AARP New Jersey Voter Survey on Family Caregiving and Long-Term Care

June 2022
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BACKGROUND AND KEY FINDINGS
Background

The **demand** for long-term care services will continue to **increase** as our population ages. It is estimated that **70 percent**\(^1\) of adults who turn 65 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 New Jersey would prefer – to **receive care at home** from a caregiver if they need help due to aging or illness.

In New Jersey, it is estimated that there are over **one million caregivers**\(^2\) who provide more than **9.1 million hours** of unpaid care valued at over **$12.9 billion** each year. It is also estimated that family caregivers spend an average of **$7,242** each year on care for their loved ones.\(^3\)

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\(^{1}\)ASPE Research Brief, HHS Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, “What is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?” Revised April 2019.


\(^{3}\)Caregiving Out-of-Pocket Costs Study 2021, AARP Research, June 2021
Key Findings

Half (50%) of New Jersey voters 50-plus do not believe that the New Jersey state government offers enough support for unpaid family caregivers. Consequently, the majority of voters support increased funding for respite care (79%) and the expansion of the income tax credit for certain Veteran caregivers to all family caregivers (84%).

Thirty-nine percent of voters age 50-plus in New Jersey have experience as family caregivers, either by currently caring for an adult loved one (13%) or previously doing so (26%). Most of these caregivers also worked while providing care (67%).

Current and former caregivers spend money transporting their loved ones (78%), buying medical equipment (46%), buying prescription drugs (42%), paying for general housing costs (39%), or modifying their home or their loved ones’ home (37%).
Key Findings

Three in four (76%) current and former caregivers say they are stressed emotionally due to their caregiving responsibilities, and three in four (77%) working caregivers say they feel stressed in balancing their work and their family. Voters in New Jersey believe it is extremely or very important that working family caregivers have access while at work to caregiver support programs (78%) and that their employers recognize the stress that they experience (80%).

Family caregivers who have looked for help say that help has been difficult to find (52%) and difficult to afford (47%).

Family caregivers who have provided care during this pandemic say they have felt more socially isolated and lonely (57%), they have fewer family and friends available to help them (45%), have had difficulty in finding community-based services (31%), and have a worse financial situation than before the pandemic (39%).

Voters also support increasing community and state services to help seniors live independently at home as they age (89%).
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. Less than one in seven would prefer another option. Across race, ethnicity, and political groups, voters most prefer receiving care at home (White-85%; Black-87%; Hispanic-85%; Republicans-85%; Independents-85%; Democrats-85%).

Q19. Long-term care assists older Americans who have chronic or acute conditions, disabilities, or frailties with the basic tasks of daily living that they can no longer handle on their own. This includes things like bathing and dressing, toileting, preparing meals, paying bills, housekeeping, helping with trips to the doctor or store, or helping with medication and nursing tasks like wound care. Long-term care can be provided at home or in a facility, like a nursing home. If you or a loved one needed long-term care, would you prefer to receive that help ... ? Base: All Respondents

- 84% Home with caregiver assistance
- 8% Assisted living facility or group home
- 3% Nursing home
- 2% Something else
- 4% Not sure/Refused
The majority of voters say that it is extremely or very important to choose where long-term care services are provided.

Nine in ten voters say it is extremely or very important to be able to choose where long-term care services are provided if needed. Voters also say it is extremely or very important to have long-term care services that help you stay at home for as long as possible. Majorities of White, Black, and Hispanic voters as well as Republican, Independent, and Democrat voters also feel choosing where to receive help and having services at home are important.

**Importance in Choosing Where Services Are Provided**

<table>
<thead>
<tr>
<th></th>
<th>Extremely/Very</th>
<th>Somewhat</th>
<th>Not very/Not at all</th>
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</thead>
<tbody>
<tr>
<td>All Respondents</td>
<td>91%</td>
<td>6%</td>
<td>2%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>92%</td>
<td>6%</td>
<td>1%</td>
</tr>
<tr>
<td>African American or Black</td>
<td>96%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>93%</td>
<td>4%</td>
<td>2%</td>
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**Importance in Having Services that Help to Stay at Home**

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<th>Extremely/Very</th>
<th>Somewhat</th>
<th>Not very/Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Respondents</td>
<td>89%</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>89%</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>African American or Black</td>
<td>95%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>91%</td>
<td>8%</td>
<td>6%</td>
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</table>

Q20. If you or a loved one needed long-term care, how important would it be to have services that would help you or your loved one stay at home for as long as possible? Is it …?
Q21. If you or a loved one needed long-term care, how important is it for you or your loved one to be able to choose where those services are provided? Is it …? Base: All Respondents
Most voters believe that the New Jersey state government should do more to support affordable housing options for seniors.

Over eight in ten voters say that the state government should do more to support affordable housing options that would allow seniors to stay in their homes as they age. White, Black, and Hispanic voters also overwhelmingly believe the government should do more as do Republicans, Independents, and Democrats.

Q22. Do you believe that the New Jersey state government should do more to support affordable housing options that would allow seniors to stay in their homes as they age? Base: All Respondents
There is overwhelming support among New Jersey voters for increasing community and state services to help seniors live independently at home.

Nine in ten voters support increasing community and state services that would help seniors live at home as they age. White, Black, and Hispanic voters also overwhelmingly support increasing such services as do Republicans, Independents, and Democrats.

**Support by Race, Ethnicity, and Political Party**

- **Support**: 89%
- **Oppose**: 6%
- **Neither support or oppose/Not sure**: 4%

- **White or Caucasian**: 90%
- **African American or Black**: 91%
- **Hispanic or Latino**: 89%
- **Republicans**: 85%
- **Independents**: 91%
- **Democrats**: 94%
Four in ten voters 50-plus in New Jersey are currently providing care to an adult family member or have provided care in the past.

Overall, more women report being a caregiver than men, and White respondents appear more likely to self-identify as a caregiver than Hispanic respondents.

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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 now or have you ever been a family caregiver who provided unpaid care to an adult loved one? Base: All Respondents. There is not enough sample data to report percentages separately by all races and ethnicities in this report.
Two in three current or former caregivers have been employed while they were providing care to their loved ones.

In our survey, two in three current and former caregivers had been employed either full- or part-time at the same time they were caring for their loved one. Younger caregivers (those under 65 years of age) appear more likely to be working while also providing care.
Nine in ten caregivers have incurred expenses while caring for their loved ones, and transportation is the most common expense.

Nearly eight in ten caregivers have spent money on transporting their loved ones where they need to go. Hispanic caregivers appear more likely to spend money on medical equipment, prescription drugs, general housing costs, home modifications, general medical costs, and respite care than do White caregivers.

<table>
<thead>
<tr>
<th>Current and Former Caregivers Who Have Incurred these Expenses</th>
</tr>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>All Caregivers</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Medical equipment</td>
</tr>
<tr>
<td>Rx</td>
</tr>
<tr>
<td>General housing costs</td>
</tr>
<tr>
<td>Home modifications</td>
</tr>
<tr>
<td>Home health aide</td>
</tr>
<tr>
<td>Medical costs</td>
</tr>
<tr>
<td>Respite care</td>
</tr>
<tr>
<td>Nursing home/assisted living</td>
</tr>
<tr>
<td>Adult day care</td>
</tr>
<tr>
<td>Vehicle modifications</td>
</tr>
</tbody>
</table>

Q3. As an unpaid caregiver, have you ever incurred any expenses for the following services to help care for your loved one? Base: Current and Former Caregivers
The majority of caregivers say it was difficult to **find** care, and four in ten say it was difficult to **afford** care.

Overall, 17% of caregivers say they have not looked for any caregiving help. But of those who have, over half say it has been very or somewhat difficult. A third of Black caregivers say it was very or somewhat difficult to find care. The majority of Hispanic caregivers say it was very or somewhat difficult to afford caregiving help.

Ease or Difficulty in **Finding** Care

<table>
<thead>
<tr>
<th>Ease or Difficulty</th>
<th>All caregivers</th>
<th>White/Caucasian caregivers</th>
<th>African American/Black caregivers</th>
<th>Hispanic/Latino caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very/somewhat easy</td>
<td>33%</td>
<td>14%</td>
<td>28%</td>
<td>28%</td>
</tr>
<tr>
<td>Neither easy/difficult</td>
<td>32%</td>
<td>16%</td>
<td>33%</td>
<td>23%</td>
</tr>
<tr>
<td>Somewhat/very difficult</td>
<td>51%</td>
<td>52%</td>
<td>39%</td>
<td>50%</td>
</tr>
</tbody>
</table>

Ease or Difficulty in **Affording** Care

<table>
<thead>
<tr>
<th>Ease or Difficulty</th>
<th>All caregivers</th>
<th>White/Caucasian caregivers</th>
<th>African American/Black caregivers</th>
<th>Hispanic/Latino caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very/somewhat easy</td>
<td>31%</td>
<td>15%</td>
<td>32%</td>
<td>33%</td>
</tr>
<tr>
<td>Neither easy/difficult</td>
<td>41%</td>
<td>12%</td>
<td>40%</td>
<td>31%</td>
</tr>
<tr>
<td>Somewhat/very difficult</td>
<td>32%</td>
<td>15%</td>
<td>12%</td>
<td>27%</td>
</tr>
<tr>
<td>Have not spent money for help</td>
<td>15%</td>
<td>7%</td>
<td>7%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Q4. How easy or difficult has it been/was it to find the help you need to care for your loved one. Has it been/was it ...?  Q5. How easy or difficult has it been/was it to afford the help you need to care for your loved one? Has it been/was it ...? Base: Current and Former Caregivers Seeking Help
Most caregivers feel stressed emotionally due to their caregiving responsibilities, and those who work feel stressed in balancing their work and family responsibilities.

Overall, three in four caregivers say they feel stressed emotionally, with more Hispanic caregivers reporting such stress. Three in four working caregivers also say they also feel stressed in balancing their work and family. Over one in three experience financial strain, with more Hispanic caregivers reporting they feel such strain.

### Stress and Strain Experienced by Current and Former Caregivers

<table>
<thead>
<tr>
<th></th>
<th>Feel stressed emotionally</th>
<th>Feel stressed in balancing job and family (of working caregivers)</th>
<th>Feel strained financially</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Caregivers</td>
<td>76%</td>
<td>77%</td>
<td>36%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>77%</td>
<td>78%</td>
<td>33%</td>
</tr>
<tr>
<td>African American or Black</td>
<td>52%</td>
<td>-</td>
<td>40%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>83%</td>
<td>-</td>
<td>54%</td>
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</tbody>
</table>

Q9. As a caregiver, do/did you ever …? Base: Current and Former Caregivers - Sample size too small to report percentages.
Nearly half of caregivers say they care for someone who suffers from Alzheimer’s, dementia, or other forms of mental confusion.

Caregivers who care for someone with a mental condition are also more likely to have hired a professional caregiver (42% vs. 23%); feel more emotional stress (82% vs. 71%); feel more strained financially (43% vs. 30%); and spend more than 40 hours a week providing care (35% vs. 21%).

Q6. Does/did the person you care for suffer from Alzheimer’s, dementia, or other forms of mental confusion? Base: Current and Former Caregivers

- All caregivers: 47%
- White or Caucasian caregivers: 48%
- African American or Black caregivers: 26%
- Hispanic or Latino caregivers: 44%
Nearly six in ten caregivers spend at least 21 hours a week providing care, and only one in three have hired a professional caregiver.

Most caregivers are spending on average each week the equivalent of a part-time or full-time job providing care to their loved ones. And, about one in three caregivers have hired a professional caregiver. Black caregivers appear less likely to hire a professional caregiver than White caregivers.

Q7. Thinking about all the kinds of help you provided to your loved one, about how many hours do/did you spend in an average week providing care? Base: Current and Former Caregivers Providing Hours
Q8. Have you ever hired a professional caregiver? Base: Current and Former Caregivers
Over half of caregivers in our survey provided care during the COVID pandemic. Of these, six in ten say they felt more socially isolated and lonely.

Just under half of caregivers say that the pandemic affected their ability to care because they had fewer family members and friends available to help them provide care. About four in ten caregivers say that their financial situation became worse than before the pandemic. Working caregivers also were affected by the pandemic – nearly four in ten reduced the hours they worked and three in ten took a leave of absence. Also, three in ten caregivers say they had difficulty finding community-based services (adult day care, meal delivery services, transportation, in-home respite).

<table>
<thead>
<tr>
<th>Q11. Has the COVID-19 pandemic affected your ability to care for your loved one in any of the following ways?</th>
<th>Base: Caregivers Providing Care During Pandemic *Working Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>More socially isolated/lonely</td>
<td>57%</td>
</tr>
<tr>
<td>Fewer family/friends to help</td>
<td>45%</td>
</tr>
<tr>
<td>Financial situation became worse</td>
<td>39%</td>
</tr>
<tr>
<td>Reduced # of hours worked*</td>
<td>38%</td>
</tr>
<tr>
<td>Difficulty finding community-based services</td>
<td>31%</td>
</tr>
<tr>
<td>Took a leave of absence from work*</td>
<td>30%</td>
</tr>
<tr>
<td>Difficulty finding home health aide services</td>
<td>27%</td>
</tr>
<tr>
<td>Difficulty finding skilled nursing care</td>
<td>21%</td>
</tr>
<tr>
<td>Transitioned from institutional care to home care</td>
<td>17%</td>
</tr>
</tbody>
</table>

*Not mutually exclusive; caregivers could choose more than one response.
Half of New Jersey voters 50+ do NOT believe that the New Jersey state government offers enough support for unpaid family caregivers.

Just one in six say that the state government offers enough support for family caregivers. And half of White and Black voters as well as Republicans and Democrats say the state government does not offer enough to help caregivers. However, one in three overall are not sure if the state government offers enough support for family caregivers.

Q13. Do you believe that the New Jersey state government offers enough support for unpaid family caregivers? Base: All Respondents
There is overwhelming support among New Jersey voters for increasing funding to New Jersey’s respite care program.

Nearly eight in ten support increasing funding to the respite care program so family caregivers can get a break from their caregiving duties. Majorities of White, Black, and Hispanic voters support this funding increase as do Republicans, Independents, and Democrats.

Q15. Do you support or oppose increasing funding for this caregiver respite program so more family caregivers can use it? Q16. Is that strongly or somewhat? Base: All Respondents
There is overwhelming support among New Jersey voters for expanding the tax credit for certain Veteran caregivers to all caregivers.

Over eight in ten voters support the expansion of the tax credit currently in place for caregivers of certain Veterans to all caregivers who provide care. Majorities of White, Black, and Hispanic voters also support the expansion of this tax credit as do Republican, Independent, and Democrat voters.

Q17. New Jersey recently enacted a tax credit to support caregivers of certain veterans who used their own money to provide care. Do you support or oppose expanding this tax credit to support all family caregivers in New Jersey who use their own money to provide care for older parents, spouses, or other loved ones? Q18. Is that strongly or somewhat? Base: All Respondents
Voters in New Jersey believe it is important that working family caregivers have access at work to caregiver support programs.

Overall, nearly eight in ten voters say it is extremely or very important that working caregivers have access at work to caregiver support programs, like flexible work hours. Importance is higher for Black and Hispanic voters compared to White voters. Importance is high for both Democrat and Republican voters.

Q12. How important is it that a. working family caregivers have access at work to caregiver support programs, such as flexible work hours? Base: All Respondents

- Extremely/very
- Somewhat
- Not too/not at all

- All respondents: 78%
- White or Caucasian: 77%
- African American or Black: 89%
- Hispanic or Latino: 85%
- Republicans: 71%
- Independents: 73%
- Democrats: 91%
Voters in New Jersey believe it is important that employers recognize the stress that working caregivers experience.

Overall, eight in ten voters say it is extremely or very important that employers recognize the stress that working family caregivers face. Importance is higher for Black and Hispanic voters compared to White voters. The majority of Republican, Independent, and Democrat voters also believe such recognition is important.

Q12. How important is it that … b. employers recognize the stress that working caregivers experience? Base: All Respondents
IMPLICATIONS
Implications

Unpaid family caregivers in New Jersey need help, and most voters 50+ do not think that the state government is doing enough to support them.

Caregivers spend money taking care of their loved ones, make professional sacrifices, and experience both financial and emotional stress. During this pandemic, caregivers have felt more isolated and lonelier, and many have fewer family and friends available to help them.

Overwhelmingly, New Jersey voters support programs to help family caregivers, such as more respite care, and an expanded family caregiver income tax credit.

Given the likelihood of needing long-term care services and the overwhelming preference to remain at home, now is the time to act and help those who provide these services and those who need them.
Methodology

- **Objectives**: To explore the attitudes and opinions of New Jersey voters on long-term care.
- **Methodology**: Telephone survey both landline and cell for statewide sample.
- **Qualifications**: Age 50 or older and registered to vote in New Jersey.
- **Sample**: Registered voter list targeting ages 50 and older from Aristotle International (N=1,200). Oversample of voters who identified their race as African American or Black or identified their ethnicity as Hispanic or Latino.
- **Interviewing dates**: December 6-29, 2021.
- **Weighting**: The data is weighted by age, gender, race, ethnicity, and AARP membership to reflect the 50-plus population of registered voters in New Jersey.
- **Questionnaire length**: Telephone interviews averaged 21 minutes in length. Full questionnaire is available upon request.
- **Confidence interval**: Total statewide sample: ± 2.83%.
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.

About American Directions Research Group

American Directions Research Group (ADRG) is a veteran-owned, research services company headquartered in Washington, DC. Founded in 1987, ADRG has over 30 years of experience and knowledge in designing, implementing and managing state-of-the-art multimodal survey research projects. ADRG is one of the largest survey research data collection providers in the United States, specializing in high-quality research to measure consumer attitudes and awareness, member satisfaction, market trends, program effectiveness and more. The key to this long-term success has been client satisfaction based on reliable data, fast turnaround, competitive costs, and a keen sensitivity to client needs. ADRG clients encompass a wide variety of industries, ranging from federal to state governments, academia, corporations, non-profits and associations. For more information, please visit www.adg-research.com.
For more information about long-term care in New Jersey, please contact Crystal McDonald, AARP New Jersey, cmcdonald@aarp.org or Rachel Auerbach, AARP New Jersey, rauerbach@aarp.org.

For more information about the survey or its methodology, please contact Terri Guengerich, AARP Research, tguengerich@aarp.org.

This research was designed and executed by AARP Research.