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

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Key Findings

Exactly half of voters age 40-plus in Illinois, have experience as family caregivers, either by currently caring for an adult loved one (17%) or previously doing so (33%).

About nine in ten help their loved ones by providing companionship (92%), shopping (90%), and transportation (87%). Others provide more complex care by managing medications (64%), bathing and dressing (52%), or medical or nursing tasks (51%).

Two in three (65%) current and former caregivers have worked while they provided care, and six in ten (62%) have used their own money to provide care, most likely on transportation.

Seven in ten (70%) current and former caregivers say they feel stressed emotionally due to their caregiving responsibilities; and two in three working caregivers (67%) feel stressed in balancing their work and family.
Key Findings (Cont.)

Most voters 40-plus in Illinois (80%) would prefer to be cared for at home by a caregiver if they or a family member needed help.

Voters 40-plus overwhelmingly support workplace flexibility for working family caregivers in terms of ensuring employers cannot fire an employee for taking time off for caregiving (84%), requiring employers to provide either a limited amount of unpaid leave (82%) or some paid leave (81%) for family caregivers.

The majority of voters (89%) also support the provision of respite care to give family caregivers a break.

While most voters are not generally aware of telehealth, they overwhelmingly support policies that increase access to telehealth services, security of health information, and insurance coverage of telehealth services.
CAREGIVER CHARACTERISTICS AND EXPERIENCES
Half of voters 40-plus in Illinois have experience as family caregivers.

In our survey, the typical family caregiver in Illinois, currently caring for an adult loved one, is a woman (53%), who is married (73%), is 61 years of age, has graduated from college with at least a two-year degree (64%), and lives in a household with income under $100,000 (62%).

- Typical current caregivers also ….
  - Are homeowners (85%)
  - Are in good health (85%)
  - Are currently working (49%), but more had worked at some point while caregiving (62%)
  - Do not have children living at home (63%), but one in three do (34%)
  - Cares for a parent who is 82 years of age

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? Q13. Have you ever been a family caregiver who provided UNPAID care to an adult loved one? Donut Base: All Respondents; Bullet Base: Current Caregivers (other surveys questions are listed in the Appendix)
Family caregivers help their loved ones with many activities of daily living.

About nine in ten family caregivers surveyed provide emotional support to their loved ones through companionship or social activities or helps their loved one with shopping. At least eight in ten family caregivers are helping their loved ones with meals, household chores, and transportation. Seven in ten maintain property, and over six in ten help oversee medications or manage finances.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing companionship/social activities</td>
<td>92%</td>
</tr>
<tr>
<td>Taking them shopping or shopping for them</td>
<td>90%</td>
</tr>
<tr>
<td>Providing transportation to appointments</td>
<td>87%</td>
</tr>
<tr>
<td>Aiding with household chores</td>
<td>83%</td>
</tr>
<tr>
<td>Helping them with meals</td>
<td>80%</td>
</tr>
<tr>
<td>Maintaining or upkeeping property</td>
<td>71%</td>
</tr>
<tr>
<td>Overseeing their medication management</td>
<td>64%</td>
</tr>
<tr>
<td>Helping them to manage finances</td>
<td>63%</td>
</tr>
<tr>
<td>Assisting with bathing or dressing</td>
<td>52%</td>
</tr>
<tr>
<td>Having responsibility for other medical or nursing tasks</td>
<td>51%</td>
</tr>
</tbody>
</table>

- A smaller but noteworthy percentage of caregivers (over half) help with more complex tasks of caregiving – medical and nursing tasks and bathing or dressing.
- At least six in ten current caregivers help with meals (69%), provide companionship (68%), help with chores (63%), or oversee medications (63%) every day.

Q4. Thinking about the person you most recently provided care to, which of the following activities did you provide? Are you …?  Q16. Thinking about the person you most recently provided care to, which of the following activities did you provide? Did you …?  Chart Base: Current and Former Caregivers  Q5. How often do you, is it …?
Most caregivers have worked while providing care.

Two in three 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 caregivers adjusted their work schedules, either by going into work early or late, or taking time off to provide care. Nearly one in four took a leave of absence to provide care. Over one in ten reduced their work hours to provide care or stopped working entirely.

Q6. Q17. 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 …? Q18. Now thinking again about the adult loved one you have most recently provided care to, did you ever have to …?

- Go into work early or late, or take time off to provide care: 73%
- Take a leave of absence from your job to provide care: 23%
- Go from working full-time to part-time to provide care: 15%
- Give up working entirely to provide care: 14%
Caregivers spend money to provide care and change their homes.

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

Q8. Now thinking again about the adult loved one you are currently providing care to, did you ever have to …?
Q19. 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

- 62% use their own money
- 36% make changes to their home
- 11% move into another home
Caregivers spend money transporting their loved ones.

Of those caregivers who say they have spent their own money to provide care (62%), eight in ten have spent money on transportation. About half have spent money on prescription drugs, assistive technology (wheelchairs, hearing devices, vision aids, wearable devices), and modifying their homes or their loved one’s home.

Q9. As a caregiver, have you ever incurred any expenses for the following to help care for your loved one?  
Q20. As a former caregiver, did you ever incur any expenses for the following to help care for your loved one?  

Chart Base: Current and Former Caregivers
Most caregivers experience some form of stress while providing care.

Over eight in ten family caregivers (86%) have experienced at least one of the stressors asked about in this survey. Seven in ten caregivers report feeling stressed emotionally due to their caregiving responsibilities, and two in three working caregivers are stressed in trying to balance their work and family responsibilities.

<table>
<thead>
<tr>
<th>Current &amp; Former Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel stressed emotionally</td>
</tr>
<tr>
<td>Feel stressed in trying to balance job and family*</td>
</tr>
<tr>
<td>Find it difficult to get enough rest</td>
</tr>
<tr>
<td>Find it difficult to take care of household</td>
</tr>
<tr>
<td>Find it difficult to exercise regularly</td>
</tr>
<tr>
<td>Find it difficult to maintain a healthy diet</td>
</tr>
<tr>
<td>Feel strained financially</td>
</tr>
<tr>
<td>Experience problems with health</td>
</tr>
<tr>
<td>Find it difficult to find time to visit doctor</td>
</tr>
</tbody>
</table>

Q10. Q21. As a caregiver do you ever …? Chart Base: Current and Former Caregivers *Asked of working caregivers
Many registered voters 40-plus in Illinois 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, two in three current caregivers say they are extremely or very likely to provide care in the future. Four in ten former caregivers and 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 (46%) than respondents 65-plus (25%).

<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>66%</td>
<td>43%</td>
<td>25%</td>
<td>38%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>11%</td>
<td>16%</td>
<td>26%</td>
<td>20%</td>
</tr>
<tr>
<td>Not very/Not at all likely</td>
<td>17%</td>
<td>37%</td>
<td>46%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Q12. Q23. Q24. How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for an adult loved one in the future? Is it …?
COMMUNITY SERVICES AND SUPPORTS
The most helpful caregiver support is information about resources for caregivers in their community.

Nearly half of voters in Illinois would also find respite care and transportation to medical appointments helpful. In addition to these helpful supports, seven in ten voters (72%) say it is extremely or very important to have more resources and training for family caregivers.

Q25. 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?

Q26. Family caregivers help older residents in Illinois 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
Health-related services top the list of important services to have in community.

At least three in four voters say that end of life services, well trained home health care providers, visiting nurse services, and special transportation services – as well as caregiver information and resources – are extremely or very important services to have in their communities.
Most voters prefer being cared for at home if they need help.

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. Just over one in ten would prefer to receive help in an assisted living facility, and two in a hundred would prefer a nursing home.

- Nine in ten caregivers (91%) also say it is extremely or very important to be able to provide care so their loved ones could keep living independently at home.

Q49. 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? Q11. 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? Q22. 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 Illinois voters 40-plus for the provision of respite care for family caregivers.

About nine in ten voters 40-plus in Illinois support the provision of short-term help by a home health aide so family caregivers can take a break from their caregiving duties. Support remains high across political parties.

Q34. 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. Q35. Is that strongly or somewhat? D8. Do you consider yourself to be a …? Chart Base: All Respondents
WORKPLACE FLEXIBILITY
There is overwhelming support by Illinois voters 40-plus for workplace flexibility for family caregivers.

Over eight in ten voters support employers not being able to fire an employee for caregiving. Likewise, eight in ten support requirements that employers provide a limited amount of unpaid leave or some paid leave for family caregiving purposes. Support remains high for workplace flexibility across political parties.

Q27. 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 …? Q28. Is that strongly or somewhat? D8. Do you consider yourself to be a …? Chart Base: All Respondents

Support by Political Party

- **Ensuring employers cannot fire an employee for taking time off for caregiving**
  - Republicans: 75%
  - Independents: 67%
  - Democrats: 69%

- **Requiring employers to provide a limited amount of unpaid leave**
  - Republicans: 87%
  - Independents: 88%
  - Democrats: 91%

- **Requiring employers to provide some paid leave**
  - Republicans: 93%
  - Independents: 82%
  - Democrats: 91%
The majority of employed voters 40-plus in Illinois receive paid time off for sick leave.

Over eight in ten of these workers who receive paid sick leave can use it to care for family members (82%). And, three in ten of such workers have used their sick leave to care for family members in 2018. Of workers without paid sick leave, seven in ten say it is at least somewhat important for their employer to provide paid sick leave.

Q29. Thinking about the job where you worked the most hours last week, do you receive paid sick leave? Q31. Does your employer allow you to use your existing sick leave benefits to attend to illnesses or injuries of your relatives, including parents and spouses? Q32. Since the beginning of this year, have you used your sick leave benefits to care for another family member or relative? Q33. You mentioned that you do not receive paid sick leave, how important is it that your employer provide paid sick leave? It is …?
NURSING SCOPE OF PRACTICE
There is overwhelming support by Illinois voters 40-plus to allow nurse practitioners to serve as primary care providers.

Allowing registered nurses with advanced training who often visit older people in their homes can improve access to health care. Over eight in ten voters support nurse practitioners, with advanced training, to serve as the primary care or acute care provider of record for patients. Support remains high across political parties.

Support by Political Party

<table>
<thead>
<tr>
<th>Support</th>
<th>Neither support or oppose/Not sure</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>86%</td>
<td>6%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Republicans: 83%
Independents: 86%
Democrats: 90%

Q36. Some states are considering a proposal that would allow registered nurses with advanced training who often visit older people in their homes to serve as the primary or acute care provider of record for a patient. These nurse practitioners have additional training in specific areas, like elder care. Do you support or oppose allowing nurse practitioners, who have advanced training, to serve as the primary or acute care provider of record for a patient? Q37. Is that strongly or somewhat? D8. Do you consider yourself to be a …? Chart Base: All Respondents
HOME AND COMMUNITY BASED SERVICES
The majority of Illinois voters 40-plus say that funding home and community-based services is a top or high priority.

Home and community-based services, like adult day programs and transportation, support family caregivers in their care of their loved ones. Six in ten voters say that funding for such services should be a top or high priority for elected officials in Illinois (62%).

Q38. How much of a priority should it be for elected officials in Illinois to fund services that support family caregivers such as home and community-based services, adult day programs, and transportation services? Should it be a … ? Chart Base: All Respondents
PRESCRIPTION DRUGS
The majority of Illinois voters 40-plus say they are extremely or very concerned about affording their prescription drugs.

This concern is even greater for caregivers who spent their own money on prescription drugs for their loved ones – nearly half (49%) are extremely concerned. Nearly eight in ten voters (77%) also believe that prescription drug companies have a lot of influence over members of Congress and state legislatures.

Q39. How concerned are you about being able to afford the cost of prescription drugs for yourself or your family? Are you …? Q40. How much influence do you think prescription drug companies have over members of Congress and state legislatures? Would you say they have…? Chart Base: All Respondents
The majority of Illinois voters 40-plus say it is extremely or very important that elected officials in Illinois take action in 2019 to improve nursing home care.

In 2015, 39% of nursing homes in Illinois received a low quality rating from the Centers for Medicaid and Medicare Services. Over eight in ten (84%) voters in Illinois say that action should be taken in 2019 to increase the quality of care in Illinois nursing homes.

Q48. In 2015, thirty-nine percent of nursing homes in Illinois received a low quality rating. They received either one or two stars in a five-star quality system by the Centers for Medicaid and Medicare Services. How important is it that elected officials in Illinois take action in 2019 to increase the quality of care in nursing homes? It is …?

Chart Base: All Respondents
The majority of Illinois voters 40-plus are not familiar with telehealth; however, many would be interested in using specific telehealth services if needed.

Over one in three voters (36%) say they have heard of the terms “telehealth” or “telemedicine.” And, six in ten are at least somewhat interested in using the six examples of telehealth services asked about in our survey. Three in ten voters (30%) also say that a telehealth provider directory would be very helpful to them and their families.

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. Would you be interested in using any of the following telehealth services for yourself or a loved one if needed? Q43. A telehealth provider directory provides easy access to information on health care providers that offer telehealth services. How helpful would this type of directory be to you and your family? Is it …?

<table>
<thead>
<tr>
<th>Service</th>
<th>Extremely/very</th>
<th>Somewhat</th>
<th>Not very/Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring device that alerts emergency care</td>
<td>57%</td>
<td>25%</td>
<td>16%</td>
</tr>
<tr>
<td>Monitoring device that tracks key health info.</td>
<td>46%</td>
<td>28%</td>
<td>24%</td>
</tr>
<tr>
<td>Phone/Video conversation to discuss symptoms, progress, etc.</td>
<td>43%</td>
<td>28%</td>
<td>27%</td>
</tr>
<tr>
<td>Video conference with specialist too far away to visit</td>
<td>42%</td>
<td>30%</td>
<td>27%</td>
</tr>
<tr>
<td>Text/phone apps that remind taking medication</td>
<td>36%</td>
<td>26%</td>
<td>36%</td>
</tr>
<tr>
<td>Online video library for instruction on medical tasks</td>
<td>34%</td>
<td>28%</td>
<td>37%</td>
</tr>
</tbody>
</table>
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 Illinois support a requirement that health care providers follow strict guidelines to protect patient information and the investment in technology to protect such information. Over eight in ten support the coverage of telehealth services regardless of the distance between a patient and doctor and greater access to in-home medical monitoring technology.

<table>
<thead>
<tr>
<th>Policy</th>
<th>Support</th>
<th>Neither support or oppose/Not sure</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Require health care providers to follow strict guidelines to protect patient data</td>
<td>89%</td>
<td>3%</td>
<td>6%</td>
</tr>
<tr>
<td>Invest in technology to protect the security of health information</td>
<td>88%</td>
<td>3%</td>
<td>8%</td>
</tr>
<tr>
<td>Allow for telehealth coverage regardless of the distance between patient’s home and provider’s office</td>
<td>84%</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>Greater access to in-home medical monitoring technologies</td>
<td>83%</td>
<td>4%</td>
<td>11%</td>
</tr>
<tr>
<td>Being able to receive telehealth services while at home from a provider in their office</td>
<td>80%</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Require private health insurance, employer-based insurance, Medicare, and Medicaid to cover telehealth services</td>
<td>78%</td>
<td>7%</td>
<td>14%</td>
</tr>
<tr>
<td>Invest in broadband Internet to improve access to telehealth services</td>
<td>73%</td>
<td>8%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Q44. Q46. Do you support or oppose policies that would …? Q45. Q47. Is that strongly or somewhat? Chart Base: All Respondents
Implications

• The demand for long-term care services will continue to increase as our population ages. It is estimated that 52 percent\(^1\) of adults who turned 65 in 2016 will need some form of long-term care services during their lifetime.

• Family and friends 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 Illinois would prefer – to receive care at home from a caregiver if they needed help due to aging or illness.

• In Illinois, it is estimated that there are 1.5 million caregivers\(^2\) who provide more than 1.4 billion hours of unpaid care valued at $18.5 billion each year.

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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 Illinois. To measure support of various policies that support family caregivers.

• **Methodology:** Telephone survey (both landline and cell).

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

• **Sample:** Registered voter list targeting ages 40 and older from Aristotle International (N=1,100).

• **Oversample:** African-American/Blacks and Hispanic/Latinos

• **Interviewing dates:** October 17 to November 14, 2018.

• **Weighting:** The data is weighted by age within gender, race, and ethnicity to reflect the 40-plus population of registered voters in Illinois.

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

• **Confidence interval:** Total sample: ± 2.95%.
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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?
S7. Which of the following best describes your current employment status?
Q2. What is the age of the person you are providing care for? Q14. What was the age of the person who you most recently provided care to?
Q3. Who are you caring for? Q15. Who did you care for?
Q6. Have you ever been employed either full- or part-time while providing care to your adult loved one? Q17. 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?
D6. What is the highest level of education that you completed?
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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