth services.
Over four in ten voters 40-plus in California have experience as family caregivers.

In our survey, the typical family caregiver in California, currently caring for an adult loved one, is a woman (59%), who is married (68%), is 58 years of age, has graduated from college with at least a four-year degree (51%), and lives in a household with income under $100,000 (55%).

- Typical current caregivers also ….
  - Are homeowners (74%) – most likely a single-family home
  - Are in good health (82%)
  - Are currently working (52%), but more had worked at some point while caregiving (66%)
  - Does not have children living at home (58%), but four in ten do (41%)
  - Cares for a parent who is 81 years of age

<table>
<thead>
<tr>
<th></th>
<th>African-American/Black</th>
<th>Hispanic/Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Caregivers</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Former Caregivers</td>
<td>19%</td>
<td>18%</td>
</tr>
<tr>
<td>Never Caregivers</td>
<td>65%</td>
<td>71%</td>
</tr>
</tbody>
</table>

Sample sizes of current caregivers who report their race/ethnicity as African-American/Black or Hispanic/Latino are too small to accurately profile.

Q1. A family caregiver is someone who provides UNPAID care for an adult loved one who is ill, frail, elderly, or has a physical, mental, or emotional disability. This unpaid care may include assisting with personal needs like bathing and dressing, household chores, meals, shopping, transportation, or managing finances or medical care. Are you currently a family caregiver providing UNPAID care to an adult loved one? Base: All Respondents Q15. Have you ever been a family caregiver who provided UNPAID care to an adult loved one? Donut Base: All Respondents Bullet Base: Current Caregivers Chart Base: Respondents by Race/Ethnicity Other surveys questions are listed in the Appendix.
Most caregivers are caring for their parents.

Six in ten current and former caregivers in California provide care to their parents – most likely their mother (39%). Nearly two in ten care for their spouse or significant others, and one in ten care for other relatives such as grandparents, uncles, or aunts. Very few care for their children who are 18 and older, siblings, or non-relatives such as neighbors or friends. African-American/Black (AA/B) caregivers were more likely to care for other relatives (18%) than non-AA/B caregivers (10%). Non-Hispanic/Latino (H/L) caregivers were also more likely to care for other relatives (13%) than H/L caregivers (4%).
Family caregivers help their loved ones with many activities of daily living.

Over nine in ten family caregivers (both current and former) surveyed provide emotional support to their loved ones through companionship or social activities, and nine in ten help their loved one with transportation or shopping. Over eight in ten help with household chores or meals, and over seven in ten help to manage medications or finances.

- At least half of all current caregivers perform many of these tasks every day: bathing/dressing (50%), medical/nursing tasks (50%), companionship (62%), medications (67%), chores (70%), and meals (78%).
- No differences exist in responsibilities of AA/B caregivers compared to non-AA/B caregivers.
- No differences exist in responsibilities of H/L caregivers compared to non-H/L caregivers.

Q4. Thinking about the person you most recently provided care to, which of the following activities did you provide? Are you …? Q18. Thinking about the person you most recently provided care to, which of the following activities did you provide? Did you …? Q5. How often do you …? Is it …? Chart Base: Current and Former Caregivers
Most caregivers have worked while providing care.

Six in ten family caregivers 40-plus held a job while providing care to their loved ones. And many of these caregivers needed to change how they worked as well. Seven in ten working caregivers adjusted their work schedules, either by going into work early or late, or taking time off to provide care – most needing to do so weekly (30%) or monthly (44%). One in three took a leave of absence to provide care. And about a quarter reduced their work hours to provide care or stopped working entirely.

Q6. Have you ever been employed either full- or part-time while providing care to your adult loved one? Q7. Now thinking again about the adult loved one you are currently providing care to, did you ever have to ...? Q19. Have you ever been employed either full or part-time while providing care to your adult loved one? Q20. Now thinking again about the adult loved one you have most recently provided care to, did you ever have to ...? Q8. Q21. How often would you say you had to take time away from work or adjust your work schedule to provide care for someone? Would you say ...? Chart Base: Current and Former Caregivers
Caregivers spend money to provide care and change their homes.

Two in three current and former caregivers 40-plus in California have used their own money to provide care to their loved ones. Over four in ten have modified their own homes, and one in seven has moved into another home.

Q9. Now thinking again about the adult loved one you are currently providing care to, did you ever have to …?

Q22. Now thinking again about the adult loved one you have most recently provided care to, while providing this care did you ever have to …? Chart Base: Current and Former Caregivers

AA/B caregivers are less likely to say they have made changes to their homes (33%) compared to non-AA/B caregivers (46%).
Caregivers spend money transporting their loved ones.

Eight in ten caregivers have spent money to transport their loved ones. About half have spent money on assistive technology (wheelchairs, hearing devices, vision aids, wearable devices) or to modify their homes or their loved ones’ homes. No differences exist in spending money on these services among AA/B or H/L caregivers.
Most caregivers experience some form of stress while providing care.

About nine in ten family caregivers (89%) have experienced at least one of the stressors asked about in this survey. About three in four working caregivers report feeling stressed in trying to balance their work and family responsibilities, and two in three feel stressed emotionally due to their caregiving responsibilities.

<table>
<thead>
<tr>
<th>Stressor</th>
<th>All CA Caregivers</th>
<th>H/L Caregivers</th>
<th>AA/B Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel stressed in trying to balance job and family*</td>
<td>74%</td>
<td>67%</td>
<td>59%</td>
</tr>
<tr>
<td>Feel stressed emotionally</td>
<td>68%</td>
<td>68%</td>
<td>55%</td>
</tr>
<tr>
<td>Find it difficult to get enough rest</td>
<td>57%</td>
<td>63%</td>
<td>52%</td>
</tr>
<tr>
<td>Find it difficult to exercise regularly</td>
<td>49%</td>
<td>57%</td>
<td>35%</td>
</tr>
<tr>
<td>Find it difficult to take care of household</td>
<td>43%</td>
<td>50%</td>
<td>32%</td>
</tr>
<tr>
<td>Experience problems with health</td>
<td>32%</td>
<td>31%</td>
<td>34%</td>
</tr>
<tr>
<td>Feel strained financially</td>
<td>31%</td>
<td>36%</td>
<td>34%</td>
</tr>
<tr>
<td>Find it difficult to maintain a healthy diet</td>
<td>31%</td>
<td>42%</td>
<td>27%</td>
</tr>
<tr>
<td>Find it difficult to find time to visit doctor</td>
<td>28%</td>
<td>33%</td>
<td>23%</td>
</tr>
</tbody>
</table>

- AA/B caregivers report less emotional stress. They also do not find it as difficult to exercise regularly or take care of their households.
- H/L caregivers find it more difficult to exercise regularly and to maintain a healthy diet.

Q11. As a caregiver do you ever …?  Q24. As a caregiver did you ever …?  Chart Base: Current and Former Caregivers  *Asked of working caregivers
Most caregivers feel that the care they provide helps their loved one and their family.

At least seven in ten caregivers believe they are helping their loved ones and their families. Six in ten also feel that the care they provide is appreciated. Fewer caregivers feel that caregiving provides them with a sense of accomplishment or companionship.

- AA/B caregivers (55%) are more likely to “always” feel caregiving provides them with a sense of accomplishment and are more likely to “always” feel their loved one appreciates the care they provide (74%).
- H/L caregivers (59%) are more likely to “always” feel that caregiving provides companionship for them.

Q12. Q25. As a caregiver, how often do you feel that…? Chart Base: Current and Former Caregivers
Many registered voters 40-plus in California say they are likely to be a caregiver in the future.

Likelihood of providing care in the future does vary by caregiver status. Not surprisingly, three in four current caregivers say they are extremely or very likely to provide care in the future. Four in ten former caregivers and about a quarter of those who have never provided care, say they are extremely or very likely to be a caregiver in the future. Younger respondents (40-64) are more likely to say they will be providing care in the future (42%) than respondents 65-plus (28%). Likelihood is similar for all H/L and AA/B voters.

<table>
<thead>
<tr>
<th></th>
<th>Current Caregivers</th>
<th>Former Caregivers</th>
<th>Never a Caregiver</th>
<th>All Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely/very likely</td>
<td>76%</td>
<td>41%</td>
<td>24%</td>
<td>37%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>9%</td>
<td>21%</td>
<td>27%</td>
<td>22%</td>
</tr>
<tr>
<td>Not very/Not at all likely</td>
<td>12%</td>
<td>35%</td>
<td>45%</td>
<td>37%</td>
</tr>
</tbody>
</table>
The most helpful caregiver support is information about caregiving resources.

Six in ten voters in California would also find helpful transportation assistance and respite care. In addition to these helpful supports, eight in ten voters (79%) say it is extremely or very important to have more resources and training for family caregivers. Overall, for most of these supports, AA/B voters and H/L voters are more likely to say that they would be extremely or very helpful.

Q29. In your opinion, as a current caregiver, how helpful would the following types of caregiving support be to you? In your opinion, as a former caregiver, how helpful would the following types of caregiving support be to you? In your opinion, as someone who may provide care in the future, how helpful would the following types of caregiving support be to you? Q30. Family caregivers help older residents in California live independently by performing services like bathing and dressing as well as managing medication and paying bills. How important do you think it is to have more resources and training for family caregivers? Chart Base: All Respondents
End of life or hospice services and well trained home health care providers top the list as the most important services to have in community.

At least eight in ten voters say visiting nurse services, special transportation services, and easily accessible caregiver information and resources are extremely or very important services to have in their communities. Overall, for many of these services, AA/B voters and H/L voters are more likely to say that they would be extremely or very helpful.

Q50. Now I’m going to ask you about some specific community services. Please tell me how important you think it is to have the following services available in your community to help older adults live independently. How important is having XXX in your community? Is it …?

Chart Base: All Respondents
Most voters prefer being cared for at home if they need help.

Over eight in ten voters say that if they or a family member needed help, they would prefer to receive that help at home with caregiver assistance. About one in ten would prefer to receive help in an assisted living facility, and three in a hundred would prefer a nursing home. No differences exist in preference among H/L or AA/B voters.

- Nine in ten caregivers (89%) also say it is extremely or very important to be able to provide care so their loved ones could keep living independently at home.

Q47. If you or a loved one needed help when the basic tasks of life become more difficult due to aging or illness, where would you prefer to receive that care or help for yourself or a loved one? Q13. How important is it to you to be able to provide care for your loved one so that they can keep living independently in their own home? Q26. How important was it to you to be able to provide care for your loved one so that they could keep living independently in their own home? Chart Base: All Respondents. Bullet Base: Current and former caregivers.
There is overwhelming support by California voters 40-plus for workplace flexibility policies for family caregivers.

Over eight in ten voters support a proposal ensuring that employers cannot fire an employee for caregiving. AA/B voters are more likely to support this – 91%. Likewise, seven in ten support a proposal that would allow employees to earn all of their wages while on leave caring for themselves or a loved one – H/L voters (84%) and AA/B voters (87%) are both more likely to support this proposal. Support for both measures of workplace flexibility is high across political parties.

Q31. Now I’m going to ask if you support or oppose some proposals that would provide help for working family caregivers. Do you support or oppose …?

Q32. Is that strongly or somewhat? Chart Base: All Respondents

Support by Political Party

Ensuring employers cannot fire an employee for taking time off for caregiving

- Republicans: 77%
- Independents: 82%
- Democrats: 90%

Allowing employees to earn 100% of their wages while they are on leave caring for themselves or a loved one

- Republicans: 57%
- Independents: 63%
- Democrats: 85%
There is overwhelming support by California voters 40-plus for the provision of respite care for family caregivers.

Nearly nine in ten voters 40-plus in California support the provision of short-term help by a home health aide so family caregivers can take a break from their caregiving duties. No differences in support exist by race and ethnicity. Support remains high across political parties.

Support by Political Party

<table>
<thead>
<tr>
<th>Party</th>
<th>Support</th>
<th>Neither support or oppose/Not sure</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Republicans</td>
<td>82%</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Independents</td>
<td>85%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Democrats</td>
<td>94%</td>
<td></td>
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</tbody>
</table>

Q33. Do you support or oppose providing short-term help from a home health aide so family caregivers can take a break from their caregiving duties? This help could be provided in-home by a trained health aide or volunteer or out-of-home through an adult day program. Q34. Is that strongly or somewhat? Chart Base: All Respondents
There is overwhelming support by California voters 40-plus for a limited tax credit for family caregivers who incur expenses while providing care.

Nine in ten voters 40-plus in California support a state income tax credit for family caregivers. No differences in support exist by race and ethnicity. Support remains high across political parties.

Q35. Do you support or oppose providing a limited state income tax credit to family caregivers who incur expenses for the care and support of a family member living in California?  Q36. Is that strongly or somewhat?  Chart Base: All Respondents
NURSING DELEGATION AND SCOPE OF PRACTICE
There is overwhelming support by California voters 40-plus for allowing registered nurses to delegate more responsibilities to other trained health care workers.

Over eight in ten voters 40-plus in California support allowing nurses to delegate more of their responsibilities to other health care workers as long as they were trained to do so. No differences in support exist by race and ethnicity. Support remains high across political parties.

Q37. Some states are considering a proposal that would allow registered nurses to give other trained health care workers under their supervision the authority to perform certain tasks, such as the administration of medication. This can relieve family caregivers from having to perform the task themselves or hiring a registered nurse to do so. Do you support or oppose allowing registered nurses in California to delegate more of their responsibilities to other health care workers as long as they were trained to do so? Q38. Is that strongly or somewhat? Chart Base: All Respondents
California voters 40-plus overwhelmingly support modernizing outdated rules to allow nurse practitioners to serve as the primary care provider for a patient.

Nine in ten voters 40-plus in California support allowing nurse practitioners, who have advanced training, to serve as the primary or acute care provider for patients. No differences in support exist by race and ethnicity. Support remains high across political parties.

Q39. Twenty-three states have passed laws that allow nurse practitioners, and other advanced practice registered nurses, to be licensed and practice to the full extent of their training. These nurse practitioners, who have additional training in specific areas like elder care, mental health, and hospice care, often visit older patients in their homes and provide preventive care for people with chronic conditions. By updating the rules, nurse practitioners can serve as the primary or acute care provider for a patient. Do you support or oppose modernizing outdated rules to allow nurse practitioners, who have advanced training, to serve as the primary or acute care provider for patients? Q40. Is that strongly or somewhat? Chart Base: All Respondents

Support by Political Party

<table>
<thead>
<tr>
<th>Political Party</th>
<th>Support</th>
<th>Neither support or oppose/Not sure</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Republicans</td>
<td>88%</td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td>Independents</td>
<td>86%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Democrats</td>
<td>91%</td>
<td></td>
<td></td>
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TELEHEALTH
The majority of California voters 40-plus are not familiar with telehealth; however, many would be interested in such services if needed.

One third of voters (33%) have heard of the terms “telehealth” or “telemedicine.” H/L voters are the least likely to have heard of these terms (H/L voters – 18%; AA/B voters – 32%). And, about eight in ten (79%) are at least somewhat interested in using telehealth services for themselves or a loved one. No differences in interest exist by race or ethnicity. However, a smaller percentage (15%) of voters 40-plus in California could NOT use telehealth services at home because they do not have access to the Internet there – AA/B voters (34%) and H/L voters (26%) are also less likely to have Internet in their households.

Q41. Have you heard of the terms telehealth or telemedicine? Q42. Telehealth offers patients more options for accessing health care. Telehealth is another way for people to have one-on-one interactions with their health care providers without having to be in the same location at the same time by using communications technologies like cell phones, computers, and tablets. Examples of how telehealth provides more connected care include a patient wearing a monitoring device that tracks vital signs or alerts a family caregiver if there is a serious injury, or an online conversation between patients and their doctors to get a diagnosis, get advice, get a prescription filled, or to get a second opinion. How interested are you in using telehealth services for yourself or a loved one if needed? Are you …?

D9. In your residence, do you or any member of your household access the Internet? Chart Base: All Respondents
There is overwhelming support for telehealth policies that require coverage of telehealth services, monitoring technologies, and how telehealth is administered.

Nearly nine in ten voters 40-plus in California support being able to receive telehealth services while at home from a medical provider located in their office, a requirement that health care providers follow strict guidelines to protect patient information, and an investment in technology to protect the security of health information. Support is similarly high for H/L and AA/B voters and across political parties.

Q43. Do you support or oppose policies that would ...? Q44. Is that strongly or somewhat? Chart Base: All Respondents

- 88% Support
- 5% Neither support/oppose/not sure
- 6% Oppose

- Invest in broadband Internet to improve access to telehealth services
- Require private health insurance, employer-based insurance, Medicare, and Medicaid to cover telehealth services
- Greater access to in-home medical monitoring technologies
- Allow for telehealth coverage regardless of the distance between patient’s home and provider’s office
- Invest in technology to protect the security of health information
- Require health care providers to follow strict guidelines to protect patient data
- Being able to receive telehealth services while at home from a provider in their office
Implications

The demand for long-term care services will continue to increase as our population ages. It is estimated that 53 percent\(^1\) of adults who turned 65 in 2016 will need some form of long-term care services during their lifetime.

Family members are often the ones who provide care to their loved ones to help them through an illness or with chronic care. And that’s exactly what most voters in California would prefer – to receive care at home from a caregiver if they needed help due to aging or illness.

In California, it is estimated that there are 4.45 million caregivers\(^2\) who provide more than 4 billion hours of unpaid care valued at over $57 billion each year. It is also estimated that family caregivers spend an average of nearly $7,000 each year on care for their loved ones.\(^3\)

Many caregivers in California have worked while they provided care to a loved one; and for many of these working caregivers, their work schedules and ability to work is disrupted. That’s why caregivers need assurance they won’t be fired for taking time off to care and can take paid leave when needed.

Caregivers help their loved ones in many ways and most spend their own money doing so. Respite care, reimbursement of money spent in the form of a Tax Credit, and giving nurses more help and responsibility will benefit caregivers in California.

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\(^1\)ASPE Issue Brief, HHS Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, Revised February 2016.


Methodology

- **Objectives**: To explore the experiences and opinions of family caregivers aged 40-plus in California. To measure support of various policies that support family caregivers.

- **Methodology**: Multimodal survey (telephone landline and cell for main sample and opt-in online panel for Asian/Pacific Islander oversample).

- **Qualifications**: Age 40 or older and registered to vote in the State of California.

- **Sample**: Registered voter list targeting ages 40 and older from Aristotle International (N=1,152). Oversample of African-Americans (n=260), Hispanic/Latinos (n=50), and Asian/Pacific Islanders (n=180)

- **Interviewing dates**: August 22-September 18, 2018.

- **Weighting**: The data is weighted by age within gender and then adjusted for the oversamples to reflect the 40-plus population of registered voters in California.

- **Questionnaire length**: Interviews averaged 26 minutes in length. Full questionnaire is available upon request.

- **Confidence interval**: Total sample: ± 2.9%.
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Other Survey Questions

S1. Our study is interested in the opinions of people in certain age groups. Could you please tell me your age as of your last birthday?
S3. To ensure it is recorded accurately, could you please state your gender?
S5. Are you of Hispanic, Spanish, or Latino origin or descent?
S6. What is your race?
Q2. What is the age of the person you are providing care for? Q16. What was the age of the person who you most recently provided care to?
Q3. Who are you caring for? Q17. Who did you care for?
Q6. Have you ever been employed either full- or part-time while providing care to your adult loved one? Q19. Have you ever been employed either full or part-time while providing care to your adult loved one?
D1. What is your current marital status?
D3. In general, when compared to most people your age, how would you rate your health?
D4. Thinking about who lives in your household, do you currently …?
D5. Do you own or rent your primary residence?
D7. What is the highest level of education that you completed?
D8. Which of the following best describes your current employment status?
D15. We realize income is a private matter and so rather than ask you anything specific about your income, I’d like to ask you to please stop me when I get to the category that includes your household’s income before taxes in 2017.
About AARP

AARP is the nation’s largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 and older to choose how they live as they age. With nearly 38 million members and offices in every state, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and advocate for what matters most to families with a focus on health security, financial stability and personal fulfillment. AARP also works for individuals in the marketplace by sparking new solutions and allowing carefully chosen, high-quality products and services to carry the AARP name. As a trusted source for news and information, AARP produces the nation’s largest circulation publications, AARP The Magazine and AARP Bulletin. To learn more, visit www.aarp.org or follow @AARP and @AARPadvocates on social media.
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This research was designed and executed by AARP Research