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

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KEY FINDINGS
Key Findings

Nearly half of voters age 40-plus in Utah, have experience as family caregivers, either by currently caring for an adult loved one (15%) or by previously doing so (33%).

About two in three care for their parents (64%) and help their loved ones by providing companionship (94%), shopping (88%), or help with household chores (87%). Others provide more complex care by managing medications (59%), medical or nursing tasks (45%), or bathing and dressing (45%).

Seven in ten (71%) current and former caregivers have worked while they provided care. Two in three working caregivers (67%) have had to adjust their work schedules to provide care. If working caregivers didn’t have job flexibility, nearly half (48%) would need to find a new job or quit working entirely (44%).

Over six in ten (63%) have used their own money to provide care.

Seven in ten (69%) current and former caregivers say they feel stressed emotionally due to their caregiving responsibilities; and two in three (66%) working caregivers say they feel stressed in trying to balance their job and family.

Two in three caregivers (66%) have difficulty dealing emotionally with their loved one’s condition.
Key Findings (Cont.)

Most registered voters 40-plus in Utah (83%) would prefer to be cared for at home by a caregiver if they or a family member needed help.

The most helpful assistance to caregivers is information about available resources in their community (58%). Most voters would turn to doctors (90%) or family members (88%) to find caregiving information and resources. Only two in ten (19%) would turn to the 211 information line.

Voters 40-plus in Utah overwhelmingly support workplace flexibility for working family caregivers in terms of allowing employees to use their existing sick leave for family caregiving purposes (86%), requiring employers to provide either a limited amount of unpaid leave (80%) or some paid leave (68%) for family caregivers.

The majority of voters (84%) also support the provision of respite care by a state or local agency 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 and insurance coverage of telehealth services.
CAREGIVER CHARACTERISTICS AND EXPERIENCES
Many voters 40-plus in Utah have experience as family caregivers.

In our survey, the typical family caregiver in Utah, currently caring for an adult loved one, is a woman (55%), who is married (81%), is 59 years of age, has graduated from college with at least a two-year degree (66%), and lives in a household with income under $100,000 (62%).

- Typical current caregivers also ....
  - Are homeowners (88%)
  - Are in good health (81%)
  - Are currently working (52%), but more had worked at some point while caregiving (68%)
  - Do have children living at home (54%), but nearly half do not (46%)
  - Cares for a parent who is 76 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? Base: All Respondents Q14. Have you ever been a family caregiver who provided UNPAID care to an adult loved one? Donut Base: All Respondents Chart Base: Current Caregivers (other surveys questions are listed in the Appendix)
Nearly every family caregiver surveyed provides emotional support to their loved ones through companionship or social activities. At least eight in ten family caregivers are helping their loved ones with meals, transportation, household chores, or shopping. Six in ten help oversee medications or manage finances.

- Providing companionship/social activities: 94%
- Taking them shopping or shopping for them: 88%
- Aiding with household chores: 87%
- Providing transportation to appointments: 85%
- Helping them with meals: 84%
- Overseeing their medication management: 59%
- Helping them to manage finances: 59%
- Having responsibility for other medical or nursing tasks: 45%
- Assisting with bathing or dressing: 45%

A smaller but noteworthy percentage of caregivers help with more complex tasks of caregiving – medical and nursing tasks and bathing or dressing.
Most caregivers have worked while providing care.

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

Most caregivers who were not working say they were retired (35%), had a disability (11%), were already out of the labor force (25%), or that too much care was needed to work (9%).

Caregivers who worked say that if their employer hadn’t provided flexibility, they would likely need to find a new job (48%) or quit working entirely (44%).
Caregivers spend money to provide care and change their homes.

Six in ten current and former caregivers 40-plus in Utah 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.

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

- Use your own money: 63%
- Make changes to your home: 35%
- Move into another home: 11%

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
Most caregivers experience some form of stress while providing care.

Over eight in ten family caregivers (84%) have experienced at least one of the stressors asked about in this survey. Seven in ten caregivers report feeling stressed out 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>Stressor</th>
<th>Current &amp; Former Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel stressed out emotionally</td>
<td>69%</td>
</tr>
<tr>
<td>Feel stressed in trying to balance job and family*</td>
<td>66%</td>
</tr>
<tr>
<td>Find it difficult to get enough rest</td>
<td>50%</td>
</tr>
<tr>
<td>Find it difficult to take care of household</td>
<td>44%</td>
</tr>
<tr>
<td>Find it difficult to exercise regularly</td>
<td>43%</td>
</tr>
<tr>
<td>Find it difficult to maintain a healthy diet</td>
<td>28%</td>
</tr>
<tr>
<td>Feel strained financially</td>
<td>24%</td>
</tr>
<tr>
<td>Experience problems with health</td>
<td>28%</td>
</tr>
<tr>
<td>Find it difficult to find time to visit doctor</td>
<td>16%</td>
</tr>
</tbody>
</table>

Q10. As a caregiver do you ever ...? Q23. As a caregiver did you ever ...? Chart Base: Current and Former Caregivers. *Asked of working caregivers
Most family caregivers do not have difficulty finding health care providers.

While many caregivers say it is “not” difficult to find caregiving help, many have also not used caregiving help. Six in ten have not used adult day care services, one in three have not used respite care, and nearly three in ten have not used home health care services.
Most family caregivers do not have difficulty getting their loved ones the care they need.

However, about one in three caregivers do encounter difficulty in getting their loved ones to the care they need and in maintaining relationships with family members. More caregivers also face difficulty in making decisions about the care their loved ones need. And, two in three caregivers say they have difficulty in dealing emotionally with their loved one’s condition.

Q11. In caring for your loved one, how difficult has it been to ...?  Q24. In caring for your loved one, how difficult has it been to ...?  Chart Base: Current and Former Caregivers

- Get your loved one to the care they need
  - Very difficult: 6%
  - Somewhat difficult: 30%
  - Not difficult: 64%

- Maintain relationships with family
  - Very difficult: 9%
  - Somewhat difficult: 24%
  - Not difficult: 66%

- Make decisions about the care needed
  - Very difficult: 11%
  - Somewhat difficult: 32%
  - Not difficult: 54%

- Deal emotionally with loved one’s condition
  - Very difficult: 25%
  - Somewhat difficult: 41%
  - Not difficult: 33%
Many registered voters 40-plus in Utah 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, eight in ten current caregivers say they are extremely or very likely to provide care in the future. Four in ten former caregivers and just over a third of those who have never provided care, say they are extremely or 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 (51%) than respondents 65-plus (32%).

<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>80%</td>
<td>42%</td>
<td>35%</td>
<td>44%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>7%</td>
<td>21%</td>
<td>30%</td>
<td>23%</td>
</tr>
<tr>
<td>Not very/Not at all likely</td>
<td>13%</td>
<td>35%</td>
<td>33%</td>
<td>31%</td>
</tr>
</tbody>
</table>

Q13, Q26, Q27. 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 …?
The most helpful caregiver support is information about resources for caregivers in their community.

Half of voters in Utah would also find respite care helpful. In addition to these helpful supports, seven in ten voters (69%) say it is extremely or very important to have more resources and training for family caregivers.

Q28. 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 Utah 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
Voters in Utah are most likely to turn to doctors or family and friends to find community information and resources for caregivers.

Over half of voters in Utah would also turn to the Internet, hospitals, places of worship, senior centers, and government agencies. Nearly half would turn to the Area Agencies on Aging, such as the Salt Lake County Aging and Adult Services or the Mountainlands Association of Governments.

Q29. Where would you turn to find information about services in your community to help family caregivers? Would you turn to …? Chart Base: All Respondents
Health-related services top the list of important services to have in community.

At least seven in ten 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.

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

- Over eight in ten caregivers (85%) also say it is extremely or very important to be able to provide care so their loved ones could keep living independently at home.

### Chart

- **Home with caregiver assistance**: 83%
- **Assisted living facility**: 11%
- **Nursing home**: 1%

Q44. 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? Q12. 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? Q25. 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?

There is overwhelming support by Utah voters 40-plus for the provision of respite care for family caregivers.

Over eight in ten voters 40-plus in Utah support the provision of short-term help by a state or local agency so family caregivers can take a break from their caregiving duties. Support remains high across political parties.

Q36. Do you support or oppose a state or local agency providing short-term help 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. Q37. Is that strongly or somewhat? Q12. Do you consider yourself to be a …? Chart Base: All Respondents
WORKPLACE FLEXIBILITY
There is overwhelming support by Utah voters 40-plus for workplace flexibility for family caregivers.

Over eight in ten voters support employees being able to use their sick leave to care for a loved one. Likewise, eight in ten support requirements that employers provide a limited amount of unpaid leave, and two in three support some paid leave for family caregiving purposes. Support remains high for workplace flexibility across political parties.

**Support by Political Party**

- **Requiring employers to allow employees to use their existing sick leave for family caregiver purposes**
  - Support: 86%
  - Not sure: 6%
  - Oppose: 8%

- **Requiring employers to provide a limited amount of unpaid leave**
  - Support: 80%
  - Not sure: 5%
  - Oppose: 16%

- **Requiring employers to provide some paid leave**
  - Support: 68%
  - Not sure: 8%
  - Oppose: 24%

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 …? a. Requiring employers to provide a limited amount of unpaid leave to employees who have to take time off for family caregiving purposes; b. Requiring employers to provide some paid leave to all employees that can be used for family caregiving purposes; c. Requiring employers to allow employees to use their existing sick leave for family caregiver purposes. Q32. Is that strongly or somewhat? D12. Do you consider yourself to be a …?

Chart Base: All Respondents

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The majority of employed voters 40-plus in Utah receive paid time off for sick leave.

But, many more (72%) can take time off without pay as sick leave. And, most employed voters with sick leave can use this leave to take care of family members (80%). Nearly seven in ten voters (68%) in Utah say that paid or unpaid leave for family caregivers is extremely or very important.
The majority of Utah voters 40-plus are not familiar with telehealth; however, many would be interested in using telehealth services if needed.

Four in ten voters (39%) say they have heard of the terms “telehealth” or “telemedicine.” And, four in ten voters say they are extremely or very interested in using these services if needed for themselves or family members.

Interest in Using Telehealth Services for Self or Family Member

- Extremely: 17%
- Very: 24%
- Somewhat: 34%
- Not very: 12%
- Not at all: 12%
- NS/REF: 1%

Q38. Have you heard of the terms telehealth or telemedicine? Q39. 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? Chart Base: All Respondents
There is overwhelming support for telehealth policies that require coverage of telehealth services, monitoring technologies, and how telehealth is administered.

Nine in ten voters 40-plus in Utah support greater access to in-home medical monitoring services for patients with chronic health conditions and requiring health care providers to follow strict guidelines to protect patient information. Nearly nine in ten support the investment in technology to protect health information as well as being able to receive telehealth services at home from a provider in their office.

<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>Greater access to in-home medical monitoring technologies</td>
<td>90%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Require health care providers to follow strict guidelines to protect patient data</td>
<td>90%</td>
<td>4%</td>
<td>7%</td>
</tr>
<tr>
<td>Invest in technology to protect the security of health information</td>
<td>88%</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Being able to receive telehealth services while at home from a provider in their office</td>
<td>88%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Allow for telehealth coverage regardless of the distance between patient's home and provider's office</td>
<td>81%</td>
<td>9%</td>
<td>10%</td>
</tr>
<tr>
<td>Require Medicare and Medicaid to cover telehealth services</td>
<td>77%</td>
<td>7%</td>
<td>16%</td>
</tr>
<tr>
<td>Invest in broadband Internet to improve access to telehealth services</td>
<td>73%</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>Require Utah's public employee's health plan to cover telehealth services</td>
<td>70%</td>
<td>10%</td>
<td>19%</td>
</tr>
<tr>
<td>Require private health insurance to cover telehealth services</td>
<td>67%</td>
<td>10%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Q40. Q42. Do you support or oppose policies that would …? Q41. Q43. Is that strongly or somewhat? Chart Base: All Respondents
IMPLICATIONS
Implications

- In Utah, there are **approximately 336,000 unpaid family caregivers providing $4.2 billion** worth of care to their loved ones. Utah does not have the ability to provide sufficient state resources to make up for the shortfall caused if these family caregivers were unable to provide services.

- **Nearly half** of survey respondents have **some experience** as a family caregiver; most were also in the **workforce**, causing both financial and emotional stress, including difficulty in balancing work and family responsibilities.

- Given the value and preferences for family caregivers and the **overwhelming support** by survey respondents for **workplace flexibility**, public policy to require employers to allow caregivers to use existing sick leave or provide paid or unpaid leave would help enable family caregivers to continue providing care to their loved ones.

- There is also **overwhelming support** for state and local agencies to provide **respite care** for family caregivers from a home health aide, as most caregivers experience high levels of burn-out with their caregiving responsibilities.
Methodology

• **Objectives:** To explore the experiences and opinions of family caregivers aged 40-plus in Utah. 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 Utah.

• **Sample:** Registered voter list targeting ages 40 and older from Aristotle International (N=801).

• **Interviewing dates:** September 12-30, 2018.

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

• **Questionnaire length:** Interviews averaged 25 minutes in length. Full questionnaire is available upon request.

• **Confidence interval:** Total sample: ± 3.5%.
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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. Which of the following best describes your current employment status?
Q2. What is the age of the person you are providing care for?  Q15. What was the age of the person who you most recently provided care to?
Q3. Who are you caring for?  Q16. Who did you care for?
Q5. Have you ever been employed either full- or part-time while providing care to your adult loved one? Q18. 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

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