

The Associated Press-NORC Center for Public Affairs Research

Long-Term Caregiving: The Types of Care Older Americans Provide and the Impact on Work and Family

Conducted by The Associated Press-NORC Center for Public Affairs Research Funded by The SCAN Foundation

Interviews: 6/27-7/31/2017 1,004 adults age 40 and older with experience with long-term care

Margin of error for adults age 40 and older with experience with long-term care: +/- 3.7 percentage points at the 95% confidence level

Margin of error for care providers: +/- 4.2 percentage points at the 95% confidence level Margin of error for care recipients: +/- 7.4 percentage points at the 95% confidence level

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

Introductory Questions

Q1. In general, how would you rate your overall health?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Excellent/Very good NET	35	15	40
Excellent	7	2	8
Very good	28	13	32
Good	37	34	38
Fair/Poor NET	28	51	21
Fair	20	31	17
Poor	7	20	4
DON'T KNOW	-	-	-
SKIP/REFUSED	-	-	-
N=	1,004	232	772

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

Q10. Some people need ongoing living assistance as they get older. This assistance can be 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 help 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 member, a friend, a volunteer, or a health care professional.

Are you currently receiving this kind of ongoing living assistance or not?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Yes	14	67	-
No	86	33	100
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	*	-	*
N=	1,004	232	772

If "No," "DON'T KNOW," skipped, or refused in Q10 Q11. Have you ever received ongoing living assistance like this or not?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Yes	8	100	-
No	92	-	100
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	851	79	772

Q10/Q11 combined.

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Currently or ever received ongoing			
living assistance	79	100	-
Never received assistance	21	-	100
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	1,004	232	772

If "Yes" in Q10 or Q11

Q12. [Are you currently receiving/did you most recently receive] this ongoing living assistance in your own home, in a friend or family member's home, in a nursing home, or in a senior community, which includes assisted living communities and facilities?

	Received long-term
AP-NORC	care currently or in
6/27-7/31/2017	the past
Own home	80
Friend or family member's home	10
Nursing home	2
Senior community	8
DON'T KNOW	*
SKIP/REFUSED	-
N=	232

If "Own home," "Friend or family member's home," "DON'T KNOW," skipped, or refused in Q12 **Q13. Have you ever received ongoing living assistance from any of the following or not?**

Received long-term care currently or in the past

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
An unpaid family member	62	36	-	2
An unpaid friend	27	67	-	6
A paid caregiver	46	50	-	4
N=210				

If "Yes" to "An unpaid family member," "An unpaid friend," or "A paid caregiver" in Q13 Q13_2. Have you ever lived together with someone while they were providing ongoing living assistance to you?

	Received long-term
AP-NORC	care currently or in
6/27-7/31/2017	the past
Yes	44
No	56
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
N=	183

Q14. Are you currently providing ongoing living assistance on a regular basis to a family member or close friend or not?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Yes	29	17	32
No	71	82	68
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	*	*	*
N=	1,004	232	772

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 member's home, in a nursing home, or in a senior community?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Own home	43	52	41
Aging friend or family member's home	39	32	40
Another friend or family member's home	7	6	7
Nursing home	5	6	5
Senior community	7	4	7
DON'T KNOW	*	-	*
SKIP/REFUSED	-	-	-
N=	304	42	262

If "No," "DON'T KNOW," skipped, 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?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Yes	87	44	100
No	13	56	-
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	700	190	510

Q14/Q15 combined.

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Total ever provided care	90	46	100
Never provided care	10	54	-
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	1,004	232	772

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?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Own home	38	39	38
Aging friend or family member's home	46	45	46
Another friend or family member's home	7	5	7
Nursing home	5	5	5
Senior community	3	6	3
DON'T KNOW	-	-	-
SKIP/REFUSED	1	-	1
N=	594	84	510

Q14_1/Q15A combined.

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Own home	40	43	39
Aging friend or family member's home	44	41	44
Another friend or family member's home	7	6	7
Nursing home	5	5	5
Senior community	4	6	4
DON'T KNOW	*	-	*
SKIP/REFUSED	*	-	*
N=	898	126	772

Providers of Long-Term Care

The next series of questions was asked among current or past providers of ongoing living assistance. Those who indicated they both received and provided care are not asked these questions.

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 Q16A. How many people have you provided ongoing living assistance to in the past 12 months?

	AP-NORC
	6/27-7/31/2017
0 [Displayed if "Yes" in Q15]	45
1	40
2	10
3 or more	5
DON'T KNOW	-
SKIP/REFUSED	-
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q17A. 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				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Your mother	45	49	-	6
Your father	21	70	-	9
Your spouse or partner	19	72	-	9
A son or son-in-law	4	84	-	12
A daughter or daughter-in-law	2	93	-	5
A parent in-law	14	82	-	4
A grandparent	9	87	-	5
A sibling(s)	8	86	-	7
Another extended family member(s)	10	87	-	3
A close friend(s)	12	83	-	5
A neighbor	9	87	-	5
N-772				

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 **Q19. Have you been paid for any of the ongoing living assistance you [provide/provided] to a family member or close friend?**

	AP-NORC
	6/27-7/31/2017
I have been paid	9
I have not been paid	91
DON'T KNOW	-
SKIP/REFUSED	*
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 **Q20A. How long [have you been providing/did you provide] ongoing living assistance?**

	AP-NORC
	6/27-7/31/2017
Less than one year	30
One year to two years	24
More than two years	46
DON'T KNOW	-
SKIP/REFUSED	-
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 Q21A. [Have/Did] you ever [moved/move] in order to be closer to the person you [are/were] providing care for, or not?

	AP-NORC
	6/27-7/31/2017
Yes	18
No	82
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 Q22A. Would you say that the person you [provide/provided] care to [needs/needed] care because of any of the following?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Loss of memory or other mental abilities, such				
as Alzheimer's disease or dementia	36	61	-	3
Short-term physical conditions or diseases, such				
as pneumonia or an injury from a fall or accident	31	64	*	5
Long-term physical conditions, diseases, or				
disabilities, such as diabetes, loss of vision, or				
loss of mobility	59	39	-	2
Something else	35	59	-	6
N 770				

N=772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q23A. [Do/did] you provide any of the following types of ongoing living assistance or home health services?

[ITEMS RANDOMIZED]

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Housekeeping, such as cleaning and laundry	81	19	-	*
Shopping for groceries	87	13	-	*
Cooking, meal preparation, and feeding	81	19	-	*
Bathing, toileting, and getting dressed	57	42	-	1
Getting around inside the home	58	41	-	1
Transportation to doctor's appointments or				
other services	85	15	-	*
Arranging or supervising services like doctor's				
appointments	74	25	-	1
Making sure bills are paid or managing finances	66	33	*	1
Reminders to take medicine	72	27	-	*
Administering medicine	53	46	-	1
Checking blood pressure or checking blood				
glucose, such as for diabetics	34	66	-	*
Preparing and inserting tubes for catheters or				
feeding tubes	6	93	-	1
Preparing or administering injections	14	85	-	1
Caring for an IV or port	7	92	-	1
Changing bandages or other wound care	30	68	*	2
Something else	19	78	*	3

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q24. [Have you learned/Did you learn] how to provide ongoing living assistance in any of the
following ways?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
You learned on the job or taught yourself how to do it	87	12	-	1
The person you [provide/provided] care for showed				
you how to do it	23	75	*	2
You received formal training from a doctor or other				
health care professional on how to provide care	24	75	*	1
You talked to friends or family who had been				
caregivers to learn from their experiences	34	65	-	2
You searched online for information about providing				
care	26	73	-	2
You read a newspaper, magazine, or book	19	80	-	2
You talked to a health care professional	61	38	-	1
You took a class on providing care to seniors	12	86	-	2
You learned in another way – please specify	4	93	*	2
You have professional/educational experience				
providing care (VOL.)	6	94	-	-
N-772				

N=772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q26. Would you say you had all, most, some, hardly any, or none of the training that you needed to provide ongoing living assistance to your older family member or friend?

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

	AP-NORC
	6/27-7/31/2017
All/Most of the training I needed NET	47
All of the training I needed	18
Most of the training I needed	29
Some of the training I needed	25
None/Hardly any of the training I needed NET	28
Hardly any of the training I needed	14
None of the training I needed	15
DON'T KNOW	*
SKIP/REFUSED	*
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

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				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Other family members or close friends who can				
cover your responsibilities	77	23	-	*
A respite care program that provides a temporary				
caregiver	27	71	1	1
Adult day care or community senior services that				
your loved one can go to	17	81	*	2
N=772				

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q28A. [When you were providing care, did you/Have you] ever [share/shared] the responsibilities of providing care with someone else?

	AP-NORC
	6/27-7/31/2017
Yes	67
No	33
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
N=	772

If "Yes" in Q28A

Q29. [Do you/Did you] share caregiving responsibilities with any of the following people?

			1	
AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Your mother	16	81	-	3
Your father	8	89	-	3
Your spouse or partner	35	63	-	2
A son or son-in-law	8	89	-	3
A daughter or daughter-in-law	16	81	-	3
A parent in-law	5	91	-	4
A grandparent	2	94	-	4
A sibling(s)	44	52	-	3
Another extended family member(s)	29	68	-	3
A close friend	15	82	-	4
A neighbor	14	82	*	3
A paid caregiver, such as a home health aide	41	56	-	3
Someone else – please specify	1	94	-	5
N-400				

N=499

If "Yes" in Q28A

Q31A. How satisfied or dissatisfied [were/are] you with the way caregiving [was/is] divided among you and the people you [provided/provide] ongoing living assistance with?

	AP-NORC 6/27-7/31/2017
Very/Somewhat satisfied NET	73
Very satisfied	45
Somewhat satisfied	28
Neither satisfied nor dissatisfied	17
Very/Somewhat dissatisfied NET	9
Somewhat dissatisfied	6
Very dissatisfied	3
DON'T KNOW	1
SKIPPED ON WEB/REFUSED	-
N=	499

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11

Q32. How would you rate the effect providing ongoing living assistance had on your life? Would you say it had a positive effect, a negative effect, or no effect at all on your life?

	AP-NORC
	6/27-7/31/2017
A major/moderate positive effect NET	56
A major positive effect	27
A moderate positive effect	28
No effect at all	13
A major/moderate negative effect NET	31
A moderate negative effect	24
A major negative effect	7
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
N=	772

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 **Q33. When you think about your personal experience providing ongoing living assistance to your**

family member or close friend, would you say that...?

[ITEMS RANDOMIZED]

	-	1	<u>г</u>	
AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
It [is/was] stressful	77	22	-	1
It [is/was] time consuming	79	19	*	2
It [is/was] fulfilling	74	23	1	2
It [is/was] worthwhile	95	4	-	1
It [is/was] frustrating	61	36	*	3
It [makes/made] me feel honorable	71	27	1	2
It [makes/made] me feel happy	58	39	*	2
It [makes/made] me feel sad	58	40	*	2
It [makes/made] me feel resentful	13	85	1	2
It [makes/made] me feel overwhelmed	52	47	*	1
It [makes/made] me feel some other way –				
please specify	12	83	*	5
It [makes/made] me feel grateful (VOL.)	1	99	-	-
It [makes/made] me feel tired/exhausted				
(VOL.)	1	99	-	-
N=772				

If "Yes" in Q14 or Q15 and "No," "DON'T KNOW," skipped, or refused in Q10 and Q11 Q34. Are you currently working, have you been employed in the past, or have you never been employed?

	AP-NORC 6/27-7/31/2017
I am currently working	45
I've been employed in the past, but I'm	
not currently working	54
I've never been employed	1
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
N=	772

If "Yes" in Q14 and "I've been employed in the past, but I'm not currently working" in Q34, or if "Yes" in Q15 and "I am currently working"/"I've been employed in the past, but I'm not currently working" in Q34 Q35. At any point when you were employed, were you also providing ongoing living assistance?

	AP-NORC 6/27-7/31/2017
Yes	64
No	36
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
N=	643

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q36. [Thinking back to when you were providing care and working...] In your main job, [are you/were you] salaried, paid by the hour, or paid in some other way?

	AP-NORC
	6/27-7/31/2017
Salaried	36
Paid by the hour	53
Paid in some other way	11
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	-
N=	527

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35 Q37. [Thinking back to when you were providing care and working...] [Does/Did] your main employer offer paid time off to use for vacation, or not?

	AP-NORC
	6/27-7/31/2017
Yes	57
No	41
DON'T KNOW	1
SKIPPED ON WEB/REFUSED	1
N=	527

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q38. [Have you ever talked/Did you ever talk] with any of the following people about your role providing ongoing living assistance, or not?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
A supervisor	45	53	*	2
Someone in human resources	15	82	*	3
A coworker	59	40	-	*
N=527				

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q39. [Would you say it is/Was it] easy, difficult, or neither easy nor difficult to balance your work responsibilities and your caregiving responsibilities?

	AP-NORC
	6/27-7/31/2017
Very/Moderately easy NET	28
Very easy	9
Moderately easy	19
Neither easy nor difficult	24
Very/Moderately difficult NET	47
Moderately difficult	35
Very difficult	12
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
N=	527

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q40. Overall, how supportive [have/was] your employer or employers [been] about your caregiving role?

	AP-NORC 6/27-7/31/2017
Extremely/Very supportive NET	48
Extremely supportive	17
Very supportive	32
Somewhat supportive	29
Not at all/Not too supportive NET	18
Not too supportive	10
Not at all supportive	9
DON'T KNOW	2
SKIPPED ON WEB/REFUSED	2
N=	527

[HALF SAMPLE ASKED RESPONSE OPTIONS IN REVERSE ORDER]

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q41A. [Have/Did] any of the following [happened/happen] at work because you needed to provide care to an aging family member or close friend, or not?

			SKP/
Yes	No	DK	REF
1	98	*	1
1	98	-	1
7	91	*	2
10	89	*	2
8	90	*	2
	1 1 7 10	1 98 1 98 7 91 10 89	1 98 * 1 98 - 7 91 * 10 89 *

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q42A. Have you ever had to miss work to provide care to an aging family member or close friend or not?

Missing work can mean anything from missing a few hours here and there to taking off work for an extended period of time.

	AP-NORC
	6/27-7/31/2017
Yes	70
No	30
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
N=	527

If "Yes" in Q42A

Q43A. What was the longest amount of time that you needed to take away from work to provide care?

	AP-NORC
	6/27-7/31/2017
A few hours, but less than a whole day	17
At least one day, but less than a week	51
At least one week, but less than a month	20
One month or more	11
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	2
N=	363

If "Yes" in Q42A

Q44. How did you take time away from work to provide ongoing living assistance? Did you ever do any of the following to provide care, or not?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Used my sick, vacation or personal time	73	26	-	1
Took unpaid leave	39	60	-	1
Took paid leave for caregivers, and I received full pay	10	87	*	3
Took paid leave for caregivers, and I received partial pay	2	95	*	3
Took time off in some other way – please specify	8	87	-	4
I have flexible hours/I'm self-employed (VOL.)	5	95	-	-
N=363				

If "Yes" in Q42A

Q45. Thinking about the care needs of your loved one, do you feel the amount of time you took away from work was enough time off to provide care or not enough time off to provide care?

	AP-NORC
	6/27-7/31/2017
Enough time off	65
Not enough time off	34
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	1
N=	363

If "Yes" in Q42A

Q46. Now, thinking about your job security, were you concerned the amount of time you took away from work was too much time off from work, or weren't you concerned?

	AP-NORC 6/27-7/31/2017
Concerned it was too much time off	29
Was not concerned	71
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
N=	363

If "Yes" in Q14 and "I am currently working" in Q34, or "Yes" in Q35

Q47. Have you ever done any of the following to change your work schedule in order to provide care to an aging family member or close friend?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
I switched from full-time to part-time	8	90	-	3
I changed the days or hours I worked	38	61	-	1
l quit my job	9	89	-	2
I retired early	10	89	-	1

Recipients of Long-Term Care

The next series of questions was asked among current or past recipients of ongoing living assistance. Those who only received care and those who indicated they both received and provided care are asked about their experiences receiving care.

If "Yes" in Q10 or Q11 and "Yes" to "An unpaid family member" or "An unpaid friend" **Q16B. Thinking about your experience** <u>receiving</u> ongoing living assistance...

How many people have you received that assistance from in the past 12 months?

	AP-NORC 6/27-7/31/2017
0 [Displayed if "Yes" in Q11]	14
1	42
2	15
3 or more	29
DON'T KNOW	-
SKIP/REFUSED	-
N=	139

If "Yes" in Q10 or Q11 and "Yes" to "An unpaid family member" or "An unpaid friend" Q17B. Are you currently receiving ongoing living assistance/Thinking back to when you received ongoing living assistance, did you receive it] from any of the following people?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Your mother	16	83	-	1
Your father	5	94	-	1
Your spouse or partner	41	59	-	*
A son or son-in-law	21	78	-	1
A daughter or daughter-in-law	33	65	-	1
A parent in-law	-	98	-	2
A grandparent	2	96	-	2
A sibling(s)	21	76	-	3
Another extended family member(s)	14	86	-	-
A close friend(s)	27	73	-	-
A neighbor	10	89	-	1

If "Yes" in Q10 or Q11

Q18. Thinking about your experience <u>receiving</u> ongoing living assistance...

Have you or has anyone in your family paid for any of that assistance you received?

	AP-NORC
	6/27-7/31/2017
I have paid	21
Someone else in my family has paid	7
No one has paid	72
DON'T KNOW	-
SKIP/REFUSED	*
N=	232

If "Yes" in Q10 or Q11

Q20B. [How long have you been receiving/did you receive] ongoing living assistance?

	AP-NORC
	6/27-7/31/2017
Less than one year	34
One year to two years	23
More than two years	42
DON'T KNOW	*
SKIP/REFUSED	-
N=	232

If "Yes" in Q10 or Q11

Q21B. [Have/Did] you ever [moved/move] in order to be closer to the person who [is/was] caring for you, or not?

	AP-NORC
	6/27-7/31/2017
Yes	14
No	85
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	*
N=	232

If "Yes" in Q10 or Q11

Q22B. Would you say that you [need/needed] care because of any of the following?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Loss of memory or other mental abilities, such as				
Alzheimer's disease or dementia	12	85	*	2
Short-term physical conditions or diseases, such				
as pneumonia or an injury from a fall or accident	40	57	-	3
Long-term physical conditions, diseases, or				
disabilities, such as diabetes, loss of vision, or loss				
of mobility	64	34	-	2
Something else	38	57	1	3
N=232				

N=232

If "Yes" in Q10 or Q11

Q23B. [Do/did] you receive any of the following types of ongoing living assistance or home health services?

[ITEMS RANDOMIZED]

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
Housekeeping, such as cleaning and laundry	70	29	-	1
Shopping for groceries	64	35	-	1
Cooking, meal preparation, and feeding	55	44	-	1
Bathing, toileting, and getting dressed	42	57	-	1
Getting around inside the home	31	68	-	1
Transportation to doctor's appointments or				
other services	70	30	-	-
Arranging or supervising services like doctor's				
appointments	46	53	-	1
Making sure bills are paid or managing finances	41	59	-	-
Reminders to take medicine	34	66	-	*
Administering medicine	32	68	-	-
Checking blood pressure or checking blood				
glucose, such as for diabetics	36	64	-	-
Preparing and inserting tubes for catheters or				
feeding tubes	4	96	-	*
Preparing or administering injections	15	84	*	-
Caring for an IV or port	11	89	*	-
Changing bandages or other wound care	28	72	-	-
Something else	16	82	2	*

If "Yes" in Q10 or Q11

Q28B. [Was/Is] there one person who [provided/provides] you with ongoing living assistance or [did/do] two or more people share the responsibilities of providing ongoing living assistance?

	AP-NORC 6/27-7/31/2017
One person [provides/provided] care	51
Two people [share/shared] responsibilities	22
Three or more people [share/shared]	23
responsibilities	
DON'T KNOW	1
SKIPPED ON WEB/REFUSED	2
N=	232

If "Two people [share/shared] responsibilities" or "Three or more people [share/shared] responsibilities" in Q28B

Q31B. How satisfied or dissatisfied [were/are] you with the way caregiving [was/is] divided among the people who [provided/provide] ongoing living assistance to you?

	AP-NORC
	6/27-7/31/2017
Very/Somewhat satisfied NET	91
Very satisfied	73
Somewhat satisfied	18
Neither satisfied nor dissatisfied	5
Very/Somewhat dissatisfied NET	4
Somewhat dissatisfied	1
Very dissatisfied	3
DON'T KNOW	*
SKIPPED ON WEB/REFUSED	*
N=	115

If "Yes" in Q10 or Q11

Q41B. [Have/Did] any of the following [happened/happen] to a family member or friend at their work because they needed to provide care to you or not?

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
They were fired	5	95	*	-
They were asked to resign	3	97	*	-
Their roles or responsibilities changed	13	87	1	-
N=232				

If "Yes" in Q10 or Q11

Q42B. Has a family member or friend ever had to miss work to provide care to you or not?

Missing work can mean anything from missing a few hours here and there to taking off work for an extended period of time.

	AP-NORC
	6/27-7/31/2017
Yes	32
No	68
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
N=	232

If "Yes" in Q42B

Q43B. What was the longest amount of time that your family member or friend needed to take away from work to provide care?

	AP-NORC
	6/27-7/31/2017
A few hours, but less than a whole day	26
At least one day, but less than a week	53
At least one week, but less than a month	14
One month or more	7
DON'T KNOW	-
SKIPPED ON WEB/REFUSED	-
N=	75

Person-Centered Care

If "Yes" in Q10 OR If "Yes" in Q14, "No," "DON'T KNOW," skipped, or refused in Q10

Q48. *Recipients:* Are you under the care of one or more health care providers or not? Health care providers include doctors, physician assistants, nurse practitioners, registered nurses, physical therapists, and occupational therapists.

Providers: Thinking of the person that you provide ongoing living assistance to, is that person under the care of one or more health care providers or not? Health care providers include doctors, physician assistants, nurse practitioners, registered nurses, physical therapists, and occupational therapists.

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
Yes	84	79	87
No	15	21	11
DON'T KNOW	*	-	*
SKIPPED ON WEB/REFUSED	1	*	1
N=	427	165	262

If "Yes" in Q48

Q49. Recipients: How many doctors or other health care providers do you receive care from regularly?

Providers: Thinking again of the person that you provide ongoing living assistance to, how many doctors or other health care providers does the person receive care from regularly?

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
1	20	21	20
2 or more	79	79	80
DON'T KNOW	*	*	*
SKIPPED ON WEB/REFUSED	-	-	-
N=	365	134	231

If "2 or more" in Q49 **Q50.** *Recipients:* Do you have...

Providers: Does the person you provide ongoing living assistance to have...

All current long-term care recipients or providers

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
A single care manager who serves as a				
point of contact and can coordinate all				
aspects of [your/their] care?	40	58	1	1
An individualized care plan designed to				
take into account [your/their] personal				
goals and preferences?	38	56	3	4
N-20C				

N=296

Currently receiving long-term care

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
A single care manager who serves as a				
point of contact and can coordinate all				
aspects of your care?	54	45	-	*
An individualized care plan designed to				
take into account your personal goals and				
preferences?	50	47	1	2
N=112				

Currently providing long-term care

AP-NORC				SKP/
6/27-7/31/2017	Yes	No	DK	REF
A single care manager who serves as a				
point of contact and can coordinate all				
aspects of their care?	32	65	1	2
An individualized care plan designed to				
take into account their personal goals and				
preferences?	32	60	4	5

If "Yes" in Q10 and "Yes" in Q50A

OR If "Yes" in Q14, "No," "DON'T KNOW," skipped, or refused in Q10, and "Yes" in Q50A Q51_1A/Q51_2A. *Recipients:* Do you feel that having a single care manager who serves as a point of contact and can coordinate all aspects of your care has improved your care a lot, a little, or not at all?

Providers: Do you feel that having a single care manager who serves as a point of contact and can coordinate all aspects of their care has improved the care of the person you provide ongoing living assistance to a lot, a little, or not at all?

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
A lot	68	71	66
A little	25	19	29
Not at all	7	11	5
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	126	56	70

If "Yes" in Q10 and "Yes" in Q50B

OR If "Yes" in Q14, "No," "DON'T KNOW," skipped, or refused in Q10, and "Yes" in Q50B Q51_1B/Q51_2B. *Recipients:* Do you feel that having an individualized care plan designed to take into account your personal goals and preferences has improved your care a lot, a little, or not at all?

Providers: Do you feel that having an individualized care plan designed to take into account their personal goals and preferences has improved the care of the person you provide ongoing living assistance to a lot, a little, or not at all?

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
A lot	56	63	51
A little	36	30	40
Not at all	8	7	9
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	1	-	1
N=	110	49	61

If "Yes" in Q10 and "No," "DON'T KNOW," skipped, or refused in Q50A

OR If "Yes" in Q14, "No," "DON'T KNOW," skipped, or refused in Q10, and "No," "DON'T KNOW," skipped, or refused in Q50A

Q52_1A/Q52_2A. *Recipients:* Do you feel that having a single care manager who serves as a point of contact and can coordinate all aspects of your care would improve your care a lot, a little, or not at all?

Providers: Do you feel that having a single care manager who serves as a point of contact and can coordinate all aspects of their care would improve the care of the person you provide ongoing living assistance to a lot, a little, or not at all?

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
A lot	31	25	32
A little	37	27	40
Not at all	30	46	25
DON'T KNOW	1	2	*
SKIPPED ON WEB/REFUSED	2	-	2
N=	170	48	122

If "Yes" in Q10 and "No," "DON'T KNOW," skipped, or refused in Q50B

OR If "Yes" in Q14, "No," "DON'T KNOW," skipped, or refused in Q10, and "No," "DON'T KNOW," skipped, or refused in Q50B

Q52_1B/Q52_2B. *Recipients:* Do you feel that having an individualized care plan designed to take into account your personal goals and preferences would improve your care a lot, a little, or not at all?

Providers: Do you feel that having an individualized care plan designed to take into account their personal goals and preferences would improve the care of the person you provide ongoing living assistance to a lot, a little, or not at all?

	All current long-term		
AP-NORC	care recipients or	Currently receiving	Currently providing
6/27-7/31/2017	providers	long-term care	long-term care
A lot	40	34	42
A little	32	31	32
Not at all	26	33	23
DON'T KNOW	1	1	*
SKIPPED ON WEB/REFUSED	2	-	2
N=	186	55	131

Demographics

INS1. Are you covered by any kind of health insurance or some other kind of health care plan or not?

Please include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills.

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Yes	92	95	92
No	7	4	8
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	*	1	*
N=	1,004	232	772

If "Yes" in INS1

INS2. Which of the following is your main source of health insurance coverage? Is it a plan through your employer, a plan through your spouse's employer, a plan you purchased yourself either from an insurance company or a state or federal marketplace, are you covered by Medicare or Medicaid, or do you get your health insurance from somewhere else?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Plan through employer	22	9	26
Plan through spouse's employer	13	5	15
Plan purchased yourself directly		2	3
from an insurance company	3		
Health insurance marketplace	4	1	5
Medicare	43	54	40
Medicaid	10	22	7
Somewhere else	4	6	4
DON'T KNOW	*	1	*
SKIPPED ON WEB/REFUSED	-	-	-
N=	937	223	714

D1. Do you consider yourself a Democrat, a Republican, an independent or none of these?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Democrat	38	44	36
Republican	26	25	27
Independent	22	16	23
None of these	14	14	14
DON'T KNOW	*	1	-
SKIPPED ON WEB/REFUSED	*	1	*
N=	1,004	232	772

If "Democrat" in D1

D2D. Do you consider yourself a strong Democrat or a moderate Democrat?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Strong Democrat	46	50	45
Moderate Democrat	54	50	55
DON'T KNOW	-	-	-
SKIPPED ON WEB/REFUSED	-	-	-
N=	387	100	287

If "Republican" in D1

D2R. Do you consider yourself a strong Republican or a moderate Republican?

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Strong Republican	40	60	36
Moderate Republican	59	40	64
DON'T KNOW	*	-	*
SKIPPED ON WEB/REFUSED	-	-	-
N=	251	56	195

If "Independent," "None of these," "DON'T KNOW," skipped, or refused in D1 **D2I. Do you lean more toward the Democrats or the Republicans?**

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Lean Democrat	27	31	26
Lean Republican	23	16	25
Don't lean	47	48	47
DON'T KNOW	1	3	1
SKIPPED ON WEB/REFUSED	2	2	1
N=	366	76	290

POLITICS. D1, D2D, D2R, and D2I combined.

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Democrat NET	47	54	46
Strong Democrat	17	22	16
Moderate Democrat	20	22	20
Lean Democrat	10	10	10
Independent/None – Don't lean	17	15	18
Republican NET	35	30	36
Lean Republican	8	5	9
Moderate Republican	16	10	17
Strong Republican	11	15	10
Unknown	1	2	1
N=	1,004	232	772

GENDER

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Male	41	42	40
Female	60	58	60
N=	1,004	232	772

EDUCATION

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
No high school diploma	8	7	8
High school graduate or		43	30
equivalent	32		
Some college	31	31	31
Bachelor's degree or above	29	19	31
N=	1,004	232	772

AGE

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
40-54	27	30	27
55-64	36	30	37
65-74	24	20	26
75-84	9	12	8
85+	3	8	2
N=	1,004	232	772

INCOME

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
Under \$10,000	5	10	4
\$10,000 to under \$20,000	12	24	9
\$20,000 to under \$30,000	16	20	15
\$30,000 to under \$40,000	11	8	12
\$40,000 to under \$50,000	9	11	8
\$50,000 to under \$75,000	18	11	20
\$75,000 to under \$100,000	12	12	12
\$100,000 to under \$150,000	10	2	12
\$150,000 or more	6	3	6
N=	1,004	232	772

RACE/ETHNICITY

	All long-term care	Received long-term	Provided long-term
AP-NORC	recipients or	care currently or in	care currently or in
6/27-7/31/2017	providers	the past	the past
White	70	62	72
African American	13	15	12
Hispanic	11	13	10
Other	6	10	5
N=	1,004	232	772

Study Methodology

This study, funded by <u>The SCAN Foundation</u>, 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% 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. Of note for this study, the panel would also exclude recipients of long-term care who live in institutional types of settings, such as skilled nursing facilities or some types of nursing homes. 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 27 and July 31, 2017, with adults age 40 and older with experience with long-term care 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 2017 Long-Term Care Trend Poll and answered that they had experience with long-term care were invited to complete the screener. Those with current or past experience as a provider or receiver of long-term care in the screener were invited to the survey, and 1,004 completed the survey—663 via the web and 341 via telephone. Interviews were conducted in both English and Spanish, depending on respondent preference. Respondents were offered a small monetary incentive (\$5) for completing the survey.

The screener completion rate is 47.0 percent, with an incidence rate of 54.9 percent. The final stage completion rate is 37.2 percent, the weighted household panel response rate is 31.4 percent, and the weighted household panel retention rate is 91.1 percent, for a cumulative AAPOR response rate 3 of 13.2 percent. The overall margin of sampling error is +/- 3.7 percentage points at the 95 percent confidence level, including the design effect. For the care providers, the margin of sampling error at the 95 percent confidence level is +/- 4.2 percentage points. For the care recipients, the margin of sampling error at the 95 percent confidence level is +/- 7.4 percentage points.

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 were 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 40 and older who have experience with 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 re-raked to the same population totals. The weighted data reflect the U.S. population of adults age 40 and over who have experience with long-term care.

Topline data and reports for all previous years, including full methodology statements, are available at <u>www.longtermcarepoll.org</u>.

About The Associated Press-NORC Center for Public Affairs Research

The AP-NORC Center for Public Affairs Research taps into the power of social science research and the highest-quality journalism to bring key information to people across the nation and throughout the world.

- The Associated Press (AP) is the world's essential news organization, bringing fast, unbiased news to all media platforms and formats.
- NORC at the University of Chicago is one of the oldest and most respected, independent research institutions in the world.

The two organizations have established The AP-NORC Center for Public Affairs Research to conduct, analyze, and distribute social science research in the public interest on newsworthy topics, and to use the power of journalism to tell the stories that research reveals.

The founding principles of The AP-NORC Center include a mandate to carefully preserve and protect the scientific integrity and objectivity of NORC and the journalistic independence of AP. All work conducted by the Center conforms to the highest levels of scientific integrity to prevent any real or perceived bias in the research. All of the work of the Center is subject to review by its advisory committee to help ensure it meets these standards. The Center will publicize the results of all studies and make all datasets and study documentation available to scholars and the public.