

LONG-TERM CARE: Perceptions, Experiences, and Attitudes among Americans 40 or Older



T. Thompson, J. Benz, J. Agiesta, D. Junius, K. Nguyen, and K. Lowell

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INTRODUCTION

The U.S. population is aging rapidly, with projections that the population of those over age 65 will nearly double by the time the last baby boomers turn 65.¹ In 2000, seniors comprised 12 percent of the U.S. population. By 2030, that number is expected to rise to 19 percent or 72 million Americans over the age of 65. U.S. Department of Health and Human Services projections estimate that 70 percent of Americans who reach the age of 65 will need some form of long-term care in their lives for an average of three years.² With the aging population come important social and public policy questions about preparing for and providing quality long-term care.

The Associated Press-NORC Center conducted a national survey of Americans 40 or older to contribute rigorous and highly relevant research to this policy issue. With a focus on understanding the experiences and attitudes of this population as they begin to plan for their own care and

interact with the long-term care system to provide care for loved ones, we examine their understanding of the long-term care system. We also explored their perceptions and misperceptions regarding the likelihood of needing long-term care services and of the cost of those services, and their attitudes and behaviors regarding planning for long-term care.

With an objective of generating new and actionable data about this population to inform the national dialogue surrounding long-term care issues, The AP-NORC Center, funded by The SCAN Foundation, conducted 1,019 interviews with a nationally representative sample of adults who are at least 40 years old.

1 Administration on Aging. 2011. Supporting data for the Profile of Older Adults. http://www.aoa.gov/aoaroot/aging_statistics/Profile/2011/docs/2011profile.xls, accessed April 17, 2012.

2 U.S. Department of Health & Human Services. National Clearinghouse for Long-Term Care Information. http://www.longtermcare.gov/LTC/Main_Site/index.aspx, accessed April 10, 2012.

The study reveals several critical issues with the potential to inform the long-term care policy dialogue.

- Although Americans 40 years or older report several concerns about aging and losing their independence, they are not taking actions to plan for their own long-term care needs. Only 41 percent of this population has taken the important first step of discussing their preferences for long-term care with their families and only 35 percent have set aside money to pay for their long-term care needs.
- There are widespread misperceptions among those 40 or over surrounding the costs of long-term care services, with significant proportions of the population underestimating the costs of nursing home care and overestimating the role of Medicare in paying for that care.

- The survey reveals majority support among Americans 40 or older for some public policy options for financing long-term care. This includes bipartisan support for tax incentives to encourage individual saving for long-term care expenses.
- Americans 40 or over count on their families to be there for them as they age, but those who are currently receiving long-term care or who have received it in the past are less likely to believe they can rely on their family in a time of need.

Key findings from the survey are provided below. Additional information, including the survey's complete Topline Findings, can be found on the AP-NORC Center's website at www.apnorc.org.

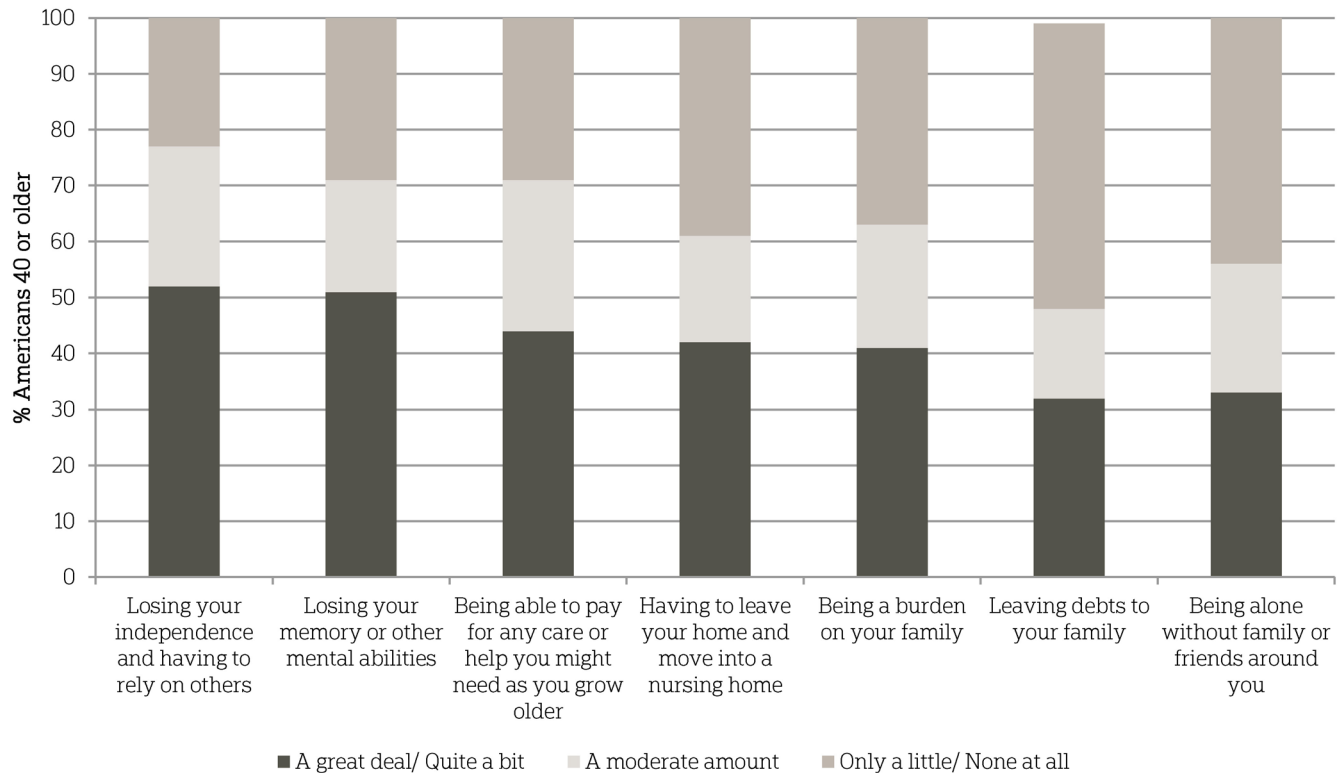
THREE IN TEN AMERICANS 40 OR OLDER WOULD RATHER NOT THINK ABOUT GETTING OLDER AT ALL, AND, WHEN PROMPTED TO THINK ABOUT IT, A MAJORITY WORRY ABOUT LOSING THEIR INDEPENDENCE.

Overall, the idea of getting older is something that 3 in 10 Americans 40 years or older would rather not think about at all. Another 32 percent are somewhat comfortable thinking about getting older and 35 percent report being very comfortable. Being older, more educated, and in better health are associated with greater levels of comfort thinking about aging. Sixty-two percent of those 40-54 years old are somewhat or very comfortable thinking about getting older; the percentage increases to 75 percent for those 65 or older. Nearly half of those 65 and older, 47 percent, report being very comfortable thinking about getting older.

Sixty percent of Americans 40 or older with a high school education or less report being at least somewhat comfortable thinking about getting older, compared to nearly three-quarters of those with more education. Seventy-two percent who report excellent, very good, or good health are at least somewhat comfortable thinking about getting older, compared to 52 percent of those who report fair or poor health.

When asked to think specifically about their own personal situation as they get older, a slight majority of Americans 40 years or older are a great deal or quite a bit concerned about losing their independence (52%) and losing their memories or other mental abilities (51%). Less than half are at least quite a bit concerned about being able to pay for the care or help they might need as they age (44%), having to move to a nursing home (42%), being a burden on their family (41%), leaving debts to their family (32%), and being alone without family or friends around them (33%). Majorities report being at least moderately concerned about all of these situations, with the exception of concern about leaving debts to family, for which 51 percent report only a little or no concern at all.

Reported levels of concern for different aging issues



For some of these situations, including losing independence and being alone as you age, levels of concern do not vary by demographic characteristics; but for other situations, levels of concern are greater for some groups, including those under 65, blacks, women, and individuals in lower-income households.

- Fifty-one percent of Americans ages 40-54 and 48 percent of Americans ages 55-64 are a great deal or quite a bit concerned about being able to pay for any care or help they might need as they age, compared to 30 percent of Americans ages 65 and older. This age difference is also true for concerns about being a burden on family (43% and 45% vs. 35%) and leaving debts to family (39% and 32% vs. 19%).
- Blacks are more likely than whites and Hispanics to be concerned about being able to pay for needed care (57% blacks vs. 41% whites and 45% Hispanics), being a burden on family (55% blacks vs. 37% whites and 50% Hispanics), leaving debts to family (47% blacks vs. 28% whites and 29% Hispanics), having to live in a nursing home (57% blacks vs. 40% whites and 44% Hispanics), and losing their memory or other mental abilities (56% blacks vs. 48% whites and 48% Hispanics).

- Women are more concerned than men about losing their memory or other mental abilities (57% of women vs. 44% of men) and leaving debts to their family (34% of women vs. 29% of men).
- Thirty nine percent of Americans 40 or over in households earning less than \$30,000 per year are a great deal or quite a bit concerned about leaving debts to their family compared to 24 percent of individuals in households earning \$75,000 per year or more.

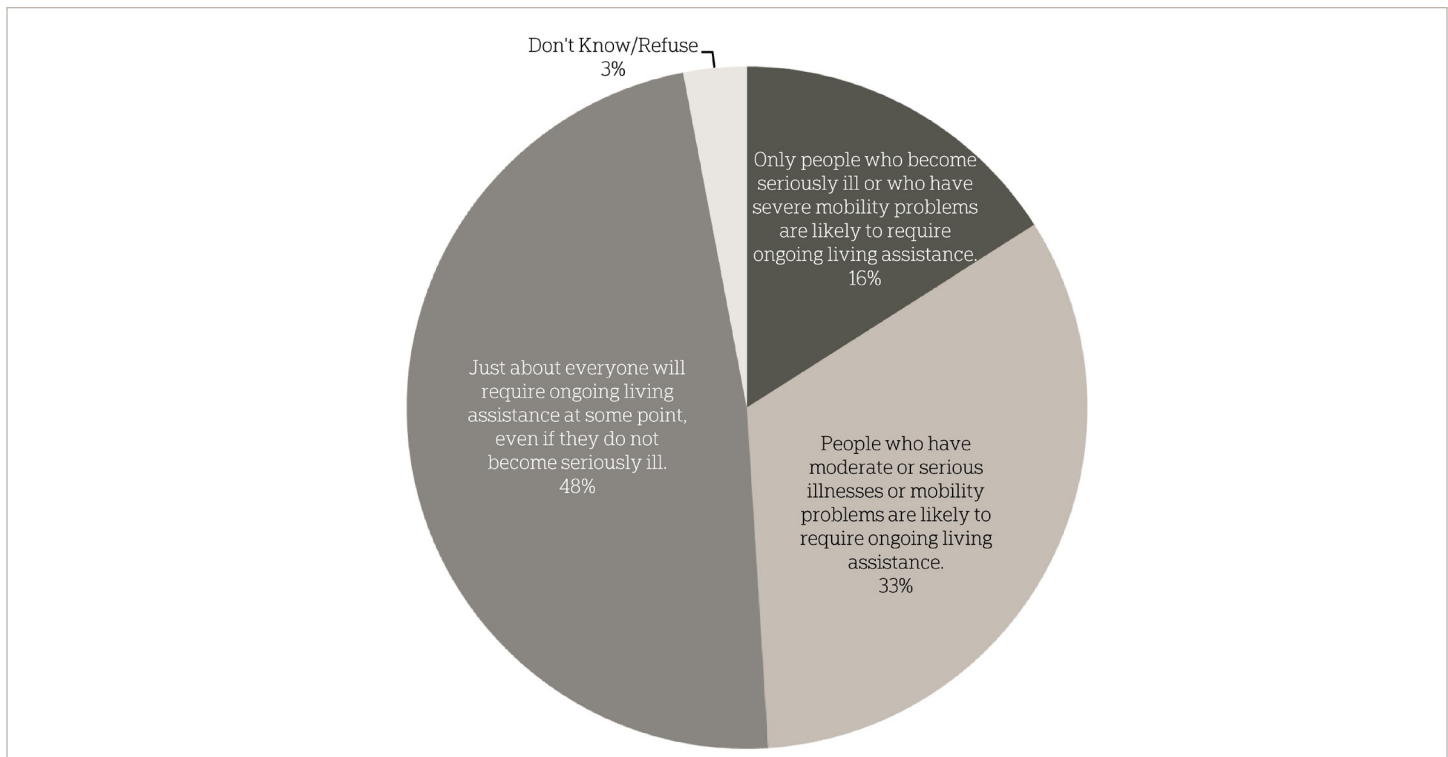
Additionally, 47 percent of individuals 40 or older with less than a college degree are concerned about having to move into a nursing home, compared to 33 percent who have more education. Individuals 40 or older who report being in fair or poor health are more concerned about being able to pay for needed care than those who report being in good, very good, or excellent health (58% vs. 40%).

EVEN WITH WIDESPREAD CONCERNS ABOUT AGING, MANY AMERICANS HAVE NOT TRANSLATED THOSE WORRIES INTO EFFECTIVE PLANNING STRATEGIES.

Nearly half, 48 percent, of Americans 40 years or older acknowledge that just about everyone will require long-term care at some point as they grow older, even if they do not become seriously ill, while significantly fewer believe that

long-term care is only for the seriously ill (16%) or those with some illnesses or mobility issues (33%).³

Perceptions of Americans 40 or older about who requires long-term care



Overall, 24 percent of the population 40 years or older who are not currently receiving long-term care believe that it is extremely or very likely that they personally will require long-term care someday. An additional 41 percent think it is somewhat likely, and 32 percent think it is not too or not at all likely. Similarly, 34 percent of Americans 40 years or older who are not currently providing long-term care believe that it is at least very likely that an aging family member or close friend will require long-term care in the next 5 years. An additional 32 percent think it is somewhat likely, and 33 percent think it is not too likely, or not at all likely. Among those who believe a family member or friend is at least somewhat likely to require long-term care in the next 5 years, 33 percent think they will be personally responsible for providing that care, 54 percent think someone else will provide that care, and 9 percent think that it will be some combination of the two.

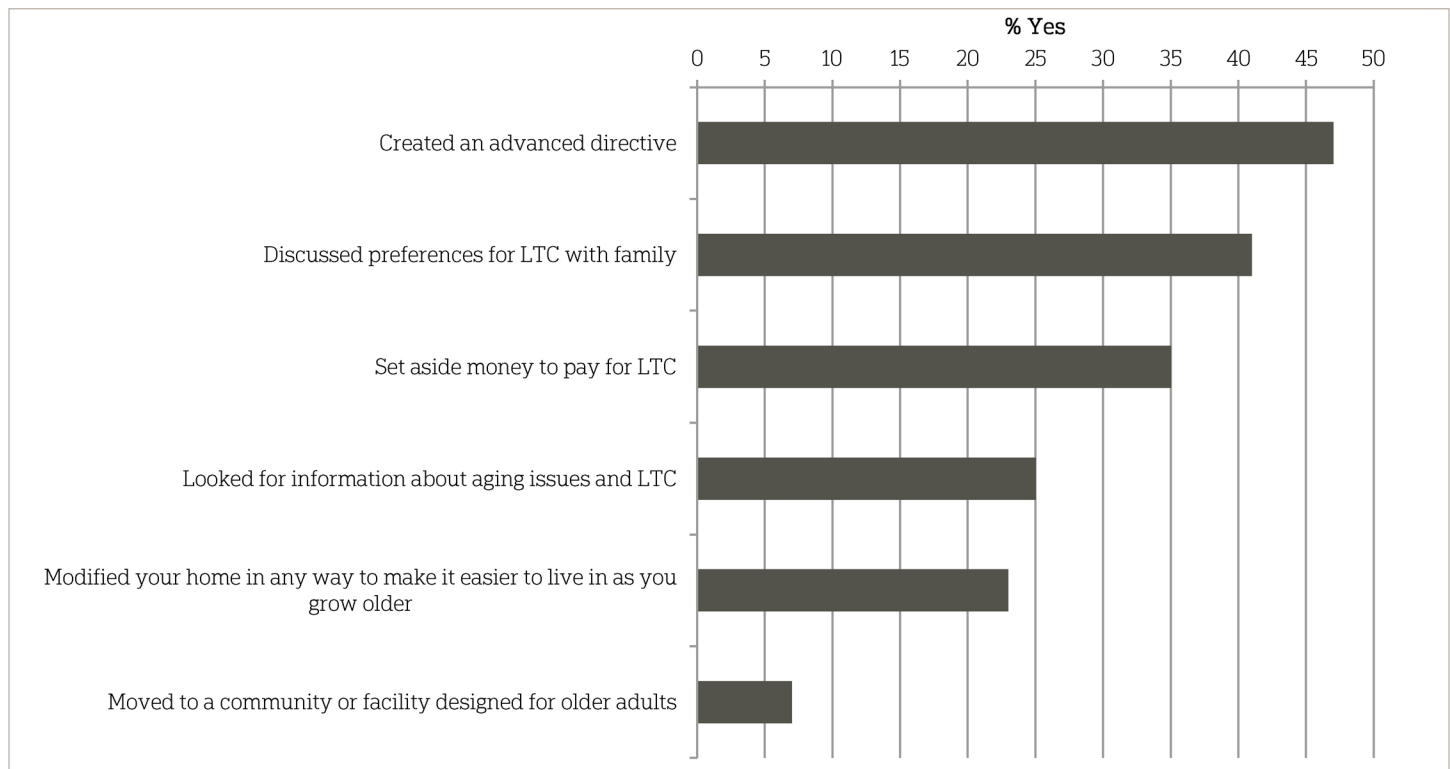
However, general perceptions about the types of people who require long-term care are closely related to how people perceive their own likelihood of requiring care personally or for a family member. Among those who believe that long-term care is only for people with severe illnesses or mobility problems, 42 percent think it is not too likely or not at all likely that they will ever require long-term care personally, and 47 percent think it is unlikely that an aging family member or close friend will require long-term care in the next 5 years. These percentages fall slightly, to 40 and 34 for people who believe that long-term care is for those with moderate illnesses or mobility problems, and fall significantly, to 22 and 25 percent for those who believe that just about everyone will require long-term care at some point.

³ For the purpose of the survey, the phrase "ongoing living assistance" was used in place of long-term care and was defined as "...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."

Although a majority of Americans 40 years or older believe that they are at least somewhat likely to need long-term care at some point, very few people in this population report planning for their own long-term care needs. Sixteen percent of Americans 40 or older report doing a great deal or quite a bit of planning for their own long-term care needs, 19 percent report only a moderate amount of planning, and 65 percent report doing only a little planning or none at all.

When asked about specific actions that might be considered planning for long-term care needs, more individuals do report planning activity. Seventy-three percent of Americans 40 or older report that they have taken at least one of the six actions listed on the survey; the most common action, creating an advanced directive, was reported by 47 percent of adults 40 or older. Even among those who report doing only a little or no planning at all for their own care, 64 percent report taking at least one specific action.

How some people 40 or older are planning for their own long-term care needs



Americans 40 or older who say that they can rely on their family a great deal or quite a bit in a time of need are more likely than those who can only rely on their families a little or none at all to report doing any planning (77% vs. 60%). Those who say they can rely on family are more likely to report that they have discussed their long-term care preferences with their family (46% vs. 27%) or that they have set aside money to pay for their long-term care expenses as they age (40% vs. 24%).

Americans are also more likely to report that they have taken specific planning actions as they get older. Sixty percent of Americans 40-54 have taken at least one action, and that number increases to 75 percent for Americans 55-64, and to 92 percent for Americans 65 years and older. Women are also more likely than men to report taking at least one planning action (77% women vs. 69% men). And, those who are

currently or who have provided long-term care to a family member or close friend are more likely to report that they have taken at least one planning action compared to those that have not provided care (77% vs. 67%).

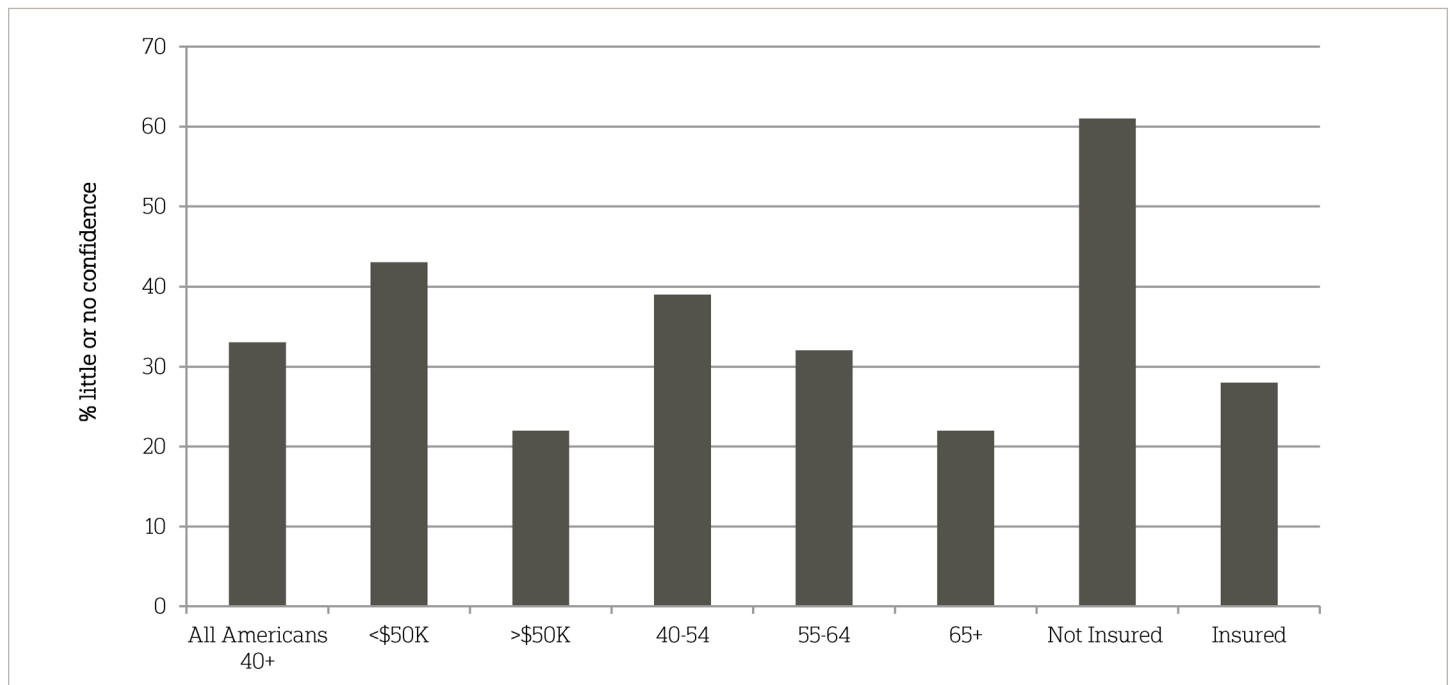
In general a majority of Americans 40 or older (52%) say they are extremely or very confident that they know where to go to find information about options for ongoing living assistance and another 31 percent say they are somewhat confident. However, there are significant differences between groups, with more highly educated and higher income individuals more likely to report being at least very confident (62% with at least some college vs. 40% with high school education or less; 59% with income \$50,000+ vs. 45% with income <\$50,000), as well as insured individuals (55% vs. 31%) and those who have provided long-term care services (54% vs. 50%).

PEOPLE FREQUENTLY MISPERCEIVE THE COSTS OF LONG-TERM CARE AND THEY OVERESTIMATE THE ROLE OF MEDICARE IN PAYING FOR THEIR CARE.

Americans 40 or older are not very confident that they will have the financial resources to pay for the long-term care they need as they grow older. Twenty-seven percent of Americans 40 or older report that they are extremely or very confident they will have the resources to pay for care, 40 percent

somewhat confident, and 33 percent not too confident or not at all confident. Having less household income, being younger, and not having health insurance are all associated with lower levels of confidence.

Percent of Americans 40 or older with little or no confidence in ability to pay for long-term care as they age



When asked about the average costs to live in a nursing home, an assisted living community, or receive care at home from a home healthcare aid, Americans 40 years or older reveal several misperceptions about the costs. This population tends to underestimate the costs of living in a nursing home, overestimate the costs of home healthcare aides, and is evenly distributed when it comes to estimating the cost of living in an assisted living community. There are only a few demographic

characteristics associated with a better understanding of the costs of long-term care. For example, higher levels of education increase the likelihood of correctly estimating nursing home costs, but being older decreases the likelihood. Being female and having experience providing or receiving care increases the likelihood of correctly estimating assisted living facility costs.

Perceived costs of long-term care providers⁴

Best guess of the national average monthly cost of...	% under estimate	% correctly estimate	% over estimate
Nursing home	58 (less than \$2,000 - \$6,000 per month)	24 (\$6,000 - \$8,000 per month)	14 (more than \$8,000 per month)
Assisted living facility	31 (less than \$1,000 - \$3,000 per month)	29 (\$3,000 - \$4,000 per month)	36 (more than \$4,000 per month)
Part-time home healthcare aide	14 (less than \$1,000)	30 (\$1,000 - \$2,000 per month)	52 (more than \$2,000 per month)

⁴ Actual figures are based on the 2012 MetLife Market Survey of Long-Term Care Costs. The national average monthly base rate in an assisted living community is \$3,550. The national average hourly rate for home health aides is \$21. Part-time care is calculated at 2 hours per day for a 30 day month, or \$1,260 per month. The national daily average of a semi-private nursing home room is \$222, or \$6,753 per month.

Many Americans 40 or older also overestimate the long-term care services that Medicare will cover. Generally, Medicare only pays for medically necessary care in a skilled nursing facility or through home health care under very limited circumstances and for relatively brief stretches of time. Medicare does not pay for the more common types of long-term care services, like daily living assistance.⁵ However, 44 percent of people 40 or older believe that Medicare pays for ongoing care at home by a licensed home healthcare aide and 37 percent believe it pays for ongoing care in a nursing home. Seventy-one percent of this population believes that Medicare pays for medical equipment such as wheelchairs and other assistive devices, which is true so long as the equipment is deemed medically necessary and prescribed by a physician.

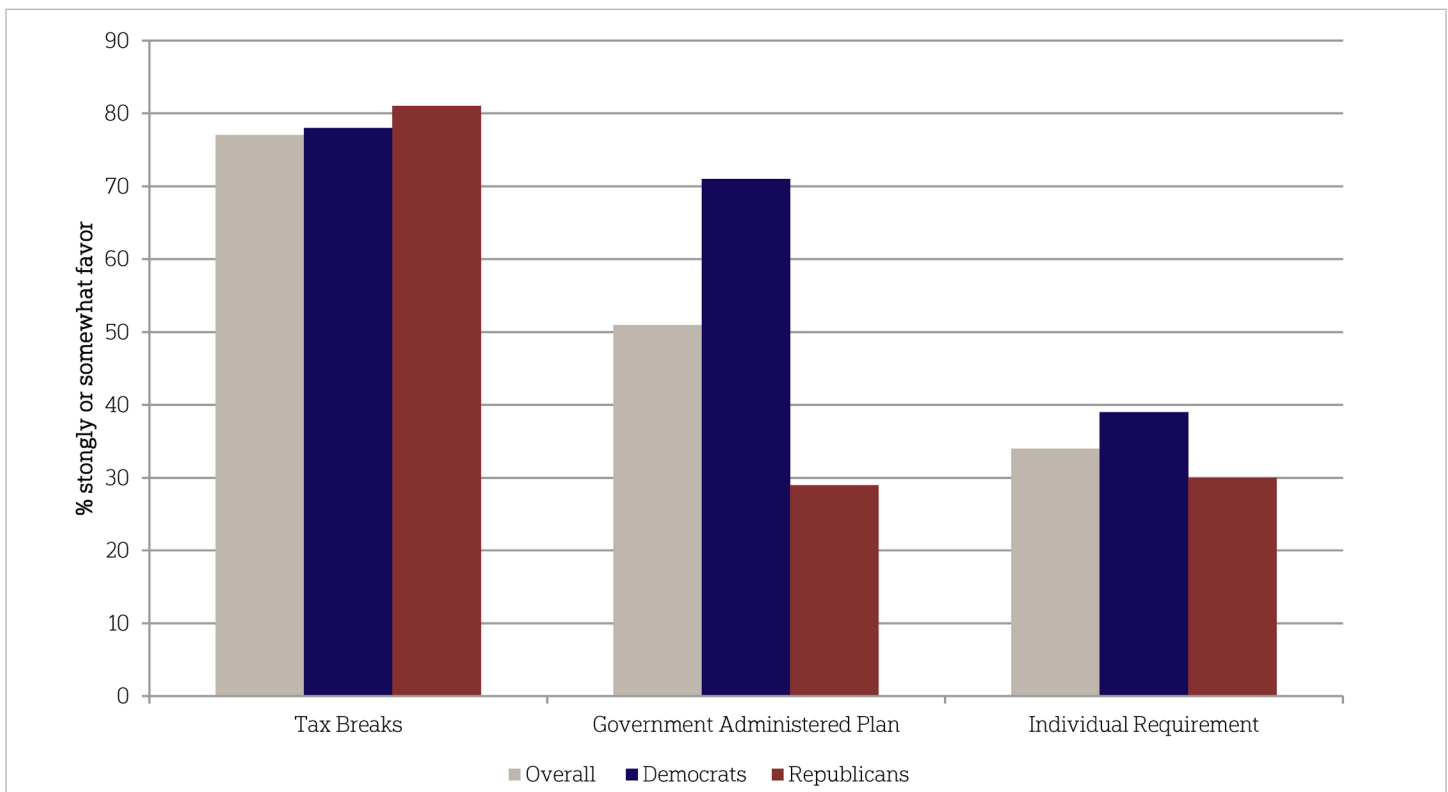
Although Medicaid is the largest payer for long-term care in the U.S.⁶ and many Americans 40 or older lack confidence in their ability to pay for long-term care services as they age, a majority (54%) do not think that they will need Medicaid to help pay for their long-term care as they grow older. Adults 40-64 years are more likely than those 65 years or older to think they will need Medicaid to help pay for their long-term care (41% of those 50-64 and 46% of those 40-54 vs. 25% of those 65+). Blacks are more likely than whites to think they will need Medicaid to help pay for long-term care (73% vs. 31%) and people in households making less than \$50,000 per year are more likely than those in wealthier households to think they will need Medicaid (56% vs. 20%).

AMERICANS 40 OR OLDER SHOW MAJORITY SUPPORT FOR SEVERAL POLICIES TO HELP INDIVIDUALS PAY FOR THE COSTS OF LONG-TERM CARE, THOUGH WITH SOME PARTISAN DIVIDES.

Overall, 77 percent of those 40 or older strongly or somewhat support tax breaks to encourage saving for long-term care expenses; 51 percent favor a government administered long-term care insurance program, similar to Medicare; and only 34 percent favor a requirement that individuals purchase long-term care insurance. Democrats are more likely than

Republicans to support a requirement for individuals to purchase long-term care insurance, as are blacks and Hispanics compared to whites. Democrats are also more likely to support a government administered plan, though members of both parties are equally supportive of tax breaks to encourage savings for long-term care expenses.

Support for long-term care policies overall and by party



⁵ <http://www.medicare.gov/longtermcare/static/home.asp>

⁶ <http://www.kff.org/medicaid/upload/2186-09.pdf>

A majority of Americans 40 years or older believe that health insurance companies should be responsible for paying for the costs of long-term care with 55 percent who believe they share a very large or large amount of the responsibility, which is significantly greater than the share assigned to individuals (40%), Medicare (39%), Medicaid (37%), and families (23%). Republicans and individuals from wealthier households are

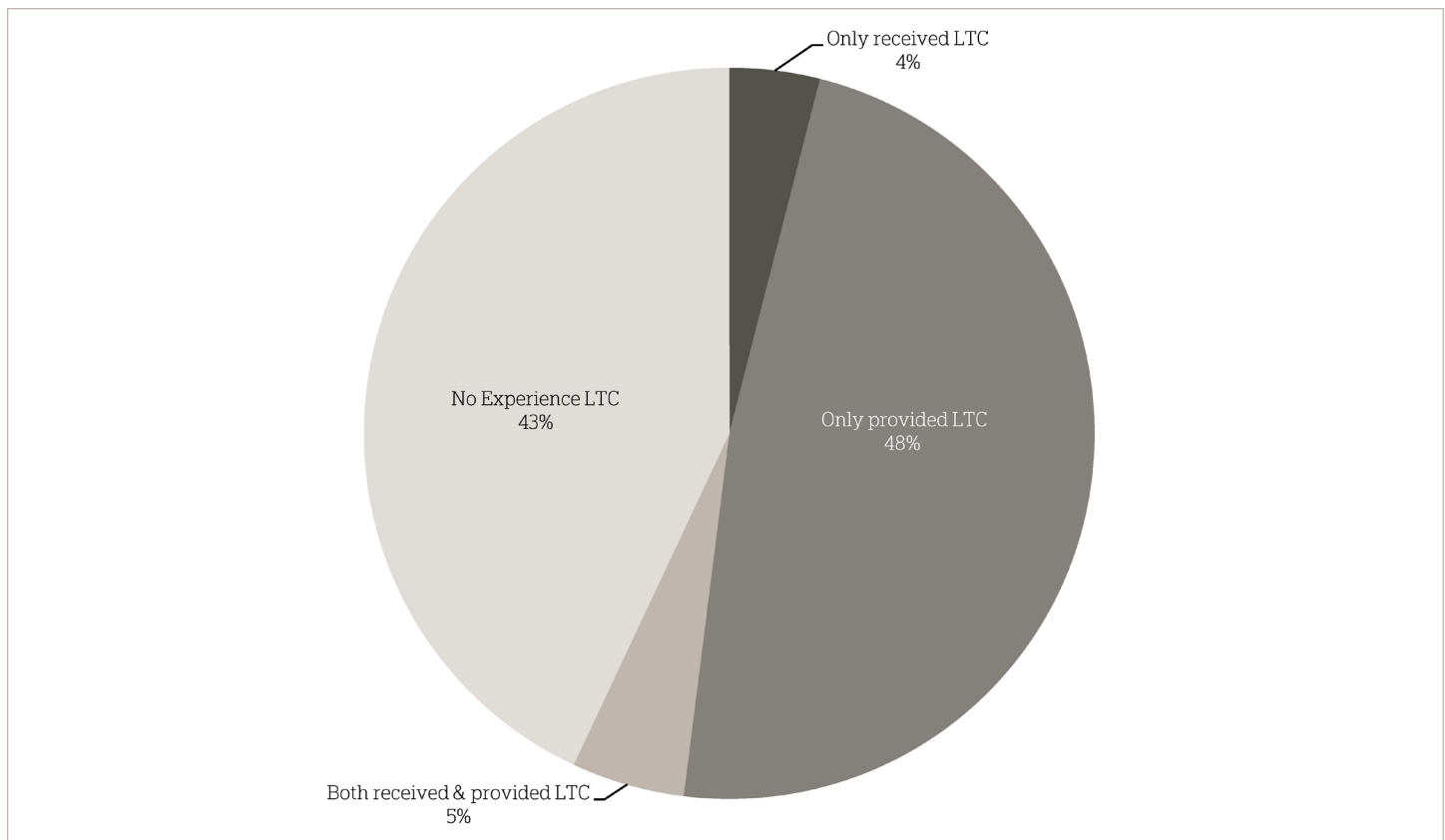
more likely than Democrats and those from less wealthy households to say that individuals and families have a greater share of the responsibility to pay. Democrats are more likely than Republicans to say that Medicare and Medicaid have a greater responsibility.

THE MAJORITY OF AMERICANS 40 OR OLDER HAVE SOME EXPERIENCE WITH LONG-TERM CARE.

Overall, 57 percent of Americans 40 years or older have some experience with long-term care. Nine percent of this population reports that they are currently receiving (5%) or have previously received (4%) long-term care services. Fifty-three percent of Americans 40 years or older have provided long-term care on a regular basis to a family member or close friend. At the time of the survey, 23 percent of this population was providing long-term care and 39 percent had

done so in the past. There is also some overlap between providers and recipients of long-term care services. Five percent of Americans 40 or older have both provided and received long-term care services at some point in their lives. Four percent have only received services and 48 percent have only provided services.

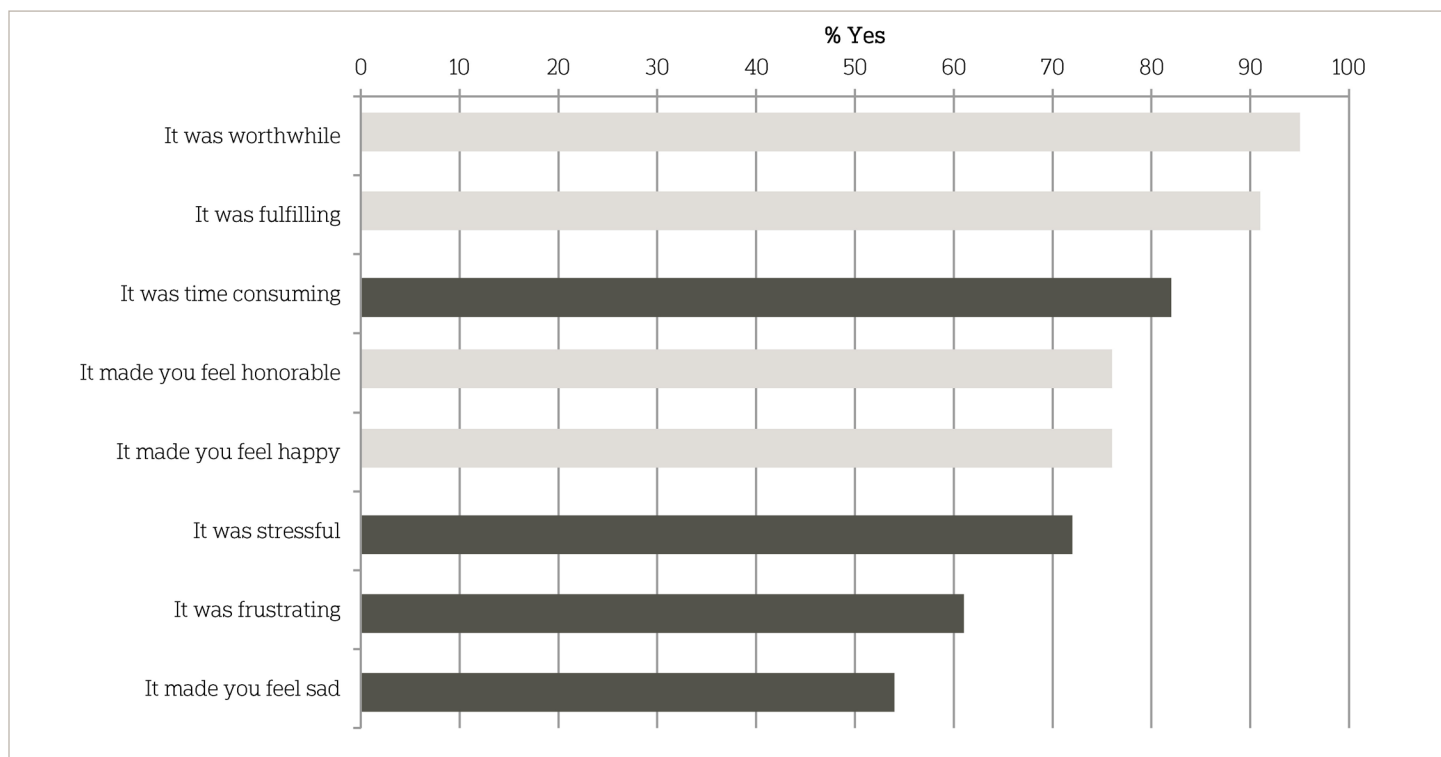
Experiences of Americans 40+ with long-term care



Of the 9 percent of Americans 40 years or older who report ever receiving long-term care, 82 percent report receiving those services in their own home, 9 percent in a friend or family member's home, 5 percent in a senior community, and 3 percent in a nursing home. Of those receiving in-home care, 46 percent report receiving long-term care at some point from a professional home healthcare aide, 46 percent from a friend, and 37 percent from a family member. Recipients of long-term care are more likely to be white than black, unemployed, have more education, have insurance, and report being less healthy overall than those who have not received long-term care.

For the 53 percent of Americans 40 years or older who report ever providing long-term care for a family member or close friend, the overall experience of providing care was positive. Nearly all those who have provided care report that the experience was worthwhile and fulfilling. Among the less positive feelings, the experience was more often cited as being time consuming compared to stressful, frustrating, or sad.

How providers of long-term care to family and close friends describe the experience



Providers of long-term care are more likely to be female, to not currently be working, and to have the majority of their family nearby. Fifty-eight percent of women report that they are currently providing long-term care or have done so in the past, compared to 47 percent of men. Fifty-eight percent of Americans 40 or older who are not currently employed report that they have provided long-term care, compared to 48

percent who are working full- or part-time. Fifty-six percent of Americans 40 years or older with most of their family living within an hour of their homes are or have provided long-term care, compared to 50 percent of those whose family is mostly located further away.

AMERICANS 40 OR OLDER COUNT ON THEIR FAMILIES TO BE THERE FOR THEM IN TIMES OF NEED AND AS THEY AGE.

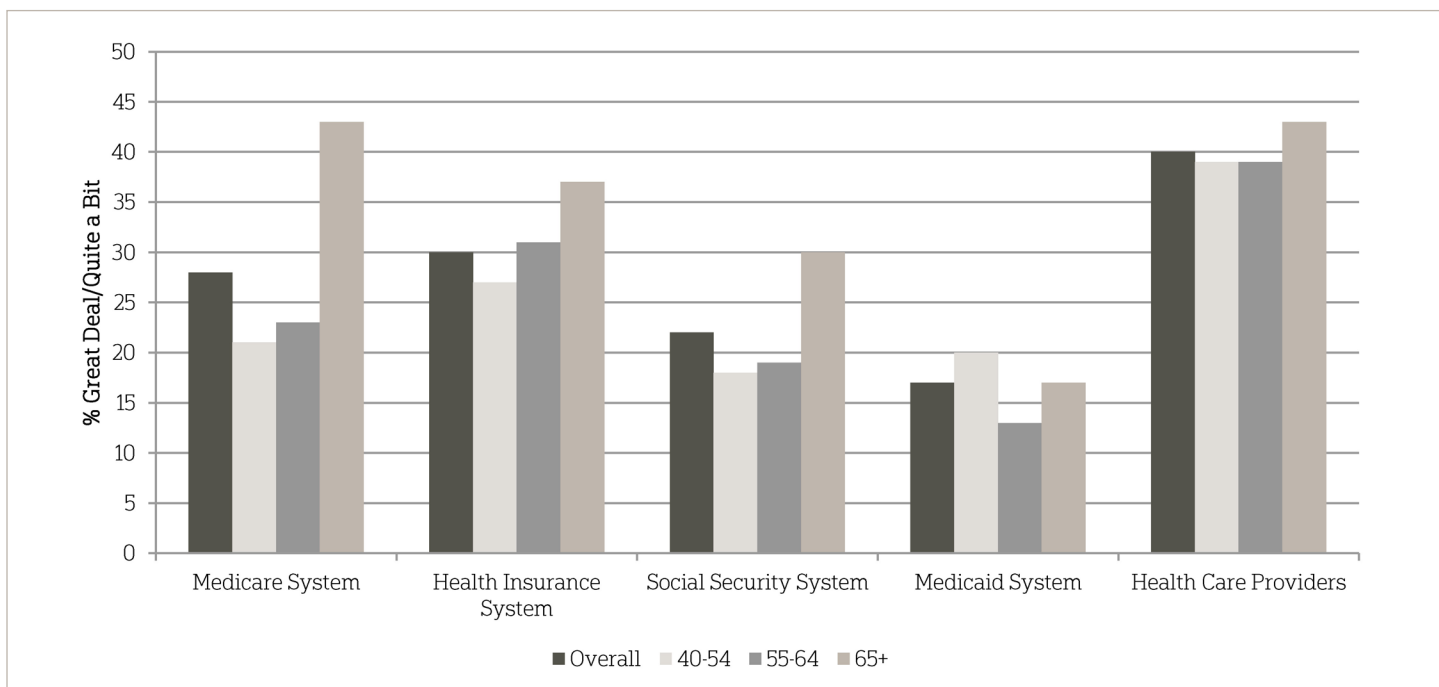
Sixty-eight percent of Americans 40 years old and older feel they can rely on their family a great deal or quite a bit in a time of need. An additional 15 percent feel they can rely on their family a moderate amount. People 40 or older who are currently receiving long-term care or who have received it in the past are less likely to believe they can rely on their family in a time of need. Fifty-five percent of those who have ever received long-term care say they can rely on their family at least quite a bit, compared to 70 percent of those who have never had the experience of receiving long-term care services. Additionally, Americans 40 or older with family members who mostly live nearby are more likely than those with family members living further away to believe they can rely on their families (81% vs. 56%).

Similarly, when asked to think about the people and systems that may provide help for them as they age, 77 percent of people 40 or older who are married or co-habiting say their spouse or partner will be there to help a great deal or quite a bit. This is especially true among those who have ever received long-term care. Eighty-seven percent of those who have received long-term care say their spouse or partner will provide a great deal of help as they age, compared to 59

percent of those who have never received long-term care. Forty-six percent of Americans 40 or older with children feel their children or grandchildren will provide a great deal or quite a bit of help. Americans 40 or older are less likely to feel that extended family (29%), religious and faith-based organizations (22%), friends or neighbors (17%), and community organizations (17%) will provide much help to them as they age. However, people with experience receiving or providing long-term care are more likely to expect that friends and neighbors will provide at least quite a bit of help as they age; those with most of their family nearby are more likely to think their children and extended family will provide help as they age.

In terms of the health care and social security systems, 40 percent of people 40 or older think that health care providers will provide at least quite a bit of help as they age, but fewer Americans say the same about the health insurance system (30%), the Medicare system (28%), the Social Security system (22%), and the Medicaid system (17%). As people age, they are more likely to think that the Medicare, health insurance and social security systems will provide a great deal or quite a bit of help to them as they get older.

Expectations for amount of help provided by the health care and social security systems by age group



WHEN THINKING ABOUT THEIR LIVING SITUATION AS THEY AGE, AMERICANS PRIORITIZE FEATURES THAT PROMOTE INDEPENDENCE.

People 40 or older reported their priorities for their living situation as they age. High priorities, cited as being extremely or very important features, include a home that is all on one level with no stairs (65%), living close to their children (63%), and being close to medical offices or hospitals (63%). Hispanics and those who live nearby most of their family are more likely to say that living close to their children is a priority. Just over half of people 40 or older cite access to nursing or medical services at home (54%) and being close to shops and services (53%) as important features of the home they will live in as they age. Fewer than half cite living in a community that offers services like meals and local transportation (48%), living close to current friends (45%), and living in a community with organized social activities (36%) as important.

ABOUT THE STUDY

This survey was conducted by The Associated Press-NORC Center for Public Affairs Research with funding from The SCAN Foundation. The survey was conducted from February 21 through March 27, 2013. AP and NORC staff collaborated on all aspects of the study, with input from NORC's Health Care Research department and AP's subject matter experts.

This nationally representative survey was conducted via telephone with 1,019 American adults age 40 years old or older. This national sample included 797 respondents on landlines and 222 respondents on cellular telephones. Cellular telephone respondents were offered a small monetary incentive for participating, as compensation for telephone usage charges. Interviews were conducted in both English and Spanish, depending on respondent preference. All interviews were completed by professional interviewers who were carefully trained on the specific survey for this study.

The final response rate was 20 percent, based on the widely accepted Council of American Survey Research Organizations (CASRO) method. Under this method, our response rate is calculated as the product of the resolution rate (72%), the screener rate (66%), and the interview completion rate (43%). The overall margin of error for the national sample was +/- 4.1

Men are less likely than women to report many of these items as priorities, including a home with no stairs (57% vs. 73%), living close to current friends (38% vs. 52%), living in a community that offers services like meals and transportation (40% vs. 55%), and having access to home-based medical care (46% vs. 61%).

Whites are less likely than blacks and Hispanics to cite being close to shops and services (47% whites vs. 69% blacks and 61% Hispanics), being close to medical offices or hospitals (58% whites vs. 77% blacks and 81% Hispanics), living in a community with organized social activities (27% whites vs. 52% blacks and 70% Hispanics), and having access to home-based medical care (47% whites vs. 75% blacks and 72% Hispanics) as at least very important priorities for their home as they age.

percentage points. Sampling weights were calculated to adjust for sample design aspects (such as unequal probabilities of selection) and for nonresponse bias arising from differential response rates across various demographic groups. Poststratification variables included age, sex, race, region, education, and landline/cellular telephone use. The weighted data, which thus reflect the U.S. general population aged 40 or over, were used for all analyses.

All analyses were conducted using STATA (version 12), which allows for adjustment of standard errors for complex sample designs. All differences reported between subgroups of the U.S. population are at the 95 percent level of statistical significance, meaning that there is only a 5 percent (or less) probability that the observed differences could be attributed to chance variation in sampling. Additionally, bivariate differences between subgroups are only reported when they also remain robust in a multivariate model controlling for other demographic, political, and socioeconomic covariates. A comprehensive listing of all study questions complete with tabulations of top-level results for each question is available on the AP-NORC Center for Public Affairs Research website: www.apnorc.org.

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- 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 Associated Press-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 The Associated Press. All work conducted by the Center conforms to the highest levels of scientific

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About the Authors:

Jennifer Agiesta, *Director of Polling*, The Associated Press

Jennifer Benz, *Senior Research Scientist*, The Associated Press-NORC Center for Public Affairs Research

Dennis Junius, *News Survey Specialist*, The Associated Press

Kristina Lowell, *Associate Director*, Health Care Research Department at NORC

Kim Nguyen, *Research Scientist*, Economics, Labor, and Population Studies at NORC

Trevor Thompson, *Director*, The Associated Press-NORC Center for Public Affairs Research

For more information, visit www.apnorc.org
or email info@apnorc.org