Pathways to Progress In Planning for Long-Term Care

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Supported by a grant from The SCAN Foundation, dedicated to creating a society in which seniors receive medical treatment and human services that are integrated in the setting most appropriate to their needs.

Langer Research Associates
SURVEY RESEARCH DESIGN • MANAGEMENT • ANALYSIS

EXECUTIVE SUMMARY

Americans age 40 and older plan too little, too late for their long-term care needs as they grow older. Survey research funded by The SCAN Foundation explores why this avoidance occurs – with useful conclusions for policymakers, practitioners and the public alike.

An in-depth analysis of national and California survey results finds that information is one key predictor of planning for long-term care.[1] People who feel they know where to get information on aging issues are more apt than others, by double-digit margins, to have prepared for these needs, including setting aside money for ongoing living assistance, discussing their care preferences with loved ones, actually seeking out information on aging issues, creating an advance directive and purchasing long-term care insurance.

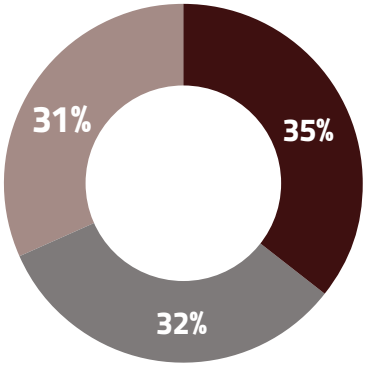
Experience also matters: Statistical modeling shows that planning is significantly higher among the 53 percent of Americans[2] who've given long-term care assistance. With increasing numbers of Americans providing assistance to their aging loved ones, this suggests that planning activities may rise in tandem.

Anxiety-fueled avoidance is a factor in planning as well. Three in 10 Americans (and four in 10 Californians) say growing older is something they "just don't want to think about," a sentiment especially expressed by those who are worried about burdening their families, who worry about being alone in their later years, who lack confidence that they know where to turn to find information on the issue and who feel they lack the financial resources to pay for long-term care costs.

1 The main findings presented in this report are based on statistical models of survey results (see Appendix C), with crosstabulated data used for illustration. All differences reported have been tested for statistical significance.

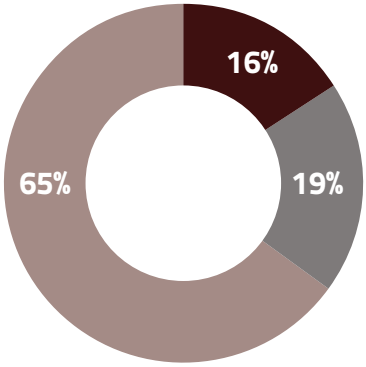
2 For convenience, throughout this report the terms "Americans" and "Californians" refer to the sampled population, nationally and in the state, of adults age 40 and older. See Appendix C for methodological details.

Comfort thinking about growing older



Very comfortable
Somewhat comfortable
Rather not think about it

Planning for long-term care



Great deal/quite a bit
Moderate amount
Little or none

Given that 65 percent of Americans age 40 and up say they've done little or no planning for ongoing living assistance in their older years, understanding the factors that motivate planning can inform efforts to encourage more adults to review and act on their options. Barely more than half, for example, express high levels of confidence that they know where to go for information on long-term care – indicating the extent to which a concerted information campaign could encourage planning activities. Further, the process of gaining information may produce greater awareness that in turn bolsters support for fresh approaches to long-term care policies and programs.

These and other results come from analysis of a 2013 public opinion survey on long-term care produced by The Associated Press-NORC Center for Public Affairs with funding from The SCAN Foundation, the nation's only nonprofit foundation devoted solely to long-term care issues. The survey was conducted both nationally and among a representative, statewide oversample of Californians. This analysis was produced under a grant from the Foundation by Langer Research Associates of New York, N.Y., based on multiple statistical models of the AP-NORC data.

Demographic trends make examination of long-term care issues essential. An estimated 8,000 members of the baby boom generation will become senior citizens each day for the next 16 years, doubling the U.S. population of seniors from 2000 to 2030. Seven in 10 in this growing population are expected to need long-term care, on average for three years, with profound impacts on their families, their finances and the nation's fragmented senior care system.

Topline results of this survey, illustrating the extent to which Americans underestimate their long-term care needs and are taking few steps to prepare, were covered in an Associated Press report in late April and in a separate report on California results for The SCAN Foundation released in June. As previous research sponsored by the Foundation has indicated, the survey found that Americans vastly misjudge their own likelihood of needing long-term care (only a quarter call it very or extremely likely), underestimate the cost of such care and, if it is needed, tend to expect their families – especially a spouse or partner – to provide it.

"Americans vastly misjudge their own likelihood of needing long-term care, underestimate its cost - and, if it is needed, tend to expect a spouse or partner to provide it."

Intended reliance on family care may be born of perceived necessity, given that just 27 percent of Americans are extremely or very confident they'll have financial resources to pay for care they may need as they age. But relying on family may be unrealistic, given the medical needs of an aging population. (In another misconception, more than four in 10 erroneously think Medicare covers the cost of ongoing care at home by a licensed healthcare aide.)

The results also show some differences in attitudes between California and the nation as a whole; in California, for instance, adults age 40 and up are more apt than Americans overall to support government efforts to address long-term care issues and are more likely to be highly concerned about those issues personally. That makes sense; concerns about the impacts of aging independently predict support for government measures such as tax-advantaged savings for long-term care and a Medicare-style, government-administered long-term care insurance plan.[3]

Planning and its Impacts

One overall result is notably positive: while substantial numbers of Americans express concerns about being able to pay for their long-term care, those worries decline as planning increases. Indeed, holding other factors constant – including personal income – the number of planning actions a person has taken is a strong independent predictor of their confidence that they can pay for their living assistance costs as they get older.

Planning therefore reflects multiple positive factors – in addition to desirable action itself, it's associated with greater willingness to think about long-term care issues, greater confidence in finding information resources and less worry about having the financial wherewithal to handle these care needs.

Overall planning is defined in this analysis as having taken steps tested in the AP-NORC survey – having set aside money for ongoing living expenses, discussed living assistance preferences with loved ones, searched for information about aging issues and long-term care, modified one's home to make it easier to live there as an older person, moved (or made plans to move) to a community or facility for older adults, purchased long-term care insurance[4] or prepared an advance directive or living will.

Demographic factors play a role in these planning activities. Modeling shows that men report less planning for their aging needs, while older, retired and more-educated Americans all report greater planning. Income is a strong factor, suggesting that those who have more immediate financial concerns are less able

3 See Section VIII for a discussion of attitudinal differences on long-term care between adults age 40 and older in California vs. nationally.
4 Because previous research has shown that people often erroneously report they have long-term care insurance when they only have health insurance, we only included those respondents who indicated they were "very sure" they had long-term care coverage.

to prepare for the future. Similarly, parents with minor children report less planning, perhaps because they are more focused on their children's health and well-being than on their own.

While planning items are combined as an index for overall analysis, several have unique individual predictors, fully described in Appendix C of this report. In one example, having close family ties is a predictor of planning overall, mostly because those who feel they can rely on their family are significantly more likely to have discussed their long-term care preferences with them. Discussing long-term care preferences with loved ones also is far more common among women and older adults.

Perceived Planning

Another measure of planning addresses not the actual steps people have taken, but more generally the extent to which they feel they have planned for their long-term care. This may reflect actions that were not measured in the survey, or a general sense of subjective preparedness to handle future needs.

Actual planning steps and perceived planning are related – there's a very strong independent relationship between the two. But some of their predictors differ, and knowing what factors help people feel prepared can separately be useful in policy.

The top predictor of feeling like you've planned is one of the planning actions: having put aside money for ongoing living assistance expenses. Others include having sought out information about long-term care and aging issues, having long-term care insurance, feeling confident about having the required financial resources and creating an advance directive. These suggest that when people have saved or otherwise prepared for their potential care needs, they feel they've planned. Those who feel financially prepared or well-informed, therefore, may benefit from continued encouragement to take other important steps, such as discussing care preferences with loved ones, lest these get set aside.

"Worries about burdening one's family and about being alone predict avoidance, which in turn reduces planning for long-term care needs."

Avoidance and Information

Additional models predict two important elements of the puzzle – avoidance, an important negative factor in planning, and confidence in finding information, as noted, a strongly positive one.

Avoidance – not wanting to think about getting older – is in part a negative reaction to perceived unpleasant consequences of aging. It's most strongly predicted by concerns about being a burden on one's family, as well as by worries about being alone, and by expecting to have, or currently having, a friend or family member in need of long-term care. Among other factors, being less healthy, having concerns about paying for care and lacking information sources also independently predict avoidance.

On the other side of the equation, confidence about knowing where to go for information about long-term care options is predicted by having close family ties, socioeconomic factors, insurance status and caregiving (or receiving) experience. People who feel they can rely on their relatives in times of need are more likely to be confident about their ability to find useful information, indicating the strong role of support networks. Education, income and having insurance also positively predict information access, as does having provided ongoing care in the past.

Conclusions

The results of this analysis align with existing literature on attitudes toward aging.[5] Despite widespread experience providing long-term care assistance to others, Americans are broadly unprepared for the needs most will face as they themselves grow older. This lack of preparation stems in large part from a dearth of readily accessible information on the topic, broad anxiety about aging and seemingly more immediate financial and familial concerns.

Those findings, in turn, suggest pathways forward. Increasing access to clear information on long-term care issues and options; stressing the importance of planning; and identifying concrete, affordable actions to prepare for aging all can help decrease the current pervasive avoidance of this critical issue.

5 See the literature review, Appendix A.

Acknowledgments

This report is based on national and California surveys conducted by The Associated Press-NORC Foundation for Public Opinion Research with funding by The SCAN Foundation, dedicated to creating a society in which seniors receive medical treatment and human services that are integrated in the setting most appropriate to their needs.

Supported by a grant from the Foundation, Langer Research Associates initiated this survey project, represented the Foundation in AP-NORC's survey development work and independently produced this secondary analysis of the AP-NORC data.

The lead author of this report is Julie E. Phelan, senior research analyst at Langer Research Associates, with Gary Langer, president, and Damla Ergun and Gregory Holyk, research analysts. All conclusions were arrived at independently by the authors. We thank The SCAN Foundation for its support for this project, including Gretchen Alkema, the foundation's vice president, and Victoria Ballesteros, its communications director.

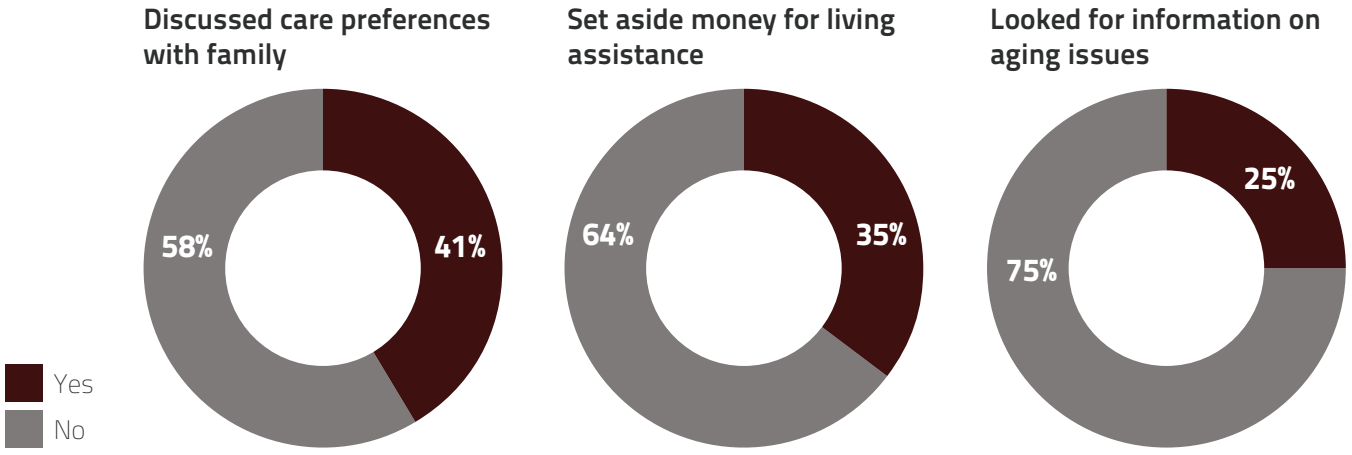
In conjunction with materials released by AP-NORC, this report complies with the Code of Professional Ethics and Practices of the American Association for Public Opinion Research and the Principles of Disclosure of the National Council on Public Polls.

Main Report

I. Predicting Planning for Long-Term Care

Most Americans age 40 and older have taken few concrete steps to plan for their aging needs. Fifty-three percent have not created an advance directive or living will, one of the easier and more routine steps to take. Nearly six in 10 have yet to discuss their preferences about living assistance with loved ones and 64 percent say they have not set aside money for any ongoing living assistance they might need. Even more, three-quarters, say they've never looked for information about aging issues, underscoring the broad information disconnect on this issue.

Other planning actions also are rare. Twenty-three percent say they've made modifications to their home to make it easier to live in as they grow older. Just 12 percent are sure they've purchased long-term care insurance and fewer than one in 10 has moved or made plans to move to a community or facility designed for older adults.



An index combining all seven of these planning behaviors was created for use in a regression model, a statistical technique that assesses the relationship between predictor variables and an outcome (in this case, the planning index) while holding other potential factors constant. This process identifies the variables that explain the most unique variance in planning behavior, providing insight into what best motivates people to plan, or not plan, for their aging needs.

As noted in the executive summary, the strongest attitudinal and experiential predictors of the planning index, shown in Table 1, indicate that information, avoidance of aging and past experience giving or receiving long-term care are critical pieces of the planning process.

Just more than half of Americans overall are confident they know where to go to get information about aging and long-term care, and they report significantly greater planning for the future than do those with less confidence. For example, highly confident Americans are 18 to 20 percentage points more likely to have set aside money for the future (45 vs. 25 percent), to have sought out information on aging issues (34 vs. 15 percent) or to have discussed their aging desires with loved ones (50 vs. 32 percent), as well as 14 points more likely to have created a living will (54 vs. 40 percent) and 10 points more likely to be sure they have purchased long-term care insurance.[6]

On the other hand, as might be expected, Americans who don't want to think about aging are less apt to have taken steps to plan for it. Compared with those who are very comfortable thinking about getting older, those who say they'd "rather not think about it" (31 percent overall) are 26 points less likely to have discussed their aging wishes with their family, 24 points less likely to have set aside money, 22 points less likely to have created an advance directive, 17 points less likely to have looked for information and 11 points less likely to have long-term care insurance.

Experience with long-term care also plays a critical role. Those who have provided or received long-term care assistance (57 percent overall) report significantly more planning for their aging than do others. Moreover, those who report strong emotions (either positive or negative) about their care-giving experience are especially apt to have planned.

People who currently are providing assistance, or have done so in the past, are far more likely than others to have discussed their aging desires with loved ones. Those who are currently receiving assistance, or have in the past, are far more likely to have written an advance directive and to have sought out information on aging – even controlling for their age and health status. And caregivers and recipients alike are more likely to have made modifications to their home.

6 As noted, cross-sectional results such as these are presented throughout this report as a convenient way to illustrate the results of statistical modeling.

Moving beyond attitudes and experience, there are important demographic predictors of planning: Being older, retired and having a higher socioeconomic status (income, education and full-time employment alike) all are associated with engaging in more planning behaviors. Men and parents with minor children, at the same time, report less planning than women and either non-parents or parents with older children.

As the literature suggests, one of the reasons Americans may resist planning for their older years is because they feel they have more pressing concerns. The fact that those with lower incomes or with minor children are less apt to plan suggests that economic and familial concerns are significant barriers to Americans attending to their own care needs as they age.

Table 1. Significant predictors of the planning index

Age	✓✓✓
Employment: Retired	✓✓✓
Income	✓✓✓
Confident can find LTC information	✓✓✓
Have provided LTC assistance	✓✓✓
Avoidance of aging	✓✓✓
Parent of a minor child	✓✓
Education	✓✓
Gender: Male	✓✓
Negative emotions providing LTC	✓✓
Positive emotions providing LTC	✓✓
Employment: Full-time	✓
Can rely on family	✓
Have received LTC assistance	✓

See Appendix C for model details.

In sum, these regression results suggest that increasing access to information on long-term care and addressing people's anxiety about aging should help to encourage planning. In particular, to the extent that concrete, affordable steps become available, planning should rise.

II. Individual Planning Behaviors

The planning behaviors index counts the number of steps (among the seven measured) that individuals have taken to prepare for aging. Regression models also were produced predicting each of the individual planning behaviors. While predictors of the index and of individual items are largely congruent, some differences emerge, shown in Table 2 and detailed below.

Table 2. Key predictors of individual planning behaviors

	Saved money	Discussed prefs.	Advance directive	Looked for info.	Modified home	Moved or made plans	LTC ins.
Age	✓✓✓	✓✓	✓✓✓	–	–	✓✓✓	–
Confident can find LTC information	✓✓	✓✓	–	✓✓✓	✓	✓	✓
Income	✓✓✓	–	✓✓	–	–	–	✓
Employment: Retired	–	–	–	✓✓✓	✓✓✓	–	–
Avoidance of aging	✓	✓✓✓	–	✓✓✓	–	–	–
Have provided LTC	–	✓✓	✓✓	–	✓✓✓	–	–
Have received LTC	–	–	✓✓	✓	✓✓✓	–	–
Education	–	–	✓	✓	–	–	✓
Parent of a minor	✓	–	–	–	✓✓	–	✓
Health status	–	✓✓	✓	–	✓✓	–	–
Employment: Full-time	–	–	–	✓	✓✓✓	–	–
Think it's likely a loved one will need LTC	✓	✓✓	✓	–	–	–	–
Think it's likely will need LTC in future	✓	–	–	✓	–	–	–
Negative emotions providing LTC	–	✓✓	–	✓	–	–	–
Gender: Male	–	✓✓✓	–	–	–	–	–
Extent can rely on family	–	✓✓	–	–	–	–	–
Ethnicity: Latino	–	–	–	–	✓✓	–	–
Married	–	–	–	–	✓✓	–	–

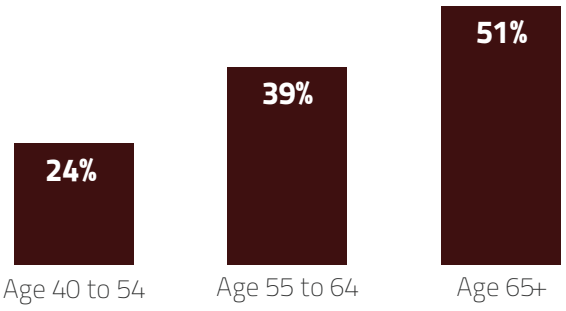
Dashes indicate the predictors that were not significant in each model. See Appendix C for model details.

A. Age

Age is a significant predictor of many of the planning behaviors. Older adults are more likely than others to have saved money, discussed their preferences about aging with loved ones, written an advance directive and moved or made plans to move to a senior community. Aging is a far more salient issue for older Americans, possibly making them less likely to delay or avoid planning.

Cross-sectional data illustrate these results. Just 24 percent of 40- to 54-year-olds have set aside money for their long-term care needs, compared with 39 percent of 55- to 64-year-olds and 51 percent of seniors. Seniors are more than twice as likely as those age 40 to 54 to have written a living will (74 vs. 31 percent) and 25 points more likely to have discussed their care preferences with loved ones (55 vs. 30 percent). And 15 percent of seniors have moved or made plans to move to a community for older adults, vs. 3 percent of those age 40 to 54.

Have saved for long-term care costs



Still, a large number of seniors have yet to take many basic steps. Nearly half have yet to set aside money for living assistance expenses, and nearly as many, 42 percent, have yet to discuss their aging preferences with loved ones. Those reflect high levels of inaction among people most likely to face aging issues in the near-term.

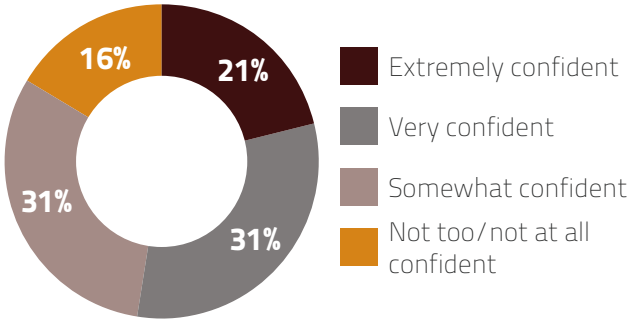
B. Confidence in Finding Information

Americans who are highly confident that they know where to find information about options for ongoing living assistance are significantly more likely than others to have taken several individual planning steps. These include saving money, discussing aging preferences with family, looking for information about aging issues,[7] modifying one's home, moving or making plans to move to a community for older adults and purchasing long-term care insurance.

For example, those who are extremely or very confident that they know where to go for information are 20 points more apt to have set aside money for long-term care (45 vs. 25 percent), 19 points more likely to have looked for information on aging and 18 points more apt to have discussed their aging preferences with family, compared with those who have less confidence about where to get information.

Just 52 percent of Americans express a high amount of confidence in their ability to find information; 31 percent are "somewhat" confident and 16 percent are less confident than that. This suggests there is ample room for greater efforts to educate the public about long-term care resources, and that such information campaigns should help to motivate greater planning.

Knowing where to find information



7 Regression analysis identifies the strength of the relationship between two variables holding others constant, but it does not establish causality. In this case the relationship between confidence and searching may go both ways. The more confident people are that they can find information, the more likely they are to look for it; at the same time, the more people search for information, the more confident they may become in their ability to find it. (A similar bi-directional relationship may also be true for purchasing long-term care insurance.)

C. Socioeconomic Status

Several socioeconomic variables – such as income, education and employment – emerge as significant positive predictors of planning behaviors. As the literature suggests, having more immediate financial concerns can be an impediment to planning for the future, especially if planning steps require money. And indeed, socioeconomic status appears most prominently in models predicting behaviors that require financial resources, such as setting aside money for long-term care, purchasing long-term care insurance, writing an advance directive (for which some may feel a need to hire a lawyer for advice) and making modifications to one's home.

For example, among people with household incomes less than $50,000 a year, just 22 percent say they've set aside money for living assistance needs as they age, while among those with incomes more than $100,000 a year this jumps to 53 percent. Likewise, among lower-income households, 40 percent have written a living will and just 7 percent have long-term care insurance, compared with 57 and 17 percent of $100,000-plus earners, respectively.

Education status also has an independent impact. To illustrate, Americans with a college degree are 16 points more likely than those without a degree to have an advance directive (57 vs. 41 percent) and 11 points more likely to have long-term care insurance (19 vs. 8 percent).

Americans with more education or who are employed full-time (controlling for retirement) also are more likely to have looked for information on aging issues; these are groups that likely possess greater comfort and experience than others in finding and using information. Being gainfully employed also positively predicts having made modifications to one's home.

D. Retirement

The survey finds that nearly four in 10 retired adults have sought out information on living assistance options and have modified their home for aging – far more than the 19 and 16 percent who've engaged in these activities, respectively, among non-retired individuals.

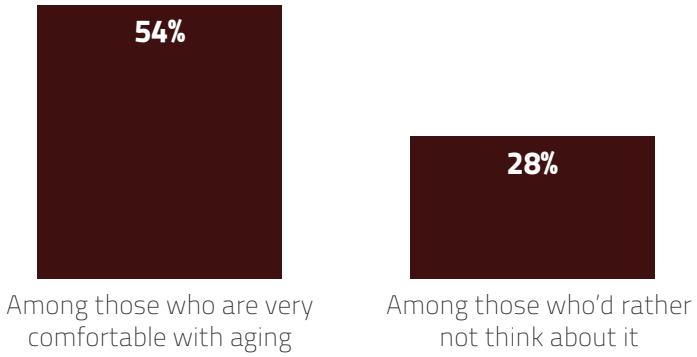
Have looked for information on aging issues

Even when controlling for age and health status, being retired is a strong predictor of both these planning steps, particularly modifying one's home.

E. Avoidance

As with the planning index overall, anxiety-fueled avoidance of aging acts as a significant impediment to several planning behaviors, including saving money, discussing preferences with loved ones and looking for information on aging issues.

Have spoken with family about preferences for care



Among the three in 10 Americans who'd rather not think about aging, just 23 percent say they have savings in place, vs. 41 percent among those who feel somewhat or very comfortable thinking about getting older. Among those who are "very" comfortable with the idea of getting older, moreover, 54 percent have spoken to their family or friends about their preferences for aging and 35 percent have looked for information on aging issues. Those drop sharply among those who'd rather not think about it, to 28 and 18 percent, respectively.

"Discomfort thinking about growing older and about losing one's independence is a significant impediment to planning."

In line with the literature, this suggests that discomfort thinking about growing older and about losing one's independence are significant impediments to planning.[8] In addition to the three in 10 Americans who would rather not think about getting older, an additional 32 percent say they're just "somewhat" comfortable with it. If people are reluctant to consider the realities of aging, it will be difficult for them to make adequate preparations for this life stage.

F. Experience with Long-Term Care

Experience with long-term care is a great motivator: Providing long-term care assistance to someone now, receiving it, or having given or received care in the past are associated with greater planning overall and with several individual planning behaviors. It's a logical result, in that first-hand experience assisting someone with their long-term care needs likely opens people's eyes to the possibility that they too may face similar problems.

Providing long-term care positively predicts having discussed aging preferences with family, having created an advance directive and having made home modifications. Illustratively, those who are giving or have

8 See Section V for independent predictors of avoidance of aging.

given care are 11 points more likely to have discussed their aging preferences with family members (46 vs. 35 percent) and 9 points more apt to have a living will. They're also 14 points more likely to have modified their home to make it easier to live in as they age.

Individuals who report particularly strong negative emotions associated with their caregiving experience are more likely than others to have discussed their aging preferences with family and to have looked for information about living assistance options. This suggests that experiencing firsthand the difficulties associated with caring for someone with long-term care needs can be a powerful motivator to seek out and prepare for more positive outcomes.

Being a recipient of living assistance, currently or in the past, similarly is an independent predictor of having written an advance directive and made home modifications, as well as having sought information on living assistance options. For example, six in 10 who have ever received long-term care have written a living will, compared with 45 percent of others. And those who've received care are about twice as likely to have looked for information on aging and living assistance options (43 vs. 23 percent) and to have made modifications to their home (45 vs. 21 percent).

G. Parents of Minor Children

As with the overall planning index, being the parent of a minor child is a significant negative predictor of some individual items, including saving money for long-term care needs, making home modifications and purchasing long-term care insurance. The fact that this predictor holds even when controlling for age suggests that parents of minors may be especially focused on their children's well-being, with less time and resources to consider their own future needs.

Indicating the planning gaps that occur, Americans with minor children are 18 points less likely than those without youngsters to have made modifications to their home (10 vs. 28 percent), 17 points less likely to have set aside money for aging (23 vs. 40 percent) and 9 points less likely to be very sure they have long-term care insurance (5 vs. 14 percent).

H. Health Status

Self-reported health status predicts several planning behaviors, but not always in the same way. Controlling for other factors, those who report being in better health are significantly more likely than others to have

written an advance directive, but significantly less likely to have discussed aging preferences with loved ones or made modifications to their home.

Fifty-six percent of Americans who say they're in excellent or very good health have created a living will, compared with about four in 10 of those in just good or worse health. On the other hand, just 17 percent of those in at least very good health have made home modifications to accommodate their aging needs, compared with three in 10 of those in fair or poor health.

I. Likelihood of Needing Long-Term Care

Respondents were asked how likely they feel it is that they personally will need long-term care someday, as well as how likely they think it is that an aging family member or close friend will need long-term care in the next five years. Both perceptions are related to some planning behaviors, but in opposite ways.

Americans who have an aging loved one who requires ongoing care now, or who think it is likely that a loved one will need long-term care in the near future, are significantly less likely than others to have saved money for their own aging needs, to have discussed their long-term care preferences with loved ones or to have an advance directive.

For example, among those who say a loved one is extremely likely to need assistance (or is receiving it now), just three in 10 have set aside money for their own care, four in 10 have discussed their aging preferences with loved ones and 43 percent have created an advance directive. Each is significantly higher among people who don't expect a family member to need care; in this group 44 percent have saved money, 51 percent have discussed their preferences with family and 55 percent have advance directives.

This may be due to several factors. Seeing or expecting to see a family member or friend struggling with long-term care needs (but not helping or expecting to help with their care, which were held constant) may encourage avoidance of the issue altogether.[9] It also may create a contrast effect, in which people who see others in need of help view themselves as being far from the same care needs. Finally, as noted, worrying about others' well-being may make it harder for people to focus on their own needs, especially if those needs are less immediate.

On the other hand, Americans who think it is likely that they themselves will someday need long-term care are significantly more apt than others to have saved money and sought out information on the subject.

These opposing results underscore the difficulties facing those who wish to bring greater attention to long-term care issues. Creating greater awareness of the likelihood that almost everyone will need some help with daily living when they grow older may help to facilitate greater planning. At the same time, people may react negatively to information that is seen as depressing, especially if they don't perceive concrete ways to reduce their concerns.

9 In a separate model (reviewed below), having or expecting to have a friend in need is associated with increased avoidance of thinking about getting older.

J. Other Predictors

Several variables emerged as significant predictors of just one type of planning behavior, briefly described below:

» Gender is a strong predictor of having discussed aging preferences with loved ones, with men less likely than women to have had such conversations, 33 vs. 49 percent. (There are other gender gaps: When thinking about growing older, women are more likely than men to prioritize community services such as meals and local transport, living near friends, having access to at-home care and living in a single-level home.)

Have discussed preferences for care with family/friends

» Not surprisingly, modeling shows that having a discussion with loved ones about aging preferences is related to the strength of an individual's relationship with his or her family. Among those who feel they can rely on their family a great deal to be there for them in a time of need, 50 percent have had a discussion about long-term care. That drops to 27 percent among those who feel they can rely on their family only a little or not at all.

» Controlling for other factors, marital status is a positive predictor of making home modifications, with those who are married or living as married more apt than others to have made changes to their home. This may reflect the fact that married individuals are more likely to want to remain in their home and to care for an ailing spouse there.

"Adults who think it is likely that they will someday need long-term care are significantly more apt than others to have saved money and sought information."

III. Perceived Extent of Planning

In a more subjective sense, not tied to specific actions, many Americans feel ill-prepared to meet their future needs for living assistance. Just 16 percent report having done a great deal or quite a bit of planning in general; 19 percent say they've done a moderate amount. That leaves nearly two-thirds, 65 percent, who feel they have done little if anything to prepare for these needs.

The strongest predictor of a perceived sense of having planned is having put aside money to help pay for living assistance expenses. That's followed by having purchased long-term care insurance and having looked for information about aging issues and long-term care options.

Being confident about having the financial resources to pay for care that one might need also predicts respondents' perceptions that they've planned for their later years, as do creating an advance directive and modifying one's home to make it easier to live in as an older person.

Table 3. Significant predictors of perceived planning

Set aside money for LTC	✓✓✓
Purchased LTC insurance (very sure)	✓✓✓
Sought out information on aging	✓✓✓
Confident can pay for any care needs	✓✓✓
Written advance directive	✓✓
Made home modifications	✓✓

See Appendix C for model details.

These results suggest that financial resources are critical for both planning behaviors and the subjective sense that one has planned. The challenge is that taking action thus may be out of reach for the many Americans who lack adequate financial resources.

"The development of more affordable care options, while a daunting task, would likely have a strong impact on planning."

The only predictor of feeling well prepared for aging that does not require financial resources is seeking out information on aging and living assistance options. The fact that that this step can be achieved by almost all Americans suggests that it may be of the most value to those who wish to increase aging preparedness. Currently just a quarter overall have looked for information about aging, indicating ample room for improvement. A concerted effort to increase people's awareness of available information resources, coupled with greater development of additional, easily accessible informational materials, appear to be achievable and potentially effective steps in encouraging greater long-term care planning.

The development of more affordable care options, while a more daunting task, also may be likely to have a strong impact on planning. Most people have immediate financial concerns, and when resources are limited, dealing with these proximal problems comes at the expense of planning for the future. If planning for later years can be done in a way that does not hinder Americans' ability to address their current financial responsibilities, then preparedness for this critical stage of life is likely to increase.

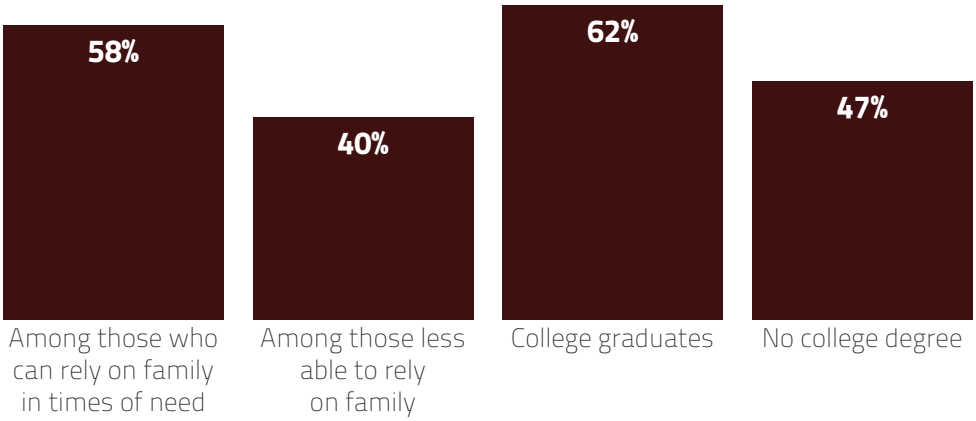
IV. Confidence in Finding Aging Information

As noted, Americans' confidence that they know where to go to find information about options for ongoing living assistance is relatively modest – two in 10 say they're extremely confident, and an additional 31 percent are very confident. That leaves nearly half who are just somewhat confident (31 percent) or less confident than that (16 percent). This matters, given the strong role of confidence in planning overall and in many of the individual planning behaviors. Therefore, a regression model was conducted to isolate the key predictors of this confidence.

As shown in Table 4, socioeconomic status is a key predictor of confidence in finding information. Americans with greater education and income are more apt to be confident they can find information on aging issues. Sixty-two percent of college graduates are very or extremely confident they know where to go to find information, compared with 47 percent of non-graduates, for example.

Family dynamics also play a role in information confidence. Those who feel they can rely on their family in times of need are more apt to think they know where to go to find information, likely reflecting the fact that trusted family members often are important information sources or references. Nearly six in 10 of those who say they can rely on their family a great deal or quite a bit in a time of need express confidence in their information-gathering ability, compared with 40 percent of those who feel their family is less reliable than that.

Confident you can find information



On the other hand, controlling for other factors, Americans who are married or living as married are less apt than others to express confidence in their information-seeking ability, perhaps expecting their spouse to handle it.

As with planning, being a parent of a minor is a significant negative predictor; those with young children are 15 points more likely than others to have little or no confidence in their information-seeking ability. Time and attention distractions could be factors.

Having experience providing or receiving long-term care is linked positively to confidence. Those who have seen or experienced long-term care needs firsthand may be more connected to resources on the topic, and therefore express greater confidence in their knowledge of where to go to find information. Having insurance also is linked positively to confidence, likely for similar reasons – insurance companies acting as an information conduit.

Table 4. Key predictors of confidence in finding aging information

Education	✓✓✓
Extent can rely on family	✓✓✓
Married	✓✓✓
Income	✓✓
Parent of minor	✓✓
Have received LTC	✓✓
Have provided LTC	✓
Have insurance	✓

See Appendix C for model details.

V. Predictors of Avoidance

In addition to the 31 percent who say getting older is something they'd "rather not think about," 32 percent are just "somewhat" comfortable with the subject. That leaves only slightly more than a third who are very comfortable thinking about aging. As described above, not wanting to think about getting older is a strong predictor of planning. Regression analysis was used to identify the factors that independently predict this avoidance.

Two aging concerns – not wanting to burden one's family and not wanting to be lonely – emerge as significant predictors of avoidance. Conveying steps that can be taken to reduce such concerns may reduce anxiety, thereby increasing planning.

Thinking that a family member or close friend soon may require living assistance, or currently having someone in need, also positively predict discomfort thinking about aging, suggesting that these experiences or expectations can trigger a level of discomfort that leads to avoidance of the issue altogether.

In contrast, those who are healthier, and older adults, are less likely to avoid thinking about getting older. Among attitudinal predictors, confidence that one can afford long-term care expenses and that one can find information about care options predict less avoidance, further underscoring the importance of information campaigns and more affordable planning options.

Table 5. Significant predictors of avoidance of aging

Concerned about being a burden on family	✓✓✓
Health	✓✓✓
Concerned about being alone	✓✓
Think it's likely a loved one will need LTC	✓✓
Age	✓
Confident can pay for any care needs	✓
Confident can find LTC information	✓

See Appendix C for model details.

VI. Experience Providing Long-Term Care

More than half of Americans – 53 percent – have experience providing long-term care for a loved one, including nearly a quarter who currently are providing such assistance on a regular basis and an additional 31 percent who have done so in the past. A model was created to find demographic predictors of having provided long-term care, given its impact on planning behavior (in particular, on talking with family about care preferences, creating an advance directive and making home modifications).

As shown in Table 6, parents of young children and those working full-time are less apt to provide ongoing living assistance to a friend or family member than their counterparts, likely given their time constraints. Specifically, 46 percent of parents of young children and 47 percent of Americans with full-time jobs have long-term caregiving experience, compared with 55 and 58 percent of those without minor children or a full-time job, respectively.

In line with previous research, there are gender and racial/ethnic differences in the provision of long-term care. Women are 11 points more likely than men to be caregivers (58 vs. 47 percent), and Latinos report greater caregiving experience than do whites and African-Americans.

Table 6. Significant predictors of providing long-term care

Parent of a minor	✓✓
Gender: Male	✓✓
Employment: Full-time	✓
Extent can rely on family	✓
Married	✓
Ethnicity: Latino	✓

See Appendix C for model details.

Finally, modeling shows that when controlling for other factors, Americans who are emotionally close to their family (i.e., feel they can rely on their family in times of need) and those who are married or living with a partner are significantly more likely to have experience providing long-term care for others.

Providing ongoing living assistance, while a positive motivator of planning, can be emotionally, physically and financially draining. Targeting the groups most apt to be giving assistance to aging loved ones could be useful in easing these burdens. For example, providing such individuals with advice on how best to care for aging adults, contact information for relevant local aid organizations and possible support groups available nearby all may help to promote a more positive caregiving experience.

VII. Group Differences in Concerns About Aging

While planning and its predictors are the chief focus of this report, other results among groups underscore the striking ways in which personal circumstances interact with attitudes and behavior on aging issues. As with other outcomes reported here, concerns about growing older also include a strong socioeconomic component; they're sharply higher among people who are less well-off financially and who are particularly worried about paying for their care as they age.

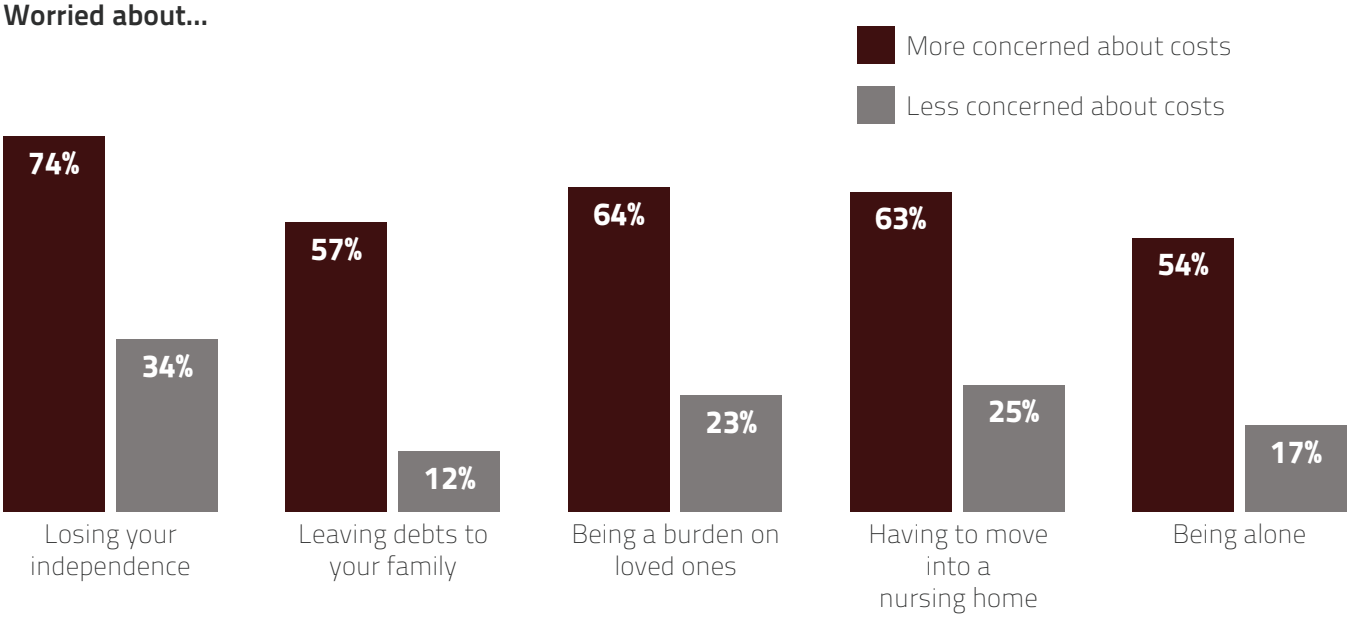
Among those who express a "great deal" or "quite a bit" of concern about paying for their care, for example, 74 percent also worry about losing their independence as they get older. Worry about losing one's independence plummets to 34 percent, by contrast, among those less concerned about affording the costs of care in their senior years.

People who are concerned about paying for their care also are more worried than others about leaving debts to their families, being a burden on their loved ones, having to move into a nursing home and being left alone without family or friends. And the margins are vast, ranging from 37 to 45 points.

Even more fundamental is the association of socioeconomic status and health. Americans who live in $100,000-plus households, college graduates and the employed all are vastly more apt than others to rate their health as excellent or very good. So are whites compared with nonwhites.

Likely given their income gap, some specific worries about aging are notably higher among nonwhites than among whites. For example, 39 percent of nonwhites express high levels of concern about leaving debts to their families; that falls to 28 percent among whites.

Worried about...



VIII. California/National Differences

There also are some differences in attitudes and behaviors on long-term care among Californians vs. all 40-plus adults nationally. Californians are better-informed on some aspects of the issue, more concerned about it in several respects and substantially more supportive of government initiatives to address it.

In one example, more than half of Californians, 53 percent, are concerned about how they'll pay for care or help they may need as they grow older, compared with 44 percent nationally. And 41 percent in California express a "great deal" of concern about the issue, vs. 29 percent nationally.

Additionally, a broad 66 percent of Californians favor creation of a government-administered insurance program similar to Medicare to cover long-term care, vs. 51 percent nationally. More, 84 percent in California, back a tax-advantaged savings plan for long-term care needs, ahead of the national figure by a smaller but still significant 7-point margin.

There's one further difference in support for government action: while half nationally oppose a mandate requiring individuals to purchase private long-term care insurance coverage, the level of opposition slips to 42 percent among Californians.

Another gap indicates more accurate information among Californians about Medicare. Forty-four percent nationally erroneously think the program covers the cost of ongoing home-based care by a licensed healthcare aide. Many fewer Californians, 30 percent, hold that misconception.

Californians also are 8 points less apt than adults nationally to think that Medicare covers the costs of ongoing care in nursing homes. And 55 percent of Californians recognize that "just about everyone" will need long-term care at some point, compared with 48 percent nationally.

Beyond the difference in worry about paying for the cost of care, Californians are 9 and 10 points more likely than adults nationally to express a great deal of concern about leaving debts to their families and about burdening their loved ones more generally as they age. They're also 7 to 10 points more likely to express a great deal of concern about losing their independence, having to move into a nursing home and losing their memory or other mental abilities.

Given those greater concerns, Californians are somewhat more apt to indicate avoidance of the issue: they're 8 points more likely than the population nationally to say that the idea of getting older is something they'd rather not think about, 39 vs. 31 percent.

Most other survey results are similar in California and nationally. Where differences exist, a variety of factors may be at play. Differences, e.g. on policy, at least to some extent reflect demographics: Compared with the national population, over-40 Californians are more apt to be unemployed and include more nonwhites and Democrats, groups that are more likely to favor government-led approaches.

IX. Summary and Conclusions

In sum, vast numbers of Americans age 40 and older are ill-prepared for a time when they may need living assistance. Though many worry about aging and most have provided living assistance to others, relatively few recognize the likelihood that they themselves will need long-term care someday. And many have yet to take important steps to plan for these potential needs.

Planning for later life gives individuals greater control over their circumstances, increasing the chances that they can grow older in the environment they desire. With an eye toward that goal, this report identifies the strongest independent predictors of preparing for future care needs. These results suggest avenues through which to understand and encourage planning actions.

The modeling shows that older adults, retirees and those with experience giving or receiving living assistance are more likely than others to have prepared for their aging needs. But even among these groups pluralities have yet to take essential actions, such as setting aside money for long-term care and having looked for information about ongoing living assistance. Moreover, those who postpone planning until they are older or retired may act too late.

There are key informational and attitudinal barriers to planning. Trusted resources on long-term care options can be difficult to find, and those who lack confidence that they know where to go for information engage in significantly fewer planning actions. A general desire to avoid contemplating getting older also is to blame; those whose concerns lead them to prefer not to think about aging are unlikely to plan for it.

As noted, there is a strong socioeconomic component as well. Many planning behaviors, such as setting aside money or purchasing long-term care insurance, require adequate resources. People with more immediate financial needs are less able or willing to save for the future. Feeling unable to pay for aging care relates strongly to worry, and in turn to avoidance.

Taken together, these results suggest ways to increase planning for long-term care. These include providing more accessible, clear and useful information on the prevalence of aging needs, available alternatives and resources on the issue; and publicizing the importance and benefits of planning for these needs, with sensitivity to the financial and emotional anxieties about aging that can produce avoidance.

Addressing the information gap will not solve the current limitations on long-term care options. But such efforts should increase planning steps, and in so doing, encourage awareness and debate about public policies on care for the nation's growing population of older Americans.

Appendix A

Literature Review

Introduction

This appendix presents a detailed synthesis of more than 70 existing academic and industry studies, reports and surveys on attitudes toward aging and long-term care, as well as a brief explanation of the psychological theories that may help to explain related behavior.

The research suggests that a vast segment of the U.S. population is moving toward an uncertain future in terms of long-term care, with little knowledge of the options available and little preparation, if any, to meet the unpredictable needs of older age.

Several factors lend urgency to discussion of these issues:

- The American Taxpayer Relief Act of 2012 repealed the previously suspended federal Community Living Assistance Services and Supports (CLASS) Act and created a long-term care commission (appointed in early 2013) that is charged with providing Congress with realistic policy options in legislative form to address U.S. long-term care needs.

- Also on the policy front is the pending debate over entitlement reform, which may aim to cut and/or restructure programs such as Medicare and Medicaid to contain cost growth – a debate in which one essential and often underappreciated element is the relationship between functional decline and Medicare and/or Medicaid spending, and the resultant pressures on these programs caused by lack of alternative financing for long-term care expenditures.

» Finally, demographic in nature, is the inexorable aging of the U.S. population itself, heralded by the fact that the first baby boomers are today senior citizens and many will in fact functionally decline as they age, leading them to need long-term care.

Background

Longer life spans have increased demand for long-term care services for older adults. The U.S. population aged 65 and older is expected to more than double from 2000 to 2030, from 35.1 million to 75.1 million.[1] The number who will require nursing home care is projected to rise at an even faster rate, doubling from 2000 to 2020, at which point it is anticipated that nearly half of seniors will require such care at some time in their lives.[2]

Many older Americans will be unable to afford these services. As of 2009, nursing home costs averaged $75,000 per year and home care costs averaged $25,000, compared with a median household income among seniors of $31,354.[3] One estimate shows that fewer than 15 percent of seniors can absorb such costs.[4]

The $90.7 billion spent on nursing home care in 2004 represented 79 percent of all long-term care costs. Government insurance covered 59 percent of nursing home costs (Medicaid, 38 percent; Medicare, 18 percent, other, 3 percent).[5] Private insurance covered 12 percent of these costs. Remaining, 31 percent was paid out of pocket. (Private insurance in this analysis included private long-term care insurance, held by just 3 percent of adults and 14 percent of seniors, and other private insurance that covered some nursing home costs.)

In contrast, of the $23.7 billion spent on home-based care (21 percent of all long-term care costs), 63 percent was covered by Medicare through time-limited rehabilitation services, 12 percent by Medicaid and 3 percent by other public programs. Out-of-pocket expenses accounted for 13 percent of the total, with private insurance covering 10 percent. (Generally, Medicare covers short-term rehabilitation; Medicaid – given eligibility – long-term stays.)

1 Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. *Outcomes and Insights in Health Management*, *2*, 1-7.
2 Spillman, B. C., & Lubitz, J. (2002). New estimates of lifetime nursing home use: Have patterns of use changed? *Medical Care*, *40*, 965-975.
3 MetLife Mature Market Institute. (2009). *Market survey of long-term care costs: The 2009 MetLife market survey of nursing home, assisted living, adult day services, and home care costs.* Westport, CT: MetLife.
4 Munnell, A. H., Webb, A., Golub-Sass, F., & Muldoon, D. (2009). *Long-term care costs and the National Retirement Risk Index.* Chestnut Hill, MA: Center for Retirement Research at Boston College.
5 As cited in Munnell et al. (2009). Centers for Medicare and Medicaid Services. (2008). *2004 national health expenditures by age.* Unpublished data provided by the Office of the Actuary, National Health Statistics Group. Washington, D.C.: Department of Health and Human Services.

Beyond seniors, long-term care may be needed by individuals of any age with long-term health problems, disabilities and other conditions that prevent independent self-care. Research and policy discussions have focused chiefly on long-term care for the aging population, as does this review. We address, most specifically, research findings pertinent to understanding Americans' perceptions, attitudes and concerns about long-term care.

Main Literature Review Findings

- **Long-term care costs are significant and growing.** The current and expected growth in an aging population that is living longer is putting increased pressure on the long-term care system. Baby Boomers, as they progress to retirement, are a main focus of much of the research.

- **Awareness and knowledge are lacking.** Few are aware of the prevalence of use of home-care and long-term care facilities among seniors. A common incorrect assumption is that Medicare will pay most long-term care costs. While many older Americans worry about being able to afford long-term care, few have made plans to handle the cost.

- **Avoidance is an impediment.** Unwillingness to talk about aging and long-term illness is a major barrier to planning for long-term care needs. People do not want to think about sickness, disability and death, and have a difficult time envisioning being older and sick when they are younger and healthy.

- **Cost of long-term care insurance is prohibitive, and its coverage limited.** The perceived and actual costs of long-term care insurance are further barriers. If the perceived and actual cost-benefit ratio does not improve, enhancing awareness of long-term care issues may be of limited effect in promoting purchasing long-term care insurance.

- **Options for meeting long-term care needs are limited.** In addition to a lack of government coverage (unless strict eligibility requirements are met), contraction within the long-term care insurance market limits consumer options, adding to the difficulties in obtaining and maintaining coverage.

- **High costs have real effects.** The inability to afford needed care and services leads to high levels of unmet care needs.

- **Family is the nexus of current long-term care for many households.** Most long-term care is provided by family caregivers, chiefly women. Caregiving by family members is emotionally, physically and financially difficult.

- **Home-based care trumps facility-based care.** Seniors and care professionals alike prefer home-care options over long-term care facilities. Home-based care also is more affordable, reducing costs for individuals and the system as a whole.

- **Race and ethnicity matter.** Factors associated with race and ethnicity are important. Socioeconomically, many older Latinos and African-Americans have fewer financial resources to pay for long-term care either in the home or in nursing facilities. Latinos and African-Americans, further, are less likely to know how to find information on long-term care and to trust long-term care facilities, and more likely to have strong familial care-giving norms.

- **Sources of information matter.** People trust family and friends foremost when it comes to planning for long-term care. Other trusted sources include healthcare professionals and respected members of the community. The news media, non-profits and insurance companies differ in their perceived trustworthiness, legitimacy, authority and level of bias.

- **A range of factors influences behavior.** Planning may be affected by age, health status, family circumstances, socioeconomic status, education, personal experience and other factors, all of which should be taken into account in predictive models.

Key Concepts and Components of Long-Term Care

The public's worries concerning long-term care are similar in many ways to those regarding health care in general; these include access, cost, quality of care, health outcomes and emotional and psychological well-being. (Organization and delivery of care are additional issues, mainly for administrators and regulators.) Concerns specific to long-term care include:

- Benefits and drawbacks of long-term care facilities[6] vs. home-based care
- Specific long-term care issues, such as dementia, physical assistance and independence
- Palliative and hospice care
- Advance directives, including do-not-resuscitate (DNR) orders
- Long-term financial planning
- Insurance issues (e.g., coverage of long-term care costs)
- Financial, emotional and physical strain on family caregivers
- Cultural differences in use of long-term care facilities. Latinos and African-Americans are less likely to place family members in such facilities,[7] and as such are more likely to undergo the emotional and physical stress of caring for a family member long term. (Larger family sizes may help mitigate this burden.)
- Quality-of-care issues including prevention and treatment of pressure sores; detection (and treatment, where possible) of depression, behavioral problems, Alzheimer's disease and sensory impairments; prevention of incontinence; facility quality differences in urban vs. rural settings; and others.

Relevant statistics highlight the prevalence and importance of these long-term care issues:

Healthcare Costs:

- Per capita healthcare expenditures on seniors are more than three times the amount spent on non-senior adults.[8]
- The prevalence of chronic conditions rises as people age, and a subset of seniors with chronic conditions also have functional impairments,

6 Including nursing homes, assisted living facilities and adult day healthcare facilities.

7 See Dinger, E. D., & Binette, J. (2008). *Health care reform and long-term care: A survey of AARP members in New Mexico.* Washington, D.C.: The American Association of Retired Persons; Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association, 292*, 961-967; Bradley, E. H., McGraw, S. A., Curry, L., Buckser, A., King, K. L., Kasl, S. V., & Anderson, R. (2002). Expanding the Anderson Model: The role of psychosocial factors in long-term care use. *Health Services Research, 37*, 1221-1242; Wallace, S. P., Levy-Storms, L., Ferguson, L. R. (1995). Access to paid in-home assistance among disabled elderly people: Do Latinos differ from non-Latino whites? *American Journal of Public Health, 85*, 970-975.

8 U.S. Department of Health and Human Services 2004 data: https: // www.cms.gov/NationalHealthExpendData /.

needing assistance with activities such as bathing and eating.[9] In 2006, per capita Medicare expenditures on seniors with chronic conditions and functional impairments were almost three times the amount spent on seniors with only chronic conditions.[10] Increased costs associated with chronic diseases have contributed to the growth in Medicare spending.[11]

» Care provided by unpaid adults to their family members was estimated to have an economic value of approximately $450 billion in 2009.[12] A majority of these caregivers care for someone aged 65 or older.[13]

» Caregiving activities by employees are estimated potentially to cost U.S. employers $17.1 to $33.6 billion a year in lost productivity and related costs, and $13.4 billion annually in higher healthcare expenses.[14]

Nursing home and home care use:

» Nearly seven in 10 nursing home residents are women. Two-thirds of them are widowed or divorced.[15] However, the 2010 Census shows that the longevity gap between women and men is shrinking.[16]

» Almost 60 percent of nursing home residents require assistance with four or more Activities of Daily Living (ADLs).[17] One in five non-institutionalized seniors living in the community has difficulty with at least one ADL.[18]

» For home care, the most frequently used services include paid, non-family home health aides and homemakers, which often are not covered, or not fully covered, by public or private insurance.[19] (This excludes unreported "gray market" care payments.)

9 *The SCAN Foundation DataBrief No. 22.* (2011). Retrieved January 14, 2013, from the SCAN Foundation website, http: //www.thescanfoundation.org/foundation-publications/databrief-no-22-medicare-spending-functional impairment-and-chronic-conditions.pdf
10 Ibid.
11 Trope, K.E., Ogden, L.L., & Galactionova K. (2010). Chronic conditions account for rise in Medicare spending from 1987 to 2006. *Health Affairs, 29*, 718-724.
12 Feinberg, L., Reinhard, S.C., Houser, A., & Choula, R. (2011). *Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving*: Washington, D.C.: The American Association of Retired Persons. Retrieved from: http: //assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf
13 National Alliance for Caregiving (2009). *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving.
14 The MetLife Mature Market Institute. (February, 2010). *The MetLife Study of Working Caregivers and Employer Health Care Costs*. Retrieved from: https: //www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf
15 Minimum Data Set Fact Sheet. (2004). http: //rtc.umn.edu/docs/factsheetnursinghomeres2000.pdf.
16 U.S. Census Bureau 2010 data: http: //www.census.gov/prod/cen2010/briefs/c2010br-09.pdf.
17 Lair, T. J., & Lefkowitz, D. (1990). Mental health and functional status of residents of nursing and personal care homes. Rockville, MD: Department of Health and Human Services.
18 Leon, J., & Lair, T. J. (1990). *Functional status of the non-institutionalized elderly: Estimates of ADL and IADL difficulties*. Rockville, MD: Department of Health and Human Services.
19 Altman, B. M., & Walden, D. C. (1993). *Home health care: Use, expenditures, and sources of payment*. Rockville, MD: U.S. Department of Health and Human Services.

Access:

» Privately insured people have more choices in nursing home care, if required, compared with those on Medicaid.

» At least 15 percent of nursing home residents could be cared for at lower levels of care (e.g., with home-based care solutions).[20]

Family care:

» Twenty-nine percent of the U.S. adult population provides care to someone who has a long-term illness, disability or requires ongoing help with care and activities.[21]

» Family caregivers are more likely to take unpaid leave, reduce work hours and rearrange their work schedules to care for their older family members.[22]

» Family caregivers also are more apt to experience adverse physical and mental health effects as a result of the stress of caregiving. [23]

» Two-thirds of family caregivers are women.[24]

» Prevalence of household caregiving varies somewhat by race. In Latino and African-American households, 36 and 34 percent, respectively, have provided care. It's 31 percent in white households and 20 percent in Asian-American households.[25]

An additional element of this overview is to summarize established guidelines used to identify those in need of long-term care and to evaluate long-term care experiences. Among the most commonly used are the Activities of Daily Living (ADL) scale;[26] the Instrumental Activities of Daily Living (IADL) scale,[27] which identifies those in need of long-term care; and the Resident Assessment Instrument (RAI), used in nursing homes for care planning and service monitoring.[28]

ADL items include, for example, bathing, dressing, feeding, toileting and transferring/walking. The IADL, further, measures the ability to live independently by assessing whether an individual can do each of the following tasks without assistance:[29]

» Using the telephone

» Grocery shopping

» Preparing meals

» Housekeeping

» Laundry

» Transportation

» Taking medications

» Handling finances

20 Spector, W. D., Reschovsky, J. D., & Cohen, J. W. (1996). Appropriate placement of nursing-home residents in lower levels of care. *The Milbank Quarterly, 74*, 139-159.
21 National Alliance for Caregiving (2009). *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving.
22 Ibid.
23 Ibid.
24 Ibid.
25 Ibid. The finding on Asian-Americans runs counter to expectations of cultural norms.
26 Katz S., Ford, A.B., Moskowitz R.W., Jackson, B.A., & Jaffe, M.W. (1963). Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function. *Journal of American Medical Association, 185*, 914-919.
27 Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, *9*, 179-186.
28 Hawes, C., Morris, J. N., Phillips, C. D., Mor, V., Fries, B. E., & Nonemaker, S. (1995). Reliability estimates for the Minimum Data Set for nursing home resident assessment and care screening. *The Gerontologist, 35*, 172-178. Another example of a quality assessment tool for use within nursing home is the Nursing Home Resident Assessment Minimum Data Set. See Mor, V., Intrator, O., Unruh, M. A., & Cai, S. (2011). Temporal and geographic variation in the validity and internal consistency of the nursing home resident assessment Minimum Data Set 2.0. *BMC Health Services Research, 11*, 78.
29 Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatrics Society, 31*, 721-727.

The RAI is an assessment of nursing home living, which includes the measurement of a resident's:[30]

- Psychological well-being
- Cognitive status (especially with signs of dementia)
- Vision
- Communication patterns
- Activity patterns
- Bowel and bladder incontinence
- Chronic diseases
- Pain
- Skin, oral and foot problems

The overarching focus of researchers, family and practitioners is for seniors to live in the best possible situation for them as individuals, whether that is in a long-term care facility or at home with adequate assistance from family and home care services. This goal is exemplified by the federal government's National Long-Term Care Channeling Demonstration project (1981-1985)[31] and has been carried forth by a wide range of other work, including previous surveys sponsored by The SCAN Foundation.

Psychological Theory and Research on Health Behavior

This section describes research on psychological theories of behavior relevant to understanding how and when people may engage in health-related behaviors, such as planning for aging or purchasing long-term care insurance.

The literature in psychology reveals that the relationship between attitudes and knowledge about health and acting on these thoughts and information is anything but simple and straightforward. In addition to the short-term

30 For a discussion of home care satisfaction see Geron, S. M., Smith, K., Tennstedt, S., Jette, A., Chassler, D., & Kasten, L. (2000). The home care satisfaction measures: A client-centered approach to assessing the satisfaction of frail older adults with home care services. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences, 55B*, S259-S270.

31 For details see http://aspe.hhs.gov/daltcp/reports/chansum.htm.

and tangible factors that influence behavior, there may be long-term and emotional factors that either encourage or inhibit people from taking action to promote their health and wellness in the long run. Below, we summarize the main lessons from this literature relevant to long-term care issues.

First, the literature suggests that a thorough understanding of health-related behavior can be achieved only through measurement of values, priorities, knowledge, attitudes, current behavior, barriers and motivators surrounding a health issue, and information sources.[32]

Although most theories of behavior are based on the precepts that people act in a reasoned, rational fashion on the basis of prior beliefs, attitudes, norms and perceptions, there also are emotional elements to health-related attitudes and behaviors, especially when they concern the difficult topics of aging, caring for loved ones, long-term illness and end-of-life decisions.

Further, there are cognitive biases that may influence how people think, or refrain from thinking, about health issues. One of these, optimism bias, refers to a tendency for people to underestimate their susceptibility to likely negative events (e.g., smokers' estimates of their likelihood of being afflicted with smoking-related illnesses).[33] Optimism bias typically is enhanced in situations with high uncertainty, which often also characterizes people's thoughts about aging.

A relatively recent theory relevant to how people might think about aging is construal level theory (CLT).[34] CLT argues that people think about an event near to them in time in terms of its specific, concrete attributes, but that as they are further removed from an event in time, detailed information about the event becomes unreliable or unavailable, so their thinking about it becomes more abstract. Applied to actions, people think about a near-future action in terms of its feasibility, but tend to think about an action in the distant future more in terms of its desirability.

32 Fraze et al. (2009). Applying core principles to the design and evaluation of the 'Take Charge. Take the Test' campaign: What worked and lessons learned. *Public Health, 123,* 23-30.

33 Armor, D.A., & Taylor, S. E. (2002). When predictions fail: The dilemma of unrealistic optimism. In T. Gilovich, D. Griffin, & D., Kahneman (Eds.), *Heuristics and Biases: The psychology of intuitive judgment* (pp. 334-347). New York, NY: Cambridge University Press.

34 Trope, Y., & Liberman, N. (2003). Temporal construal. *Psychological Review, 110,* 403-421.

With respect to issues of aging, construal level theory implies that older people for whom aging-related ailments and concerns are closer in time may focus more on concrete factors such as feasibility and ease of actions, while younger people may focus on more abstract, essential, high-level concerns, e.g., ideals of independence, dignity and self-sufficiency in thinking about and planning for aging.

Also relevant is social cognitive theory (SCT),[35] which holds that for any behavior to be initiated or changed, individuals need to have confidence that they can perform the recommended behavior and to believe that the benefits of or incentives for performing the desired behavior outweigh the costs.[36] This point is critical for long-term care planning, in which the perceived short-term costs often seem to outweigh the benefits.

Other commonly used theories include the theory of planned behavior,[37] the theory of reasoned action (TRA)[38] and, specific to health issues, the health belief model.[39] The theory of planned behavior suggests that the intention to perform a behavior is influenced by personal beliefs, attitudes and norms related to the behavior as well as by perceived ability to act.[40] TRA, similarly, holds that intention to act is the most important determinant of behavior, and that intention depends both on attitudes toward the behavior and on how an individual thinks others will view their behavior (i.e., subjective norms).[41]

The health belief model argues that individual attitudes and beliefs determine health behaviors, and predicts that people will carry out health behaviors if they see themselves as susceptible, perceive the condition as severe, think there are benefits to taking the health action, believe the benefits of taking that action outweigh the costs and are confident that they can take the recommended action successfully.[42]

Some argue that because these theories are individualistic and cognitively oriented,[43] they may not adequately describe the experience of individuals who operate in a more collectivist cultural framework, and may downplay the role of emotional factors in health behaviors. To address the first concern, another approach, the ecological model, focuses on the relationship between an individual and the contexts in which he or she lives.[44] It argues that there are four levels of influence:

1. Individual (e.g., demographics, personality)

2. Relationships (e.g., friends, family)

3. Community (e.g., workplace, media, shopping areas)

4. Society (e.g., cultural norms, laws)

This model argues that larger and longer-lasting behavioral changes occur when multiple levels operate in concert with each other.[45] Perceived and actual attitudes and behaviors of family members, colleagues at the workplace, and societal patterns also may help us understand how individuals approach long-term care.

35 Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychology Review, 84*, 191-215.
36 Randolph, W., & Viswanath, K. (2004). Lessons learned from public health mass media campaigns: Marketing health in a crowded media world. *Annual Review of Public Health, 25*, 419-37; Also see Noar (2006).
37 Azjen, I. (1985). From intentions to actions: A theory of planned behavior. In J. Kuhl & J. Beckman (Eds.), *Action-control: From cognition to behavior* (pp. 11-39). Heidelberg, Germany: Springer.
38 Azjen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior.* Englewood Cliffs, NJ: Prentice-Hall.
39 Strecher, V. J., & Rosenstock, I.M. (1997). The Health Belief Model. In K. Glanz, F.M. Lewis, & B.K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice.* San Francisco, CA: Jossey-Bass.
40 Fraze et al. (2009). Applying core principles to the design and evaluation of the 'Take Charge. Take the Test' campaign: What worked and lessons learned. *Public Health, 123*, 23-30.
41 Dutta-Bergman, M. J. (2005). Theory and practice in health communication campaigns: A critical interrogation. *Health Communication, 18*, 103-122.
42 Fraze et al. (2009). Applying core principles to the design and evaluation of the 'Take Charge. Take the Test' campaign: What worked and lessons learned. *Public Health, 123*, 23-30.
43 Dutta-Bergman, M. J. (2005). Theory and practice in health communication campaigns: A critical interrogation. *Health Communication, 18*, 103-122.
44 Parvanta, C. Nelson, D. E., Parvanta, S. A., & Harner, R. N. (2011). *Essentials of public health communication.* Sudbury, MA: Jones & Barlett Learning.
45 Abroms, L. C., & Maibach, E. W. (2008). The effectiveness of mass communication to change public behavior. *The Annual Review of Public Health, 29*, 219-234.

Studies and Reports

There are a limited number of representative – and therefore generalizable – studies of long-term care attitudes and needs. Many studies rely, instead, on convenience samples, e.g., of people who are beginning to contemplate or already are thinking about their long-term care needs.[46] Studies on long-term care also usually are confined to one state or residents within a community. Despite the lack of broad-based representative survey work in the field of long-term care, these studies do provide useful background, as well as point to several promising avenues of research.

The main findings on long-term care replicate established themes, e.g., that older Americans are worried that they will not be able to afford long-term care; inability to afford care leads to high levels of unmet needs, especially among Latinos; home-based care is preferred; most long-term care is provided by female family caregivers, and is emotionally, physically and financially difficult; people lack information about the levels of coverage provided by government programs; Latinos and African-Americans in particular have less information on long-term care, have less trust in long-term care facilities and prefer familial care-giving; and people trust family and friends foremost as sources of information on the subject.

Detailed summaries of important long-term care studies follow.

The SCAN Foundation's Survey of California Registered Voters

The SCAN Foundation's 2011 study included 1,490 California registered voters aged 40 and older.[47] According to the report, about six in 10 in this population:[48]

- Are worried about not being able to afford long-term care and future healthcare costs.
- Are worried their household income will not be enough to meet living expenses.
- Say making long-term care insurance more affordable should be a high priority for elected officials. (Although it should be noted that this priority was not contextualized by comparison with other possible health or broader policy priorities.)
- Want more information about how they can care for people who can no longer care for themselves – a key option for many of those who cannot afford a long-term care facility or would not consider placing a family member in a care facility.
- Underestimate the likelihood seniors will need help in their daily activities.
- Are worried just as much about long-term healthcare costs as they are about regular healthcare costs.

Thirty-eight percent of California registered voters aged 40 and older said that in the past year they have provided ongoing help to a friend or family member who could not care for themselves. Among them, six in 10 said providing this care was emotionally stressful and three in 10 said it caused them financial hardship.

However, these estimates of worry, stress and hardship may be overstated given a presumption in the questions on which they are based. Respondents were asked: "Thinking about growing older, how worried are you about being able to pay for long-term care if you or a family member needed it?" and "How emotionally

46 There are exceptions to this general pattern, e.g., certain studies sponsored by the AARP, TSF and USAToday, which use appropriate methodologies to obtain representative samples.
47 SCAN Foundation. (2011). *California voters 40 and older are struggling to make ends meet and financially unprepared for growing older.* Long Beach, CA: The SCAN Foundation.
48 Findings were mirrored in the Foundation's 2012 and 2010 surveys of California registered voters.

stressful would you say caring for your friend of family member is?" These questions assume worry and stress rather than neutrally measuring its presence or absence (e.g., "Do you find it emotionally stressful to provide this care, or not?").

Latinos in this study were 24 percentage points more apt to be worried that their income will not be enough to pay their expenses and bills and 20 points more likely to be unable to afford a single month of nursing home care. They also were a slight 5 points more likely (71 vs. 66 percent) to worry about affording long-term care services for family members, although it is not clear from the report whether or not this difference is statistically significant, nor clear whether or not the differences simply reflect an effect of income. Modeling with controls for socioeconomic status would help clarify if the effects for Latinos are independently significant. The survey also found 88 percent support for the CLASS act, albeit using an unbalanced question.

AARP Studies

AARP is one of the most active organizations in research on the issue of long-term care, with studies conducted in New Mexico (2008) and Michigan (1992), on female baby boomers (2009) and on Latinos and Boomers (2007 and 2010). It should be noted that the questionnaire design in these studies is suboptimal and in many cases biasing, likely distorting their measurements.

Eight in 10 Michigan residents over age 50 said ensuring affordable long-term care options exist should be a top or high priority for their state, and nearly six in 10 were not confident they could afford long-term care services for more than five years at then-current rates.[49] A lack of comparison of policy priorities leaves no indication of the relative priority of long-term care, but clearly there was anxiety about the ability to pay for such services. Seventy percent indicated that family and friends were the sole caregivers of older family members, a pattern common across all studies of long-term care.

Sixty percent of AARP members in New Mexico were worried about affording health care in general, and about half were worried about affording long-term care.[50] After receiving information on the average costs of long-term care in their state, two-thirds said they were not confident they could afford care for one year. Forty percent self-assessed themselves as not very or not at all informed about long-term care services in their community.

Baby boomer women (aged 50 to 62) account for both a disproportionate number of residents of long-term care facilities and those providing at-home family care to others. AARP analyzed their propensity to make long-term care plans,[51] finding that the likelihood of planning was increased by having a friend or family member who required care, a clear understanding of the options for care and fear of what may happen without a plan. The most influential barriers to planning included a lack of information and knowledge of what to do, thinking that no plan was necessary given current good health, cost issues, control issues (not wanting to give up independence) and lack of confidence in the healthcare system, which makes staying at home seem like the better option.

49 Silberman, S. (2002). *AARP Michigan long-term care survey.* Washington, D.C.: The American Association of Retired Persons.
50 Dinger, E. D., & Binette, J. (2008). *Health care reform and long-term care: A survey of AARP members in New Mexico.* Washington, D.C.: The American Association of Retired Persons.
51 Brown, H. W. (2009). *Boomer women's long-term care planning: Barriers and levers.* Washington, D.C.: The American Association of Retired Persons.

A factor analysis identified five types of groups according to their long-term care attitudes and behaviors, each accounting for roughly 20 percent of the sample. The groups (named based on their characteristics) include:

1. Open and uninformed: unaware of the need for long-term care planning and uninformed about it, but willing to explore planning options.

2. Planners: people who have long-term care plans. They are more likely to have had close experiences with long-term care among friends and family.

3. Procrastinators: too busy to think about long-term care and waiting to deal with it until it becomes necessary.

4. Crossroads: people who think they might need long-term care in the future, but are unsure. They are anxious about being unprepared.

5. Pessimistic: these people think it's too late to plan for long-term care and that making plans is futile. They are counting on Medicare to cover their costs.

The United States of Aging Survey

In a 2012 study, USA Today, the National Council on Aging and UnitedHealthcare interviewed 2,250 adults aged 60 and older to assess older Americans' readiness for aging and perceptions of their communities' preparedness for supporting older adults.[52] The sample's restricted age limits its potential to develop a comprehensive view of aging readiness. As reviewed above, younger adults also have caregiving experiences that are immediately relevant to how they plan for aging and wish to be taken care of in old age. Further, actions earlier in life, such as retirement plans and investments, generally will strongly influence future resources.

Although the study reports a nationally representative sample, methodological details are not well-disclosed, making it difficult to establish the study's reliability and validity. Further, many of the questions are biasing (e.g., agree/disagree questions) or use unbalanced response options, and some constructs are not worded precisely enough to elicit consistent interpretations.

52 *The United States of Aging Survey: National Findings* (2012). Retrieved August 8, 2012 from National Council on Aging Website, http: / /www.ncoa.org/improve-health/community-education/united-states-of-aging/united-states-of-aging.html; Penn Schoen and Berland Associates (2012). *UHC, NCOA & USA Today Present: The United States of Aging, Topline Results*. Penn Schoen and Berland Associates: New York. http: / /www.ncoa.org/assets/files/pdf/unitedstates of-aging / 2012-survey/USA-Topline-Results.pdf

The survey found that nine in 10 respondents intend to keep living in their current homes in the next 5-10 years and three-quarters expect their overall quality of life to stay the same (45 percent) or get better (30 percent). As noted, such broadly positive expectations may result from optimism bias. Asking specifically about common problems in old age may lead to a fuller description of respondents' anticipated difficulties in the near future.

More than six in 10 older adults expressed confidence that they would be able to meet their regular monthly expenses over the next five to 10 years, and seven in 10 said they'd be able to cover the costs should an accident or unexpected medical issue occur. Vague description of an unexpected medical issue might have inflated this estimate, and results could be very different if respondents were asked about their ability to afford specific care needs, for example, two months of home-care aide service during recovery from an injury.

While affordability of care in retirement and old age was assessed (albeit with suboptimal questions), noticeably lacking from the study were questions about current and intended future financial planning for long-term care, including among others, having/purchasing long-term care insurance and relying on children and/or savings.

Also unexamined were attitudes about living in nursing homes or assisted living facilities, care-taking and financial expectations from children, value priorities in old age, and knowledge about perceived coverage from government insurance.

Studies on Family-Member Caregiving

Academic studies show that the role of family and friends as potential or actual caregivers is a major factor in attitudes toward long-term care. Along with financial constraints, having (or lacking) social support is a main determinant of whether or not seniors obtain long-term care assistance at home or in a long-term care facility.[53]

Non-institutionalized seniors who require long-term care often rely on family and friends for help. Family caregivers are more likely to take unpaid leave from work, reduce work hours and rearrange work schedules to care for their older family members. They often also take on a direct financial burden of paying for long-term care services, whether in the home or at an institution. The combined financial strain can be significant, as can the emotional and physical toll.

53 Kaiser Family Foundation. (November, 2005). *Long-Term Care: Understanding Medicaid's role for the elderly and disabled.* Retrieved from: http://www.kff.org/medicaid/upload/long-term-care-understanding-medicaid-s-role-for-the-elderly-and-disabled-report.pdf

Caregiving is widespread; more than 17 percent of adults employed part- or full-time are already caring for a family member or friend,[54] and many more, 62 percent of all adults think they will be responsible for caring for an aging parent or another older person at some point in the future.[55]

The SCAN Foundation's work and several other studies indicate that caregiving can have serious effects on mental and physical health.[56] Depression and anxiety are common, especially for spouse caregivers before and after they place their spouse into a long-term care facility.[57]

Caregiving does not have only negative effects on caregivers. One study found that caregivers said that caring for their relative made them feel more useful, needed, appreciated and important, and that those who felt this way were less likely to feel stress and less apt to institutionalize their care recipient. Among those who institutionalized their relative, their reported symptoms of depression and anxiety were just as high as they were when they were undergoing the stresses of at-home caregiving.

However, the overall effects of caregiving on family members are more often than not negative. Families are in a tough spot. Nursing home costs are high and families are reluctant to put their relatives in institutions for a variety of reasons, but the difficulties of caring for functionally impaired relatives at home also are significant. Nursing facilities have sought to combat negative stereotypes, including an attempt to change the culture of long-term care homes.[58]

Most healthcare professionals, seniors and their families agree that it is optimal to keep those who need help in their home and family situations as long as possible.[59] This means focusing on and enhancing the availability, affordability and effectiveness of long-term at-home care services.

54 Cynkar, P., & Mendes, E. (2011). More than one in six American workers also act as caregivers. Retrieved from http: //www.gallup.com/poll/148640/one-six-american-workers-act-caregivers.aspx

55 Pew Social Trends Poll (2011). Retrieved November 30, 2012 from the iPOLL Databank, The Roper Center for Public Opinion Research, University of Connecticut, http: //www.ropercenter.uconn.edu/data_access/ipoll/ipoll.html

56 SCAN Foundation. (2011). *California voters 40 and older are struggling to make ends meet and financially unprepared for growing older.* Long Beach, CA: The SCAN Foundation; Herrera, A. P., Lee, J., Palos, G., & Torres-Vigil, I. (2008). Cultural influences in the patterns of long-term care use among Mexican American family caregivers. *Journal of Applied Gerontology, 27*, 141-165; Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association, 292*, 961-967; Feder, J., Komisar, H. L., & Niefeld, M. (2011). Long-term care in the United States: An overview. *Health Affairs, 19*, 40-56.

57 Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961-967.

58 See Sterns, S., Miller, S. C., Allen, S. (2010). The complexity of implementing cultural change practices in nursing homes. *Journal of the American Medical Directors Association, 11*, 511-518; Miller, S. C., Miller, E. A., Jung, H-Y., Sterns, S., Clark, M., & Mor, V. (2010). Nursing home organizational change: The "culture change" movement as viewed by long-term care specialists. Medical Care Research and Review, *67*, 65S-81S.

59 Dinger, E. D., & Binette, J. (2008). *Health care reform and long-term care: A survey of AARP members in New Mexico.* Washington, D.C.: The American Association of Retired Persons.

Studies that Address Culture, Ethnicity and Race

Differences among Latinos, African-Americans and whites in views of long-term care are a consistent finding in the literature, especially when it comes to the perceived acceptability of placing a family member in a long-term care facility.

A qualitative study of focus groups to examine racial differences in long-term care use suggests that African-Americans are less likely than whites to have access to needed information.[60] They also are more likely to have strong familial caregiving norms and greater concerns about loss of privacy and self-determination at long-term facilities. The study found that whites tend to put more emphasis on the burdens of caregivers and the importance of getting relief from that burden through the use of long-term care services, while African-Americans are more apt to stress that family members should provide care services. This tendency toward family care among African-Americans likely is partially attributable to greater mistrust of doctors and the medical system within this community.[61]

These attitudinal differences are apparent behaviorally. Whites are more apt to place family members who are suffering from dementia in long-term care facilities than are African-Americans or Latinos.[62] African-Americans also are less likely to make use of Medicare hospice care.[63] Nonetheless there has been considerable growth in the use of nursing homes within some minority populations, exceeding the effect of population growth.[64] From 1999 to 2008 the number of older Latinos and Asians in nursing homes grew by roughly 50 percent, while the number of African-Americans in these facilities grew by 10 percent and whites declined by 10 percent.[65] However, for socioeconomic reasons, Latinos' and African-Americans' access to high-quality nursing homes still lags behind whites'. Racial and ethnic minorities tend to be located in facilities that have poor performance ratings, are understaffed, use restraints and rely heavily on Medicaid funding.[66]

60 Bradley, E. H., McGraw, S. A., Curry, L., Buckser, A., King, K. L., Kasl, S. V., & Anderson, R. (2002). Expanding the Anderson Model: The role of psychosocial factors in long-term care use. *Health Services Research, 37*, 1221-1242.

61 Braunstein, J. B., Sherber, N. S., Schulman, S. P., Ding, E. L., & Powe, N. R. (2008). Race, medical researcher distrust, perceived harm, and willingness to participate in cardiovascular prevention trials. *Medicine, 87*, 1-9; Hammond, W. P. (2010). Psychosocial correlates of medical mistrust among African American men. *American Journal of Community Psychology, 45*, 87-106.

62 Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association, 292*, 961-967.

63 Lepore, M. J., Miller, S. C., & Gozalo, P. (2010). Hospice use among urban black and white U.S. nursing home decedents in 2006. *The Gerontologist, 51*, 251-260.

64 Smith, D. B., Feng, Z. F., Fennell, M. L., Zinn, J., & Mor, V. (2008). Racial disparities in access to long-term care: The illusive pursuit of equity. *Journal of Health Politics, Policy and Law, 33*, 861-881; Fennell, M. L., Feng, Z., Clark, M. A., & Mor, V. (2010). Elderly Latinos more likely to reside in poor-quality nursing homes. *Health Affairs, 29*, 65-73.

65 Feng, Z., Fennell, M. L., Tyler, D. A., Clar, M., & Mor, V. (2011). Growth of racial and ethnic minorities in U.S. nursing homes driven by demographics and possible disparities in options. *Health Affairs, 30*, 1358-1365.

66 Fennell, M. L., Feng, Z., Clark, M. A., & Mor, V. (2010). Elderly Latinos more likely to reside in poor-quality nursing homes. *Health Affairs, 29*, 65-73; Smith, D. B., Feng, Z., Fennell, M. L., Zinn, J. S., & Mor, V. (2007). Separate and unequal: Racial segregation and disparities in quality across U.S. nursing homes. *Health Affairs, 26*, 1448-1458.

A study of access and use of paid home care assistance among Latinos revealed several differences compared with whites.[67] For whites, increased impairments in ability to carry out daily activities (as measured by the ADL) were associated with higher use of paid home care services. For Latinos, the pattern was opposite. The authors hypothesize that Latinos are less able to afford care when impairments become more severe, and at that point, begin to rely more heavily on informal care such as friends and family.

In terms of costs, Latinos, especially those between age 45 and 64, were particularly hard-hit by the Great Recession.[68] This financial pressure may have reduced many Latinos' ability to afford health care in general and long-term care specifically.

Purchasing Long-Term Care Insurance

A study by America's Health Insurance Plans (AHIP) examines propensity to buy long-term care insurance.[69] This study included mail surveys of buyers and non-buyers, as well as a survey of the general population over age 50. Small sample sizes and lack of weighting beyond gender in the general population survey undermine the generalizability of the findings, but the patterns may be useful for conceptualization.

Buyers experience less worry about long-term care than non-buyers, but non-buyers are twice as apt to think the government will pay for most of the costs of long-term care if needed – a perception that does not in any way reflect the reality of high-cost burdens for individuals and their families.[70]

Nearly all of the respondents in the general survey (95 percent) did not have long-term care insurance, an estimate close to the 97 percent rate quoted by the American Association for Long-Term Care Insurance (AALTC). Common reasons for not buying insurance include high cost, skepticism about insurance companies, lack of understanding of the risk and confusion about how much government coverage will pay for long-term care.

67 Wallace, S. P., Levy-Storms, L., & Ferguson, L. R. (1995). Access to paid in-home assistance among disabled elderly people: Do Latinos differ from non-Latino whites? *American Journal of Public Health, 85*, 970-975.
68 Perron, R. (2010). *Recession takes toll on Latinos 45+: Boomers particularly hard hit.* Washington, D.C.: The American Association of Retired Persons.
69 America's Health Insurance Plans. (2007). *Who buys long-term care insurance? A 15-year study of buyers and non-buyers, 1990-2005.* Washington, D.C.: America's Health Insurance Plans.
70 Differences in understanding of Medicare coverage between buyers and non-buyers of long-term care insurance were not replicated in the present study.

And the costs continue to increase; AALTC recently reported that prices have increased as much as 17 percent for policies offered by 10 large insurers for comparable coverage compared with a year ago,[71] leading the association's executive director to conclude "the problem is, it's an expensive product."[72]

Many economists would argue that it is rational for most people not to purchase long-term care insurance given limited benefits.[73] For example, economic models show that utility-maximizing behavior for long-term illness usually involves little to no insurance even when the insurance policy is offered at a fair price and inaccurate beliefs and lack of information are held constant. Indeed, it's estimated that two-thirds of seniors would not buy long-term care insurance because of the availability of Medicaid, even if the insurance were offered at affordable prices, given what researchers call a "crowd-out" of private long-term insurance by the alternative option of spending down or distributing one's resources in order to become Medicaid eligible.[74]

Another study suggests that the percentage of households at risk of being unable to maintain their standard of living in retirement rises only slightly when costs of long-term care are included. The figure goes from 44 percent to 61 percent when general healthcare costs are taken into account, then to 65 percent when long-term care costs are added.[75]

People appear averse to buying a product they don't know they'll ever need. Some see it as unnecessary, too complicated or too expensive. The CLASS Act recently was repealed for both political and policy reasons. On the policy front, CLASS was hampered by the same problem facing the private long-term care insurance industry – adverse selection, meaning that only people who need the benefits of an insurance plan will enroll, preventing the plan from spreading costs across the broader population, and thus leading to high premiums and low enrollment, making the program financially unsustainable. Mandatory coverage would address adverse selection, but is politically controversial.

71 American Association for Long-Term Care Insurance. (2012). 2012 Long Term Care Insurance Price Index. Retrieved from http: //www.aaltci.org/news/long-term-care-insurance-association-news/2012-long-term-care-insurance-price-index

72 Carrns, A. (2012, March 15). Cost of long-term care insurance keeps rising. *The New York Times*. Retrieved from http: //bucks.blogs.nytimes.com/2012/03/15/cost-of-long-term-care-insurance-keeps-rising/.

73 Pauly, M V. (1990). The Rational nonpurchase of long-term-care insurance. *Journal of Political Economy, 98*, 153-168.; Brown, J. R., & Finkelstein, A. (2007). Why is the market for long-term care insurance so small? *Journal of Public Economics, 91*, 1967-1991.

74 Brown, J. R., & Finkelstein, A. (2008). The interaction of public and private insurance: Medicaid and the long-term care insurance market. *The American Economic Review, 98*, 1083-1102.

75 Munnell, A. H., Webb, A., Golub-Sass, F., & Muldoon, D. (2009). *Long-term care costs and the National Retirement Risk Index*. Chestnut Hill, MA: Center for Retirement Research at Boston College. This study suggests a lower additional risk of having long-term care costs damage living standards than might be anticipated, given the low rates of private insurance, lack of public coverage and long-term care costs.

Appendix B

Topline Results

This appendix presents full questions and topline results of the AP-NORC survey on long-term care, sponsored by The SCAN Foundation.

Dashes indicate no responses in the category, asterisks indicate responses less than .5 percent.

Q1. What is the most important problem facing you and your family today?
[OPEN END, VERBATIM RESPONSE RECORDED]

	National Sample	California Sample
Personal financial issues	37%	42%
Personal financial situation/money	24	27
Lack of work/unemployment/trying to stay employed	4	7
Cost of healthcare/medical bills	4	4
High costs/prices (unspecified)	3	2
Other personal financial issues	-	2
Health issues	19	13
Personal health	9	9
Health (unspecified)	5	2
Aging	3	2
Health of family members	2	*
Economy	12	11
Economy, general	10	9
Debt/deficit/government spending/taxes	1	1
Unemployment/jobs	1	*
Other economic issues	*	*
Domestic Political/Policy Issues	9	8
Health care/Medicare	5	4
Politics/partisanship/political leadership	2	2
Energy/environment	*	1
Education	1	-
Other domestic issues	*	1

	National Sample	California Sample
Children/family issues	4	8
Other family issues	2	5
Trouble raising kids	*	1
Other issues with children	*	1
Aging parents	1	1
Don't know	1	2
No problems	11	8
Other	5	5
Refused	*	1

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

	National Sample	California Sample
Excellent/Very good	41	39
Excellent	12	14
Very good	29	26
Good	35	35
Fair/Poor	24	26
Fair	18	18
Poor	5	7
Don't know	-	-
Refused	-	-

Q2. Thinking about your own personal situation as you get older, for each item please tell me if it causes you a great deal of concern, quite a bit of concern, a moderate amount, only a little, or none at all? How about (ITEM)?

National Sample

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Losing your independence and having to rely on others	52	36	15	25	23	12	11	1	*
Losing your memory or other mental abilities	51	35	15	20	29	15	14	*	*
Being able to pay for any care or help you might need as you grow older	44	29	15	27	29	14	15	*	*
Having to leave your home and move into a nursing home	42	31	10	19	39	18	21	*	*
Being a burden on your family	41	29	12	22	37	15	22	*	*

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Leaving debts to your family	32	23	9	16	51	18	33	1	*
Being alone without family or friends around you	33	24	9	23	44	20	23	*	*

California Sample

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Losing your independence and having to rely on others	61	46	15	22	17	10	7	-	-
Losing your memory or other mental abilities	57	44	14	22	21	12	9	*	-
Being able to pay for any care or help you might need as you grow older	53	41	13	22	24	13	11	*	-
Having to leave your home and move into a nursing home	50	38	12	15	35	22	13	*	-
Being a burden on your family	45	39	6	21	33	14	19	*	-
Leaving debts to your family	38	32	6	12	50	12	37	*	-
Being alone without family or friends around you	35	26	9	20	45	21	24	-	-

Q3. Now a few questions about your family. What is your marital status? Are you married; living as married, co-habitating; separated; divorced; widowed; or never married?

	National Sample	California Sample
Married	59	57
Living as married/Co-habitating	4	6
Separated	4	4
Divorced	13	17
Widowed	9	9
Never married	11	6
Don't know	-	*
Refused	*	1

Q4. Are you a parent or guardian, regardless of the age of your children, or not?

	National Sample	California Sample
Yes	78	78
No	22	22
Don't know	-	-
Refused	*	-

Q5. *Asked among those saying "Yes" in Q4:*
Are any of your children under 18 years of age, or not?

	National Sample	California Sample
Yes	35	40
No	65	60
Don't know	-	-
Refused	-	-

Q6. *Intro if Q3=married or Q3=living as married/co-habitating AND Q5=Yes*: Thinking about family members other than your spouse or partner and children under 18…

Intro if Q3=married or Q3=living as married/co-habitating AND Q5=No, DK or Refused: Thinking about family members other than your spouse or partner…

Intro if Q3 not married or living as married/co-habitating AND Q5=Yes: Thinking about family members other than your children under 18…

…do you live in the same home with members of your family, or not?

	National Sample	California Sample
Yes	34	36
No	66	63
Don't know	*	*
Refused	-	-

Q7. *Intro if Q3=Married or Q3=Living as married/co-habitating or Q5=Yes or Q6=yes*: Thinking about family members other than those in your household…
Which of the following statements comes closest to describing how near or far you live from your family?

	National Sample	California Sample
Most of your family lives an hour or less away from you	51	47
Most of your family lives more than an hour away	48	51
No family (Vol.)	1	1
Don't know	1	1
Refused	*	-

Q8. How much do you feel you can rely on your family to be there for you in a time of need? Would you say a great deal, quite a bit, a moderate amount, only a little, or not at all?

	National Sample	California Sample
A great deal/Quite a bit	68	64
A great deal	51	49
Quite a bit	18	15
A moderate amount	15	18
Only a little/None at all	15	16
Only a little	10	9
None at all	5	7
It depends (Vol.)	*	1
No family (Vol.)	*	-
Don't know	*	1
Refused	1	-

Q9. Now I am going to read a list of support systems that might provide help for you as you age. How much help do you think (ITEM) will provide to you as you age… a great deal, quite a bit, a moderate amount, only a little, or not at all?

National Sample

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Your spouse or partner (asked if married or living with partner/co-habitating) (n=570)	77	60	17	13	9	6	4	1	1
Your children or grandchildren (asked if a parent or guardian) (n=763)	46	28	19	29	23	14	9	1	*
Doctors, nurses, and other health care providers (n=1,019)	40	20	19	39	20	14	5	1	*
The health insurance system (n=1,019)	30	19	11	36	31	22	9	2	1
Extended family members (asked if they have family members) (n=1,012)	29	16	13	29	41	24	17	1	*
The Medicare system, which provides health care insurance for seniors (n=1,019)	28	17	12	36	31	22	9	4	*

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
The Social Security system (n=1,019)	22	13	9	33	43	29	13	2	*
Religious and faith-based organizations (n=386)	22	13	9	26	49	28	21	2	1
The Medicaid system, which provides health care coverage for low-income adults and people with certain disabilities (n=1,019)	17	9	8	20	57	27	31	4	*
Friends or neighbors (n=1,019)	17	8	9	27	56	33	23	*	-
Community organizations (n=1,019)	11	6	5	27	56	33	23	5	*

California Sample

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Your spouse or partner (asked if married or living with partner/co-habitating) (n=231)	79	61	18	10	9	5	4	2	*
Your children or grandchildren (asked if a parent or guardian) (n=282)	48	31	17	29	20	11	9	2	-
Doctors, nurses, and other health care providers (n=386)	43	24	19	34	22	18	4	1	-
The health insurance system (n=386)	27	14	12	34	35	25	10	4	*
Extended family members (asked if they have family members) (n=382)	27	17	11	29	42	24	18	1	-
The Medicare system, which provides health care insurance for seniors (n=386)	27	14	13	44	27	18	9	2	-
The Social Security system (n=386)	20	11	8	37	40	24	16	2	1

	A great deal/Quite a bit	A great deal	Quite a bit	A moderate amount	Only a little/None at all	Only a little	None at all	DK	Ref.
Religious and faith-based organizations (n=386)	16	11	4	28	53	20	34	3	1
The Medicaid system, which provides health care coverage for low-income adults and people with certain disabilities (n=386)	13	7	6	23	59	25	34	4	*
Friends or neighbors (n=386)	11	7	4	30	58	34	24	*	*
Community organizations (n=386)	10	6	4	23	64	39	25	2	*

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.

Q10. Are you currently receiving this kind of ongoing living assistance, or not?

	National Sample	California Sample
Yes	5	3
No	95	97
Don't know	*	-
Refused	-	-

Q11. *Asked among those saying "No," "Don't know" or "Refused" in Q10:*

Have you ever received ongoing living assistance like this, or not?

	National Sample	California Sample
Yes	4	7
No	95	93
Don't know	*	-
Refused	*	-

Q10/Q11 combined.

	National Sample	California Sample
Currently or ever received ongoing living assistance	9	10
Never received assistance	90	90
Don't know	*	-
Refused	*	-

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?

	National Sample	California Sample
Own home	82	90
Friend or family member's home	9	1
Nursing home	3	3
Senior community	5	4
Don't know	1	2
Refused	*	-

Q13. *Asked among those who said "Own home" or "Friend or family member's home" in Q12:*
Have you ever received ongoing living assistance from (ITEM), or not?

National Sample

	Yes	No	Don't know	Refused
A family member	37	63	-	-
A friend	46	54	-	-
A professional home healthcare aide	46	54	-	-

California Sample

	Yes	No	Don't know	Refused
A family member	54	46	-	-
A friend	29	71	-	-
A professional home healthcare aide	55	42	3	-

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

	National Sample	California Sample
Yes	23	19
No	77	81
Don't know	-	-
Refused	*	-

Q15. *Asked among those who said "No," "Don't know" or "Refused" in Q14:*
Have you ever provided ongoing living assistance on a regular basis to a family member or close friend, or not?

	National Sample	California Sample
Yes	39	40
No	60	60
Don't know	*	-
Refused	-	-

Q14/Q15 Combined.

	National Sample	California Sample
Total ever provided care	53	51
Never provided care	47	49
Don't know	*	-
Refused	*	-

Q16. When you think about your personal experience providing ongoing living assistance to your family member or close friend, would you say that (ITEM), or not?

National Sample

	Yes	No	Don't know	Refused
It is/was worthwhile	95	4	1	-
It is/was fulfilling	91	9	*	*
It makes/made you feel honorable	76	22	2	*
It is/was time consuming	82	17	1	*
It is/was stressful	72	27	1	*
It makes/made you feel happy	76	21	1	1
It is/was frustrating	61	38	*	*
It makes/made you feel sad	54	45	1	1

California Sample

	Yes	No	Don't know	Refused
It is/was worthwhile	95	5	-	-
It is/was fulfilling	86	14	-	*
It makes/made you feel honorable	81	16	3	*
It is/was time consuming	76	24	-	-
It is/was stressful	74	26	-	*
It makes/made you feel happy	70	29	2	-
It is/was frustrating	66	34	*	-
It makes/made you feel sad	56	43	1	-

Q17. Would you say that the idea of getting older is…something that you'd rather not think about, or is it something that you're comfortable thinking about? IF COMFORTABLE: Would you say you are somewhat comfortable or very comfortable thinking about getting older?

	National Sample	California Sample
Very comfortable	35	34
Somewhat comfortable	32	25
Something rather not think about	31	39
Don't know	1	1
Refused	1	*

Q18. *Asked of those who said they do not currently receive ongoing living assistance in Q10:*
How likely do you think it is that you will personally require ongoing living assistance some day? Would you say extremely likely, very likely, somewhat likely, not too likely or not at all likely?

	National Sample	California Sample
Extremely/Very likely	24	25
Extremely likely	8	9
Very likely	16	16
Somewhat likely	41	43
Not too/Not at all likely	32	28
Not too likely	23	19
Not at all likely	9	9
Don't know	2	4
Refused	*	*

Q19. *Asked of those who said they are not currently providing ongoing living assistance in Q14:*
How likely do you think it is that an aging family member or close friend will need ongoing living assistance in the next five years? Would you say extremely likely, very likely, somewhat likely, not too likely or not at all likely?

	National Sample	California Sample
Extremely/Very likely	34	35
Extremely likely	13	13
Very likely	20	22
Somewhat likely	32	30
Not too/Not at all likely	33	32
Not too likely	19	19
Not at all likely	14	13
Don't know	1	3
Refused	*	-

Q19C. *Asked of those saying somewhat, very or extremely likely in Q19:*
Do you think you, personally, will be responsible for providing that ongoing living assistance, or will someone else be providing that care?

	National Sample	California Sample
You	33	35
Someone else	54	52
Combination (Vol.)	9	10
Don't know	3	3
Refused	*	-

Q20. Which of the following statements best describes your view about the type of people who are likely to require ongoing living assistance as they grow older?

	National Sample	California Sample
Only people who become seriously ill or who have severe mobility problems are likely to require ongoing living assistance.	16	13
People who have moderate or serious illnesses or mobility problems are likely to require ongoing living assistance.	33	30
Just about everyone will require ongoing living assistance at some point, even if they do not become seriously ill.	48	55
Don't know	2	2
Refused	1	*

Q21. When you think about the home you will live in as you age, how important is each of the following? Would you say not important at all, not too important, somewhat important, very important, or extremely important?

National Sample

	Extremely/ Very important	Extremely important	Very important	Somewhat important	Not too/ Not at all important	Not too important	Not important at all	DK	Ref.
Being close to medical offices or hospitals (n=1,019)	63	15	48	26	10	7	3	*	*
Having a home that is all on one level with no stairs (n=1,019)	65	20	45	21	13	8	5	1	*
Living close to your children (asked only of those with children) (n=763)	63	17	46	26	10	6	4	1	*
Being close to shops and services (n=1,019)	53	10	43	34	13	9	4	*	-
Having access to nursing care or other medical services without having to leave your home (n=1,019)	54	12	41	30	15	9	6	1	*

	Extremely/ Very important	Extremely important	Very important	Somewhat important	Not too/ Not at all important	Not too important	Not important at all	DK	Ref.
Living in a community that offers services like meals and local transportation (n=1,019)	48	11	37	33	18	12	6	1	*
Living close to the friends you have today (n=1,019)	45	9	36	35	19	13	6	1	*
Living in a community with organized social activities (n=1,019)	36	8	28	34	30	16	13	*	*

California Sample

	Extremely/ Very important	Extremely important	Very important	Somewhat important	Not too/ Not at all important	Not too important	Not important at all	DK	Ref.
Being close to medical offices or hospitals (n=386)	67	18	50	28	4	3	1	*	-
Having a home that is all on one level with no stairs (n=386)	65	18	47	20	14	10	4	1	-
Living close to your children (asked only of those with children) (n=282)	65	19	46	25	10	6	4	*	-
Being close to shops and services (n=386)	58	11	47	32	9	6	3	*	*
Having access to nursing care or other medical services without having to leave your home (n=386)	57	18	39	30	12	9	3	1	-
Living in a community that offers services like meals and local transportation (n=386)	50	10	40	35	15	11	4	*	-
Living close to the friends you have today (n=386)	44	9	35	37	18	12	6	*	*
Living in a community with organized social activities (n=386)	43	7	35	30	27	19	7	*	-

Q22. How confident are you that you know where to go to find information about options for ongoing living assistance? Would you say extremely confident, very confident, somewhat confident, not too confident, or not confident at all?

	National Sample	California Sample
Extremely/Very confident	52	48
Extremely confident	21	19
Very confident	31	30
Somewhat confident	31	35
Not too/Not at all confident	16	16
Not too confident	10	10
Not confident at all	6	7
Don't know	*	-
Refused	*	-

Q23. Thinking about your current/possible needs for ongoing living assistance, how confident are you that you will have the financial resources to pay for any care you need as you get older? Would you say extremely confident, very confident, somewhat confident, not too confident, or not confident at all?

	National Sample	California Sample
Extremely/Very confident	27	28
Extremely confident	9	11
Very confident	18	17
Somewhat confident	40	33
Not too/Not at all confident	33	38
Not too confident	21	21
Not confident at all	11	17
Don't know	1	1
Refused	*	-

Q24. A nursing home is a facility that provides residents with a room, meals, personal care, nursing care, and medical services. Just a guess, what's your best estimate of the national average monthly cost to live in a nursing home? Is it: less than $2,000, $2,000-$4,000, $4,000-$6,000, $6,000-$8,000, or more than $8,000?

	National Sample	California Sample
Less than $2,000	4	3
$2,000-$4,000	23	21
$4,000-$6,000	31	34
$6,000-$8,000	24	26
More than $8,000	14	11
Don't know	3	5
Refused	*	*

Q25. An assisted living community provides services to people who are not able to live independently, but do not require the level of care provided by a nursing home or other medical facility. Just a guess, what's your best estimate of the national average monthly cost to live in an assisted living community? Is it: less than $1,000, $1,000-$2,000, $2,000-$3,000, $3,000-$4,000, or more than $4,000?

	National Sample	California Sample
Less than $1,000	4	4
$1,000-$2,000	6	7
$2,000-$3,000	21	22
$3,000-$4,000	29	27
More than $4,000	36	38
Don't know	3	2
Refused	*	-

Q26. Home healthcare aides are trained to provide hands-on care and assistance to people in their homes who need help with daily activities. Just a guess, what's your best estimate of the national average monthly cost of home healthcare aide who visits every day for 2 hours? Is it: less than $1,000, $1,000-$2,000, $2,000-$3,000, $3,000-$4,000, or more than $4,000?

	National Sample	California Sample
Less than $1,000	14	14
$1,000-$2,000	30	33
$2,000-$3,000	29	28
$3,000-$4,000	14	15
More than $4,000	9	8
Don't know	4	2
Refused	*	*

Q27. How much planning, if any, did you do/have you done for your own needs for ongoing living assistance?

	National Sample	California Sample
A great deal/Quite a bit	16	12
A great deal	7	5
Quite a bit	9	6
A moderate amount	19	22
Only a little/None at all	65	67
Only a little	20	21
None at all	45	45
Don't know	-	-
Refused	-	-

Q28. *Asked if Q27 does not equal "None at all":*

The following actions might be considered planning for living assistance even if you haven't thought about them that way. What actions have you taken to plan for your own needs as you age? Have you (ITEM) or not?

National Sample

	Yes	No	Don't know	Refused
Created an advanced directive, sometimes called a living will, that allows someone you trust to make decisions for you if you cannot on your own	47	53	*	*
Discussed your preferences for the kinds of ongoing living assistance you do or do not want with your family	41	58	1	*
Set aside money to pay for ongoing living assistance expenses including nursing home care, senior community, or care from a home healthcare aide	35	64	*	1
Looked for information about aging issues and ongoing living assistance	25	75	*	-
Modified your home in any way to make it easier to live in as you grow older	23	77	*	*
Moved/made plans to move to a community or facility designed for older adults	7	93	*	-

California Sample

	Yes	No	Don't know	Refused
Created an advanced directive, sometimes called a living will, that allows someone you trust to make decisions for you if you cannot on your own	51	48	*	*
Discussed your preferences for the kinds of ongoing living assistance you do or do not want with your family	43	57	-	-
Set aside money to pay for ongoing living assistance expenses including nursing home care, senior community, or care from a home healthcare aide	34	66	-	-
Looked for information about aging issues and ongoing living assistance	30	70	-	-
Modified your home in any way to make it easier to live in as you grow older	27	73	*	-
Moved/made plans to move to a community or facility designed for older adults	10	90	*	-

Q29. Medicare is the national health care insurance program mainly for seniors. As far as you know, does Medicare pay for (ITEM), or not?

National Sample

	Yes	No	Depends (Vol.)	Don't know	Refused
Medical equipment such as wheelchairs and other assistive devices	71	13	6	10	*
Ongoing care at home by a licensed home healthcare aide	44	30	5	21	*
Ongoing care in nursing home	37	36	8	18	*

California Sample

	Yes	No	Depends (Vol.)	Don't know	Refused
Medical equipment such as wheelchairs and other assistive devices	66	19	4	11	-
Ongoing care at home by a licensed home healthcare aide	30	39	9	22	*
Ongoing care in nursing home	29	43	10	18	-

Q30. Medicaid is a government health care coverage program for low income people and people with certain disabilities. Do you think you will need Medicaid to help pay for your ongoing living assistance expenses as you grow older or not?

	National Sample	California Sample
Yes	39	42
No	54	51
Don't know	7	7
Refused	1	1

Q31. Now, thinking about who should be responsible for paying for the costs of ongoing living assistance… How much responsibility should (ITEM) have for paying for the costs of ongoing living assistance?

National Sample

	Very large/ Large	Very large	Large	Moderate	Small/None at all	Small	None at all	DK	Ref.
Health insurance companies	55	20	35	28	12	7	5	3	1
Medicare	39	13	25	41	17	12	5	2	1
Medicaid	37	13	23	37	22	16	6	4	1
Individuals	40	15	25	39	17	12	5	3	1
Families	23	8	15	35	40	20	20	2	1

California Sample

	Very large/ Large	Very large	Large	Moderate	Small/None at all	Small	None at all	DK	Ref.
Health insurance companies	57	25	31	32	8	5	4	2	1
Medicare	40	15	25	43	13	9	4	3	*
Medicaid	39	16	24	37	18	13	5	5	1
Individuals	37	13	24	38	22	13	8	3	1
Families	21	5	15	40	38	20	17	1	*

Q32. To help Americans prepare for the costs of ongoing living assistance, would you favor, oppose, or neither favor or oppose (ITEM)? Is that strongly (favor/oppose) or somewhat (favor/oppose)?

National Sample

	Strongly/ Somewhat favor	Strongly favor	Somewhat favor	Neither favor nor oppose	Somewhat/ Strongly oppose	Somewhat oppose	Strongly oppose	DK	Ref.
Tax breaks to encourage saving for ongoing living assistance expenses	77	48	29	7	12	6	6	3	1
A government administered long-term care insurance program, similar to Medicare	51	30	21	11	32	11	21	5	1
A requirement that individuals purchase private long-term care insurance	34	13	21	13	50	20	30	2	1

California Sample

	Strongly/ Somewhat favor	Strongly favor	Somewhat favor	Neither favor nor oppose	Somewhat/ Strongly oppose	Somewhat oppose	Strongly oppose	DK	Ref.
Tax breaks to encourage saving for ongoing living assistance expenses	84	52	32	5	7	3	4	3	2
A government administered long-term care insurance program, similar to Medicare	66	43	24	11	21	6	15	1	-
A requirement that individuals purchase private long-term care insurance	38	14	24	15	42	13	29	3	2

The following questions are for classification purposes only. Be assured that your responses will be aggregated with those of other participants to this survey.

Ins1. The next questions are about health insurance. 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. Are you covered by any kind of health insurance or some other kind of health care plan or not?

	National Sample	California Sample
Yes	87	80
No	13	19
Don't know	*	-
Refused	*	1

Ins2. *Asked if Ins1 equals "Yes," "Don't know" or "Refused":*
What kind of health insurance or health care coverage do you have? Is it Medicare, Medicaid, private insurance that you buy through your employer or on your own, or some other type?

	National Sample	California Sample
Medicare	20	19
Medicaid	4	1
Private	60	57
Other	7	10
More than one kind (Vol.)	9	10
Don't know	1	2
Refused	*	1

Ins3. Do you currently have long-term care insurance from a private insurance company, or not? That's extra insurance that covers expenses of ongoing living assistance.

	National Sample	California Sample
Yes	21	14
No	76	82
Don't know	2	4
Refused	*	1

Ins4. *Asked of those who said "Yes" in Ins3:*
Some people sometimes mistakenly think that other kinds of health insurance cover long-term care. How sure are you that you have private insurance that specifically covers long-term care – are you very sure of this, somewhat sure, neither sure nor unsure, somewhat unsure or very unsure?

	National Sample	California Sample
Sure	80	78
Very sure	55	60
Somewhat sure	25	18
Neither sure nor unsure	2	3
Unsure	15	18
Somewhat unsure	5	5
Very unsure	11	14
Don't know	3	-
Refused	-	-

INS3/INS4 Combined.

	National Sample	California Sample
Have LTC insurance	21	14
Very sure	12	8
Somewhat sure	5	3
Less sure/Don't know	4	3
Do not have LTC insurance	76	82
Don't know	2	4
Refused	*	1

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

	National Sample	California Sample
Democrat	33	40
Republican	21	17
Independent	22	18
None of these	18	22
Don't know	1	-
Refused	4	4

D2. *IF "Democrat," ASK:* Do you consider yourself a strong or moderate Democrat?

IF "Republican," ASK: Do you consider yourself a strong or moderate Republican?

IF "INDEPENDENT" OR "NONE," DK OR REFUSED ASK: Do you lean more toward the Democrats or the Republicans?

	National Sample	California Sample
Democrat	45	52
Democrat – strong	19	23
Democrat – moderate	14	17
Democrat – unknown intensity	*	*
Ind/None/DK/Ref. – Lean Democrat	12	12
Ind/None/DK/Ref.	12	14
Republican	34	27
Ind/None/DK/Ref. – Lean Republican	13	10
Republican – unknown intensity	*	-
Republican – moderate	10	8
Republican – strong	11	9

	National Sample	California Sample
None/Other/DK/Refused	9	6
None/DK/Ref. – lean others	1	2
Independent – lean others	1	*
None – lean DK/Refused	3	4
DK – lean DK/Refused	1	-
Refused – lean DK/Refused	3	3

D4. Are you, yourself, currently employed…

	National Sample	California Sample
Full-time	41	38
Part-time	11	8
Not employed	48	55
Don't know	-	-
Refused	-	-

D5. *Asked of those saying "Not employed" in D4:*
Are you…

	National Sample	California Sample
Retired	66	62
Homemaker	13	13
Student	1	1
Temporarily unemployed	15	21
Don't know	5	3
Refused	*	1

D6. Age.

	National Sample	California Sample
40-54	46	41
55-64	24	26
65-74	16	18
75-84	9	6
85+	3	2
Refused	2	7

D7. What is the last grade of school you completed?

	National Sample	California Sample
Less than high school graduate	14	11
High school graduate	30	26
Technical/trade school	3	3
Some college	17	19
College graduate (BA or BS)	19	20
Some graduate school	3	3
Graduate degree (PhD, MD, JD, Master's Degree)	13	15
Don't know	*	1
Refused	*	2

D8. Do you consider yourself a born-again or evangelical Christian, or not?

	National Sample	California Sample
Yes, born-again/evangelical	44	28
No	50	60
Don't know	2	6
Refused	3	5

D9. What is your religious preference? Is it Protestant, Catholic, Mormon, Jewish, Muslim, some other religion, or don't you belong to any religious denomination?

	National Sample	California Sample
Protestant	25	20
Catholic	25	26
Mormon	2	1
Jewish	2	3
Muslim	*	*
Other religion	25	18
Don't belong to religious denomination	20	30
Don't know	*	-
Refused	1	2

D10. *Asked if D9 equals "Other religion":*
Do you consider yourself a Christian, or not?

	National Sample	California Sample
Yes, a Christian	90	83
No, not a Christian	8	17
Don't know	1	-
Refused	*	-

D11. Aside from weddings and funerals, how often do you attend religious services? Would you say more than once a week, once a week, once or twice a month, a few times a year, less often than a few times a year, or never?

	National Sample	California Sample
More than once a week	12	11
Once a week	25	19
Once or twice a month	14	16
A few times a year	23	19
Less often than a few times a year	11	10
Never	13	22
Don't know	*	-
Refused	1	2

D12. Are you of Hispanic, Latino, or Spanish origin?

	National Sample	California Sample
Yes	11	26
No	87	70
Don't know	*	-
Refused	2	4

Race/ethnicity NET.

	National Sample	California Sample
White, non-Latino	68	52
Black, non-Latino	9	5
Latino/Hispanic	11	26
Other race	9	11
Don't know	*	-
Refused	3	5

D16. How many different cell-phone numbers, if any, could I have reached you for this call?

	National Sample	California Sample
0	14	13
1	74	75
2	9	1
3	1	*
4	*	*
5 or more	1	*
Don't know	*	*
Refused	1	2

D17. How many different landline telephone numbers, if any, are there in your home that I could have reached you on for this call? This includes listed or unlisted numbers. To answer this question, please don't count cell phones or landlines used ONLY for faxes or modems.

	National Sample	California Sample
0	24	21
1	72	75
2	3	3
3	*	1
4	*	-
5 or more	-	*
Don't know	*	-
Refused	*	*

D18. *Asked only of those who did not say "0" in D16 and D17:*
Generally speaking, would you say you use your landline phone most of the time, your cell phone most of the time, or would you say you use both about equally?

	National Sample	California Sample
Landline	31	34
Cellphone	34	38
Both equally	35	28
Don't know	-	-
Refused	-	1

D19. *Asked only of those cellphone respondents:*
How many adults, in addition to you, carry and use this cell phone at least once a week or more?

	National Sample	California Sample
0	66	52
1	20	20
2	11	19
3	2	4
4	1	2
5 or more	*	1
Don't know	-	-
Refused	1	1

D20. Does your total household [IF SINGLE: "PERSONAL"] income fall below $50,000 dollars, or is it $50,000 or higher?

INTERVIEWER NOTE: If asked, this is 'yearly' household income

	National Sample	California Sample
Below $50,000 (ASK D29)	48	41
$50,000+ (ASK D30)	46	52
Don't know	1	1
Refused	5	6

D21. Ask if "BELOW $50K" in D20:
And in which group does your total household [IF SINGLE: "PERSONAL"] income fall?

D22. Ask if "$50K or higher" in D20:
And in which group does your total household [IF SINGLE: "PERSONAL"] income fall?

	National Sample	California Sample
Under $10,000	7	11
$10,000 to under $20,000	13	14
$20,000 to under $30,000	11	6
$30,000 to under $40,000	10	5
$40,000 to under $50,000	8	6
$50,000 to under $75,000	16	13
$75,000 to under $100,000	11	14
$100,000 to under $150,000	11	13
$150,000 or more	8	11
Don't know	1	1
Refused	4	5

D32. INTERVIEWER RECORD GENDER (IF YOU ARE UNSURE, ASK THE FOLLOWING: Are you male or female?)

	National Sample	California Sample
Male	47	48
Female	53	52
Don't know	*	-
Refused	-	-

Topline results were provided by AP-NORC.

Appendix C

Methodology and Modeling

Methodology

This survey was conducted among a random national sample of 1,019 adults aged 40 and older, plus an oversample of 289 in California, by landline and cellular telephone, in English and Spanish, from Feb. 21-March 27, 2013, by The Associated Press-NORC Center for Public Affairs Research, with funding from The SCAN Foundation.

In the full sample of 1,308 interviews, 386 interviews were conducted with Californians. The survey has a margin of sampling error of plus or minus 4.1 percentage points for the national sample (including a design effect caused by weighting of 1.79) and the California sample has an error margin of plus or minus 6.7 percentage points (including a design effect of 1.69).

The national sample included 797 respondents contacted on landlines and 222 respondents via cell phones. The California sample included 207 landline and 82 cell phone interviews. Cell phone respondents were offered a small monetary incentive for participating.

AP-NORC reports response rates of 20 percent for the national and California samples alike, calculated by the method promulgated by the Council of American Survey Research Organizations.

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. Post-stratification variables included age, sex, race, region, education and landline/cellular telephone use.

Modeling

Langer Research Associates produced the statistical models reported in this analysis using linear regression, which measures the relationships among attitudinal and demographic variables and predicted outcomes, such as planning for long-term care needs.

A regression measures the independent strength of the relationship between each predictor with the posited outcome, known as the dependent or outcome variable. While it does not establish causality, the model reveals the strength of the relationship between each predictor and the dependent variable with other predictors held constant. It therefore illustrates what variables explain the most unique variation in the dependent variable.

To conduct the modeling, key questions were recoded as continuous variables where possible (e.g., 1 = not confident at all, 2 = not too confident, 3 = somewhat confident, 4 = very confident and 5 = extremely confident). Categorical or dichotomous variables, including many demographic measures, were recoded as binary variables (e.g., 0 = female, 1 = male).

The dependent variables modeled include:
1. A planning index that reflects how many of the seven planning behaviors tested in the survey respondents say they have done.

2-8. Each of the individual planning actions, i.e., saving money for long-term care needs, discussing living assistance preferences with family, writing an advance directive, looking for information on aging issues and long-term care options, making home modifications for aging needs, moving or making plans to move to a community for older adults and being very sure one has long-term care insurance.

9. Respondents' perceptions of the extent to which they've planned for their needs for ongoing living assistance.

10. Respondents' confidence that they know where to go to find information about options for ongoing living assistance.

11. The degree to which respondents would rather not think about getting older.

12. Whether or not respondents currently are providing long-term care to an aging loved one or have done so in the past.

All models included the following demographic variables: age, gender, race/ethnicity, education, region, employment status, household income, marital status, parenting status, religiosity, insurance status and self-reported health status. Attitudinal and behavioral variables differed depending on the outcome variable. Modeling results, including tables showing statistically significant predictors, can be found in the main report.

Full tables follow

Table 1. Significant predictors of the planning index

	Beta	*t*-test
Age	.22	5.40**
Employment: Retired	.18	4.39**
Income	.17	4.19**
Confident can find LTC information	.16	5.39**
Have provided LTC assistance	.13	4.39**
Avoidance of aging	-.13	4.26**
Parent of a minor child	-.10	2.95*
Education	.10	2.87*
Gender: Male	-.09	2.96*
Negative emotions providing LTC	.09	2.98*
Positive emotions providing LTC	.08	2.75*
Employment: Full-time	.08	2.21†
Can rely on family	.06	2.12†
Have received LTC assistance	.06	2.02†

$R^2 = .38$, $p < .001$

Here and below: $**p < .001$, $*p < .01$, $\dagger p < .05$

Table 2. Key predictors of individual planning behaviors

	Saved money	Discussed prefs.	Advance directive	Looked for info.	Modified home	Moved or made plans	LTC ins.
R^2	.25**	.20**	.24**	.18**	.18**	.08**	.13**
Age	.19**	.14*	.28**	–	–	.21**	–
Confident can find LTC information	.10*	.10*	–	.17**	.08†	.07†	.08†
Income	.29**	–	.12*	–	–	–	.10†
Employment: Retired	–	–	–	.18**	.30**	–	–
Avoidance of aging	-.07†	-.16**	–	-.12**	–	–	–
Have provided LTC	–	.11*	.11*	–	.13**	–	–
Have received LTC	–	–	.10*	.09†	.14**	–	–
Education	–	–	.09†	.10†	–	–	.10†
Parent of a minor	-.07†	–	–	–	-.11*	–	-.10†
Health status	–	-.10*	.08†	–	-.10*	–	–
Employment: Full-time	–	–	–	.09†	.17**	–	–
Think it's likely a loved one will need LTC	-.06†	-.09*	-.07†	–	–	–	–
Think it's likely will need LTC in future	.08†	–	–	.08†	–	–	–
Negative emotions providing LTC	–	.09*	–	.07†	–	–	–
Gender: Male	–	-.15**	–	–	–	–	–
Extent can rely on family	–	.12*	–	–	–	–	–
Ethnicity: Latino	–	–	–	–	-.12*	–	–
Married	–	–	–	–	.10*	–	–

Dashes indicate the predictors that were not significant in each model.

Table 3. Significant predictors of perceived planning

	Beta	*t*-test
Set aside money for LTC	.22	6.35**
Purchased LTC insurance (very sure)	.16	5.34**
Sought out information on aging	.16	5.26**
Confident can pay for any care needs	.14	4.19**
Written advance directive	.10	2.89*
Made home modifications	.09	3.10*

$R^2 = .38$, $p < .001$

Table 4. Key predictors of confidence in finding aging information

	Beta	*t*-test
Education	.17	4.34**
Extent can rely on family	.16	4.69**
Married	-.14	3.93**
Income	.13	2.70*
Parent of minor	-.11	2.88*
Have received LTC	.10	2.75*
Have provided LTC	.08	2.41†
Have insurance	.08	2.16†

$R^2 = .17, p < .001$

Table 5. Significant predictors of avoidance of aging

	Beta	*t*-test
Concerned about being a burden on family	.19	4.15**
Health	-.17	4.55**
Concerned about being alone	.11	2.76*
Age	-.11	2.23†
Think it's likely a loved one will need LTC	.09	2.69*
Confident can pay for any care needs	-.09	2.29†
Confident can find LTC information	-.07	2.12†

$R^2 = .23, p < .001$

Table 6. Significant predictors of providing long-term care

	Beta	*t*-test
Parent of a minor	-.11	2.60*
Employment: Full-time	-.11	2.47†
Gender: Male	-.09	2.61*
Extent can rely on family	.09	2.45†
Married	.09	2.32†
Ethnicity: Latino	.09	2.15†

$R^2 = .06, p < .001$

Appendix D

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