

Long-Term Caregiving: The True Costs of Caring for Aging Adults

**Conducted by The Associated Press-NORC Center for Public Affairs Research
With funding from The Associated Press and NORC at the University of Chicago**

Interviews: 6/26-7/10/2018

1,024 adults with past or current experience providing long-term care

Margin of error: +/- 4.1 percentage points at the 95% confidence level among all adults

NOTE: All results show percentages among all respondents, unless otherwise labeled.

Q14. Some people need ongoing living assistance as they get older. This assistance can be a help with things like keeping house, cooking, bathing, getting dressed, getting around, paying bills, remembering to take medicine, or just having someone check in to see that everything is okay. This can happen at your own home, in a family member’s home, in a nursing home, or in a senior community. And, it can be provided by a family members, a friend, a volunteer, or a health care professional.

Are you currently providing ongoing living assistance on a regular basis to a family member or close friend or not?

	AP-NORC 6/26-7/10/2018
Yes	48
No	52
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>1,024</i>

If “Yes” in Q14

Q14_1. Are you currently providing this ongoing living assistance in your own home, in your aging friend or family member’s home, in another friend or family members’ home, in a nursing home, or in a senior community?

	AP-NORC 6/26-7/10/2018
Own home	38
Aging friend or family member’s home	38
Another friend or family member’s home	12
Nursing home	7
Senior community	5
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
<i>N=</i>	<i>481</i>

If “No,” “DON'T KNOW”, “SKIPPED ON WEB”, OR “REFUSED” in Q14

Q15. Have you ever provided ongoing living assistance on a regular basis to a family member or close friend or not?

	AP-NORC 6/26-7/10/2018
Yes	100
No	-
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
<i>N=</i>	<i>543</i>

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If “Yes” in Q15

Q15A. Did you most recently provide this ongoing living assistance in your own home, in your aging friend or family member’s home, in another friend or family member’s home, in a nursing home, or in a senior community?

	AP-NORC 6/26-7/10/2018
Own home	36
Aging friend or family member’s home	44
Another friend or family member’s home	10
Nursing home	8
Senior community	1
DON’T KNOW	1
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>543</i>

SCR1. Have you ever provided unpaid ongoing living assistance on a regular basis to someone else in your community who you didn’t know well prior to providing that care?

	AP-NORC 6/26-7/10/2018
Yes, doing so currently	13
Yes, did so in the past	22
No, never done that	65
DON’T KNOW	*
SKIPPED ON WEB/REFUSED	-
<i>N=</i>	<i>1,024</i>

Q16A. How many people have you provided ongoing living assistance to in the past 12 months?

	AP-NORC 6/26-7/10/2018
0	34
1	45
2	15
3 or more	6
DON’T KNOW	*
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>1,024</i>

Q16B. [When you were providing ongoing living assistance, about/About], how many hours per week [did/do] you provide unpaid care?

	AP-NORC 6/26-7/10/2018
1-10 hours per week	41
11-20 hours per week	22
21-30 hours per week	12
31-40 hours per week	4
More than 40 hours per week	20
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*

N= 1,024

Q17. Are you currently providing ongoing living assistance to any of the following people/Thinking back to when you provided ongoing living assistance, did you provide it to any of the following people?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Your mother	40	56	-	4
Your father	25	69	-	6
Your spouse or partner	16	76	*	8
A grandparent	16	79	-	4
A close friend(s)	16	81	*	3
A parent-in-law	13	84	*	3
A neighbor	13	85	-	3
Another extended family member(s)	12	86	*	2
A sibling(s)	11	87	*	3
A son or son-in-law	5	85	*	10
A daughter or daughter-in-law	5	91	*	4

N=1,024

Q19. Have you been paid for any of the ongoing living assistance you [provide/provided]?

	AP-NORC 6/26-7/10/2018
I have been paid	14
I have not been paid	86
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N= 1,024

Q20. How long [have you been providing/did you provide] ongoing living assistance?

	AP-NORC 6/26-7/10/2018
Less than one year	24
One year to two years	27
More than two years	48
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*

N= 1,024

Q22. Would you say that the [primary person you provide care to needs/most recent person you provided care to] needed care because of any of the following?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/ REF
Loss of memory or other mental abilities, such as Alzheimer's disease or dementia	32	66	*	2
Short-term physical conditions or diseases, such as pneumonia or an injury from a fall or accident	32	64	*	3
Long-term physical conditions, diseases, or disabilities, such as diabetes, loss of vision, or loss of mobility	69	30	-	1
Mental health conditions, such as anxiety or depression	28	69	*	3
Something else	6	81	1	13

N=1,024

Q23. [Do/Did] you provide any of the following types of ongoing living assistance or home health services?

[ITEMS RANDOMIZED]

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Shopping for groceries	83	17	-	*
Housekeeping, such as cleaning and laundry	79	20	*	*
Transportation to doctor's appointments or other services	75	25	*	*
Cooking, meal preparation, and feeding	74	25	*	1
Arranging or supervising services like doctor's appointments	66	33	*	*
Reminders to take medicine	66	33	-	*
Making sure bills are paid or managing finances	62	37	-	*
Getting around inside the home	56	44	*	1
Administering medicine	47	53	-	*
Bathing, toileting, and getting dressed	43	56	-	1
Checking blood pressure or checking blood glucose, such as for diabetics	34	66	*	1
Changing bandages or other wound care	28	72	*	*
Preparing or administering injections	12	88	*	*
Care for an IV or port	8	92	-	*
Preparing and inserting tubes for catheters or feeding tubes	6	94	*	*
Something else	16	81	*	3

N=1,024

Q24. When the person you [assist has/assisted had] an appointment with a doctor or another health care provider, how often [do/did] you attend the appointment together?

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

	AP-NORC 6/26-7/10/2018
Always/Often NET	54
Always	37
Often	18
Sometimes	26
Rarely/Never NET	20
Rarely	10
Never	10
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

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If “Rarely” or more often in Q24

Q25A. When you [attend/attended] medical appointments with the person you [assist, do/assisted, did] you usually stay in the waiting room or go with them into the exam room?

	AP-NORC 6/26-7/10/2018
Stay in the waiting room	29
Go with them into the exam room	70
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
N=	929

If “Rarely” or more often in Q24

Q25B. How often [do/did] the doctors and other health care providers who [care/cared] for the person you [assist/assisted] . . .

[ITEMS RANDOMIZED]

AP-NORC 6/26-7/10/2018	Always/ Often NET	Always	Often	Sometimes	Rarely/ Never NET	Rarely	Never	DK	SKP/REF
Explain things to you in a way that is easy to understand?	72	41	31	17	11	6	5	*	*
Listen carefully to you?	67	38	29	23	10	4	6	*	1
Talk with you about the person you [assist’s/assisted/s] preferences for care?	57	34	23	24	19	11	7	*	*
Involve you in decision-making?	53	31	23	25	21	12	9	*	*

N=929

If “Rarely” or more often in Q24

Q25C. Thinking about your interactions with the doctors and other health care providers who [care/cared] for the person you [assist/assisted] please indicate if each of the following words describes or does not describe how you have been treated.

AP-NORC 6/26-7/10/2018	Does describe	Does not describe	DK	SKP/REF
Respected	86	14	*	*
Valued	82	17	*	1
Dismissed	18	81	*	1
Ignored	16	82	*	1

N=929

If "Rarely" or more often in Q24

Q25D. [Has/Did] a health care provider who [cares/cared] for the person you [assist/assisted] ever talked with you about . . .

[ITEMS RANDOMIZED]

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Services that provide a temporary caregiver so that you can take a break	40	60	*	*
How to take care of yourself while providing care	38	62	*	*
Social support networks for caregivers	35	64	*	*
Other supports or services to take the burden off of you as a caregiver	38	62	*	*

N=929

Q26A. As far as you know [does/did] the person you [assist/assisted] have a legal document, sometimes called a health care proxy or surrogate, or durable power of attorney, to allow you to make decisions about their medical care if they [can/could] no longer make them on their own?

	AP-NORC 6/26-7/10/2018
Yes	45
No	35
Not sure	20
SKIPPED ON WEB/REFUSED	*

N=

1,024

Q26B. As far as you know, [does/did] the person you [assist/assisted] have any formal authorizations, such as a HIPAA release form, to allow one or more health care providers to discuss their health and treatment with you?

	AP-NORC 6/26-7/10/2018
Yes	46
No	26
Not sure	27
SKIPPED ON WEB/REFUSED	*

N=

1,024

Q26C. [Have you talked/Did you ever talk] with your own personal doctor about your caregiving responsibilities?

	AP-NORC 6/26-7/10/2018
Yes	24
No	76
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>1,024</i>

Show if "Yes" in Q26C

Q26D. [Has/Did] your personal doctor ever talked with you about . . .

[ITEMS RANDOMIZED]

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
How to take care of yourself while providing care	75	25	-	*
Services that provide a temporary caregiver so that you can take a break	59	41	-	*
Social support networks for caregivers	53	46	-	1
Other supports or services to take the burden off of you as a caregiver	56	44	-	*
<i>N=262</i>				

Q27. [When you were providing care, if you ever needed/If you ever need] to go away or take a break from providing ongoing living assistance [did you/do you] have access to any of the following, or not?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Other family members or close friends who [can/could] cover your responsibilities	75	25	-	*
A respite care program that [provides/provided] a temporary caregiver	25	74	*	1
Adult day care or community senior services that the person you assist [can/could] go to	21	77	*	1
<i>N=1,024</i>				

Q28. [When you were providing care, did you/Have you] ever [share/shared] the responsibilities of providing care with someone else?

	AP-NORC 6/26-7/10/2018
Yes	62
No	38
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N= 1,024

Q29. [Do/Did] you have the social and emotional support that you [need/needed] to provide ongoing living assistance? Would you say you [have/had] . . .

	AP-NORC 6/26-7/10/2018
All/Most of the support NET	60
All the support you [need/needed]	30
Most of the support you [need/needed]	30
Some of the support you [need/needed]	23
Hardly any/None of the support NET	17
Hardly any of the support you [need/needed]	11
None of the support you [need/needed]	6
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*

N= 1,024

Q31. [Is/Was] there anyone who [supports/supported] you by . . .

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Listening when you [want/wanted] to talk about caregiving	77	22	*	1
Cheering you up when you [are/were] feeling down	70	28	*	1
Helping you to stay calm when you [are/were] feeling stressed	66	33	*	1
Helping to take your mind off caregiving	60	40	*	1
Giving you practical tips on how to provide care	57	42	*	1
Making sure you [are/were] taken care of while you [are/were] providing care	52	47	*	1

N=1,024

Q32. How much of the time during the past week have you felt lonely?

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

	AP-NORC 6/26-7/10/2018
All/most of the time NET	25
All or almost all of the time	17
Most of the time	7
Some/None of the time NET	75
Some of the time	22
None or almost none of the time	53
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

If "Some of the time" or more often in Q32

Q33. Thinking about the times when you feel lonely, have you talked with anyone about your feelings of loneliness or not?

	AP-NORC 6/26-7/10/2018
Yes	43
No	57
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-

N=

469

Q34. People cope with difficult situations in different ways. [Have you done/Did you do] any of the following to cope with difficult caregiving situations or not?

[ITEMS RANDOMIZED]

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Pray, meditate, or engage in other spiritual practices	63	37	-	*
Spend time outside	51	48	*	*
Sleep less	44	55	*	*
Avoid talking to people about the situation	38	62	-	*
Eat more	32	68	*	*
Avoid making tough decisions about the situation by putting them off and focusing on other activities instead	32	68	*	*
Exercise more	28	72	-	*
Work more	27	73	-	*
Sleep more	26	73	*	*
Shop more	22	78	-	1
Drink more alcoholic beverages	17	83	*	*
Smoke or use tobacco more	17	83	-	*

N=1,024

Q35. At any point, have you ever been employed while you were providing ongoing living assistance?

	AP-NORC 6/26-7/10/2018
Yes	61
No	38
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

If "Yes" in Q35

Q41. Have any of the following happened at work because you needed to provide care, or not?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
My roles or responsibilities changed	13	86	-	*
I was treated differently by management or coworkers	12	87	-	1
I was excluded from further job growth opportunities	12	87	*	*
I was fired	3	96	*	*
I was asked to resign	3	97	*	*

N=644

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If “Yes” in Q35

Q47. Have you ever done any of the following to change your work schedule in order to provide care?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
I used my vacation time for care instead of leisure	45	54	-	1
I changed the days or hours I worked	34	65	-	1
I took leave without pay	25	75	-	*
I switched from full-time to part-time	19	80	-	1
I used the Family Medical Leave Act, sometimes called FMLA, to take time off	14	85	*	1
I retired early	10	90	-	*
I quit my job	9	91	-	1

N=644

Q48. [Have/Did] any of the following [resulted/result] from your responsibilities as a caregiver, or not?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
You had less free time or “downtime” for yourself	62	37	*	*
You had less time for socializing with friends	59	40	-	1
You had less time with your spouse, partner, or romantic relationships	47	53	*	*
You were not able to get away for a vacation you wanted to take	44	56	*	*
You had less time to sleep	43	57	*	1
You had less time with other family members	38	61	-	1
You stopped or reduced the amount you exercise or work out	38	62	*	1
You had to give up a hobby or activity you enjoy	36	64	-	*
You had less time with your children	29	70	*	1
You had to stop or delay your own education	13	87	-	*

N=1,024

Q49. Just a guess, about how much of your own money [do/did] you spend per month on costs related to providing ongoing living assistance?

	AP-NORC 6/26-7/10/2018
\$0	21
\$1 to \$99	30
\$100 to \$499	35
\$500 to \$999	6
\$1000 or more	6
DON'T KNOW	1
SKIPPED ON WEB/REFUSED	1
<i>N</i> =	1,024

If more than \$0 in Q49

Q50. [Have/Did] you ever [done/do] any of the following as a result of caregiving, or not?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Dip into your personal savings to cover expenses	41	59	-	*
Reduce how much you save for retirement	25	75	-	*
Take out a loan, borrow from a friend or a family member, or assume other debts to cover expenses	18	81	-	*
Reduce how much you put into educational savings for children or other family members	17	83	-	*
Dip into your retirement savings to cover expenses	16	84	-	-

N=795

Q51. Please indicate if you [have/have ever] cut back on spending on any of the following as a result of caregiving, or not?

AP-NORC 6/26-7/10/2018	Yes	No	DK	SKP/REF
Eating out, delivery, or take-out	49	51	-	*
Entertainment like going to movies, or subscriptions to cable or other entertainment services	42	58	-	*
Household maintenance or renovations	37	62	*	*
Clothes or personal care items for yourself or your family	30	70	*	*
Groceries	25	74	*	*
Spending on your own health care or medicine	18	82	*	*
Basic utilities like heat or electricity	12	88	-	*
Your own or your children's education	11	88	-	1

N=1,024

Q52. Please think about your own personal identity, that is, the various ways that you define yourself as a person. [When you were providing care, how/How] important [was/is] your role as a caregiver to your own personal identity?

	AP-NORC 6/26-7/10/2018
Essential/Important to identity NET	67
Essential to my identity	24
Important but NOT essential	43
Not too/Not at all important to identity NET	32
Not too important	18
Not important at all to my identity	14
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>1,024</i>

If "Yes" in Q14

Q53. In the event you were no longer able to provide ongoing living assistance to the person you care for, is there a plan in place for who would provide that care?

	AP-NORC 6/26-7/10/2018
Yes	54
No	46
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
<i>N=</i>	<i>481</i>

Q54. In general, how would you rate your overall health?

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

	AP-NORC 6/26-7/10/2018
Excellent/very good NET	39
Excellent	9
Very good	30
Good	38
Fair/poor NET	23
Fair	20
Poor	3
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
<i>N=</i>	<i>1,024</i>

Q55. In general, how would you rate your overall mental or emotional health?

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

	AP-NORC 6/26-7/10/2018
Excellent/very good NET	45
Excellent	15
Very good	30
Good	33
Fair/poor NET	22
Fair	18
Poor	4
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

Q56. Do you have any health conditions, physical limitations, or mental health conditions that impact your daily life or limit your activities?

	AP-NORC 6/26-7/10/2018
Yes	39
No	61
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

If "Yes" in Q14

Q57. Has your caregiving role made it easier or harder to manage your own health, or has it made no real difference?

	AP-NORC 6/26-7/10/2018
Much or somewhat easier NET	10
Much easier	2
Somewhat easier	7
No real difference	62
Much or somewhat harder NET	28
Somewhat harder	21
Much harder	7
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-

N=

481

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If "Yes" in Q14

Q58. In the past 12 months, how often have you personally done any of the following as a result of caregiving?

[ITEMS RANDOMIZED; HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

AP-NORC 6/26-7/10/2018	More than once	One time	Never	Not applicable	DK	SKP/REF
Forgotten or never got around to filling one of your own prescriptions	16	12	57	14	-	1
Skipped or didn't get around to scheduling a recommended medical test or treatment.	18	15	55	11	-	*
Gone without a routine physical or other preventative health care	21	13	55	10	-	*
Didn't go to the doctor when you were sick or injured	18	14	57	12	-	*
Gone without a routine dental care	23	13	51	13	-	*

N=481

Q59. On average, how many hours of sleep do you get per night?

	AP-NORC 6/26-7/10/2018
4 hours or less	7
More than 4 but less than 6 hours	42
More than 6 but less than 8 hours	44
More than 8 hours	6
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	2

N=

1,024

Q60. How often do you exercise or participate in vigorous physical activity?

	AP-NORC 6/26-7/10/2018
Every day	13
A few times a week	40
A few times a month	19
Less often than that	27
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*

N=

1,024

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AGE

	AP-NORC 8/16-20/2018
18-24	11
25-34	14
35-44	7
45-54	21
55-64	23
65-74	16
75+	8
<i>N=</i>	<i>1,024</i>

GENDER

	AP-NORC 8/16-20/2018
Male	41
Female	59
<i>N=</i>	<i>1,024</i>

RACE/ETHNICITY

	AP-NORC 8/16-20/2018
White	64
Black or African American	11
Hispanic	16
Other	9
<i>N=</i>	<i>1,024</i>

MARITAL STATUS

	AP-NORC 8/16-20/2018
Married	47
Widowed	9
Divorced	12
Separated	2
Never married	22
Living with partner	8
<i>N=</i>	<i>1,024</i>

EMPLOYMENT STATUS

	AP-NORC 8/16-20/2018
Employed	51
Not employed	49
<i>N=</i>	<i>1,024</i>

EDUCATION

	AP-NORC 8/16-20/2018
Less than a high school diploma	7
High school graduate or equivalent	30
Some college	35
College graduate or above	28
<i>N=</i>	<i>1,024</i>

INCOME

	AP-NORC 8/16-20/2018
Under \$10,000	4
\$10,000 to under \$20,000	11
\$20,000 to under \$30,000	15
\$30,000 to under \$40,000	11
\$40,000 to under \$50,000	11
\$50,000 to under \$75,000	18
\$75,000 to under \$100,000	12
\$100,000 to under \$150,000	12
\$150,000 or more	5
<i>N</i> =	1,024

Study Methodology

This study, funded by [The SCAN Foundation](#), was conducted by The Associated Press-NORC Center for Public Affairs Research. Data were collected using AmeriSpeak®, NORC’s probability-based panel designed to be representative of the U.S. household population. During the initial recruitment phase of the panel, randomly selected U.S. households were sampled with a known, non-zero probability of selection from the NORC National Sample Frame and then contacted by U.S. mail, email, telephone, and field interviewers (face-to-face). The panel provides sample coverage of approximately 97 percent of the U.S. household population. Those excluded from the sample include people with P.O. Box only addresses, some addresses not listed in the USPS Delivery Sequence File, and some newly constructed dwellings. Staff from NORC at the University of Chicago, The Associated Press, and The SCAN Foundation collaborated on all aspects of the study.

Interviews for this survey were conducted between June 26 and July 10, 2018, with adults age 18 and older with experience providing long-term care to a family member or friend representing the 50 states and the District of Columbia. Panel members were randomly drawn from AmeriSpeak and invited to complete a screener to determine their eligibility for the survey. In addition, panelists who completed the 2018 Long-Term Care Trend Poll and answered that they had experience providing long-term care were invited to complete the screener. Those with current or past experience providing long-term care in the screener were invited to the survey, and 1,024 completed the survey—871 via the web and 153 via telephone. Interviews were conducted in both English and Spanish, depending on respondent preference. Respondents were offered a small monetary incentive (\$4) for completing the survey.

The screener completion rate is 28.6 percent, with an incidence rate of 47.9 percent among newly screened panelists. The final stage completion rate is 97.6 percent, the weighted household panel response rate is 33.7 percent, and the weighted household panel retention rate is 87.2 percent, for a

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cumulative AAPOR response rate 3 of 8.2 percent. The overall margin of sampling error is +/- 4.1 percentage points at the 95 percent confidence level, including the design effect.

Once the sample has been selected and fielded, and all the study data have been collected and made final, base sampling weights for the selected sample are adjusted for screener nonresponse, and then a poststratification process is used to adjust for any survey nonresponse. Poststratification variables included age, gender, census division, race/ethnicity, and education. Population totals for U.S. adults age 18 and older who have experience providing long-term care were obtained using the screener nonresponse adjusted weight for all eligible respondents from the screener questions. At the final stage of weighting, any extreme weights were trimmed based on a criterion of minimizing the mean squared error associated with key survey estimates, and then, weights were re-raked to the same population totals. The weighted data reflect the U.S. population of adults age 18 and over who have experience providing long-term care.

Topline data and reports for all previous years, including full methodology statements, are available at www.longtermcarepoll.org. For more information, email info@apnorc.org.

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