**Title**

How do Expectations about Future Use of Long-Term Supports and Services vary by Current Living Arrangement?

**Running Header**

*Future Care Expectations by Living Arrangement*

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**ABSTRACT**

Given the aging population, it is increasingly important to understand the expectations of middle-aged adults around future long-term supports and services (LTSS) use. Using national data, we examine expectations around future LTSS use among adults ages 40-65 and how these expectations vary by current living arrangement. We find differences by living arrangement both in expectations about needing LTSS in the future and in expectations about who would provide such care. For the entire sample, we find a disconnect between expectations of use and reality: 60 percent of respondents think it is unlikely that they will need LTSS in the future, whereas current evidence suggests that nearly 70 percent of older adults will need LTSS at some point. Policies and programs designed to help individuals plan for future care needs should take current living arrangement into account in order to understand how decision-making and planning vary among middle-aged adults.

## INTRODUCTION

Nearly 11 million people need long-term supports and services (LTSS) in the community (1) and the need for care will grow in coming decades as the population ages.(2) About 70 percent of older Americans will experience some level of need for LTSS (3) and those surviving to age 65 have a 46 percent chance of spending time in a nursing home.(4) These rates may even be understated, as rates of disability among today's middle-aged adults and "younger" older adults (under 70) are higher than their older counterparts demonstrated at comparable ages.(5,6) Yet, most Americans know little about LTSS options and underestimate their need for care.(7) The majority do not know how much LTSS costs or who pays for it.(8,9) Nearly 60 percent of adults age 40 and older underestimate the cost of nursing home care and more than half do not expect to use Medicaid to pay for LTSS, despite Medicaid being the largest payer for LTSS services in the U.S. Those same adults overestimate the role that Medicare will play in paying for ongoing LTSS and just over one-third have set aside any money to pay for future LTSS.(10)

Individuals' assessments of personal risk comprise a vital determinant of LTSS planning and depend on age, health status, retirement goals, income, assets, and knowledge about LTSS.(11,12) In a study examining financial literacy and retirement planning among Baby Boomers (ages 51-56), findings showed that most respondents had low financial literacy, but those who were more financially knowledgeable were more likely to have thought about their LTSS needs.(13) Individuals with prior experiences of caregiving and those with a high risk of impoverishment are more receptive to the need for financial planning, including considering LTSS insurance.(14) Conversely, individuals who expect to rely on family members for care are less likely to purchase LTSS insurance.(15)

Although the existing literature has contributed to our understanding of attitudes regarding LTSS planning, it remains limited in key areas. The majority of studies have employed descriptive analyses without adequate controls for demographic and other factors. Most studies have focused on particular aspects of general LTSS knowledge or long-term care (LTC) insurance, but have not comprehensively examined the factors that shape attitudes toward perceived LTSS need in the future. In particular, the role of the current living arrangements is absent from much of the literature.

In recent decades, there has been an increase in multi-generational households and households with single parents, and a decline in the "traditional" family structure of two parents and their children living together.(16-18) Meanwhile, policies such as The Olmstead Act, Medicaid Home and Community-Based Services (HCBS), and Money Follows the Person have made it increasingly possible for individuals with disabilities to age in the community (vs. institutional settings). Such policies shift the burden of care from institutional to household settings, making living arrangements a potentially important determinant of where one receives LTSS. Currently, more than 90 percent of all community-based LTSS is provided by unpaid caregivers,(2) despite the growth of formal HCBS. Therefore, because the majority of care is provided by family and friends in home settings, current living arrangements may offer important insights into future expectations about LTSS. Individuals may have an expectation that those they live with will provide care, should they need it, and such expectations might prevent individuals from making alternate plans. Indeed, there is evidence that middle-aged adults are not actively planning for LTSS use by, for example, saving for services.(19)

This disconnect between expectations and projected needs is a significant barrier to helping Americans become more prepared for their future and has resulted in low uptake of LTC

insurance.(7) Often, lack of individual investment in LTC insurance is driven by high costs. This challenge was supposed to be offset via the Community Living Assistance Services and Supports (CLASS) Act legislation under the Affordable Care Act, through which consumers could choose to pay monthly premiums out of their paychecks to receive future LTC benefits. However, the CLASS Act did not pass. In its place, the Commission on Long-Term Care was established (January 2013) and charged with developing a plan for the establishment, implementation, and financing of a comprehensive system of LTSS. The commission concluded that the LTSS system "is not sufficient for current or future needs".(20) Nearly two-thirds of the cost of LTSS today is financed by the federal and state governments through the Medicaid program.(20) This is unsustainable with the projected dramatic increase in the need for LTSS in coming decades, due to increases in older adult populations with chronic illness and dementia.(21) Thus, the need for better LTSS planning is especially critical in the absence of federal or state programs that help financially support older adults in their desire for independence and well-being in later life.

A better understanding of what drives future expectations around LTSS use will be useful in designing policies and programs to encourage LTSS planning and in estimating where there may be gaps between expectations and future reality. This study uses nationally-representative survey data to examine whether current living arrangements are associated with expectations around future need for LTSS and whether expectations about who will provide LTSS vary by current living arrangement.

## METHODS

*Data.* Data come from the 2012 Wave of the Integrated Health Interview Series, a harmonized version of the National Health Interview Survey (NHIS).(22) The NHIS is a nationally-representative survey of U.S. civilian, non-institutionalized households. Within

households, one sample adult and one sample child are randomly chosen to answer additional questions. Questions on expectations about LTSS were first added in 2011 and are asked of all sample adults ages 40-65. For the present study, we use data from all sample adults ages 40-65 who answered questions on LTSS expectations (n=11,796).

To assess expectations about needing LTSS in the future, respondents were asked, "How likely is it that you may someday need help with daily activities like bathing, dressing, eating, or using the toilet due to a long-term condition?" Four response options ranged from "very likely" to "very unlikely". Regardless of their answer, respondents were also asked "If you needed such help, who would provide this help?" Response options included family, hiring someone, home health agency, nursing home/assisted living facility, or other source of care. Respondents could select all multiple options. We also created a binary variable indicating whether respondents expect to use more than one source of care.

The key independent variable was current living arrangement, including with a spouse/partner only, alone, with a spouse/partner and minor child(ren) only, with minor child(ren) only, or with extended family or unrelated others. Extended family and others includes adults living as roommates; adult-only families (other than couples), including adult siblings or parents living with adult children; at least one parent and minor child(ren) living with other related adults; or related or unrelated adults living with one or more minor child(ren), without the child's parent(s) present (as in the case of grandparents raising grandchildren). Covariates included gender, age, race/ethnicity (White, Black/African American, Hispanic, and Asian/other), family income, educational attainment (less than high school, high school degree, some college, four-year college degree or more), and employment status (employed vs. unemployed or not in the labor force). We also adjust for several health characteristics, including

self-rated physical health (fair/poor health vs. good, very good, and excellent health), serious psychological distress (assessed by asking how often in the past 30 days the respondent felt sad, restless, worthless, hopeless, nervous, and that everything was an effort; a score of 13 or higher, out of a possible 24, indicates serious psychological distress),(23) and presence of an activity limitation (including needing help with personal care needs and limitations in the amount or kind of work or other activities the respondent is able to do). Finally, models adjust for whether the respondent had a close relative (parent, spouse, sibling, or adult child) who has needed help for at least a year with activities of daily living due to a chronic illness or disability.

*Analysis.* Bivarate analyses used chi-squared tests of significance to assess differences in independent variables by type of living arrangement. Next, we used ordered logistic regression models to estimate the odds of expecting to need LTSS in the future, first adjusting only for living arrangement and then adjusting for the full list of covariates. Ordered logistic regression is appropriate for the categorical response options and allows us to make use of variation between all four categories.(24) We present results from these models as odds ratios, which can be interpreted as the change in odds from one level (i.e., "very unlikely") to the next (i.e., "somewhat unlikely"). Finally, we used logistic regression models to estimate the odds of using each type of LTSS by living arrangement, adjusting for all covariates. All analyses use survey weights to account for the complex sampling design and to generate nationally-representative estimates.

*Limitations.* This study should be considered in light of its limitations. The data are cross-sectional, so cannot control for the direction of causality between living arrangements and needing LTSS. However, the majority of the respondents in the sample report good health, without activity limitations, so are unlikely to currently receive care. Further, we believe that for

middle-aged adults, the majority of whom do not expect to need LTSS, expectations about future care needs are unlikely to determine current living arrangements. To better ensure that living arrangements are not endogenous to our outcomes of interest, we conducted sensitivity analyses and found that our results were largely robust to various specifications. We did find differences by age group, which are discussed in the Results section and Appendix Exhibits 5-6.(25)

Additionally, limited information exists on the composition of extended households. The NHIS provides information on respondents' relationship to the household head (e.g., spouse, child, parent, sibling); however, it is not possible to discern the exact relationships between other adults within the household. Given increasing variation in living arrangements, future research should address this gap by collecting more detailed information on intra-household relationships and investigating differences between types of extended households (e.g., differences in LTSS expectations between a parent living with an adult child vs. two unrelated adults living together).

**RESULTS**

Exhibit 1 reports sample characteristics. (For p-values, see the online Appendix Exhibit 1).(25) The most common living arrangements are living with a spouse only or living alone (29 percent each). Women made up 53 percent of the sample, but 75 percent of all single parents. Those living with minor children (with or without a spouse) were younger than the average. Living arrangements differed by race/ethnicity, with White respondents constituting 83 percent of all respondents living with a spouse only (vs. 72 percent of the full sample), Black respondents making up a disproportionate amount of single parent households, and Hispanic respondents making a disproportionate share of those living in extended family households. Family income, educational attainment, and employment rates were highest among those living with a spouse and minor children. Respondents living alone were most likely to report fair/poor

health, psychological distress, and to have activity limitations. Eleven percent of the total sample had a close relative who needs LTSS, though this also differed by living arrangement, with respondents living with minor children being the least likely.

INSERT EXHIBIT 1 ABOUT HERE

The majority of respondents (60 percent) believed that is was unlikely that they would need LTSS in the future (Exhibit 2). Only 14 percent responded that it was "very likely" that they would need care. Perceived likelihood varied by living arrangement. Respondents living with minor children (with or without a spouse) were the most likely to report that it was "very unlikely" that they would need LTSS.

INSERT EXHIBIT 2 ABOUT HERE

When asked about expected sources of LTSS, respondents overwhelmingly believed that family would provide care (73 percent). Twelve percent believed that they would hire someone, 11 percent believed that they would use a home health care organization and/or a nursing home/assisted living facility, and four percent responded that they would use some other source of care. (Response options were not mutually exclusive.) Seven and a half percent of respondents believe that they will use multiple sources of care. Of those, more than 30 percent believed that they would use three or more types of care.

INSERT EXHIBIT 3 ABOUT HERE

Respondents living alone or in extended households did not differ from those living with a spouse only in their expectations about needing LTSS in the future, while those living with minor children (with or without a spouse) had lower odds of expecting to need LTSS (Exhibit 4). Those differences persisted after we adjusted for individual characteristics, although the strength of the association diminished. Being female, older, college educated, in fair/poor health, having

psychological distress or an activity limitation, and having a close relative who has needed LTSS were all associated with higher odds of expecting to need LTSS. Being Black or Asian were both associated with lower odds. For complete results, including standard errors, see Appendix Exhibit 2.(25)

INSERT EXHIBIT 4 ABOUT HERE

There were significant differences by living arrangement in expected sources of care, should a need arise (Exhibit 5). After adjusting for all covariates, living alone was associated with lower odds of expecting to rely on family and higher odds of expecting to use each of the other options (hiring someone, home health agency, nursing home/assisted living, and other), compared with those living with a spouse only. Living with a spouse and minor children was associated with higher odds of expecting to rely on family and lower odds of expecting to hire someone or use other sources of care. Living in a single-parent household was associated with lower odds of expecting to rely on family and higher odds of expecting to use a nursing home/assisted living facility. Finally, living in an extended family setting was associated with higher odds of expecting to rely on family and lower odds of expecting to hire someone. There were no differences by living arrangement in expecting to use multiple sources of care. For complete results, including standard errors, see Appendix Exhibit 3.(25)

INSERT EXHIBIT 5 ABOUT HERE

In order to determine whether living arrangements were differentially associated with expected sources of care by how much individuals expect to need LTSS, we modeled expected sources of care for individuals who believed it was “very likely” they would need LTSS. We found less diversity by living arrangements than in the full sample, indicating that current living arrangements are less influential in expected sources of care for those who expect to need LTSS.

For full results, refer to the Appendix Exhibit 4.(25) Additionally, we conducted sensitivity analyses by age (40-49 vs. 50-65) and found differences by age cohort in the relationship between living arrangements and expectations around LTSS. In particular, there were fewer differences in LTSS expectations by living arrangement for adults ages 50-65 (vs. 40-49). For full results, refer to the Appendix Exhibits 5-6.(25)

## DISCUSSION

These results provide insight into the expectations of middle-aged adults about future LTSS use. The majority of respondents do not believe that they will need LTSS in the future, despite current estimates that 70 percent of older Americans will need some form of LTSS.(3) Regardless of whether they expected to need LTSS, respondents were asked who they would rely on for care, should a need arise. Respondents were nearly seven times as likely to expect family to help, compared with relying on formal systems (e.g., home health care organizations and nursing home/assisted living facilities). This aligns with the current reality that the majority of LTSS is provided by unpaid family and friend caregivers, but may pose an even larger burden on the informal caregiving system, given the growing aging population.

Future care expectations varied by current living arrangement. In particular, respondents living with minor children (with or without a spouse) had the lowest odds of expecting to need LTSS in the future. Single parents and those living alone were the most likely to be low income, the least likely to expect to rely on family for LTSS in the future, and the most likely to expect to rely on formal systems of care. This may indicate that if, and when, they do need LTSS, they will be more likely to rely on public funding (e.g., Medicaid) to support that care. Policy-makers should be especially concerned about the nearly 30 percent of the sample who live alone, as they are in the worst health and have the highest prevalence of activity limitations of any group in the

sample. They are, therefore, likely to need LTSS sooner than some of the other groups, and they have considerably lower odds of expecting to rely on family for support. They are also the only group to have higher odds of expecting to use each type of formal care system. Policy-makers should consider using this information to make projections about future spending needs for LTSS. Single parents should also be of particular concern as their current caregiving responsibilities may make it difficult to plan for future LTSS use.

Respondents living in two-parent households with minor children had higher odds of expecting to rely on family for LTSS support and lower odds of expecting to hire someone. In the unadjusted model, they were also the least likely to expect to need LTSS in the future. While this may be explained by their younger age and better health, relative to the rest of the sample, as well as by their current familial support system, policy-makers should be concerned that this group may be less motivated to make advanced plans for LTSS. If they expect family to provide help, they may not be as proactive about saving for LTSS or putting plans in place, despite the fact that their household composition is likely to change in coming decades.

Respondents living in extended households expect to rely on family, should a care need arise. These household formations are increasingly common,(16-18) and not well-understood. Future research should attempt to better understand differences by type of extended family structure in LTSS expectations and by actual caregiving that takes place within these households. In the case of our sample (ages 40-65), it is likely that most caregiving currently happening within these households is being provided by the respondent, either to children or aging parents (or both, as in the case of the sandwich generation). Given that such arrangements are increasingly common, it would be useful to understand how they impact expectations about

one's own future care use. Further, research should examine longitudinally the association between expectations and actual LTSS use for all living arrangements.

In addition to variation by living arrangement in LTSS expectations, we also found differences by demographic and health characteristics. Being female, older, and college educated were all associated with higher expectations of needing LTSS, as was being in fair/poor health, having psychological distress, having an activity limitation, and having a close relative who has needed LTSS. Being Black and Asian were associated with lower expectations of needing LTSS. This information can be used to design and target educational outreach campaigns for LTSS planning. For example, if knowing someone who has needed LTSS increases one's odds of expecting to need LTSS oneself, then it may be useful to provide personal narratives to engage the public in thinking realistically about their own future need for LTSS.

Overall, more education is needed to counter negative views and inform consumers of the risks that LTSS may pose for their future financial security. One strategy to address this issue includes translating awareness of LTC insurance into ownership. Only about eight percent of Americans owns a LTC insurance policy,(26) despite the high projected needs for care. Changing attitudes, beliefs, and preparedness for LTSS can happen through a multi-faceted approach, one that targets consumers (educational awareness), engages financial consultants and employers (employer-sponsored LTC insurance), and builds on the current national efforts to reform the LTSS system, including the CLASS Act proposal in 2010, the creation of the LTC Commission in 2013, and efforts to reimburse family members when they assume caregiver roles, among others.(26)

*Conclusion*

The majority of middle-aged adults in this study do not expect to need LTSS in the future, despite projections of increasing need for LTSS as the population ages. Further, we found that middle-aged adults overwhelmingly expect to rely on family vs. formal care systems, should a need arise. LTSS expectations varied by living arrangement, with respondents living with minor children being the least likely to expect to need LTSS in the future. Respondents living alone expect to rely on formal care systems more than any other group. Respondents living with extended family or other blended household compositions were no more likely than those living with a spouse only to expect to need LTSS, but they were more likely to expect to rely on family and less likely to expect to hire someone if they do need care. Current living arrangements offer insight into expectations about future LTSS use, which can be used in encouraging LTSS planning and in developing projections for future LTSS needs.

ENDNOTES

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(25) To access the Appendix, click on the Appendix link in the box to the right of the article online.

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## EXHIBIT LIST

**Exhibit 1: Sample Characteristics**

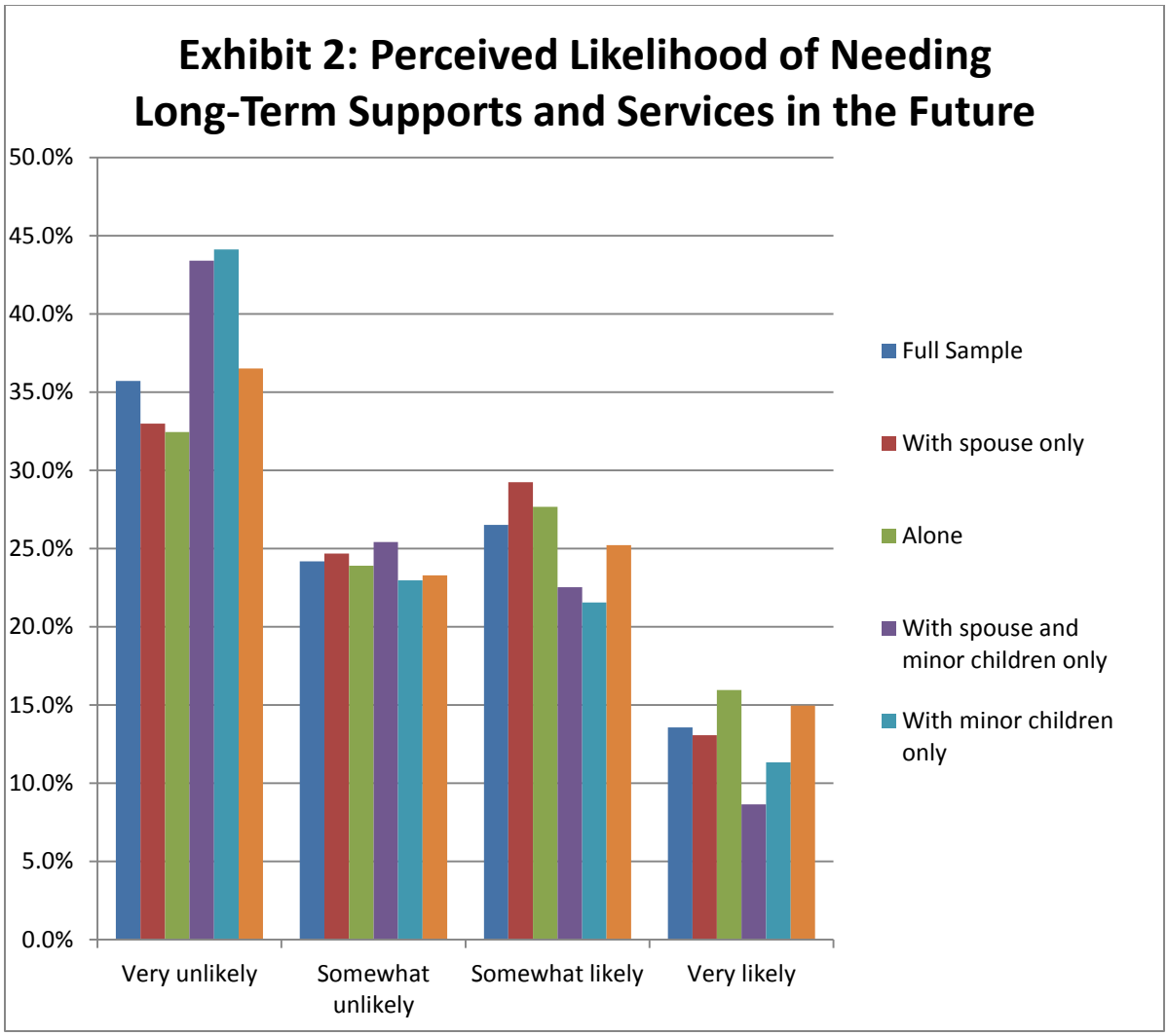
| | | Living Arrangement | | | | |
|---|---|---|---|---|---|---|
| | **Full sample** | **With spouse only** | **Alone** | **With spouse and minor children only** | **With minor children only** | **Extended family and unrelated adult households** |
| Frequency of living arrangement | -- | 29.0% | 29.0% | 15.2% | 4.7% | 22.1% |
| Female | 52.9% | 52.9% | 50.2% | 45.4% | 74.9% | 56.82%*** |
| Age (M) | 52.4 | 55.8 | 53.8 | 45.5 | 46.8 | 51.8*** |
| Race/ethnicity | | | | | | |
| White | 71.8% | 83.4% | 69.3% | 70.4% | 60.2% | 63.2%*** |
| Black/African American | 12.4% | 6.8% | 18.2% | 6.9% | 21.3% | 14.0%*** |
| Hispanic | 11.3% | 6.6% | 9.2% | 14.3% | 14.4% | 17.4%*** |
| Asian/all other | 4.6% | 3.3% | 3.4% | 8.5% | 4.1% | 5.4%*** |
| Family income | | | | | | |
| $0-34,999 | 29.9% | 15.0% | 51.7% | 11.7% | 54.4% | 28.1%*** |
| $35,000-49,999 | 13.2% | 12.5% | 16.0% | 8.5% | 14.7% | 13.2%*** |
| $50,000-74,999 | 18.9% | 21.2% | 17.0% | 16.9% | 18.0% | 20.1%*** |
| $75,000-99,999 | 13.3% | 18.0% | 7.0% | 17.9% | 6.8% | 13.8%*** |
| $100,000 or more | 24.7% | 33.3% | 8.3% | 45.0% | 6.2% | 25.0%*** |
| Educational attainment | | | | | | |
| Less than high school | 9.8% | 6.6% | 9.7% | 6.7% | 13.1% | 15.5%*** |
| High school degree | 27.3% | 29.9% | 26.9% | 19.5% | 22.8% | 30.9%*** |
| Some college | 30.5% | 29.1% | 33.0% | 27.2% | 37.4% | 29.8%*** |
| College and beyond | 32.4% | 34.4% | 30.5% | 46.6% | 26.7% | 23.9%*** |
| Employed | 66.2% | 63.1% | 62.7% | 77.9% | 71.0% | 65.9%*** |
| Fair/poor health | 16.6% | 14.3% | 21.1% | 7.3% | 20.1% | 19.5%*** |
| Serious psychological distress | 4.2% | 2.8% | 6.7% | 1.9% | 4.1% | 4.6%*** |
| Has any activity limitation | 19.1% | 16.3% | 29.6% | 6.4% | 17.5% | 17.8%*** |
| Close relative needs LTSS | 11.2% | 12.4% | 12.0% | 7.4% | 7.1% | 12.2%*** |

Source: Authors' analysis of the National Health Interview Survey, 2012

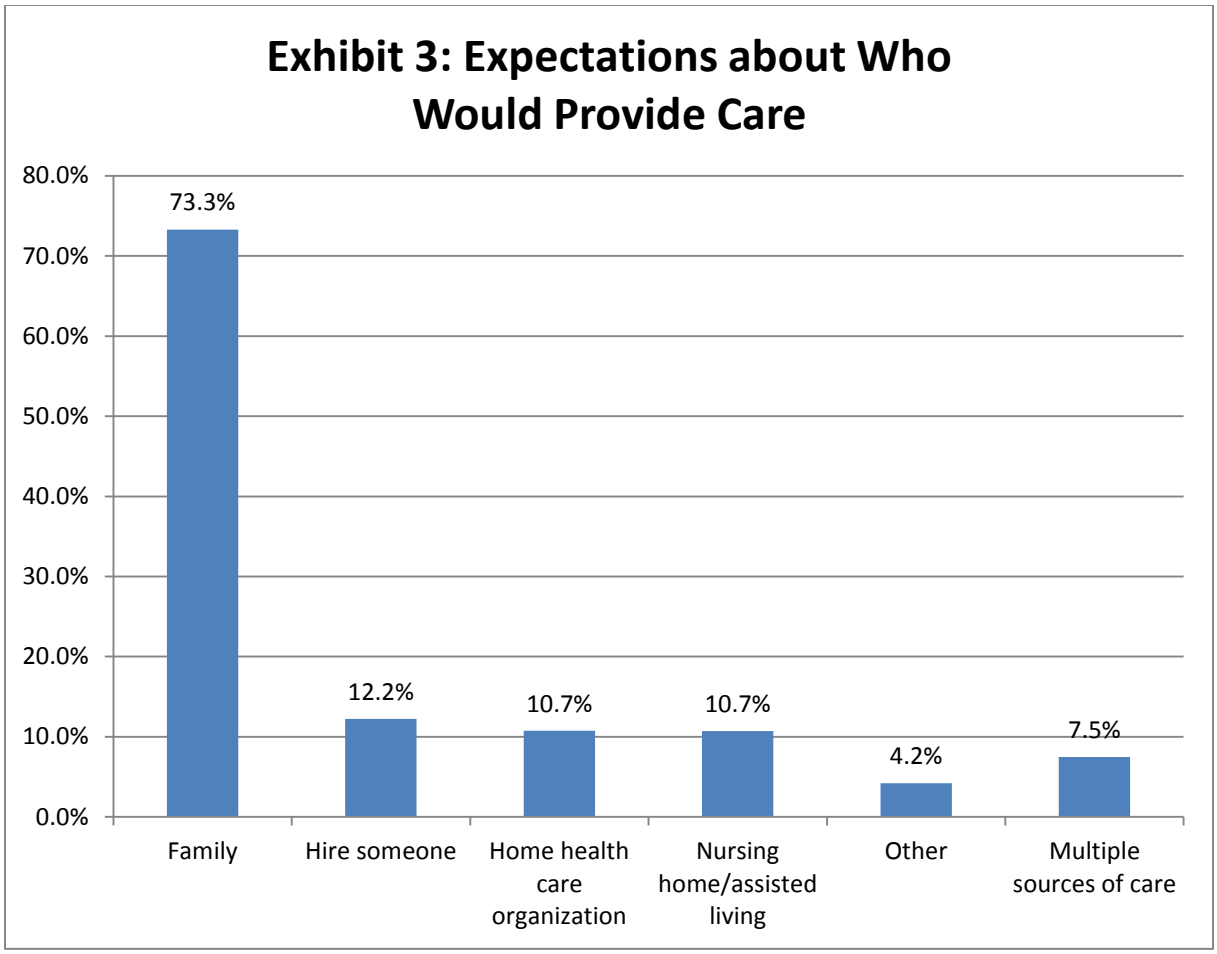
Notes: Analyses weighted to approximate nationally-representative estimates.

***Significant difference between living arrangements at p<0.001.

Sample n=11,796; Population N=34,480,308




*Source: Authors' analysis of the National Health Interview Survey, 2012*
*Notes: Analyses weighted to approximate nationally-representative estimates.*
*Differences in perceived likelihood between living arrangements significant at p<0.001.*
*Sample n=11,796; Population N=34,480,308*




*Source: Authors' analysis of the National Health Interview Survey, 2012*
*Notes: Analyses weighted to approximate nationally-representative estimates.*
*Sample n=11,796; Population N=34,480,308*

**Exhibit 4: Odds of Expecting to Need Long-Term Supports and Services**

| | Unadjusted Model | Fully Adjusted Model |
|---|---|---|
| | Odds Ratio | Odds Ratio |
| Living arrangement | | |
| With spouse only (Ref.) | 1.00 | 1.00 |
| Alone | 1.07 | 0.96 |
| With spouse and minor children | 0.64*** | 0.85* |
| With minor children only | 0.67*** | 0.84** |
| Extended family and unrelated adult households | 0.92 | 0.96 |
| Female | | 1.10* |
| Age | | 1.01*** |
| Race/ethnicity | | |
| White (Ref.) | | 1.00 |
| Black/African American | | 0.89* |
| Hispanic | | 0.98 |
| Asian/all other | | 0.75** |
| Family income | | 1.00 |
| Educational attainment | | |
| High school (Ref.) | | 1.00 |
| Less than high school | | 1.07 |
| Some college | | 1.02 |
| College and beyond | | 1.23*** |
| Employed | | 0.96 |
| Fair/poor health | | 1.96*** |
| Serious psychological distress | | 1.65*** |
| Has any activity limitation | | 2.08*** |
| Close relative needs LTSS | | 1.98*** |
| F-statistic | 22.97*** | 48.71*** |
| N | 11,796 | 11,796 |

Source: Authors' analysis of the National Health Interview Survey, 2012

Notes: Analyses weighted to approximate nationally-representative estimates.

*Results significant at *p<0.05, **p<0.01, ***p<0.001*

Sample n=11,796; Population N=34,480,308

**Exhibit 5: Expectations about Using Each Type of Long-Term Supports and Services**

| | Family | Hiring someone | Home health agency | Nursing home/ Assisted living | Other | Multiple types |
|---|---|---|---|---|---|---|
| | Odds Ratio | Odds Ratio | Odds Ratio | Odds Ratio | Odds Ratio | Odds Ratio |
| Living arrangement | | | | | | |
| With spouse only (Ref.) | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Alone | 0.35*** | 1.88*** | 1.72*** | 1.78*** | 2.15*** | 1.01 |
| With spouse and minor children | 1.51*** | 0.56*** | 0.91 | 0.92 | 0.54** | 0.81 |
| With minor children only | 0.62** | 0.71 | 1.37 | 1.84* | 1.17 | 0.72 |
| Extended family and unrelated adult households | 1.25** | 0.69** | 0.97 | 1.13 | 1.01 | 1.07 |

Source: Authors' analysis of the National Health Interview Survey, 2012

Notes: Analyses weighted to approximate nationally-representative estimates.

All models adjust for gender, age, race/ethnicity, family income, educational attainment, employment, health status, psychological distress, presence of an activity limitation, having a close relative who needs long-term supports and services, and personal expectations of long-term supports and services use.

Results significant at *p<0.05, **p<0.01,
***p<0.001

Sample n=11,796; Population N=34,480,308