



The power to make it better.®

2011 Survey of Nebraska Members on Long-Term Care and Caregiving Issues

February 2012



2011 Survey of Nebraska Members on Long-Term Care and Caregiving Issues

**Report Prepared by
Erin Pinkus**

**Copyright © 2012
AARP
Research & Strategic Analysis
601 E Street NW
Washington, DC 20049
<http://www.aarp.org/research/>
Reprinting with Permission**

AARP is a nonprofit, nonpartisan organization with a membership that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce AARP The Magazine, the definitive voice for 50+ Americans and the world's largest-circulation magazine with nearly 35 million readers; AARP Bulletin, the go-to news source for AARP's millions of members and Americans 50+; AARP VIVA, the only bilingual U.S. publication dedicated exclusively to the 50+ Hispanic community; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

Acknowledgements

AARP staff from the Nebraska State Office, Government Affairs, and Research & Strategic Analysis contributed to the design and implementation of this study. Special thanks go to AARP staff including Connie Benjamin and Mark Intermill, AARP Nebraska State Office; Ilene Henshaw, Government Affairs; Rachelle Cummins, Joanne Binette, Jennifer Sauer, Tanya Disselkoen and Cheryl Barnes, Research & Strategic Analysis, who assisted with survey design and report preparation. Thanks also go to Michael Schuster, Jami Wyatt and Daniel Koslofsky of the Office of General Counsel, for their review of the report. Bob Blackwood, John Venzke and Amanda Harms of Questar Data Systems, Inc. insured a timely high quality survey. Erin Pinkus, AARP Research & Strategic Analysis, managed all aspects of the project and wrote the report. For more information, contact Erin Pinkus at 202.434.6362.

Executive Summary

The older adult population is rapidly increasing and in Nebraska, there will be 375,811 individuals ages 65 and older by the year 2030¹. This will be a 54 percent increase from the estimated 243,313 individuals ages 65 and older in 2010. It is estimated that about 70 percent of adults age 65 and older will need some type of long-term care (LTC) at some point in their lifetime and these LTC services and supports vary greatly in cost and are not covered by traditional medical health plans². The National Clearinghouse for Long-Term Care Information defines long-term care as, "...a range of services and supports needed to meet health or personal needs over a long period of time. Most long-term care is not medical care, but rather assistance with the basic personal tasks of everyday life".

One tool intended to assist states with improving the performance of their long-term care services was the State Long-Term Care Services and Supports Scorecard released in 2011 which assessed the LTSS system based on: affordability and access; choice of setting and provider; quality of life and quality of care; and support for family caregivers. Nebraska ranked 14th overall. However, on matters of high importance to Nebraskans, their ranking was much lower with respect to the choice of setting and provider, ranking 36th out of the 50 states and Washington, DC³.

Of great importance in the delivery of long-term care is the support provided by unpaid, informal caregivers. Nationally, there are 42.1 million family caregivers at any given point in time who provide unpaid services to family members who might otherwise turn to expensive institutional options. This care is valued at approximately 450 billion dollars not including care provided to those non-family members⁴. Specifically, in Nebraska, caregivers provide 210 million hours of unpaid care valued at \$2.2 billion dollars annually.

In October 2011, AARP conducted a mail survey to explore the opinions and experiences of AARP Nebraska members ages 50 and older regarding long-term care and caregiving issues. Survey findings will assist AARP Nebraska in their long-term care services and supports advocacy efforts. The findings in this report are based on a member mail survey conducted between October 21st and December 15th, 2011.

Nebraska needs to begin preparing for 2030 today. The older baby boomer will reach the age of 80 in fourteen years⁵. At that point, Nebraska will begin to see a dramatic increase in the demand for long-term care that will continue for decades. Nebraskans have the opportunity to begin planning to support this growth in long-term care demand to ensure that all Nebraskans have the option to choose the most appropriate long-term care services for themselves and their families.

¹ U.S. Census Bureau. State Population Projections. Retrieved Jan. 2011.

<http://www.census.gov/population/www/projections/files/SummaryTabB1.pdf>

² National Clearinghouse for Long-Term Care Information, U.S. Dept. of Health and Human Services.

http://www.longtermcare.gov/LTC/Main_Site/Planning/Index.aspx

³ Reinhard, Susan, Kassner, Enid, Houser, Ari & Mollica, Robert. *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*. AARP Public Policy Institute, Washington, DC. September 2011

<http://longtermscorecard.org/~media/Files/Scorecard%20site/Nebraska%20State%20Fact%20Sheet%20817.pdf>

⁴ Feinberg, Lynn, Reinhard, Susan C., Houser, Ari and Choula, Rita. 2011. *Valuing the Invaluable: The Growing Contribution and Costs of Family Caregiving 2011 Update*. AARP Public Policy Institute, Washington, DC.

⁵ Baby Boomers are defined as those born between the years 1946-1964.

The survey shows that AARP members age 50 and older in Nebraska want to be able to stay in their homes when faced with the need for long-term care and they support additional funding for informational and support services.

Key findings from the survey include:

- ✚ Eighty-nine percent say it would be extremely or very important to stay at home as long as possible if they or their family members needed long-term care. Further, 86 percent believe it should be a top or high priority for AARP in Nebraska to ensure the availability of a broad range of long-term care services that will allow them to stay in their homes.
- ✚ Sixty-five percent surveyed say they are not very or not at all confident that they could afford long-term care services for themselves or their family and only 23 percent are extremely or very confident they could find long-term care services to remain in their home if needed.
- ✚ Nearly 20 percent of AARP members in Nebraska say they are currently or have previously provided caregiving services within the past two years.
 - One-third (33%) of caregivers surveyed live with the person they care for and almost half (49%) have been providing care between one and five years.
 - Sixty-nine percent of caregivers spend up to twenty hours each week on average providing care and half (51%) have an annual household income before taxes of less than \$50,000.
- ✚ Most AARP Nebraska members surveyed (85%) find it either extremely or very important to have access to long-term care information in one place.
 - The large majority (93%) of those who rate their health as poor find that it is extremely or very important to have a central place to receive unbiased information.
- ✚ AARP members in Nebraska indicate that they would find the following caregiver support resources extremely or very helpful:
 - Information about available caregiver resources in their community (72%)
 - Assistance in completing government forms and applications (71%)
 - Establishing a state income tax credit for caregivers (64%)
 - Short breaks from caregiving (63%)
 - Assistance with transportation (62%)
 - Help with understanding medical bill (61%)

Recommendations

As previously mentioned, 70 percent of adults age 65 and older are going to need long-term care at some point in their lifetime, a need that increases with age, and Nebraska's aging population will increase dramatically in the future. Most AARP members who were surveyed want to remain in their homes in the event they need long-term care services and are concerned about being able to find affordable long-term care services when needed.

Based on these facts and findings, AARP Nebraska recommends that the Nebraska Legislature conduct an interim study to:

- Assess the future demand for long-term care in Nebraska and the capacity of state programs, including the Community Aging Services Act, Older Americans Act, Medicaid and Care Management Services Act to meet that need.
- Examine effective ways to provide: a) unbiased information about all types of long-term care services through an aging and disabilities resource center, and b) assistance applying for long-term care services, including through ACCESS Nebraska.
- Improve consumer access to long-term care services through a single point of entry or no wrong door approach.
- Balance funding between in-home and institutional care recognizing the desire of most people to continue to live at home and the need to provide quality care in a safe setting.
- Identify and pursue resources, options, and programs that will improve the long-term care system including Balancing Incentives Payment Program (BIPP), Veterans Directed Home and Community-Based Services Program, Program of All-Inclusive Care for the Elderly (PACE), and Community-Based Care Transitions Program, and
- Take steps to increase supportive services for caregivers including:
 - Respite services to provide a caregiver with time off
 - Caregiver tax credits to offset the cost of caregiving
 - Transportation assistance, particularly for a persons with disabilities
 - Information about caregiver resources
 - Help in understanding medical bills and applying for assistance

Methodology

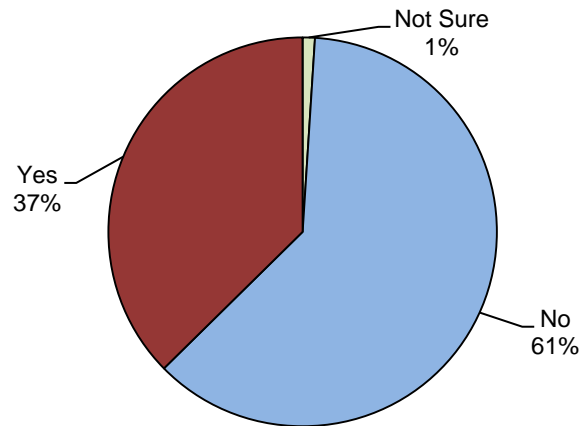
AARP commissioned a mail survey of 2,000 members in Nebraska between October 2011 and December 2011. Surveys were mailed to a statewide sample of members, stratified by age to select members proportionate to each of three age groups: 50-59, 60-74, and 75+. Each sampled member was contacted about the survey in four ways: a pre-notification postcard, the survey itself, a reminder postcard, and a second survey. Of those surveyed, 827 completed questionnaires were used yielding a response rate of 41 percent. The survey has a sampling error of plus or minus 2.6 percent at the 95% level of confidence. This means that in 95 out of 100 samples of this size, the results would be within \pm 2.6 percentage points of the results obtained had everyone in the population completed a survey. Responses were weighted to reflect the actual distribution of members by age and gender. Throughout the report, statistics representing member responses are reported in percentages which may not add up to 100 due to rounding and non-response.

Detailed Findings

Long-Term Care Services Use

Long-term care services are defined in this survey as services that assist people of all ages who are ill, disabled or frail and need assistance with regular daily activities, like bathing, dressing, preparing meals or eating and typically take place over an extended period of time at home, in an assisted living facility or in a nursing home. Of those surveyed, nearly 40 percent of members indicate that either they or a member of their family has received long-term care services at some point over the past five years. Over half (51%) of respondents in their 50's indicate that they or their family member have used long-term care services within the last five years.

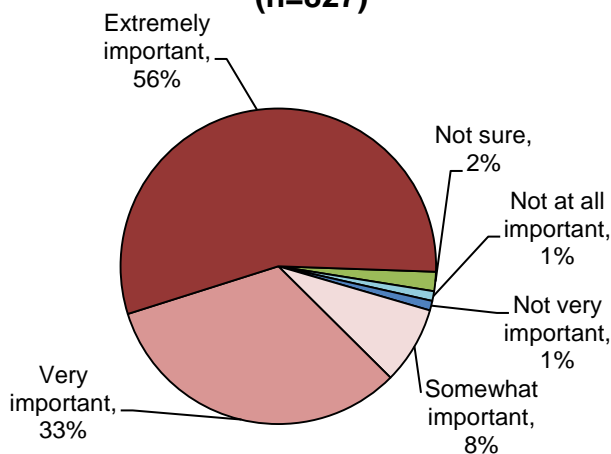
**LTC Used Within Last 5 Years
(n=827)**



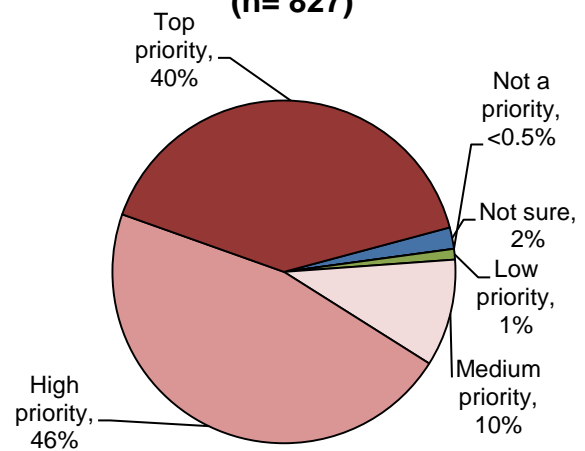
Choice of Utting

The vast majority (89%) of respondents note that it is extremely or very important that they have services that would help them or a family member stay at home as long as possible. Eighty-six percent of respondents believe that AARP Nebraska should make a top or high priority the availability of a broad range of services throughout Nebraska to help them stay in their homes. Not surprisingly, individuals who rate their health as poor more often rate it as top priority than those who say they are in good health (*Top Priority--58% Poor health, 38% Good health*).

**Importance of LTC Services to Stay at Home
(n=827)**



**AARP NE Priority to Help Keep People in Their Homes
(n= 827)**



*Percentages do not add up to 100 due to rounding and respondents not answering the question

Choice of Setting: Scenarios

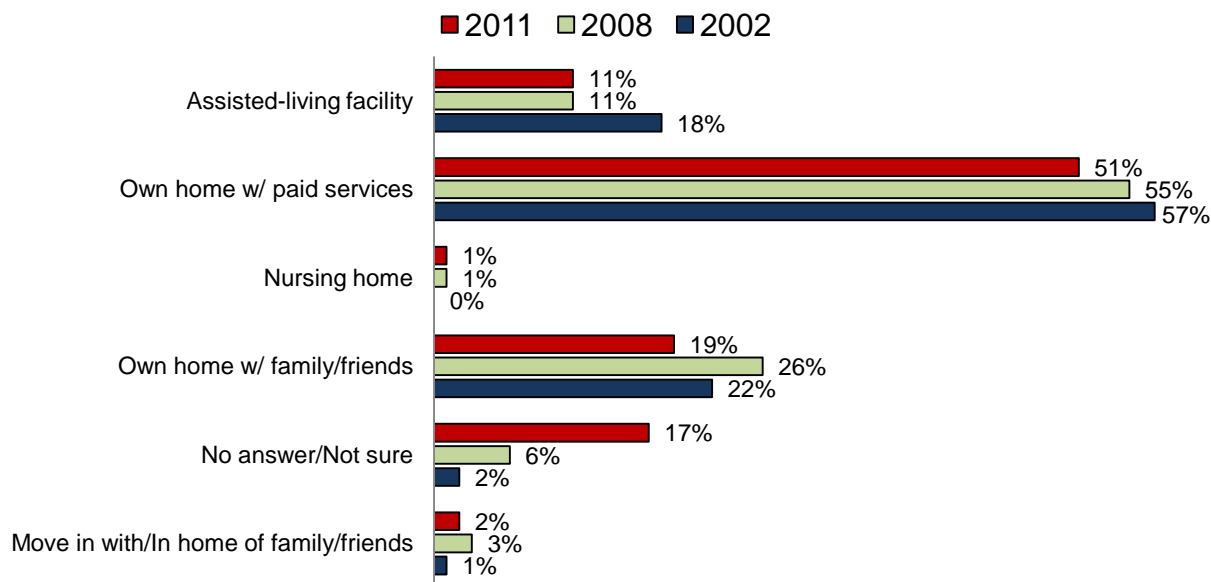
AARP members in Nebraska were asked where they would want to live given three different scenarios. Members indicate a strong preference to receive care in their home even under circumstances in which a high level of care is needed. In the first scenario, members were asked where they would like to live if they began to have difficulty cleaning their home, doing yard work, or making minor home repairs. In this scenario, the majority of respondents (70%) indicate they want to remain in their own homes with paid services or help from their family and friends.

These results are similar to those generated by the same question asked of AARP members in Nebraska in the AARP 2008 and 2002 LTC surveys. In the 2008 survey, 81 percent preferred home-based services; 55 percent paid services at home and 26 percent help from family and friends. Members who were asked the same question in 2002 indicate that almost eight in ten (79%) would prefer to live at home with either help from paid services or their family and friends. Eleven percent in 2008 and 2011 and 18 percent in 2002 would opt for an assisted-living facility given the difficulty with home responsibilities scenario presented. Both 2011 and 2008 AARP LTC survey respondents would select a nursing facility as the preferred place to reside in less than one half of a percent of cases and nobody selected a nursing facility in the 2002 sample.

From the 2002, 2008, and 2011 AARP LTC surveys, the amount of “no answer” or “don’t know” responses grows from two percent to 15 percent. A possible explanation for this increase in non-response could be the respondents’ lack of information about what the actual costs would be for each care option, or it might reflect that they have not thought through the situation and are considering how to be least burdensome to family members and friends. A deeper exploration into why respondents do not provide an answer to this question should be considered in similar future surveys.

Scenario 1: Difficulty with home responsibilities

Difficulty with Home Responsibilities
(2011 n= 827; 2008 n=967; 2002 n= 1643)



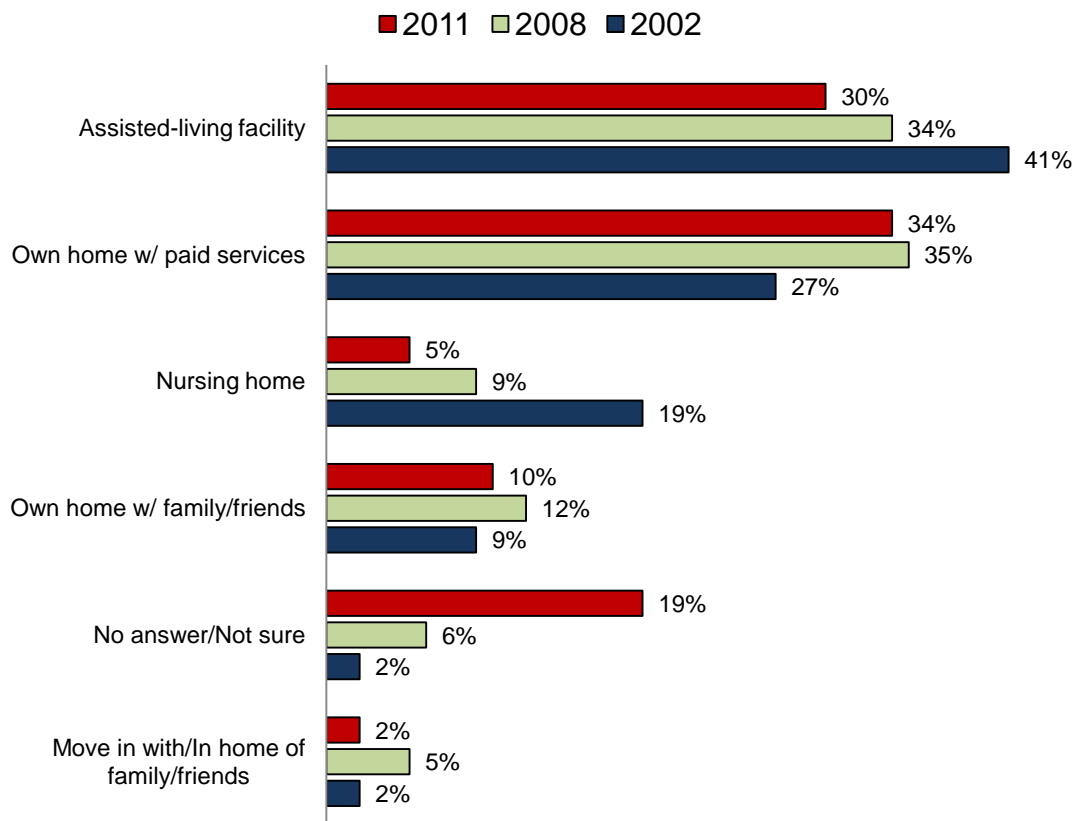
*Percentages do not add up to 100 due to rounding and respondents not answering the questions.

In the second scenario, respondents were asked where they would like to live if they were not able to get out of bed without some help, and many still prefer to live in their own homes with assistance. A total of 44 percent indicate they would want to stay home; 34 percent would opt for

paid services and 10 percent would prefer help from family and friends. Responses from the same question asked in the 2008 AARP LTC survey closely aligned with the 2011 responses where 35 percent would prefer at home paid services, five percent would prefer at home assistance from family and friends and 34 percent would want to live in an assisted-living facility. Three in ten respondents would choose to live in an assisted-living facility if they had difficulty getting out of bed without assistance (30 %). That percentage declined in both the 2008 and 2011 survey. Almost 20 percent of respondents marked either “Not sure” or did not answer the question. Similar to the first scenario, respondents who did not answer or said they were not sure may be weighing heavier the burden the decision to stay home with help from family and friends may have on others.

Scenario 2: Need assistance getting out of bed

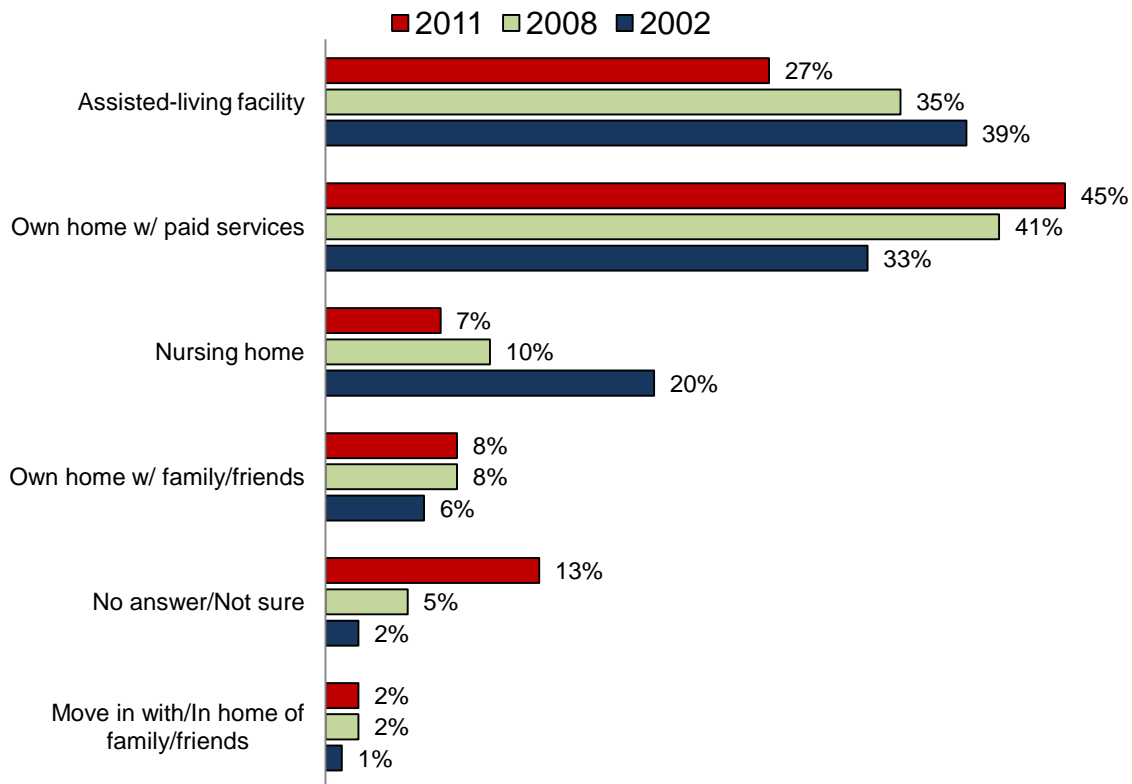
**Where to Live if You Can't Get Out of Bed
(2011 n=827; 2008 n= 967; 2002= 1643)**



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

The third scenario presented asked where members would like to live if they had a medical condition that required regular monitoring or treatment by a nurse. In the current 2011 survey, more than half would prefer at home services (53%), with help from paid services (45%) or from family and friends (8%). Just over one-quarter of respondents would opt for moving to an assisted-living facility if they had a medical condition that required regular monitoring or treatment by a nurse (27%). State law prohibits nurses employed by an assisted living facility from engaging in nursing procedures that require nursing judgment.

Medical Condition Requiring Monitoring/Treatment
2011 n=827; 2008 n= 967; 2002 n= 1643



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

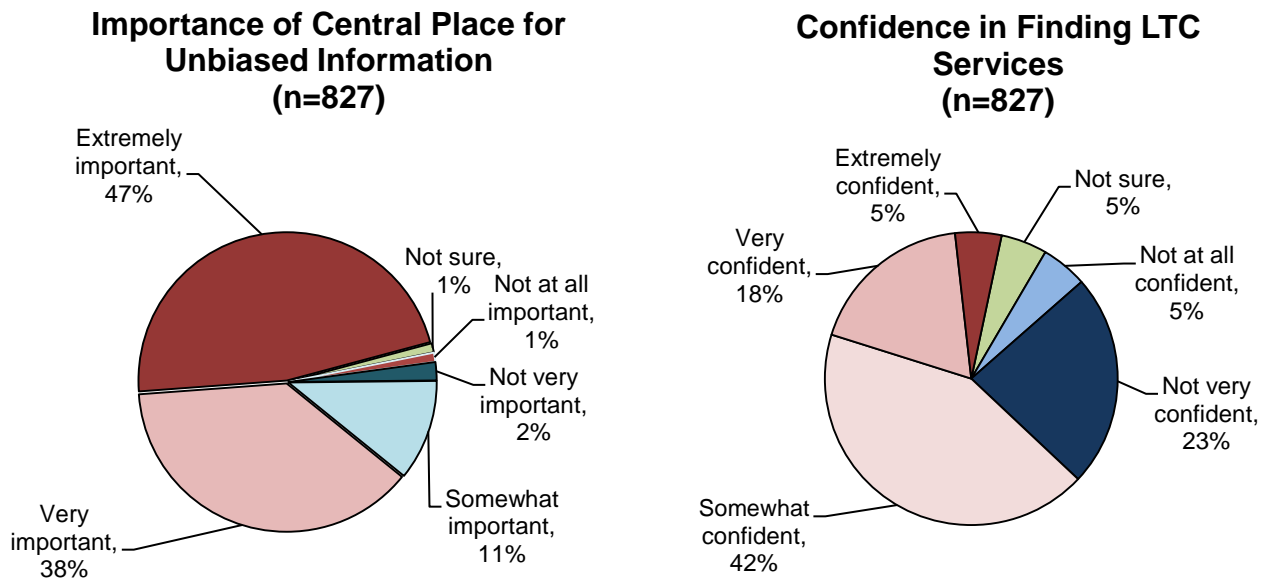
In the 2008 AARP LTC survey, nearly half (49%) of the respondents preferred staying at home with either paid services (41%) or help from family and friends (8%) and 35 percent would opt for moving to an assisted-living facility. Over the past decade, the three AARP LTC surveys illustrate a trend towards an increasing desire to remain in ones' home as one ages and a decrease in a preference for institutional care.

Increasingly, Nebraskans want to receive long-term care at home. There is a growing desire among Nebraskans to receive long-term care services outside of a licensed facility in each of the three scenarios. Assisted living was a relatively new care option in 2002. As the public has become more familiar with assisted living, there is a decline in the proportion of the population that wishes to live there. The proportion of the population that wants to live in a nursing facility has declined at a more precipitous rate than in an assisted-living facility. We also see a larger share of the population that is not sure where they want to live, which indicates a need for more public information about long-term care options.

Centralized Information

Because it can be difficult to know who to trust and how to navigate the LTC system, having a central place to get unbiased information about all types of long-term care services and also apply for benefits for which one is eligible is important to Nebraska members. The majority of those surveyed (85%) find it either extremely (47%) or very (38%) important to have such a service with access to LTC information in one place. Particularly the majority (93%) of those who rate their health as poor find that it is extremely or very important to have a central place to receive unbiased information (extremely, 62%; very, 32%). An additional 11 percent find it somewhat important.

Along the same lines, finding the appropriate long-term care services when they are needed is critical. However, less than one half (42%) feel somewhat confident that they could find LTC services when they need them and an additional 28 percent are either not very or not at all confident. Regardless of annual household income levels, many respondents are only somewhat confident they could find LTC services when needed (<30k, 40%; 30-60k, 46%; 60-100k, 49%; 100k and up, 36%).

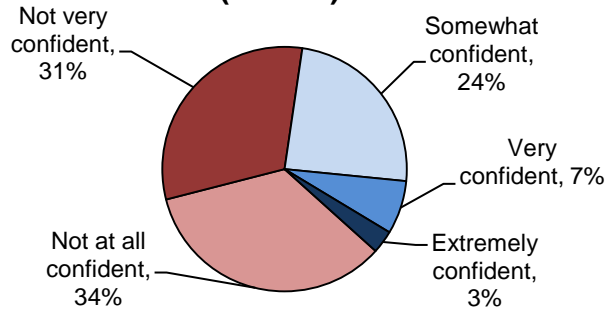


*Percentages do not add up to 100 due to rounding and respondents not answering the question.

Confidence in Ability to Afford Long-Term Care Costs

Most respondents (65%) are not confident they could afford long-term care costs for themselves or their family if they needed it. Not surprisingly, as income rises, so does confidence in respondents' ability to afford long-term care services. Members with household incomes amounting to less than \$30,000 annually express the least confidence when it comes to affording long-term care services with over three-fourths (79%) of Nebraska members surveyed saying they are not at all or not very confident they can afford the costs associated with long-term care. Members reported low confidence across the lower incomes groups with 67 percent of those in the \$30,000-\$60,000 group, 58 percent of those in the \$60,000-\$100,000 group and almost 36 percent of individuals whose household income is \$100,000 and higher citing they are not at all or not very confident.

Able to Afford LTC for Yourself and Family (n= 827)



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

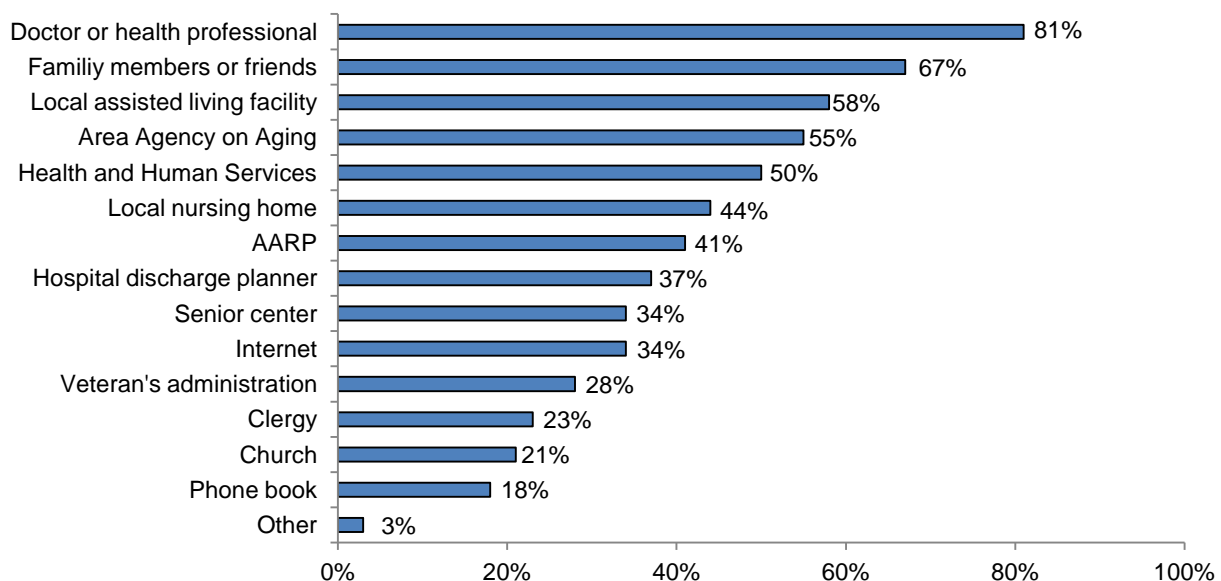
Sources of LTC Information

When it comes to finding resources on LTC services, respondents noted they would turn to many different sources to get additional information. Most (81%) members surveyed indicate they would reach out to their doctors or other health professionals for this information. Another highly cited source (67%) is one’s family members or friends. Over three-fourths (78%) of those ages 50-64 would turn to family and friends and a similar number of members (74%) who indicate they are caregivers would turn to family and friends as well.

Endorsed by a over half of the respondents is tapping local assisted-living facilities (58%), Area Agencies on Aging (55%) and state Department of Health and Human Services (50%) if they or a family member needed long-term care information. Respondents who identified themselves as caregivers more often cited the Area Agency on Aging as a source they would turn to if they or a family member needed LTC services information (*Caregiver, 67%; Non-Caregivers, 53%*).

AARP was a source cited by 41 percent of responents. Other sources that respondents would use include the hospital/Veterans Administration, religious organizations/leaders, online sources and phone books. Percentages of the full list presented to those surveyed are displayed below.

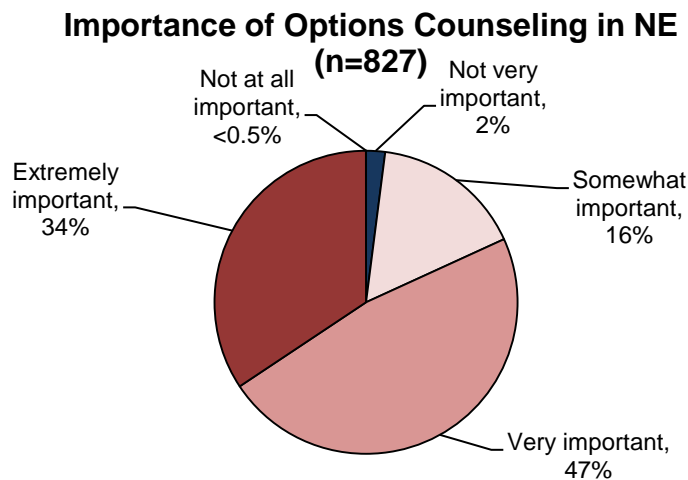
Sources Tapped for LTC Information (n= 827)



*Percentages exceed 100 due to multiple answers solicited

Options Counseling

Options Counseling is a service where those individuals that are in need of LTC for themselves or their family members can get information on available services including providers and what is important to consider when making decisions about LTC⁶. An Options Counselor works with the care recipient and family members to help them determine what is most appropriate based on their individual needs and concerns. The Nebraska Care Management Program provides Options Counseling to Nebraskans who need long-term care⁷. This type of service is valued by the members surveyed. Eighty-one percent of members surveyed indicate that it is extremely or very important (*Extremely 34%; Very 47%*) to make Options Counseling services available in the state of Nebraska. An additional sixteen percent found it somewhat important. Further, 89 percent of those in poor health rate this service as extremely or very important.



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

Many members surveyed support the idea of increasing state funding to support Options Counseling services. While 59 percent either strongly or somewhat support this increase, 24 percent neither support nor oppose and less than 10 percent oppose this proposition. Over half of the members surveyed from all income groups support increasing state funding to support Options Counseling services.

Annual Household Income	Strongly/Somewhat Support Increasing State Funding for Options Counseling
Less than \$30,000	63%
\$30,000 - < \$60,000	60%
\$60,000 - <\$100,000	61%
\$100,000 and up	52%

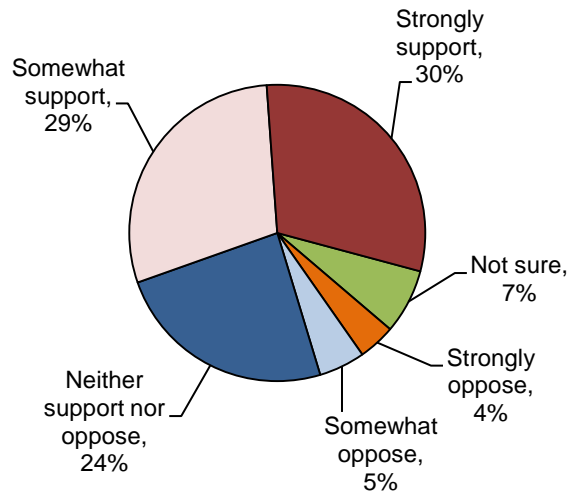
⁶ This is currently a working definition for “Options Counseling” being used in the development of the Nebraska Aging and Disability Resource Center (ADRC)

⁷ U.S. Dept. of Health and Human Services, Nebraska. Division of Medicaid & Long-Term Care State Unit on Aging 2012 - 2015 Plan for Aging Services <http://dhhs.ne.gov/medicaid/Documents/AgingServicesStatePlanFY2012-FY2015.pdf>

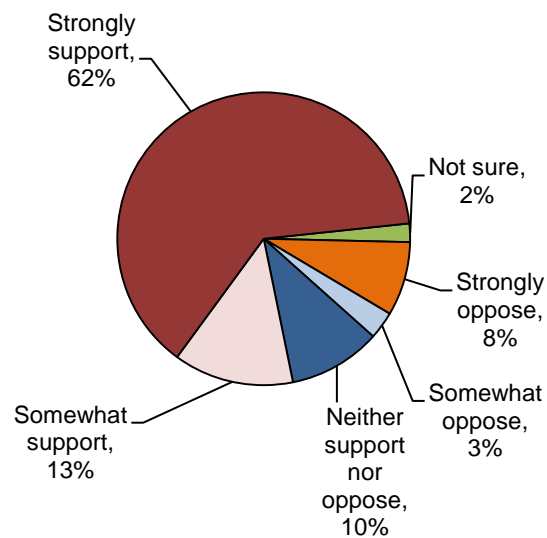
Funding Options Counseling

One possible method of funding Options Counseling services is to increase the current Nebraska cigarette tax by two cents from 64 cents to 66 cents. This tax would generate approximately two million dollars in revenue annually. Three-fourths of members surveyed support this cigarette tax increase to fund the provision of this long-term care informational service for families in Nebraska. When looking at support for increasing the cigarette tax by age group, support of Nebraska members surveyed is high for all ages. Seventy-one percent of those ages 50-64 support the increase (*Strongly support, 60%; Somewhat support, 12%*) and 78 percent of those ages 65 and older support the tax as well (*Strongly support, 64%; Somewhat support, 14%*).

Support/Oppose Increase in State Funding for Counseling Services (n=827)



Increasing NE Cigarette Tax (n=827)



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

Cost of Care

Many people are not aware of the costs associated with long-term care, do not have long-term care insurance, and incorrectly believe that their medical insurance will cover their long-term care services costs. In 2011 in Lincoln, Nebraska, 25 hours of in-home care can cost approximately \$26,000 annually, assisted living runs approximately \$38,616 each year and services offered in a nursing home cost \$59,130 a year⁸.

⁸ Estimates from the Federal Long Term Care Insurance Program (FLTCIP) website from October 2011 are shown in text. Current costs have risen in January 2012 since last retrieved in October 2011 to \$27,000 for 25 hours of home health care, \$42,000 for assisted living and \$67,000 for nursing home services. The Federal Long Term Care Insurance Program. *Find the Cost of Care in Your Area. Lincoln, NE.* Retrieved Jan.2012 https://www.ltcfed.com/ltcWeb/do/assessing_your_needs/costofcare?action=costofcare

Based on that information, many respondents (65%) are not very confident or not at all confident that they will be able to afford the costs of the long-term care services for themselves or their family members.

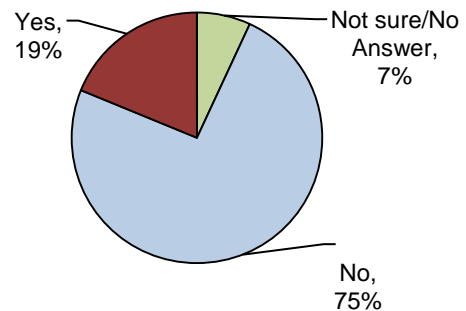
Of those respondents that rated their health as poor, eight in ten (81%) indicate that they are not at all or not very confident that they would be able to afford long-term care services. Similarly, respondents who have a disability are less confident they can afford the costs of long-term care (*Not at all/Not very confident; 72%*) when compared to those surveyed who say they do not have any disabilities (*Not at all/Not very confident, 62%*).

Caregiving Experience

At any given time during the year, there are approximately 320,000 caregivers providing 210 million hours of unpaid care which amounts to 2.2 billion dollars worth of unpaid care being provided to Nebraskans⁹. Caregivers have first-hand experience and can offer unique insight into how Nebraska can best support its residents that are caring for their family and friends that might otherwise rely on institutional settings for care.

Nearly 20 percent of AARP members in Nebraska surveyed identified themselves as providing unpaid care currently or within the past two years to someone 18 years of age or older who is ill, frail, elderly, or has a physical, mental or emotional disability. As in the general population, more of the caregivers surveyed are female. Nearly one-fourth (24%) of respondents ages 50-64 are providing care and 21 percent are currently employed.

Providing/Provided Unpaid Caregiving Services (n=827)



Relationship to Care Recipient

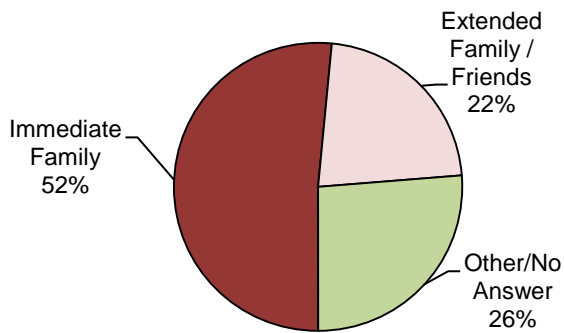
Caregivers are providing invaluable unpaid assistance to their family, friends and neighbors. Of those surveyed, 52 percent of care recipients are immediate family, 22 percent are extended family members and friends and an additional 26 percent did not indicate for whom they are providing care. Nearly half (49%) of respondents who are ages 75 and older are providing care for their spouse/partner.

Providing care for another while caring for oneself can be a difficult balancing act. Of those members surveyed, 48 percent of respondents who consider themselves to be in poor health are also providing care to their spouse or partner. Income can also limit the resources that caregivers have to assist them with caregiving needs.

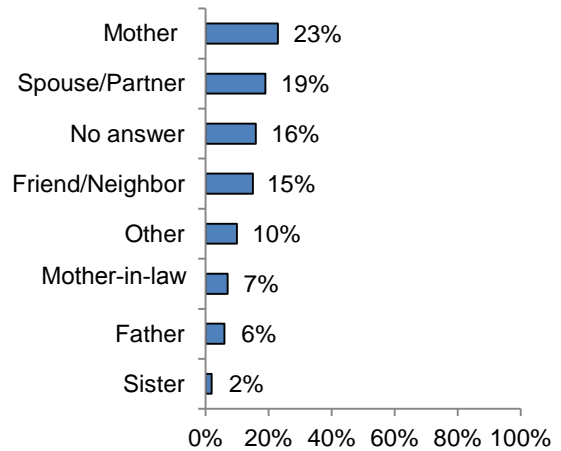
Thirty-seven percent of respondents receiving less than \$30,000 annually in terms of their household income are caring for their spouse/partner which likely means that costs associated with care create an added stress when income is low.

⁹ Feinberg, Lynn, Reinhard, Susan C., Houser, Ari and Choula, Rita. 2011. Valuing the Invaluable: The Growing Contribution and Costs of Family Caregiving 2011 Update. AARP Public Policy Institute, Washington, DC. <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>

Care Recipient's Relation to Caregiver (n=155)

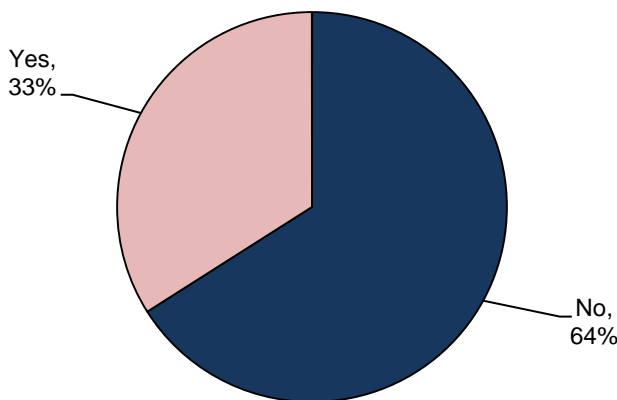


Caregiver/Care Recipient's Relationship (n=155)



One-third of caregiver respondents indicate that while providing care, the care recipient is living with them. Caregivers in this survey will likely have additional household costs to sustain and support their care recipient. Sixty-one percent of those surveyed who rate their health as poor live with their care recipient. Over half (55%) of the caregivers in this survey whose care recipient is living with them have an annual household income before taxes of less than \$30,000 annually and 41 percent are retired. Although retired caregivers may have more time available to provide care, caregivers on a fixed income may struggle with meeting costs of caregiving as well as everyday and unexpected expenses.

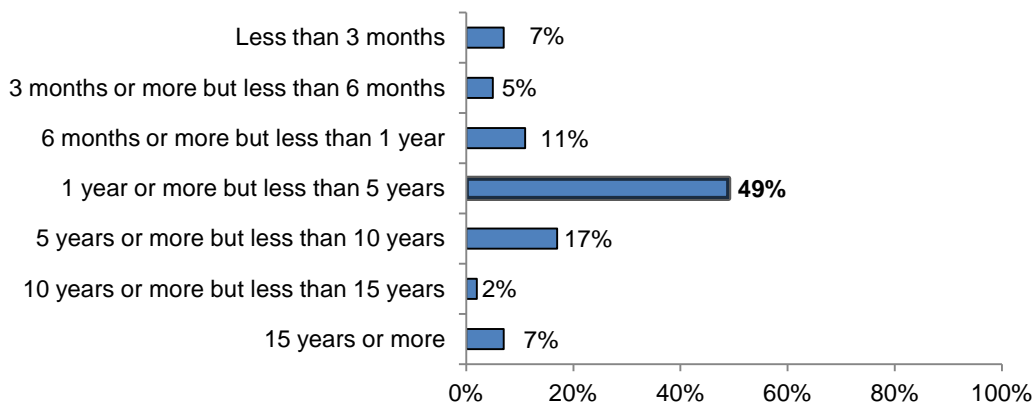
Live with Care Recipient (n= 155)



Length of Time Providing Care

Caregiving takes a physical and emotional toll on the caregiver and can increase over time. Of those surveyed, 26 percent have been providing caregiving services for over five years. Over one-fourth of caregivers surveyed indicate that they have been providing caregiving services for at least five years and of that amount seven percent have been caregiving for over 15 years. Forty-three percent of Nebraska caregiver respondents who rate their health as poor have been providing care for at least one year or more but less than five years. Fifty-eight percent of the respondents who are employed have been providing care for the same amount of time.

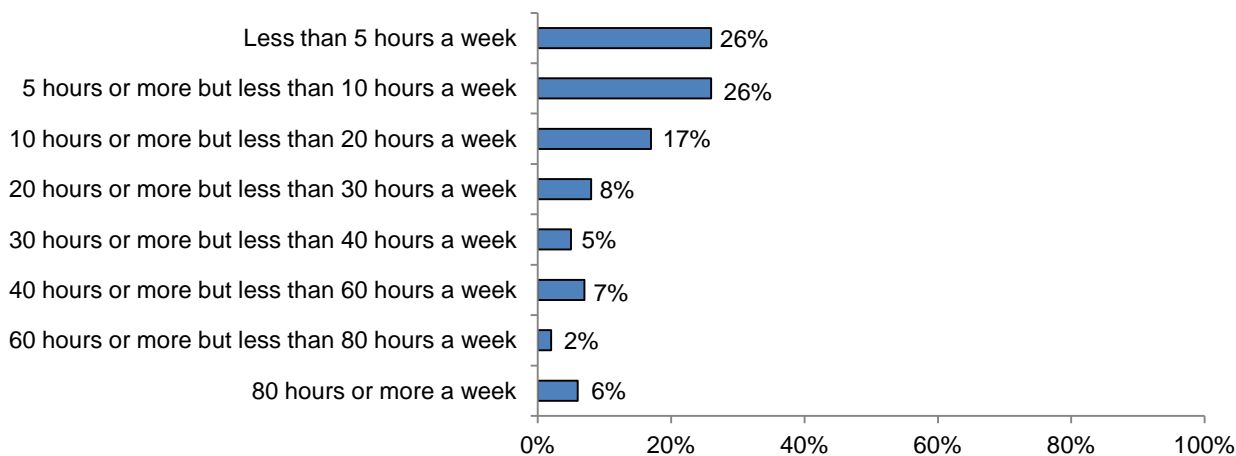
How Long Have You Been Providing Care (n= 155)



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

Caregiving often takes place over an extended period of time and can be cyclical which can contribute to financial and emotional stressors on the caregiver and care recipient. Fifteen percent of caregivers in this survey provide care for at least 40 hours per week and some provide care for as much as 80 hours or more each week. On the other hand, over half of the respondents say they spend less than 10 hours each week on caregiving duties. This number may not accurately reflect the amount of time spent providing care as caregivers often do not recognize what they are doing as “caregiver tasks”.

How much Time Spent Caregiving (n=155)

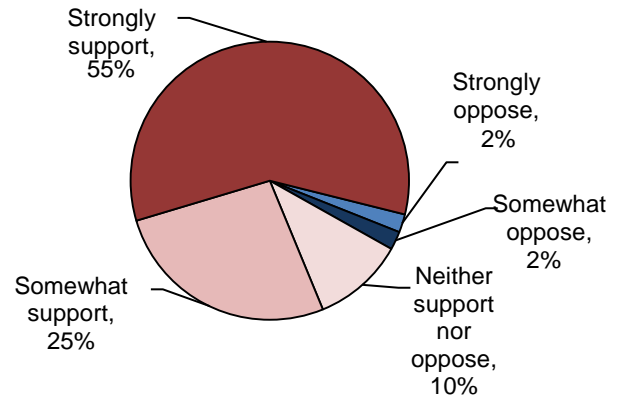


*Percentages do not add up to 100 due to rounding and respondents not answering the question.

Caregiving Resources

Eighty-percent of all survey respondents support providing caregivers with a modest state income tax credit to help them when providing caregiving services. Seventy-one percent of those who are employed, indicate that having the state income tax credit for caregivers would be extremely or very helpful (*Extremely helpful*, 38%; *Very helpful*, 34%). Even Nebraska members surveyed who have not yet provided caregiving services would support a modest state income tax credit to help caregivers (81% Strongly or Somewhat support).

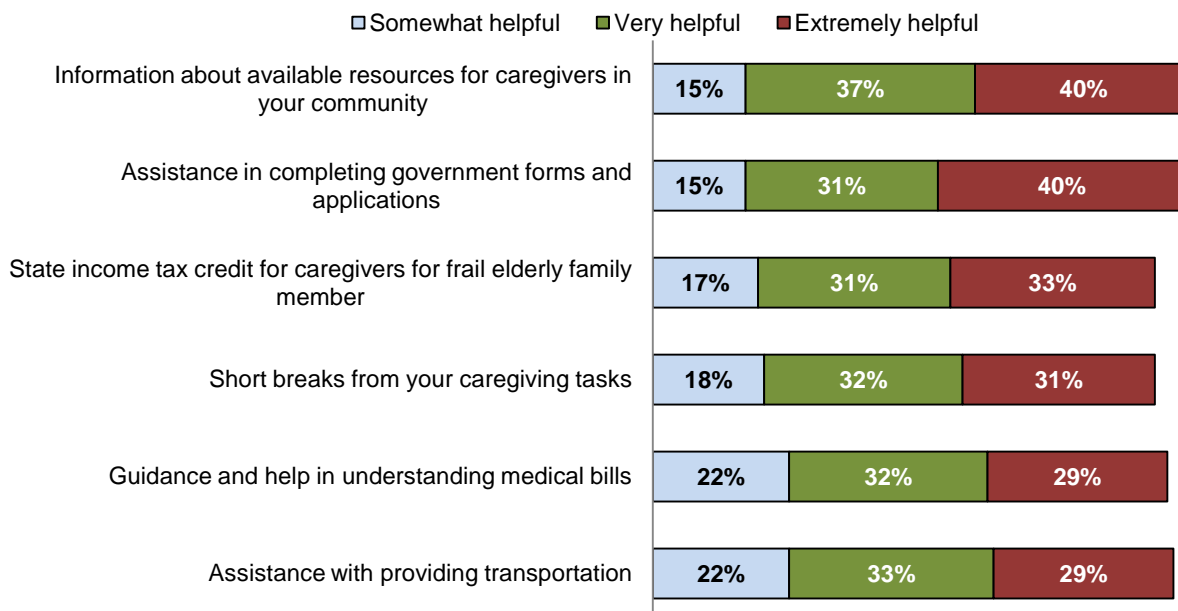
Providing Caregivers a State Income Tax Credit (n= 827)



*Percentages do not add up to 100 due to rounding and respondents not answering the question.

All members surveyed were asked to consider, as a former, current or caregiver of the future, how helpful they would find specific types of support. The response most cited by 72 percent of the members surveyed is having information about available resources for caregivers in your community (*Extremely helpful*, 35%; *Very helpful*, 37%). Over 70 percent for all income groups would find information about caregivers' resources in their community to be helpful (*Extremely/Very helpful*: <30k, 70%; 30-60, 75%; 60-100k, 78%; 100k, 74%). Additionally, 70 percent overall would find assistance in completing government forms and applications helpful. The remaining resources are listed in the graph below with their percentage of how helpful respondents found each item presented.

Resources Caregivers Find Helpful (n=827)



Summary of Respondents (n=827)

Disability		Education	
Yes	25%	K-12 th grade, no diploma	5%
No	74%	High school graduate/GED	28%
		Post-high school (no degree)	19%
		2-year college degree	9%
Gender		4-year college degree	13%
Male	55%	Post-graduate study, no degree	5%
Female	44%	Graduate or professional degree	16%
Age		Income	
50-59 years	23%	Less than \$30,000	30%
60-74 years	50%	\$30,000 to \$75,000	39%
75+ years	26%	\$75,000 or more	19%
Marital Status		Household Compositions	
Married	64%	Child under age 18 living with you	5%
Not married, living with partner	2%	Child age 18 or older with you	13%
Separated/Divorced	12%	Children away at college	4%
Widowed	17%		
Never married	5%		
Race		Received LTC Services Since 2006	
White or Caucasian	90%	Yes	37%
Hispanic or Latino	1%		
Black or African-American	3%	Options Counseling Cigarette Tax	
American Ind. or Alaskan Native	<0.5%	Strongly/Somewhat support	75%
Asian	1%	Neutral	10%
Native Hawaiian or Pac. Islander	<0.5%	Strongly/Somewhat oppose	11%
Other	1%	Not sure/No answer	4%
Employment		Caregivers Since 2009	
Employed, full-time	31%	Yes	19%
Employed, part-time	15%		
Retired	46%	Support/Oppose Caregiver Tax Credit	
Unemployed, but looking for work	1%	Strongly/Somewhat support	80%
Other	4%	Neutral	10%
		Strongly/Somewhat oppose	4%
		Not sure/No answer	7%

Annotated Questionnaire

**2011 AARP LONG-TERM CARE SURVEY
OF NEBRASKA MEMBERS
Weighted N=827; Unweighted N=823
Weighted by Age & Gender**

Long-term Care

- 1. People of all ages who are ill, disabled, or frail and need assistance with regular daily activities, like bathing, dressing, preparing meals or eating, may receive long-term care services. These services are typically provided over an extended period of time either at home, in an assisted living facility, or in a nursing home. In the past 5 years, since October 2006, have you or a member of your family, such as your spouse, parents, brothers or sisters, grandparents or other relative, received any long-term care services?**

<u>%</u>	
37	Yes
61	No
1	Not sure
<.5	No answer

- 2. If you or a family member became ill or disabled and needed long-term care services, how important would it be to have services that would help you or your family member to stay at home as long as possible?**

<u>%</u>	
56	Extremely important
33	Very important
8	Somewhat important
1	Not very important
1	Not at all important
2	Not sure
1	No answer

- 3. How much of a priority should it be for AARP in Nebraska to work to ensure the availability of a broad range of long-term care services throughout the state that will allow people to remain in their own homes?**

<u>%</u>	
40	Top priority
46	High priority
10	Medium priority
1	Low priority
<.5	Not a priority
2	Not sure
1	No answer

4. Currently, in Nebraska the cost of long-term care services can vary greatly depending on your needs. For example, in Lincoln, 25 hours a week of care in the home costs about \$26,000 a year. Assisted living costs about \$38,616 each year. Care in a nursing home costs about \$59,130 a year. How confident are you about being able to afford long-term care services for you or your family?

%

3	Extremely confident
7	Very confident
24	Somewhat confident
31	Not very confident
34	Not at all confident
1	No answer

5. Options Counseling provides individuals in need of long-term care and their family members with information on available long-term care services including providers and what things to consider when making decisions about long-term care. An options counselor works with the care recipient and their family members to help them determine what is the most appropriate long-term care option based on the care recipient's needs and preferences. How important do you think it is to make these services available in Nebraska?

%

34	Extremely important
47	Very important
16	Somewhat important
2	Not very important
<.5	Not at all important
2	No answer

6. How strongly do you support or oppose increasing state funding for options counseling services?

%

30	Strongly support
29	Somewhat support
24	Neither support nor oppose
5	Somewhat oppose
4	Strongly oppose
7	Not sure
2	No answer

7. Nebraska has a 64-cent tax per pack on cigarettes. This tax is below the national average of a \$1.45 tax per pack. It was last increased in 2002. One possible way to generate money for options counseling for long-term care services would be to increase the cigarette tax from 64 cents to 66 cents. This 2-cent increase would generate about \$2 million annually. How strongly do you support or oppose increasing Nebraska’s cigarette tax from 64 cents to 66 cents to provide this long-term care informational service for individuals and families in Nebraska?

<u>%</u>	
62	Strongly support
13	Somewhat support
10	Neither support nor oppose
3	Somewhat oppose
8	Strongly oppose
2	Not sure
2	No answer

8. If you or a family member needed long-term care services, would you turn to the following sources to get more information?

	Yes	No	Not sure	No answer
	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>
a. Family members or friends	67	13	11	10
b. Your doctor or other health professional.....	81	4	7	7
c. Clergy	23	35	25	17
d. Area Agency on Aging.....	55	13	19	13
e. Hospital discharge planner	37	21	26	16
f. AARP	41	14	32	14
g. Health and Human Services	50	14	23	14
h. Senior Center.....	34	23	26	17
i. Local assisted living facility.....	58	11	19	13
j. Internet	34	29	19	17
k. Phone book.....	18	41	22	20
l. Church.....	21	34	26	19
m. Veteran’s Administration	28	42	14	16
n. Local nursing home.....	44	19	21	17
o. Other, please specify:_____	3			97

9. If you or a family member needed long-term care services, how important would it be to you to have a central place where you could get unbiased information about all types of long-term care services as well as apply for the services and benefits you or your family member are eligible for?

<u>%</u>	
47	Extremely important
38	Very important
11	Somewhat important
2	Not very important
1	Not at all important
1	Not sure
1	No answer

10. If you needed long-term care services to remain in your home, how confident are you that you could find these services?

<u>%</u>	
5	Extremely confident
18	Very confident
42	Somewhat confident
23	Not very confident
5	Not at all confident
5	Not sure
1	No answer

11. If you began to have difficulty cleaning the house, doing yard work, or making minor home repairs, where would you want to live?

<u>%</u>	
<.5	In a nursing home
11	In an assisted-living facility
2	Move in with family or friends
51	In my own home with paid services to help me
19	In my own home with help from family and friends
9	Not sure
8	No answer

12. If you could not get out of bed without some help, where would you want to live?

<u>%</u>	
5	In a nursing home
30	In an assisted-living facility
2	Move in with family or friends
34	In my own home with paid services to help me
10	In my own home with help from family and friends
12	Not sure
7	No answer

13. If you had a medical condition that required regular monitoring or treatment by a nurse, where would you want to live?

<u>%</u>	
7	In a nursing home
27	In an assisted-living facility
2	Move in with family or friends
45	In my own home with paid services to help me
8	In my own home with help from family and friends
6	Not sure
7	No answer

Caregiving

14. An informal caregiver can be anyone who provides unpaid care for a relative, friend, spouse, companion, or partner 18 years or older who is ill, frail, elderly, or has a physical, mental, or emotional disability. Unpaid care may include assisting with personal needs, household chores, meals, shopping, transportation, financial or medical management, arranging for outside services, or a variety of other tasks. The person you provide care for may live with you or somewhere else.

Are you currently providing unpaid assistance, or have you provided unpaid assistance in the past two years, since October 2009, to care for a relative, friend, spouse, companion, or partner 18 years or older who is ill, frail, elderly, or has a physical, mental, or emotional disability?

<u>%</u>	
19	Yes
75	No → SKIP TO Q19
2	Not sure → SKIP TO Q19
5	No answer

15. What is the care recipient's relationship to you? If you are a former caregiver, what was the care recipient's relationship to you? n=155

<u>%</u>	
19	Spouse or partner
23	Mother
6	Father
7	Mother-in-law or Father-in-law
2	Sister
1	Brother
15	Friend or neighbor
16	No answer
10	Other, please specify

16. Does the person you provide care for live with you? If you are a former caregiver, did the person you provided care for live with you? n=155

<u>%</u>	
33	Yes
64	No
3	No answer

17. How long have you been providing care for this person? If you are a former caregiver, how long did you provide care for this person? n=155

<u>%</u>	
7	Less than 3 months
5	3 months or more but less than 6 months
11	6 months or more but less than 1 year
49	1 year or more but less than 5 years
17	5 years or more but less than 10 years
2	10 years or more but less than 15 years
7	15 years or more
3	No answer

18. Considering all types of care you provide for this person, how much time do you spend in an average week doing these things? If you are a former caregiver, how much time did you spend in an average week? n=155

<u>%</u>	
26	Less than 5 hours a week
26	5 hours or more but less than 10 hours a week
17	10 hours or more but less than 20 hours a week
8	20 hours or more but less than 30 hours a week
5	30 hours or more but less than 40 hours a week
7	40 hours or more but less than 60 hours a week
2	60 hours or more but less than 80 hours a week
6	80 hours or more a week
3	No answer

19. As a current or former caregiver or someone who may provide care in the future, how helpful would the following types of support be to you?

	Extremely helpful	Very helpful	Somewhat helpful	Not very helpful	Not at all helpful	No answer
	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>	<u>%</u>
a. Assistance with providing transportation	29	33	22	4	3	10
b. State income tax credit for caregivers for frail elderly family member	33	31	17	5	3	11
c. Guidance and help in understanding medical bills	29	32	22	5	2	10
d. Information about available resources for caregivers in your community	35	37	15	2	1	11
e. Short breaks from your caregiving tasks	31	32	18	4	3	12
f. Assistance in completing government forms and applications	40	31	15	4	2	10

20. The care provided by Caregivers is estimated at a value of 450 billion dollars across the United States and 2.2 billion dollars in Nebraska. Caregivers also keep their loved ones out of the hospital and nursing homes and save taxpayers millions of dollars. How strongly do you support or oppose providing caregivers with a modest state income tax credit to help them?

<u>%</u>	
55	Strongly support
25	Somewhat support
10	Neither support nor oppose
2	Somewhat oppose
2	Strongly oppose
4	Not sure
3	No answer

About You

D1. How would you rate your overall health today?

<u>%</u>	
15	Excellent
38	Very good
34	Good
9	Fair
3	Poor
1	No answer

D2. Does any disability, handicap, or chronic disease keep you from participating fully in work, school, housework, or other activities?

<u>%</u>	
25	Yes
74	No
1	No answer

D3. Are you male or female?

<u>%</u>	
55	Male
44	Female
1	No answer

D4. What is your age as of your last birthday? _____ (in years)

<u>%</u>	
23	50-59
50	60-74
26	75+
1	No answer

D5. What is your current marital status?

<u>%</u>	
64	Married
2	Not married, living with partner
1	Separated
11	Divorced
17	Widowed
5	Never married
1	No answer

D6. Thinking about who lives in your household, do you currently?

	Yes	No	No answer
	<u>%</u>	<u>%</u>	<u>%</u>
a. Have any children under age 18 living with you	5	88	7
b. Have any children over 18 living with you	13	80	7
c. Have any children away at college	4	86	10

D7. What is your 5-digit ZIP Code? (Write in your ZIP CODE): ____ ____ ____ ____ ____

D8. What is the highest level of education that you completed?

<u>%</u>	
5	0-12 th grade (no diploma)
28	High school graduate (or equivalent)
19	Post-high school education (no degree)
9	2-year college degree
13	4-year college degree
5	Post-graduate study (no degree)
16	Graduate or professional degree
5	No answer

D9. Which of the following best describes your current employment status?

<u>%</u>	
4	Self-employed, part-time
6	Self-employed, full-time
11	Employed, part-time
25	Employed, full-time
46	Retired, not working at all
4	Not in labor force for other reasons
1	Unemployed, but looking for work
4	No answer

D10. Are you of Hispanic, Spanish, or Latino origin or descent?

<u>%</u>	
1	Yes
94	No
5	No answer

D11. What is your race?

<u>%</u>	
90	White or Caucasian
3	Black or African American
<.5	American Indian or Alaska Native
1	Asian
<.5	Native Hawaiian or other Pacific Islander
1	Other
<.5	More than one
4	No answer

D12. What was your annual household income before taxes in 2010?

<u>%</u>	
4	Less than \$10,000
11	\$10,000 to less than \$20,000
15	\$20,000 to less than \$30,000
12	\$30,000 to less than \$40,000
10	\$40,000 to less than \$50,000
8	\$50,000 to less than \$60,000
10	\$60,000 to less than \$75,000
8	\$75,000 to less than \$100,000
8	\$100,000 to less than \$150,000
3	\$150,000 to less than \$200,000
<.5	\$200,000 or more
12	No answer

**Thank you very much for completing this survey.
Your assistance in providing this information is very much appreciated.**

**Please return your completed survey by November 30, 2011
in the enclosed postage-paid envelope to:**

**AARP State Research
601 E Street, NW
Washington, DC 20049**



AARP
Research & Strategic Analysis
For more information, please contact Erin Pinkus
202.434.6362 or e-mail epinkus@aarp.org.