

Informal Caregivers: 2002

Outreach Survey

Forward

Acknowledgments

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Executive Summary

Introduction

A survey of residents in North Dakota who serve as informal caregivers was conducted during the Summer and Fall of 2002. The purpose of this study was to gain insight into the barriers to informal care in order to assist policy makers in exploring ways to improve caregiving and the lives of those who provide informal care. A rather broad definition of informal caregiving was used to collect the data. In brief, the definition of informal caregiving that we used to determine who should be included in the data set was:

*An **informal caregiver** provides needed care on a long term basis to a **care recipient**, who is most often a relative, friend, or neighbor. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group), or those who provide care as a career. Long-term care often involves assisting the care receiver with personal hygiene, getting dressed, using the bathroom, or household tasks such as preparing meals. It does not include recovery from an injury after which the recipient no longer needs care. Currently we are interested only in those recipients of care who are at least 60 years of age.*

A total of 652 face-to-face interviews of persons who provided informal care were conducted by outreach case workers in each of the states eight regions. Survey instruments were provided to the outreach workers who were responsible for finding and interviewing the informal caregivers in their area. Outreach workers were encouraged to obtain roughly 10 caregiver interviews from each county in an attempt to assemble a reasonable distribution of caregivers throughout North Dakota. The interview instrument was divided into six sections and gathered information on: characteristics of caregiving, caregiving difficulties/concerns, services available to the care recipient, services available to the caregiver, services provided by the caregiver, and demographics.

Survey Results

Characteristics of Informal Caregiving

- Results indicated that more than 43 percent of caregivers are caring for their spouse.
- More than 93 percent of caregivers indicated they do not receive monetary compensation for their caregiving services.
- Approximately 58 percent of caregivers indicated their care recipient lives with them.
- Of those who do the caregiving in their home, a majority indicated they can leave the care recipient alone for a few hours.
- Approximately 82 percent of caregivers live less than 20 minutes away from the care recipient.
- More than one-fourth of caregivers spend more than 16 hours a week providing care.
- Most caregivers said they have spent up to three years caregiving. More than 23 percent of caregivers have been caregiving for at least seven years.

Informal Caregiving Difficulties/Concerns

- More than 30 percent of caregivers indicated that emotional aspects and the lifestyle change are serious difficulties they face when providing care.
 - Less time for family, having the responsibility for making major life decisions for a loved one, no consistent help from other family members, and less time for themselves were difficulties experienced by approximately a fourth or more of caregivers.
- Nearly a quarter of caregivers agreed that it is difficult for them to accept support or assistance when caregiving because it is their duty to provide care and it is difficult for them to find support or assistance when caregiving.
- The majority of caregivers said there are other informal caregivers who provide care. Of these, the highest proportion of other informal caregivers is family, followed by a sister.
 - In situations where there are no other caregivers, the three most common reasons why others are not providing care are because they live farther away, others have full-time jobs, and there are no other immediate family members.

Services Available to the Informal Care Recipient

- More than three-fourths of caregivers indicated that home delivered meals, congregate meal settings, and homemaker services/home health aides are available to their care recipient. More than half of caregivers indicated the care recipient has escort/transportation services, visiting nurse, outreach programs, and dietician services available to them.
 - For more than half of caregivers, the following services are not available to their care recipients: adult day centers and parish nurse.
- More than half of caregivers who said outreach programs were not available to the care recipient indicated they would like them to be available.
 - Overall, caregivers were reluctant to indicate that they would like more services to be available to their care recipient. However, approximately a third of caregivers indicated they would like a visiting nurse, adult day centers, homemaker services/home health aides, escort/transportation services, congregate meal settings, and shopping assistance to be available to their care recipient.
- Regardless of the type of service, the most common reason the care recipient does not use the service (if it was available to them) is because they do not need it.
 - In the instances where the service is available, outreach programs and congregate meal settings are the top two services that care recipients will not use.

Services Available to the Informal Caregiver

- More than half of caregivers indicated that information about available services, assistance with accessing available services, and respite care are available to them.
 - Approximately one-third of caregivers said caregiver support groups, individual caregiver counseling, and caregiver training or education are not available to them.
- In instances where the service is not available, the top three services caregivers would like to have available to them are information about available services, respite care, and assistance with accessing available services.

- Another one-third of caregivers would like caregiver support groups, training or education, and counseling services to be available to them.
- More than one-third of caregivers reported they use information about available services, assistance with accessing available services, individual caregiver counseling services, caregiver training or education, and respite care.
- More than one-third of caregivers indicated that information or services that would be valuable to caregivers, now or in the future, are respite care, information about the care recipient's condition or disability, information about developments/changes in laws affecting your situation and an info-line.

Services Provided by Informal Caregivers

- The vast majority of all caregivers reported they do provide each of the services listed in Table 14.
 - Although helping with legal assistance was the service provided least by caregivers, nearly two-thirds of them have done so.
- The majority of caregivers provided many services on a daily basis; listening to the care recipient , providing companionship, assisting with meals/nutritional needs, providing phone contact, helping with worries, anxiety, and emotional needs, and assisting with medicines.
 - More than one-third of caregivers provided transportation and assisted with errands/shopping on a weekly basis.
 - Approximately one-fourth of caregivers communicated with medical providers on a monthly basis.
 - Nearly half of caregivers provided legal assistance and got other family members involved in caregiving on an occasional basis.
- Caregivers were reluctant to indicate they would like help providing services to their care recipient. However, at least a third of caregivers indicated they would like help assisting with maintenance/repair, providing companionship, listening to the care recipient/being someone for them to talk to, and assisting with household tasks.
- Caregivers experience a wide variety of financial difficulties associated with caregiving, although nearly 34 percent experience none at all.

Demographics

- More than 40 percent of caregivers indicated it is hard for them to separate their expenses from those of the care recipient. However, approximately 32 percent of caregivers reported that they have spent an average of \$0 to \$1,000 within the last year caring for the care recipient.
- More than half of caregivers are 65 years of age or older.
- Approximately 73 percent of caregivers are married or living with a partner.
- Approximately 34 percent of caregivers indicated the highest level of education they have reached was high school diploma or GED. Twenty-eight percent of caregivers have some college or have graduated college.
- Nearly 46 percent of caregivers are retired.

- ❑ Approximately 29 percent of caregivers had a household income in 2001 before taxes of \$20,001 to \$35,000. More than half of caregivers had a household income in 2001 before taxes of \$20,000 or less.
- ❑ It is interesting to note that according to the 2000 Census, the median household income in North Dakota was \$34,604 (Source: US Census Bureau, 2000 Census, SF3 Table P53).
- ❑ The majority of caregivers are white (non-Hispanic).
- ❑ Approximately 99 percent of caregivers indicated their principle language is English.
- ❑ Nearly 73 percent of caregivers are female.
- ❑ Approximately 62 percent of caregivers indicated their place of residence is rural.

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Introduction

Study Objectives

The overall purpose of this study was threefold. First, the study was undertaken to gather information that would give policy makers an understanding of the array of barriers that impede informal caregiving. Second, the findings from the study are intended to serve as a tool to explore ways to better serve those who provide informal care to residents of the state. Finally, the study serves as a baseline for documenting the characteristics of those who provide informal care within the state.

Methodology

A survey instrument was designed by the staff of the North Dakota State Data Center (NDSDC) in cooperation with the staff at Aging Services. The instrument was pre-tested through a series of focus groups conducted by the NDSDC staff. Focus groups were conducted in both urban and rural settings. Participants in the focus groups included caregivers, care recipients, health care professionals, and service providers. Surveys were then distributed to Outreach workers at the county and regional levels. The Outreach workers conducted face-to-face interviews with caregivers whom they had identified within their service region. An attempt was made to obtain at least 10 surveys from each county. Data were collected throughout the Summer and Fall of 2002. Approximately 652 useable surveys were returned.

Analysis

The analysis was conducted in a three-step process. First, data from the surveys were hand entered into the Statistical Packages for the Social Sciences (SPSS) by the NDSDC staff. Next, a frequency distribution was computed for all questions, with the exception of those with open-ended responses. Incomplete survey items were excluded from the calculation of means. Finally, the open-ended responses were thematically coded by the NDSDC staff.

Tests of Statistical Significance

Tests of statistical significance were conducted in order to determine whether responses varied by various demographic categories. This type of analysis allows one to explore the unique needs of informal caregivers. We used the analysis to determine if there were differences in caregiving with respect to whom the caregiving was provided. A standard Chi-square test was used in the analysis.

Tests of statistical significance indicate whether the distribution of responses are statistically different to the degree that one could not reasonably conclude that it was due to sampling. Indicators that revealed a statistically significant difference in responses are noted in the section beginning on page 41, entitled "Tests of Statistical Significance."

Limitations

Identifying and contacting informal caregivers is a challenging task. It is estimated that only 6.5 percent of the households in the state have informal caregivers. Thus, it was unreasonable to attempt to collect a sufficiently large enough random sample of households in the state in order to compile the data set. Therefore, we used a nonprobability design and asked Outreach workers to interview a large sample of caregivers. This approach is not random, therefore, one's ability to make generalizations for the entire state is in question. However, the statistical community realizes that a very large sample, even though it may not be randomly drawn, will take on the characteristics of a normal distribution. In short, what we could not do by using a random sample, was compensated for by drawing a very large sample. Therefore, we feel confident that the data depicted in this study accurately reflect the profile of caregivers in North Dakota. Nonetheless, caution is always advised when drawing conclusions from a single data set. Therefore, these data should be used in combination with other information, especially when making policy regarding informal caregiving in North Dakota.

Recommendations

The findings from the 2002 North Dakota Family Caregivers Support project are very compelling with regard to the urgent need to address informal caregiving in North Dakota. The recommendations we offer are organized into three parts. First, we address the broad overall policy concerns. We feel these major themes should serve as the foundation for an effective action oriented approach to addressing informal caregiving in North Dakota. Second, we provide a chart that outlines our suggestions for targeted legislation or agency specific initiatives. This chart is intended to serve as an illustration of the kinds of legislation or initiatives that are needed to create positive movement with regard to caregiving in North Dakota. Finally, we offer some ideas and insights from the research literature regarding initiatives and legislation that have been attempted. The intent of this section is to offer illustrations and some perspective regarding the success of other programs.

I. Broad Policy Recommendations

- The finding from this research suggest there are three broad policy directions that should be considered. First, a sustainable initiative should be established that monitors the changing demand for caregiving in the state.
Rationale: Results from this study indicate that informal caregiving is occurring in more than 6% of the households in the state. This translates into more than 16,700 households. For perspective, this is equal to all the households in the state's smallest 17 counties. More importantly, demographic forecasts indicate that the demand for caregivers in the state will rise sharply in the near future. Currently, 14.7 percent of the state's total population is 65 years of age and older. By the year 2020, that percentage will jump to 23 percent. The distribution of this exploding senior population will vary greatly throughout the state, creating an uneven demand for caregivers. For example, nearly two-thirds of the state's 39 rural counties already have senior populations that exceed 20 percent. By 2020, seniors will represent nearly one in three residents in these rural counties. In contrast, only one of the 14 urban counties in the state has a similar concentration of elderly. Nonetheless, nearly two-thirds of the state's elderly (i.e., those persons 65 years of age and older) live in the 14 urban counties of the state. Equally important is the fact that the state's oldest seniors, those in most need of caregiving, are the fastest growing segment of North Dakota's population. Currently, North Dakota has the highest proportion (2.3 percent) of residents 85 years of age and older in the nation. This population is projected to nearly double by the year 2020, expanding from 14,726 to 24,258.
- Second, priority needs to be given to providing support services that will enhance the abilities of current and potential informal caregivers.
Rationale: The state's extremely tight labor market combined with the low wages for in-home care creates a significant demand for caregivers. It is in the best interest of the state to encourage those who are currently performing voluntary informal caregiving to continue doing so. One way to create a conducive environment for caregiving is by providing an effective support system. Findings from this research demonstrate there is an important need for continued support for those providing informal care. For example, 3 out of 4 caregivers report having access to information about available services, and nearly 70 percent say they receive assistance in accessing information. However, of those who do not have access to information, over two-thirds say they desire such access. The type of services needed and desired varies widely. This is probably due to a lack of exposure or insight into various forms of services. For example, less than 20 percent of caregivers report they have counseling or caregiver support groups available to them. Although only one-third of the caregivers desire such services, the greatest amount of concern among caregivers relates to emotional difficulties.
- Third, significant cost savings in elder care can be gained through enhanced support of family caregiving. Therefore, public and private incentive programs should be vigorously explored.
Rationale: Informal caregivers contributed an estimated market value of \$196 billion in Long Term Care services within in the U.S. in 1998. For perspective, the cost of home health care during that same year was estimated at \$32 billion and the cost of nursing home care was approximately \$83 billion. The savings to the state for having an effective informal care system are obvious and compelling. Therefore, public and private support for an integrated statewide informal caregiving system should be a high priority. The active informal caregiving

program, facilitated through the Aging Services Division of the North Dakota Department of Human Services, is an important starting point. However, legislative action is needed to create effective incentives for participation in informal caregiving. This includes a targeted campaign aimed at employers to encourage them to provide benefits for those who provide care. Research indicates that the kind of services employed caregivers find most useful include: a) flexible work schedules, b) unpaid family leave, c) help locating services, and d) assistance with insurance paperwork. The following chart offers an overview of specific recommendations for policy initiatives by these three target areas.

II. Chart of Recommendations for Targeted Legislation or Agency Initiatives

Target Areas for Legislation or Initiatives	Policy Initiative	Objectives of Policy Initiatives	Targeted Agencies for Administration of Policy Initiatives
A. Monitor changing demand for caregiving and create corresponding training programs for caregivers	Create on-line tracking and referral system for caregivers	<ul style="list-style-type: none"> Provide monitoring system to assess changing demand for caregivers by region 	<ul style="list-style-type: none"> Administration on Aging
	Create comprehensive programs that coordinate volunteers with the professional workforce	<ul style="list-style-type: none"> Provide a more desirable and comprehensive service module for a better quality of life for elderly at lower costs 	<ul style="list-style-type: none"> Administration on Aging Statewide integrated task force Department of Human Services
B. Integrated support system	On-line caregivers website	<ul style="list-style-type: none"> Provide cost effective and reliable 24-hour access to informal caregiver resources 	<ul style="list-style-type: none"> Department of Health Administration on Aging ND State Data Center DHS/Aging Services
	Distance education programs targeted to caregivers	<ul style="list-style-type: none"> Reduce training costs for caregivers and increase skill levels and/or available specialty sources of education 	<ul style="list-style-type: none"> Department of Health Department of Human Services
	Create educational programs that assist elderly or caregivers in understanding health issues, insurance, and caregiving	<ul style="list-style-type: none"> Increase awareness for elderly and caregivers Decrease end-of-life costs for families and hospitals 	<ul style="list-style-type: none"> Department of Human Services Department of Health Senior Health Insurance Counseling Program
C. Incentive programs	Long-term care health insurance	<ul style="list-style-type: none"> Get public to participate in long-range financial planning for elder care 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services Statewide Grants
	Tax breaks for caregivers	<ul style="list-style-type: none"> Retention incentives to enhance the caregiver pool to eliminate current shortages 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services
	Tax breaks for employers who provide elder-care assistance	<ul style="list-style-type: none"> Promote employer based caregiving assistance 	<ul style="list-style-type: none"> Administration on Aging Department of Human Services

III. Research Support of Policy Initiatives

1. Volunteer Services

The legislature should promote community-based programs that tap the professional and volunteer services of local residents to assist in elderly caregiving. A model program using this approach is the Elderberry Institute's "Living at Home/Block Nurse Program" which is widely used in Minnesota and in Oregon. Its philosophy is to utilize resources within the community that are not fully utilized to assist in elder care. For example, the program facilitates the use of professional and volunteer services of local residents to provide nursing, companionship, and chore services to senior residents, allowing them to remain outside a formal institution. The program identifies capabilities of individuals and their families and coordinates resources in the community to provide care and support for particular needs of seniors. This collaborative approach is based on the recognition that community residents realize the need for interdependence and are willing to act in ways that benefit others. Volunteer services include counseling, training for family caregivers, and in-home support programs such as elder daycare.

Program Advantages:

- Care is more fulfilling because it builds on the "spirit of community" to meet families' needs.
- Maximizes self-reliance and minimizes the use of costly professional services.
- Focuses on early intervention and treatment, prevention and recovery, and coordination and integration of services.
- Fees may be charitable contributions.

Program Implications:

- Model successfully implemented in 30 communities in Minnesota, Texas, and Colorado.
- Estimated cost of program is 24% less than the minimum cost of a nursing home stay *before* nursing services.
- Increases and enhances family and community involvement in the care of elderly.
- 85% of Block Nurse Clients would be forced to enter nursing homes if home care was not available.
- Strong data indicate that Medicare/Medicaid dollars are being saved as a result of these programs.
- In 1997, 15 programs reported a total of 379 people kept out of nursing homes for estimated savings of \$4,700,040. During this time, 35,307 volunteer hours were contributed.

2. Equipment Stipends

The legislature should fund equipment stipends which allow elderly or caregivers to purchase equipment that facilitates independence. These stipends promote caregiving by easing its financial burden. Greater use of informal caregivers reduces the long-term care cost both to the family and to the state. In addition, subsidies such as equipment stipends will assist middle-income families who are the hardest hit financially. These families cannot afford nursing home care or home health care, nor do they qualify for Medicaid or other public health programs because their incomes are too high.

3. Distance Education

North Dakota should focus resources on advancing distance education as a way to assist rural communities in providing support services to caregivers. The Caregiver College is one such example of a successful program. This program was formed by a multi-disciplinary group of rehabilitation professionals to provide free community health education to informal caregivers of the elderly. Classes can be conducted anywhere that has appropriate videoconferencing facilities. North Dakota is a leader in telecommunications, and its videoconferencing capabilities are rapidly spreading, making this a viable policy option. Results from over 700 people receiving "certificates of completion" from the Caregiver College found no significant difference in knowledge gained between students using videoconferencing technology and other methods (<http://tie2.telemed.org>).

4. Incentives

The legislature should fund caregiver incentive programs. Examples from other states include:

- New York's Health Care Reform Act of 2000 authorizes the establishment of a state-funded health insurance initiative specifically targeted to uninsured home care workers. The New York Association of Homes and Services for the Aging, the state association for non-profit Long Term Care (LTC) providers, has recommended that all workers in home care, nursing homes and residential care settings across the state be covered.
- In 2000, California appropriated \$25 million for its Caregiver Training Initiative, designed to improve recruitment and retention of entry-level staff.
- Created incentives for long term care insurance: New York, Minnesota, and Washington have health insurance initiatives that assist small employers, including LTC providers, in gaining access to coverage for themselves and their employees.
- Providing funding for community-based well-being programs that include daily monitoring of elderly through phone calls and/or visits from community volunteers: this improves senior involvement with the community as well as opportunities for social interaction. One model program, "Walk in My Shoes" (<http://www.urbanext.uiuc.edu>), is aimed at orienting new staff at nursing homes, senior care groups, and agency personnel to the needs and limitations of older adults.

5. On-line Computer Assistance

There should be ongoing support for an on-line resource assistance website for caregiving. The benefits of this resource includes:

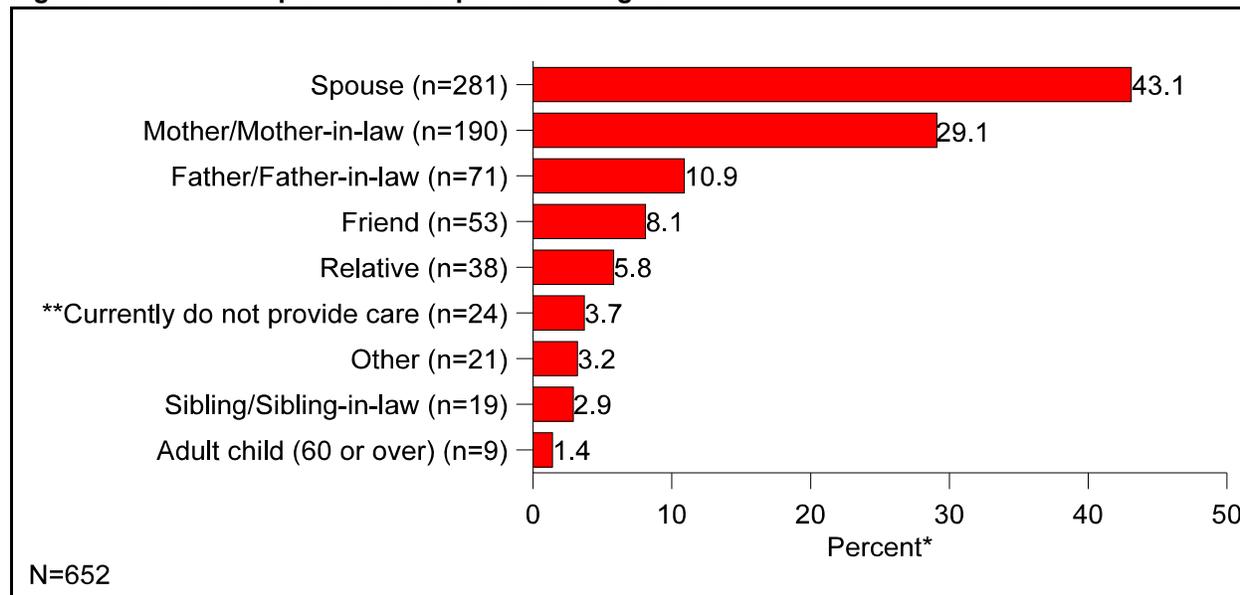
- cost effective way of delivering information, resources, training, and monitoring activities
- provides social anonymity which increases candid communication
- creates social interaction while decreasing social isolation, especially for those in very rural areas
- provides access to peers, services, and health care professionals
- easy 24-hour access

SURVEY RESULTS

Characteristics of Informal Caregiving

- ▶ Results indicated that approximately 43 percent of caregivers are caring for their spouse. An additional 29 percent of caregivers are caring for their mother or mother-in-law (Figure 1, Appendix Table 1).

Figure 1. Relationship of Care Recipient to Caregiver

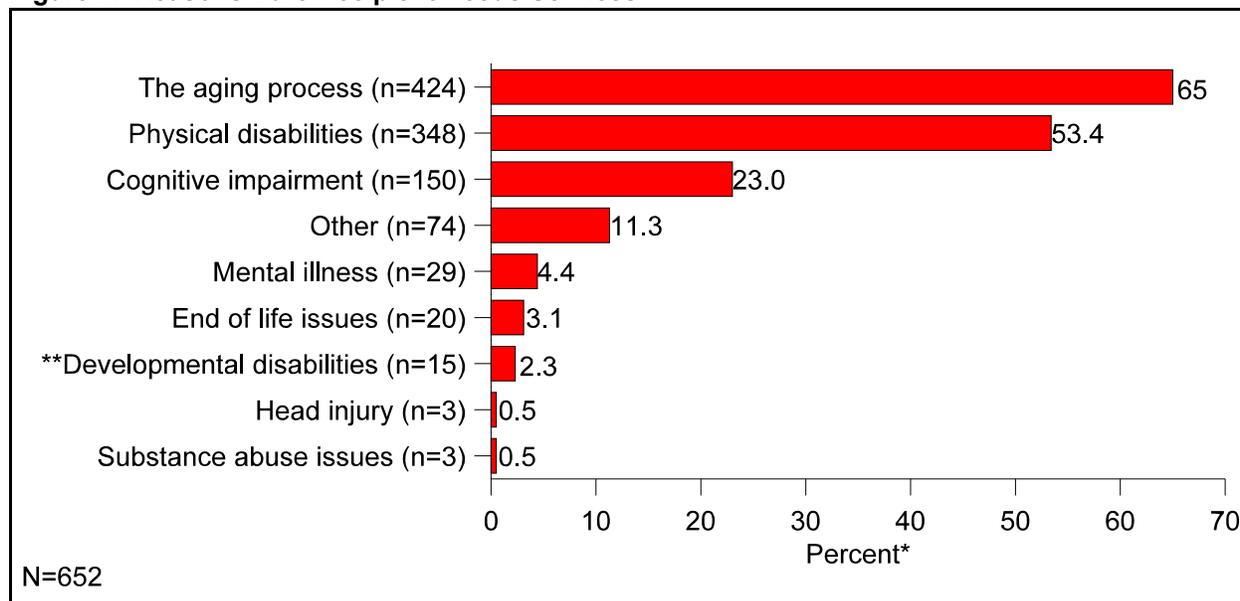


*Percents do not always add to 100.0 due to multiple responses; N=652.

**Full response category states: "I currently do not provide care, but have done so within the last year."

- ▶ Sixty-five percent of caregivers indicated the care recipient needs care because of the aging process. More than 53 percent of caregivers indicated that the care recipient needs care because of physical disabilities (Figure 2, Appendix Table 2).

Figure 2. Reasons Care Recipient Needs Services

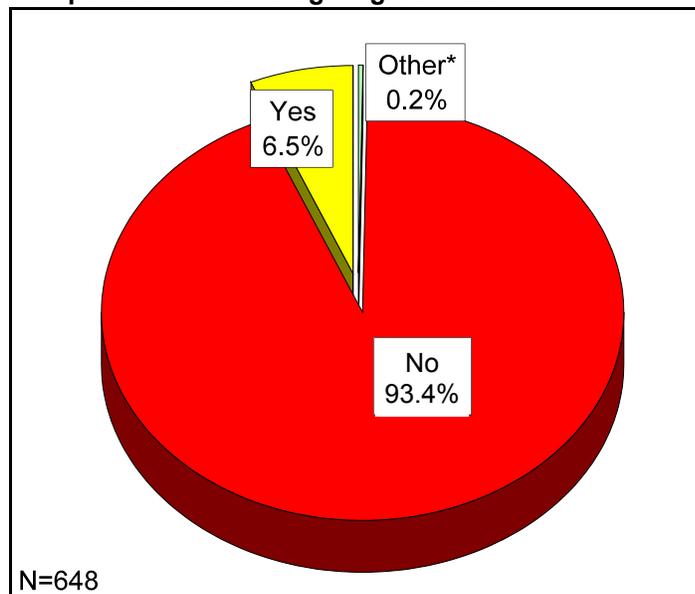


*Percents do not always add to 100.0 due to multiple responses; N=652.

**Full response category states: "Developmental disabilities/mental retardation."

- ▶ Approximately 93 percent of caregivers indicated they do not receive monetary compensation for their caregiving services (Figure 3, Appendix Table 3).

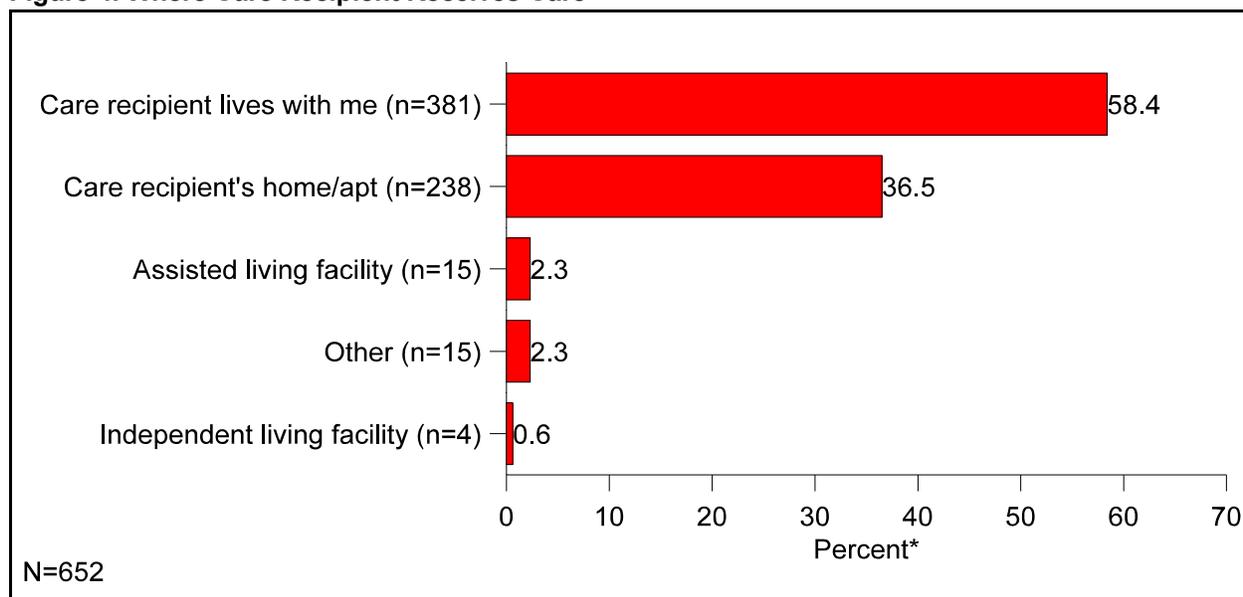
Figure 3. Whether Caregiver Receives Monetary Compensation For Caregiving Services



*See Appendix Table 3 for other statements regarding compensation.

- ▶ More than half (58.4 percent) of caregivers said the care recipient lives with them. More than a third (36.5 percent) of care recipients live in their own home/apartment (Figure 4, Appendix Table 4).

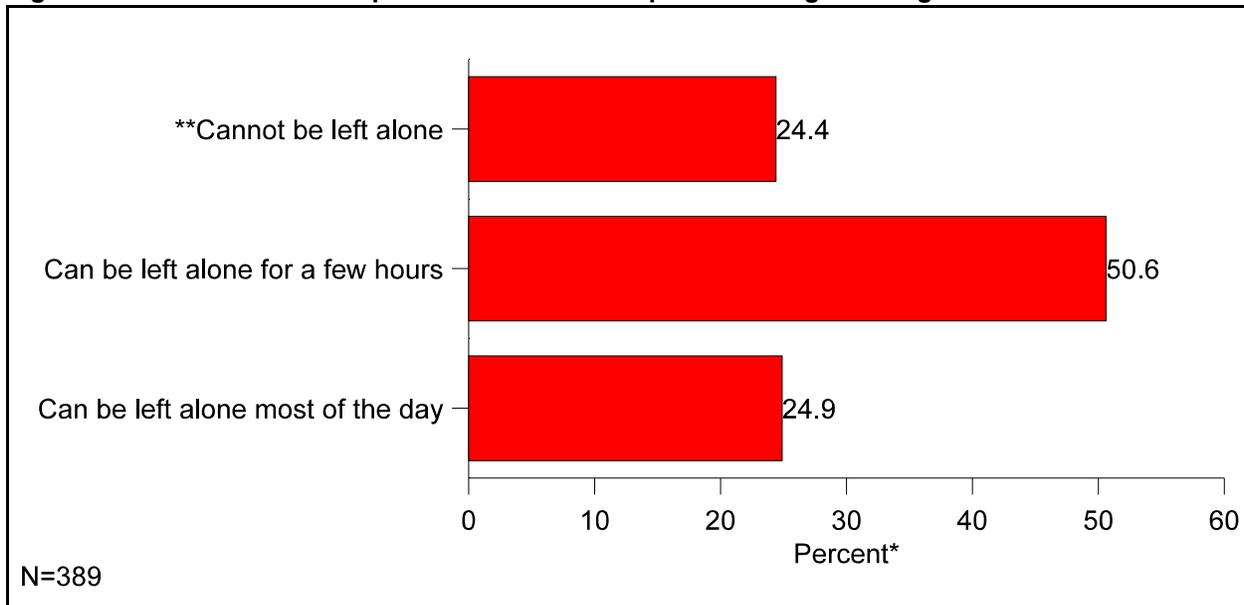
Figure 4. Where Care Recipient Receives Care



*Percents do not always add to 100.0 due to multiple responses; N=652.

- ▶ Care was generally seen to occur “around the clock.” More than half of caregivers who do the caregiving in their home said the care recipient can only be left alone for a few hours. One in four caregivers said their care recipient could not be left alone (Figure 5, Appendix Table 5).

Figure 5. Amount of Care Required For A Care Recipient if Living in Caregiver’s Home

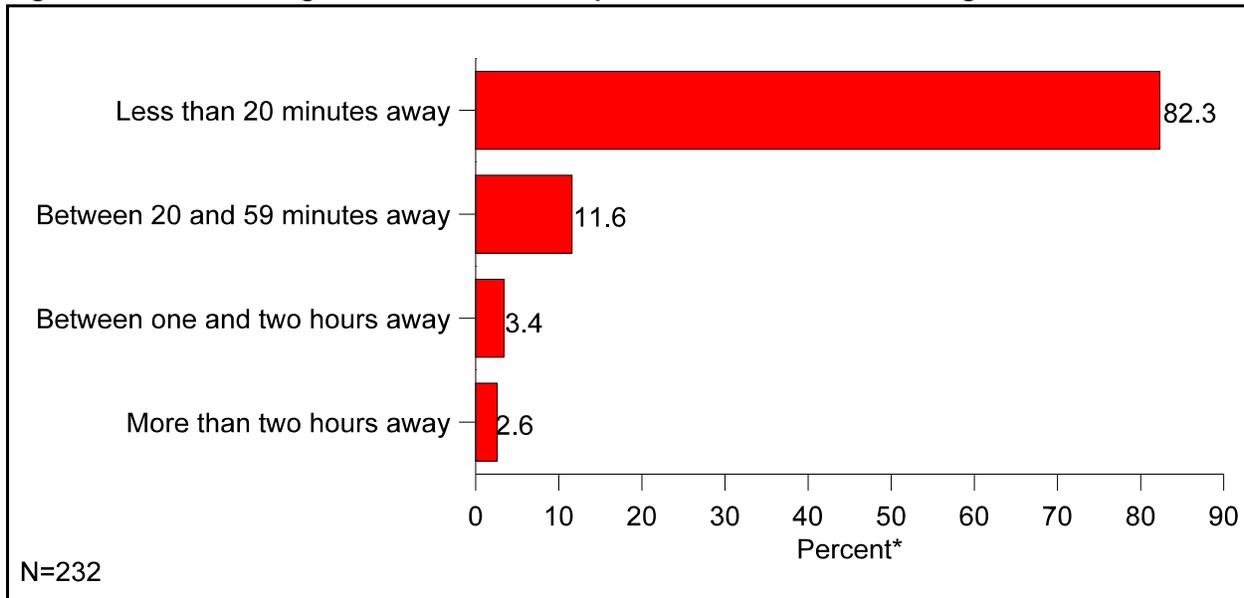


*Percents do not always add to 100.0 due to rounding.

**Full response: “Around the clock care, care recipient cannot be left alone.”

- ▶ Approximately 82 percent of caregivers who do caregiving outside of their home live less than 20 minutes away from the care recipient (Figure 6, Appendix Table 6).

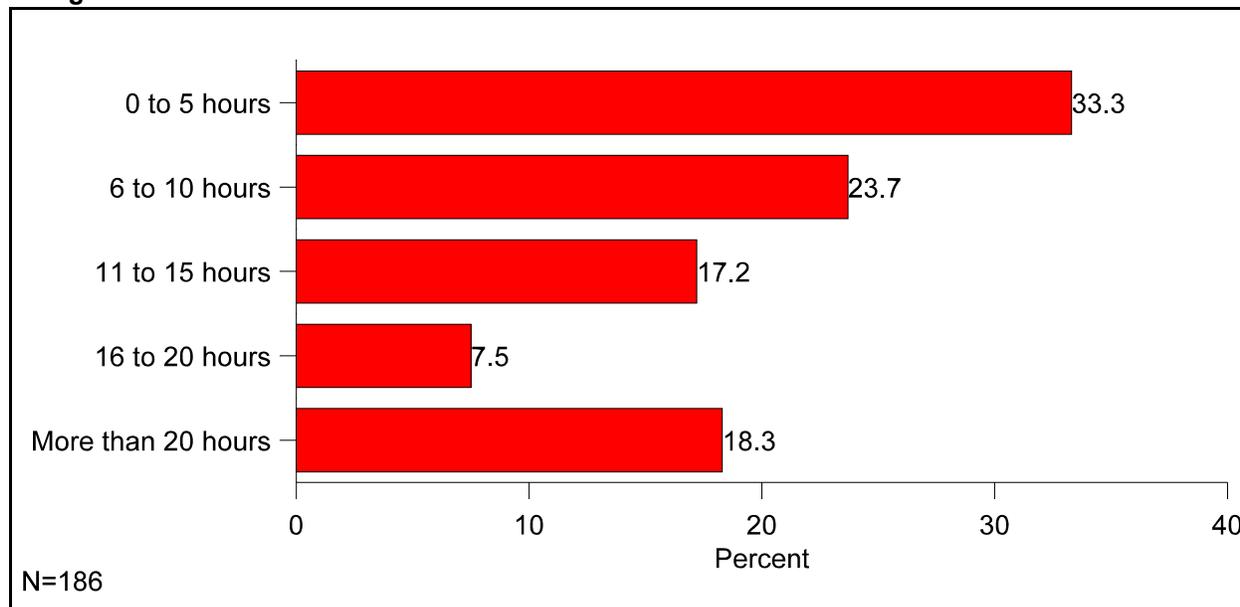
Figure 6. Distance Caregiver is From Care Recipient if Not Cared For in Caregiver’s Home



*Percents do not always add to 100.0 due to rounding.

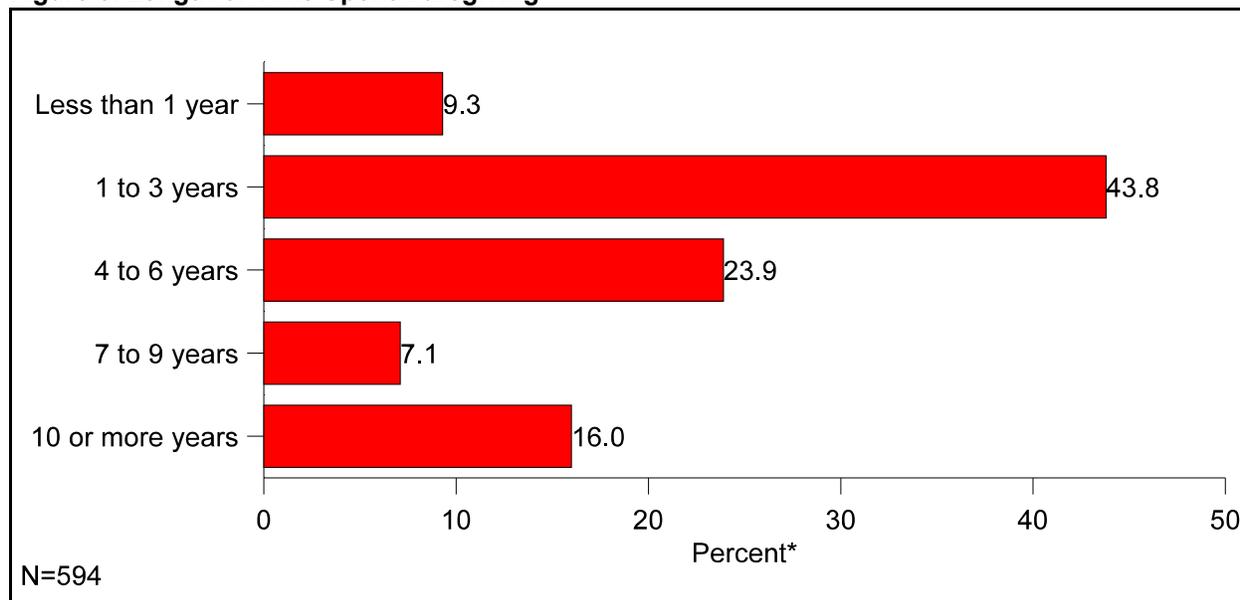
- ▶ Fifty-seven percent of caregivers who do caregiving outside the home said they spend up to 10 hours per week on average providing care. However, more than one-fourth of caregivers spend 16 or more hours per week providing care (Figure 7, Appendix Table 7).

Figure 7. Average Hours Spent Caregiving Per Week if Care Recipient is Not Cared For in Caregiver's Home



- ▶ Most caregivers said they have spent up to three years caregiving (53.1 percent). More than 23 percent of caregivers have been caregiving for at least seven years (Figure 8, Appendix Table 8).

Figure 8. Length of Time Spent Caregiving



*Percents do not always add to 100.0 due to rounding.

Informal Caregiving Difficulties/Concerns

- ▶ More than 30 percent of caregivers indicated that emotional aspects (35.8 percent) and the lifestyle change (33.9 percent) are serious difficulties they face when providing care (Table 1, Figure 9).
- ▶ Less time for family (29.9 percent), having the responsibility for making major life decisions for a loved one (29.3 percent), no consistent help from other family members (28.7 percent), and less time for themselves (27.6 percent) were difficulties experienced by approximately a fourth or more of caregivers (Table 1, Figure 9).

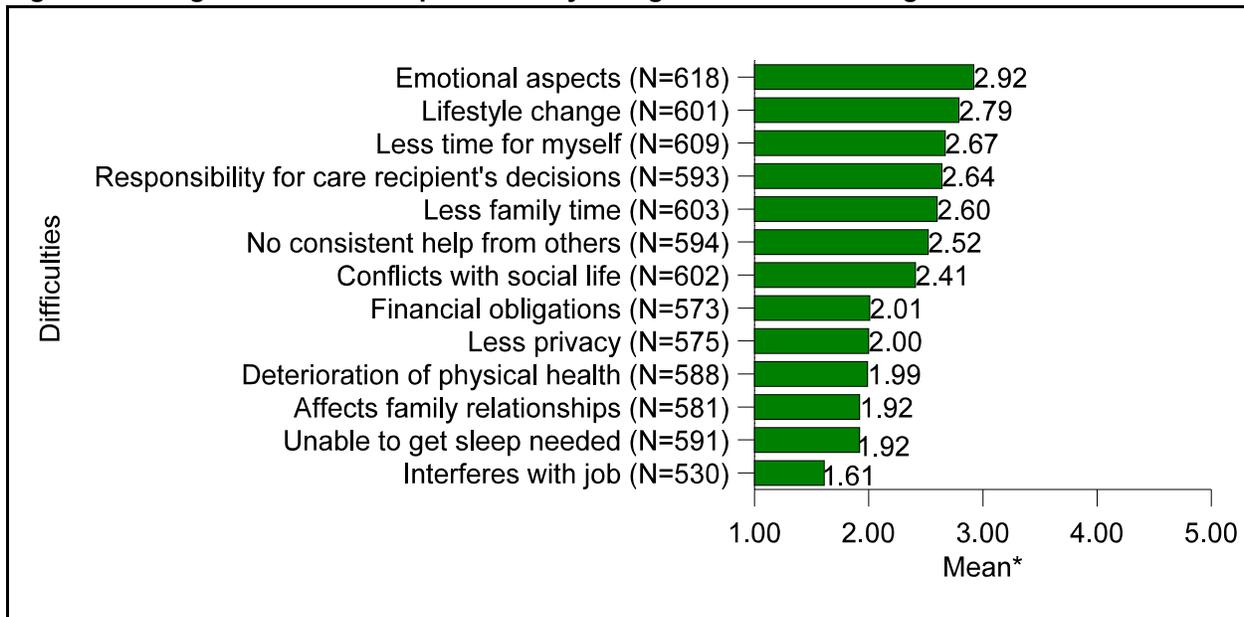
Table 1. Rating of Difficulties Experienced by Caregiver When Providing Care

Difficulties Experienced	Mean	Responses											
		Not at all serious 1		2		3		4		Very serious 5		Total	
		#	%	#	%	#	%	#	%	#	%	#	%*
Emotional aspects (frustration, stress, sadness, anxiety, etc.)	2.92	124	20.1	112	18.1	161	26.1	129	20.9	92	14.9	618	100.1
Lifestyle change	2.79	163	27.1	102	17.0	132	22.0	104	17.3	100	16.6	601	100.0
Less time for myself (shopping, hobbies, etc.)	2.67	150	24.6	134	22.0	157	25.8	106	17.4	62	10.2	609	100.0
Having the responsibility for making major life decisions for care recipient	2.64	201	33.9	93	15.7	125	21.1	69	11.6	105	17.7	593	100.0
Less time for my family (shorter vacations, missed events, etc.)	2.60	200	33.2	113	18.7	110	18.2	91	15.1	89	14.8	603	100.0
No consistent help from other family members	2.52	220	37.0	113	19.0	91	15.3	74	12.5	96	16.2	594	100.0
Conflicts with my social life (eating out, movies, visiting friends, etc.)	2.41	227	37.7	114	18.9	116	19.3	77	12.8	68	11.3	602	100.0
Financial obligations	2.01	321	56.0	79	13.8	71	12.4	50	8.7	52	9.1	573	100.0
Less privacy	2.00	305	53.0	93	16.2	86	15.0	56	9.7	35	6.1	575	100.0
My physical health is deteriorating due to caregiving	1.99	304	51.7	109	18.5	88	15.0	49	8.3	38	6.5	588	100.0
Affects my family relationships	1.92	320	55.1	98	16.9	81	13.9	53	9.1	29	5.0	581	100.0
I am unable to get the sleep I need due to caregiving	1.92	318	53.8	114	19.3	79	13.4	46	7.8	34	5.8	591	100.1
Interferes with my job	1.61	366	69.1	68	12.8	54	10.2	23	4.3	19	3.6	530	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ The ranked mean scores of difficulties experienced by caregivers when providing care can be found below (Figure 9).

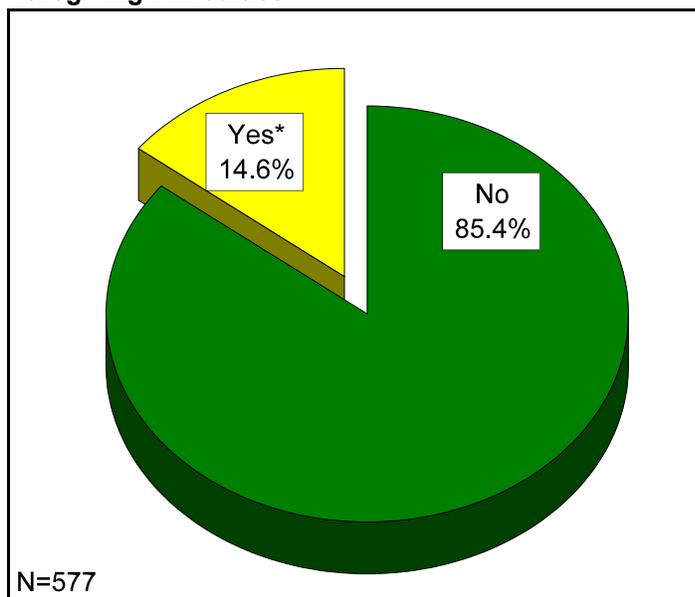
Figure 9. Rating of Difficulties Experienced by Caregiver When Providing Care



*Means were based on a one to five scale, with one being "not at all serious" and five being "very serious."

- ▶ Approximately 15 percent of caregivers experience caregiving difficulties other than those listed in Figure 9 (Figure 10, Appendix Table 9a).
- ▶ The responses of caregivers who experience other caregiving difficulties are listed in Appendix Table 9b.

Figure 10. Whether Caregiver Experiences Other Caregiving Difficulties



*See Appendix Table 9b for other caregiving difficulties.

- Caregivers were asked to rate the extent to which they agreed or disagreed with various concerns associated with being a caregiver. Nearly a quarter of caregivers agreed that it is difficult for them to accept support or assistance when caregiving because it is their duty to provide care (24.6 percent) and it is difficult for them to find support or assistance when caregiving (24.1 percent) (Table 2, Figure 11).

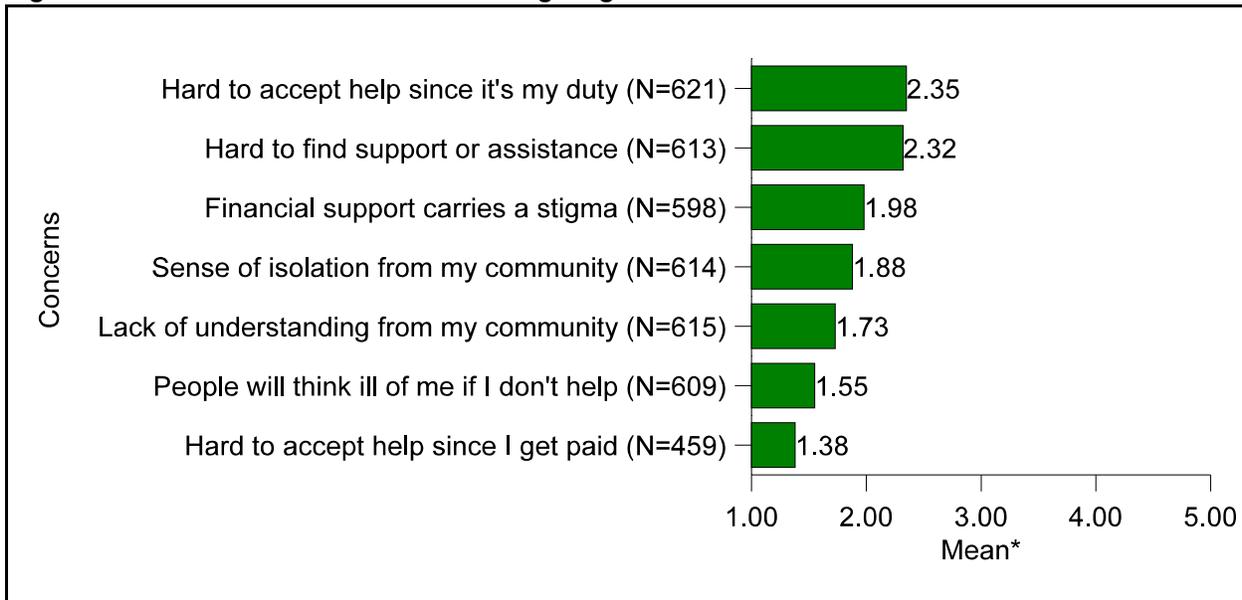
Table 2. Concerns Associated With Caregiving

Concerns	Mean	Responses											
		Strongly disagree 1		2		3		4		Strongly agree 5		Total	
		#	%	#	%	#	%	#	%	#	%	#	%*
It is difficult for me to accept support or assistance when caregiving because it is my duty to provide care	2.35	268	43.2	103	16.6	97	15.6	72	11.6	81	13.0	621	100.0
It is difficult for me to find support or assistance when caregiving (I feel like I don't have help)	2.32	267	43.6	100	16.3	98	16.0	76	12.4	72	11.7	613	100.0
It is difficult for me to accept financial support or assistance when caregiving because it sometimes carries a negative stigma	1.98	342	57.2	82	13.7	71	11.9	52	8.7	51	8.5	598	100.0
Since I have started caregiving services I've experienced a sense of isolation from others in my community	1.88	362	59.0	94	15.3	67	10.9	49	8.0	42	6.8	614	100.0
Since I have started caregiving services I've experienced a lack of understanding from others in my community	1.73	408	66.3	73	11.9	64	10.4	33	5.4	37	6.0	615	100.0
I'm providing caregiving services because people in my community will think ill of me if I don't	1.55	458	75.2	51	8.4	43	7.1	29	4.8	28	4.6	609	100.1
It is difficult for me to accept help from others when caregiving because I'm being paid (e.g. Qualified Service Provider)	1.38	378	82.4	32	7.0	21	4.6	13	2.8	15	3.3	459	100.1

*Percents do not always add to 100.0 due to rounding.

- ▶ The mean scores of concerns associated with caregiving can be found below (Figure 11).

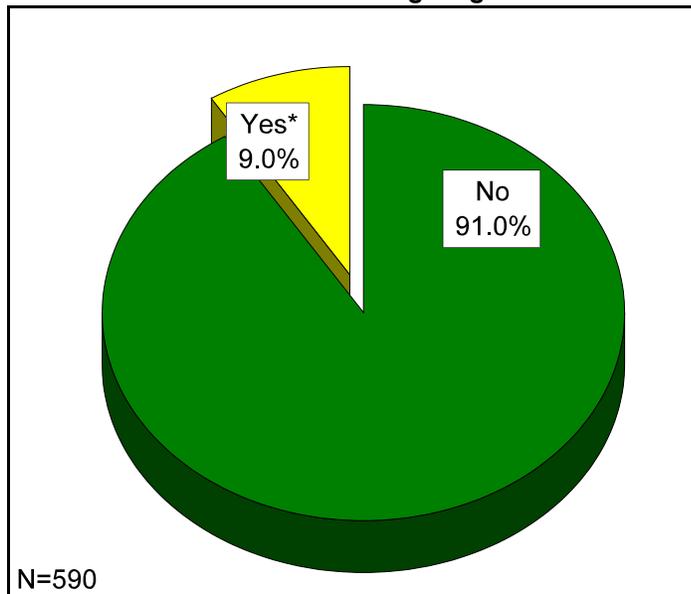
Figure 11. Concerns Associated With Caregiving



*Means were based on a one to five scale, with one being "strongly disagree" and five being "strongly agree."

- ▶ Nine percent of caregivers indicated they experience concerns associated with caregiving other than those listed in Figure 11 (Figure 12, Appendix Table 10a).
- ▶ The responses of caregivers who have other concerns are listed in Appendix Table 10b.

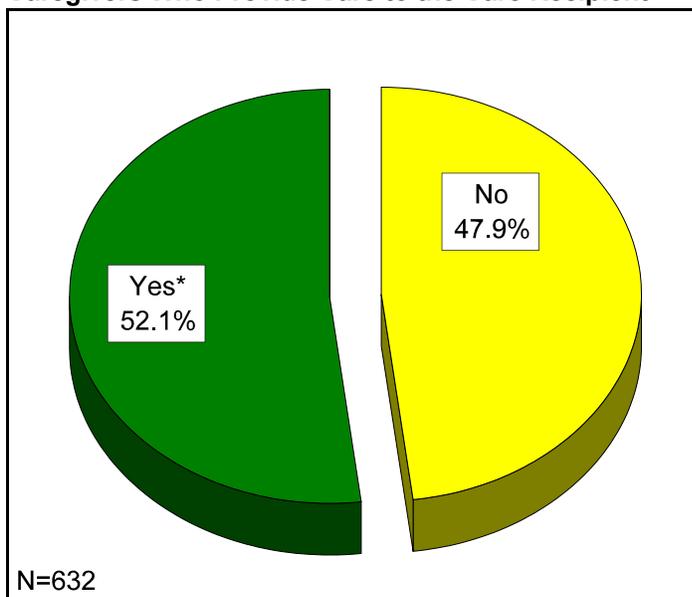
Figure 12. Whether Caregiver Experiences Other Concerns Associated With Caregiving



*See Appendix Table 10b for other concerns associated with caregiving.

- ▶ The majority of caregivers said there are other informal caregivers who provide care to the care recipient (Figure 13, Appendix Table 11a).
- ▶ Caregivers were asked to identify the relationship between themselves and the other caregivers providing care to the care recipient. Due to the way in which the question was asked, the relationship between the caregiver (respondent) and the other caregivers is often not clearly specified. For example, if the respondent indicated “sister”, it is unclear whether it is the sister of the caregiver or the sister of the care recipient. For these reasons, the results should be interpreted with caution.
- ▶ Family members were most commonly identified as other informal caregivers followed by sisters (Appendix Table 11b).
- ▶ See Appendix Table 11b for a list of other caregivers.

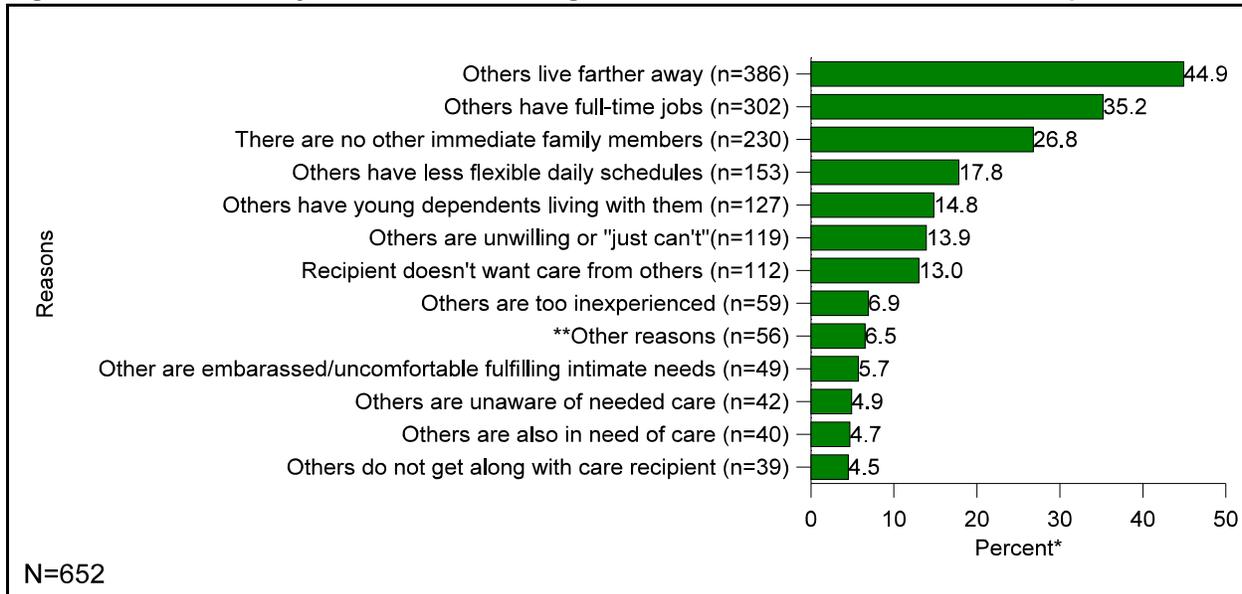
Figure 13. Whether There Are Other Informal Caregivers Who Provide Care to the Care Recipient



*See Appendix Table 11b for other informal caregivers.

- ▶ The top three reasons why other informal caregivers do not provide care were: others live farther away (44.9 percent), others have full-time jobs (35.2 percent), and there are no other immediate family members (26.8 percent) (Figure 14, Appendix Table 12).
- ▶ See Appendix Table 12 for a list of reasons why others don't provide care.

Figure 14. Reasons Why Other Informal Caregivers Do Not Provide Care to Care Recipient



*Percents do not always add to 100.0 due to multiple responses; N=652.

**See Appendix Table 12 for other reasons why other informal caregivers do not provide care.

Services Available to the Informal Care Recipient

- ▶ More than three-fourths of caregivers indicated that home delivered meals (89.7 percent), congregate meal settings (86.8 percent), and homemaker services/home health aides (77.3 percent) are available to their care recipient. More than half of caregivers indicated the care recipient has escort/transportation services (71.9 percent), visiting nurse (69.7 percent), outreach programs (63.3 percent), and dietician services (52.7 percent) available to them (Table 3).
- ▶ For more than half of caregivers, the following services are not available to their care recipients: adult day centers (52.4 percent) and parish nurse (60.2 percent) (Table 3).

Table 3. Whether Services Are Available to Care Recipient

Care Recipient Services	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
Home delivered meals (e.g., Meals on Wheels, community volunteering, or church)	567	89.7	55	8.7	10	1.6	632	100.0
Congregate meal settings (e.g., Senior centers, restaurants, etc.)	550	86.8	64	10.1	20	3.2	634	100.1
Homemaker services/home health aides	488	77.3	60	9.5	83	13.2	631	100.0
Escort/transportation services	454	71.9	109	17.3	68	10.8	631	100.0
Visiting nurse	435	69.7	97	15.5	92	14.7	624	99.9
Outreach programs (e.g., senior companions)	392	63.3	101	16.3	126	20.4	619	100.0
Dietician services	331	52.7	162	25.8	135	21.5	628	100.0
Shopping assistance	277	44.7	213	34.4	130	21	620	100.1
Pet service (e.g., grooming, vet needs, etc.)	171	31.0	205	37.2	175	31.8	551	100.0
Adult day centers	136	21.4	333	52.4	166	26.1	635	99.9
Parish nurse	68	11.1	367	60.2	175	28.7	610	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ More than half of caregivers who said outreach programs were not available to the care recipient indicated they would like them to be available (54.3 percent) (Table 4).
- ▶ Overall, caregivers were reluctant to indicate that they would like more services to be available to their care recipient. However, more than a third of caregivers indicated they would like a visiting nurse (47.2 percent), adult day centers (41.5 percent), homemaker services/home health aides (40.2 percent), escort/transportation services (36.0 percent), congregate meal settings (33.8 percent), and shopping assistance (32.8 percent) to be available to their care recipient (Table 4).

Table 4. If Services Are Not Available to Care Recipient, Whether Caregiver Would Like Them to be Available

Unavailable Care Recipient Services	Respondents by Desire for Services					
	Yes		No		Total	
	#	%	#	%	#	%
Outreach programs (i.e., senior companions)	107	54.3	90	45.7	197	100.0
Visiting nurse	77	47.2	86	52.8	163	100.0
Adult day centers	182	41.5	257	58.5	439	100.0
Homemaker services/home health aides	51	40.2	76	59.8	127	100.0
Escort/transportation services	58	36.0	103	64.0	161	100.0
Congregate meal settings (e.g., at Senior centers, restaurants, etc.)	22	33.8	43	66.2	65	100.0
Shopping assistance	101	32.8	207	67.2	308	100.0
Parish nurse	125	28.5	314	71.5	439	100.0
Home delivered meals (i.e., Meals on Wheels, community volunteering, or church)	14	23.7	45	76.3	59	100.0
Dietician services	46	17.6	215	82.4	261	100.0
Pet service (grooming, vet needs, etc.)	21	6.5	301	93.5	322	100.0

- ▶ More than half of caregivers indicated the care recipient uses outreach programs (66.1 percent), home delivered meals (54.1 percent), and a visiting nurse (54.0 percent) when those services are available (Table 5).
- ▶ Approximately one-third of respondents indicated the care recipient uses homemaker services/home health aides (39.7 percent), congregate meal settings (38.6 percent), dietician services (37.7 percent), escort/transportation services (32.8 percent), parish nurse (32.5 percent), and shopping assistance (32.2 percent) when those services are available (Table 5).
- ▶ With the exception of the three services listed above, a majority of care recipients are not using the services listed in Table 5.

Table 5. Whether Services Are Being Used if Services Are Available to Care Recipient

Available Care Recipient Services	Respondents by Use of Services					
	Yes		No		Total	
	#	%	#	%	#	%
Outreach programs (e.g., senior companions)	250	66.1	128	33.9	378	100.0
Home delivered meals (e.g., Meals on Wheels, community volunteering, or church)	295	54.1	250	45.9	545	100.0
Visiting nurse	223	54.0	190	46.0	413	100.0
Homemaker services/home health aides	186	39.7	283	60.3	469	100.0
Congregate meal settings (e.g., Senior centers, restaurants, etc.)	204	38.6	325	61.4	529	100.0
Dietician services	118	37.7	195	62.3	313	100.0
Escort/transportation services	137	32.8	281	67.2	418	100.0
Parish nurse	26	32.5	54	67.5	80	100.0
Shopping assistance	84	32.2	177	67.8	261	100.0
Pet service (e.g., grooming, vet needs, etc.)	32	18.2	144	81.8	176	100.0
Adult day centers	19	13.6	121	86.4	140	100.0

- ▶ With the exception of congregate meal settings, the most common reason the care recipient does not use the services (if they are available) listed in Table 6 because they are not needed.
- ▶ Nearly a fourth of caregivers indicated that their care recipient will not use congregate meals settings and more than 35 percent of caregivers indicated their care recipient will not use outreach programs (Table 6).
- ▶ Other reasons why care recipients does not use the services available to them are listed in Appendix Table 13 by type of service.

Table 6. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient

Care Recipient Services	Respondents by Reason of Non-use of Service							
	Do not need it		Care recipient won't use		Other reasons**		Total	
	#	%	#	%	#	%	#	%*
Pet service (grooming, vet needs, etc.)	129	91.5	0	0.0	12	8.5	141	100.0
Dietician services	146	80.2	23	12.6	13	7.1	182	99.9
Shopping assistance	136	78.2	15	8.6	23	13.2	174	100.0
Visiting nurse	135	74.6	15	8.3	31	17.1	181	100.0
Parish nurse	33	70.2	4	8.5	10	21.3	47	100.0
Homemaker services/home health aides	179	66.5	30	11.2	60	22.3	269	100.0
Home delivered meals (Meals on Wheels, community volunteering, or church)	160	64.8	36	14.6	51	20.6	247	100.0
Outreach programs (i.e. senior companions)	63	63.6	35	35.4	1	1.0	99	100.0
Adult day centers	74	62.7	13	11.0	31	26.3	118	100.0
Escort/transportation services	162	58.9	45	16.4	68	24.7	275	100.0
Congregate meal settings (as Senior centers, restaurants, etc.)	104	33.4	73	23.5	134	43.1	311	100.0

*Percents do not always add to 100.0 due to rounding.

**See Appendix Table 13 for other reasons services were not being used.

- ▶ For care recipient services, caregivers rated the services listed in Figure 14 quite good. The means range from 3.95 to 4.43 on a one to five scale, with one being “not good at all” and five being “very good” (Table 7, Figure 15).

Table 7. Ratings of Services Available to Care Recipient

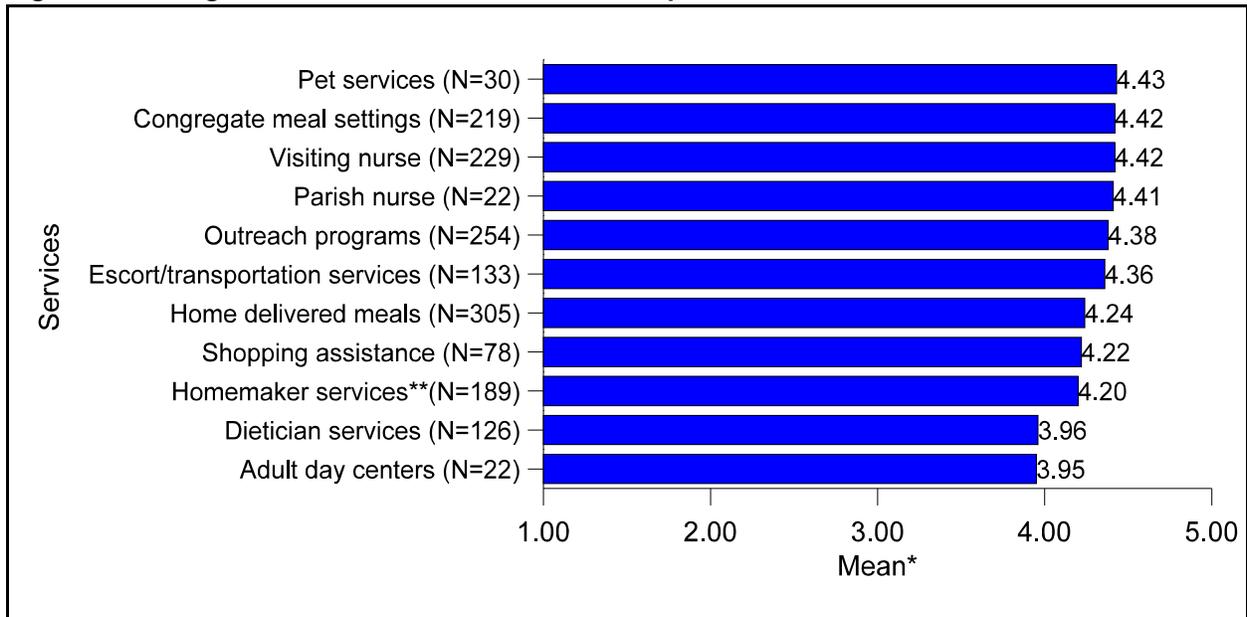
Care Recipient Services	Mean	Responses											
		Not good at all 1**		2**		3		4		Very good 5		Total	
		#	%	#	%	#	%	#	%	#	%	#	%*
Pet service (grooming, vet needs, etc.)	4.43	0	0.0	0	0.0	4	13.3	9	30.0	17	56.7	30	100.0
Congregate meal settings (senior centers, restaurants, etc.)	4.42	0	0.0	6	2.7	25	11.4	59	26.9	129	58.9	219	99.9
Visiting nurse	4.42	0	0.0	4	1.7	27	11.8	66	28.8	132	57.6	229	99.9
Parish nurse	4.41	1	4.5	0	0.0	1	4.5	7	31.8	13	59.1	22	99.9
Outreach programs (i.e. senior companions)	4.38	0	0.0	1	0.4	38	15.0	79	31.1	136	53.5	254	100.0
Escort or transportation services	4.36	2	1.5	2	1.5	14	10.5	43	32.3	72	54.1	133	99.9
Home delivered meals (Meals on wheels, community volunteering, or church)	4.24	5	1.6	10	3.3	43	14.1	97	31.8	150	49.2	305	100.0
Shopping assistance	4.22	2	2.6	1	1.3	16	20.5	18	23.1	41	52.6	78	100.1
Homemaker services/home health aides	4.20	1	0.5	5	2.6	37	19.6	59	31.2	87	46.0	189	99.9
Dietician services	3.96	0	0.0	6	4.8	35	27.8	43	34.1	42	33.3	126	100.0
Adult day centers	3.95	0	0.0	2	9.1	7	31.8	3	13.6	10	45.5	22	100.0

*Percents do not always add to 100.0 due to rounding.

**Reasons why services were rated 1 or 2 are listed in Appendix Table 14.

- ▶ The mean scores of ratings of services available to care recipients can be found below (Figure 15).

Figure 15. Ratings of Services Available to Care Recipient

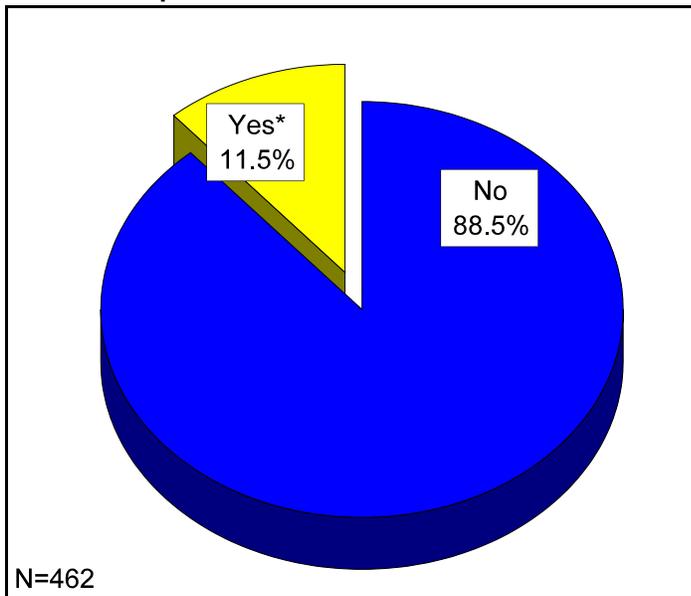


*Means were based on a one to five scale, with one being "not good at all" and five being "very good."

**Full response category states: "Homemaker services/home health aides."

- ▶ Approximately 89 percent of caregivers said there are no other care recipient services, other than those mentioned in Figure 15, that they would like to have available to their care recipient (Figure 16, Appendix Table 15a).
- ▶ The responses of caregivers who would like other services to be available to the care recipient can be found in Appendix Table 15b.

Figure 16. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Care Recipient



*See Appendix Table 15b for other services.

Services Available to the Informal Caregiver

- ▶ More than half of caregivers indicated that information about available services (75.2 percent), assistance with accessing available services (69.9 percent), and respite care (50.6 percent) are available to them (Table 8).
- ▶ Approximately one-third of caregivers said caregiver support groups (33.4 percent), individual caregiver counseling (32.4 percent), and caregiver training or education (30.3 percent) are not available to them (Table 8).

Table 8. Whether Services Are Available to Caregiver

Caregiver Services	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
Information about available services	472	75.2	42	6.7	114	18.2	628	100.1
Assistance with accessing available services	424	69.9	39	6.4	144	23.7	607	100.0
Respite care (someone else provides short-term relief for you)	316	50.6	141	22.6	167	26.8	624	100.0
Caregiver training or education	144	23.2	188	30.3	288	46.5	620	100.0
Individual caregiver counseling services	122	19.6	202	32.4	299	48.0	623	100.0
Caregiver support groups	121	19.5	207	33.4	292	47.1	620	100.0

*Percents do not always add to 100.0 due to rounding.

- ▶ The top three unavailable services that caregivers would like available to them are information about available services (68.5 percent), respite care (51.1 percent), and assistance with accessing available services (48.4 percent) (Table 9).
- ▶ Another one-third of caregivers would like caregiver support groups (38.2 percent), training or education (33.7 percent), and counseling services (30.1 percent) to be available to them (Table 9).

Table 9. If Services Are Not Available to Caregiver, Whether Caregiver Would Like Them to be Available

Unavailable Caregiver Services	Respondents by Desire for Services					
	Yes		No		Total	
	#	%	#	%	#	%
Information about available services	100	68.5	46	31.5	146	100.0
Respite care (i.e., someone else provides short-term relief for you)	141	51.1	135	48.9	276	100.0
Assistance with accessing available services	76	48.4	81	51.6	157	100.0
Caregiver support groups	166	38.2	269	61.8	435	100.0
Caregiver training or education	139	33.7	273	66.3	412	100.0
Individual caregiver counseling services	129	30.1	299	69.9	428	100.0

- ▶ More than one-third of caregivers reported they use information about available services (66.5 percent), assistance with accessing available services (63.5 percent), individual caregiver counseling services (40.5 percent), caregiver training or education (37.0 percent), and respite care (34.0 percent) (Table 10).

Table 10. Whether Services Are Being Used if Services Are Available to Caregiver

Available Caregiver Services	Respondents by Use of Services					
	Yes		No		Total	
	#	%	#	%	#	%
Information about available services	298	66.5	150	33.5	448	100.0
Assistance with accessing available services	250	63.5	144	36.5	394	100.0
Individual caregiver counseling services	51	40.5	75	59.5	126	100.0
Caregiver training or education	57	37.0	97	63.0	154	100.0
Respite care (i.e., someone else provides short-term relief for you)	101	34.0	196	66.0	297	100.0
Caregiver support groups	35	26.1	99	73.9	134	100.0

- ▶ The most common reason caregivers do not use the services listed in Table 8 (if they are available) is because they do not need it. (Table 11).
- ▶ Other reasons why services are not being used if the services are available to the caregiver are typically “do not need it,” “too busy,” care recipient won’t use it,” and “distance.” A complete list of other reasons why caregivers do not use the services available to them are listed in Appendix Table 16 by type of services.

Table 11. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver

Available Caregiver Services	Respondents by Reason for Non-use of Service					
	Do not need it		Other reasons*		Total	
	#	%	#	%	#	%
Information about available services	117	86.7	18	13.3	135	100.0
Assistance with accessing available services	111	87.4	16	12.6	127	100.0
Individual caregiver counseling services	63	90.0	7	10.0	70	100.0
Caregiving training or education	62	78.5	17	21.5	79	100.0
Respite care (i.e., someone else provides short-term relief for you)	153	85.0	27	15.0	180	100.0
Caregiver support programs	70	76.1	22	23.9	92	100.0

*See Appendix Table 16 for other reasons services were not being used.

- ▶ For caregiver services being used, caregivers in Figure 17 rated the services listed quite good. The means range from 3.76 to 4.35 on a one to five scale, with one being “not good at all” and five being “very good” (Table 12, Figure 17)

Table 12. Ratings of Services Available to Caregiver

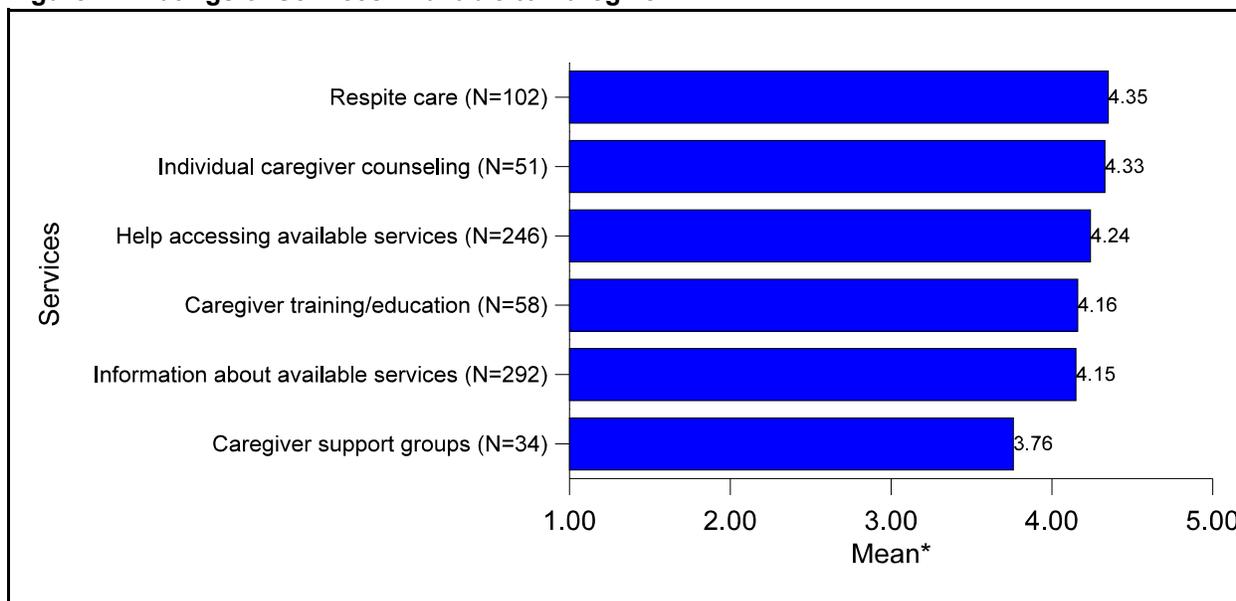
Caregiver Services	Mean	Responses											
		Not at all good 1**		2**		3		4		Very Good 5		Total	
		#	%	#	%	#	%	#	%	#	%	#	%*
Respite care (someone else provides short-term relief for you)	4.35	0	0.0	3	2.9	14	13.7	29	28.4	56	54.9	102	99.9
Individual caregiver counseling services	4.33	0	0.0	1	2	10	19.6	11	21.6	29	56.9	51	100.1
Assistance with accessing available services	4.24	4	1.6	4	1.6	39	15.9	82	33.3	117	47.6	246	100.0
Caregiver training or education	4.16	1	1.7	0	0	15	25.9	15	25.9	27	46.6	58	100.1
Information about available services	4.15	4	1.4	7	2.4	58	19.9	95	32.5	128	43.8	292	100.0
Caregiver support groups	3.76	2	5.9	4	11.8	4	11.8	14	41.2	10	29.4	34	100.1

*Percents do not always add to 100.0 due to rounding.

**Reasons why services were rated 1 or 2 are listed in Appendix Table 17.

- ▶ The mean scores of ratings of services available to the caregiver can be found below (Figure 17).
- ▶ Reasons why caregivers rated certain services lower (by giving the service a score of one or two) can be found in Appendix Table 17.

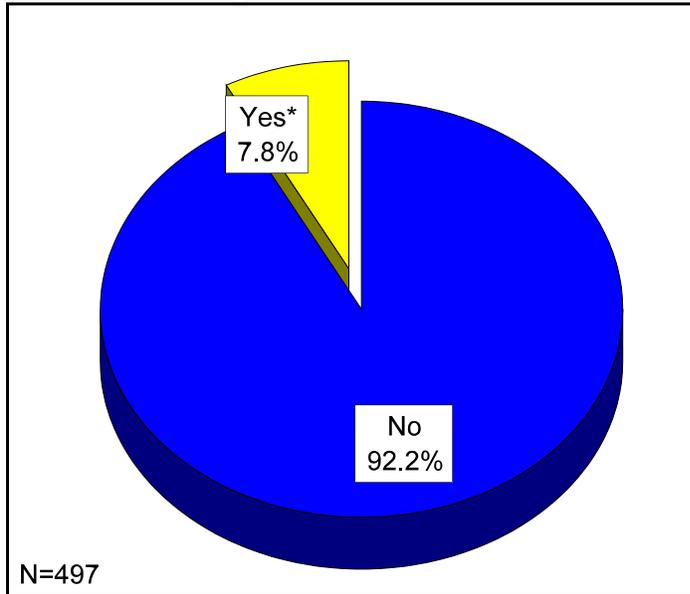
Figure 17. Ratings of Services Available to Caregiver



*Means were based on a one to five scale, with one being “not good at all” and five being “very good.”

- ▶ Approximately 92 percent of caregivers said there are no services, other than those mentioned in Figure 17, that they would like available to them (Figure 18, Appendix Table 18a).
- ▶ The other services that caregivers would like available to them are listed in Appendix Table 18b.

Figure 18. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver



*See Appendix Table 18b for other services.

- ▶ More than one-third of caregivers indicated that information or services that would be valuable to caregivers, now or in the future, are respite care (39.1 percent), information about the care recipient's condition or disability (38.2 percent), information about developments/changes in laws affecting your situation (37.6 percent) and an info-line (36.8 percent) (Table 13).

Table 13. Information or Services That Would be Valuable to Caregiver

Information or Services	Respondents (N=652)	
	#	%*
Respite care or adult day care	255	39.1
Information about the care recipient's condition or disability	249	38.2
Information about developments/changes in laws affecting your situation	245	37.6
Info-line (central place to call and find out what kind of help is available)	240	36.8
Financial Support	207	31.7
Help in understanding how to pay for nursing homes/adult day care, etc.	204	31.3
Help in dealing with agencies (bureaucracies) to get services	202	31.0
Someone to help you arrange for services, assess your situation	190	29.1
Someone to talk to/counseling services/support group	190	29.1
Tax break, stipend, government subsidy	179	27.5
Information on end of life issues	176	27.0
Help in assessing the timing of placement in formal caregiving institutions	155	23.8
Help in understanding how to select a nursing home/other care facility	145	22.2
Aftercare/grief counseling	101	15.5
Hotline (for dealing with immediate emotional needs while preserving dignity)	94	14.4
None of the above	81	12.4
Other**	12	1.8

*Percents do not always add to 100.0 due to multiple responses; N=652.

**Twelve caregivers indicated that there was "other" information or services that would be useful to them, however, they did not indicate what those might be.

Services Provided by the Informal Caregiver

- ▶ The vast majority of all caregivers reported they do provide each of the services listed in Table 14.
- ▶ Although helping with legal assistance was the service provided least by caregivers, nearly two-thirds (65.1 percent) of them have done so (Table 14).

Table 14. Whether Caregiver Provides Any of the Following Services

Services Provided by the Caregiver	Respondents By Provision of Service					
	Yes		No		Total	
	#	%	#	%	#	%
Listen to them-someone for them to talk to	598	99.8	1	0.2	599	100.0
Provide companionship	594	99.0	6	1.0	600	100.0
Assist with errands/shopping	582	98.0	12	2.0	594	100.0
Assist with household tasks (including pet care)	559	96.4	21	3.6	580	100.0
Provide transportation, getting places	569	95.3	28	4.7	597	100.0
Help with worries, anxiety, and emotional needs (i.e. loss of independence, leaving home behind, fear of death, crying, anger, etc.)	541	94.4	32	5.6	573	100.0
Communicate with medical providers	530	92.8	41	7.2	571	100.0
Assist with meals/nutritional needs	534	91.3	51	8.7	585	100.0
Provide phone contact	463	91.3	44	8.7	507	100.0
Manage finances	528	88.7	67	11.3	595	100.0
Assist with medicines (administering, side effects, etc.)	485	85.4	83	14.6	568	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	478	83.7	93	16.3	571	100.0
Assist with maintenance/repair (indoor/outdoor)	452	82.9	93	17.1	545	100.0
Get other family members involved in caregiving	428	79.1	113	20.9	541	100.0
Contribute financially	347	71.1	141	28.9	488	100.0
Help with legal assistance	332	65.1	178	34.9	510	100.0

- ▶ The majority of caregivers provided many services on a daily basis; listening to the care recipient (85.5 percent), providing companionship (82.3 percent), assisting with meals/nutritional needs (69.1 percent), providing phone contact (69.0 percent), helping with worries, anxiety, and emotional needs (65.1 percent), and assisting with medicines (60.6 percent) (Table 15).
- ▶ More than one-third of caregivers provided transportation and assisted with errands/shopping on a weekly basis (35.7 percent and 38.9 percent, respectively) (Table 15).
- ▶ Approximately one-fourth of caregivers communicated with medical providers on a monthly basis (25.2 percent) (Table 15).
- ▶ Nearly half of caregivers provided legal assistance (47.8 percent) and got other family members involved in caregiving (45.7 percent) on an occasional basis (Table 15).

Table 15. Frequency of Service Delivery if Caregiver Provides Service

Services	Respondents by Frequency of Service Delivery											
	Daily		Weekly		Monthly		On occasion		Never		Total	
	#	%	#	%	#	%	#	%	#	%	#	%*
Assist with medicines (administering, side effects, etc.)	344	60.6	51	9.0	10	1.8	80	14.1	83	14.6	568	100.1
Assist with meals/nutritional needs	404	69.1	55	9.4	3	0.5	72	12.3	51	8.7	585	100.0
Provide companionship	494	82.3	80	13.3	2	0.3	18	3.0	6	1.0	600	99.9
Listen to them-someone for them to talk to	512	85.5	61	10.2	0	0.0	25	4.2	1	0.2	599	100.1
Assist with household tasks (including pet care)	357	61.6	95	16.4	21	3.6	86	14.8	21	3.6	580	100.0
Provide phone contact	350	69.0	60	11.8	6	1.2	47	9.3	44	8.7	507	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	225	39.4	105	18.4	29	5.1	119	20.8	93	16.3	571	100.0
Help with worries, anxiety, and emotional needs (e.g., loss of independence, leaving home behind, fear of death, crying, anger)	373	65.1	57	9.9	7	1.2	104	18.2	32	5.6	573	100.0
Contribute financially	140	28.7	33	6.8	82	16.8	92	18.9	141	28.9	488	100.1
Manage finances	222	37.3	104	17.5	115	19.3	87	14.6	67	11.3	595	100.0
Provide transportation, getting places	218	36.5	213	35.7	25	4.2	113	18.9	28	4.7	597	100.0
Assist with errands/shopping	274	46.1	231	38.9	26	4.4	51	8.6	12	2.0	594	100.0
Assist with maintenance/repair (indoor/outdoor)	172	31.6	90	16.5	33	6.1	157	28.8	93	17.1	545	100.1
Get other family members involved in caregiving	79	14.6	77	14.2	25	4.6	247	45.7	113	20.9	541	100.0
Help with legal assistance	56	11.0	10	2.0	22	4.3	244	47.8	178	34.9	510	100.0
Communicate with medical providers	81	14.2	89	15.6	144	25.2	216	37.8	41	7.2	571	100.0

*Percents do not always add to 100.0 due to rounding.

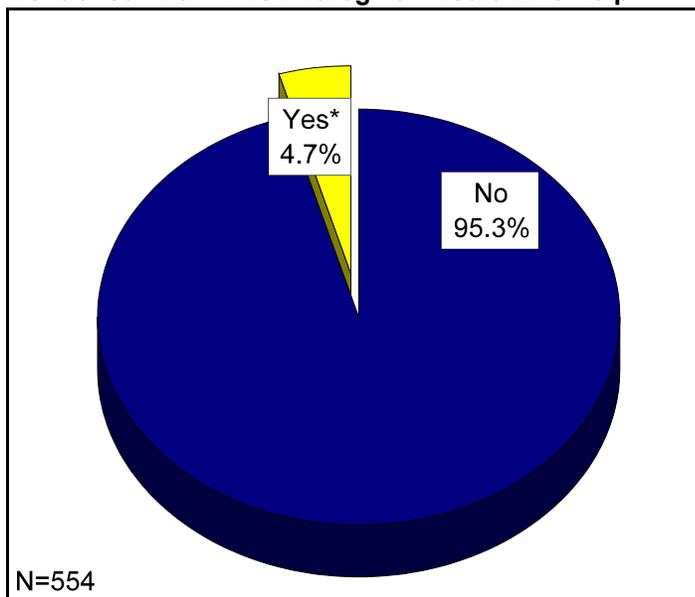
- Caregivers were reluctant to indicate they would like help providing services to their care recipient. However, at least a third of caregivers indicated they would like help assisting with maintenance/repair (37.9 percent), providing companionship (35.5 percent), listening to the care recipient/being someone for them to talk to (35.5 percent), and assisting with household tasks (35.3 percent) (Table 16).

Table 16. Whether Caregiver Would Like Help Providing the Service

Services	Respondents by Whether They Would Like Help Providing the Service					
	Yes		No		Total	
	#	%	#	%	#	%
Assist with maintenance/repair (indoor/outdoor)	158	37.9	259	62.1	417	100.0
Provide companionship	158	35.5	287	64.5	445	100.0
Listen to them-someone for them to talk to	161	35.5	292	64.5	453	100.0
Assist with household tasks (including pet care)	152	35.3	278	64.7	430	100.0
Provide transportation, getting places	151	32.3	316	67.7	467	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	134	31.0	298	69.0	432	100.0
Assist with meals/nutritional needs	130	30.2	300	69.8	430	100.0
Help with worries, anxiety, and emotional needs (i.e. loss of independence, leaving home behind, fear of death, crying, anger, etc.)	117	27.3	312	72.7	429	100.0
Assist with errands/shopping	116	26.0	331	74.0	447	100.0
Contribute financially	83	22.0	295	78.0	378	100.0
Provide phone contact	86	21.7	311	78.3	397	100.0
Get other family members involved in caregiving	85	20.0	341	80.0	426	100.0
Assist with medicines (administering, side effects, etc.)	85	19.5	350	80.5	435	100.0
Help with legal assistance	79	18.5	348	81.5	427	100.0
Communicate with medical providers	64	14.4	379	85.6	443	100.0
Manage finances	32	7.2	412	92.8	444	100.0

- ▶ Approximately 95 percent of caregivers said there are no other services, other than those mentioned in Table 16, with which they would like help (Figure 19, Appendix Table 19a).
- ▶ Comments from caregivers regarding other services with which they would like help can be found in Appendix Table 19b.

Figure 19. Whether There Are Other Services Not Mentioned With Which Caregiver Would Like Help



*See Appendix Table 19b for other services.

- ▶ Nearly 34 percent of caregivers indicated they have not experienced any of the financial difficulties listed in Table 17 as a result of caregiving. However, more than 14 percent of caregivers report they have taken off work early or arrived to work late because of caregiving (17.2 percent), changed locations to accommodate care recipients needs (15.2 percent), had time conflicts between working and caregiving (14.7 percent), and used vacation time to provide care (14.0 percent) (Table 17).

Table 17. Financial Difficulties Caregiver Experiences Because of Caregiving

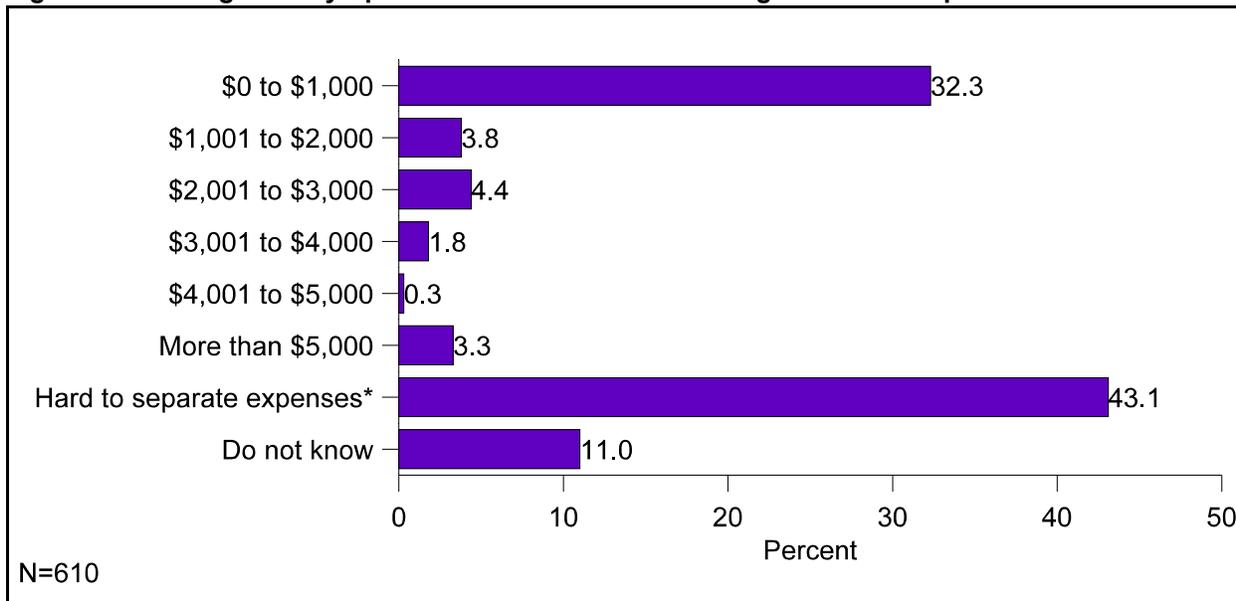
Financial Difficulties Experienced by Caregiver Because of Caregiving	Respondents (N=652)	
	#	%*
None of the difficulties below	221	33.9
Taken off work early or arrived to work late because you provided care	112	17.2
Changed locations to accommodate care recipients needs (handicap access)	99	15.2
Had time conflicts between working and caregiving	96	14.7
Used your vacation time to provide care	91	14.0
Stopped working	47	7.2
Retired early	42	6.4
Reduced your official working hours	37	5.7
Changed from full-time to part-time work	32	4.9
Sold a home to move in with care recipient	26	4.0
Taken a leave of absence to provide care	25	3.8
Lost some of your employment fringe benefits	23	3.5
Taken a less demanding job	20	3.1
Lost a promotion	3	0.5
Other:	17	2.6
<i>Blank</i>	2	
<i>Retired</i>	2	
<i>Confined to being with care recipient</i>	1	
<i>Confined to home</i>	1	
<i>Confined to home b/c does not want to leave home</i>	1	
<i>Possibly more confined to being recipient</i>	1	
<i>Had a part-time job-gave up for full-time caregiving after retirement</i>	1	
<i>Lunch hrs taken extra time</i>	1	
<i>Never worked out of home</i>	1	
<i>Not taken other employment opportunities</i>	1	
<i>Did not take employment due to caregiving</i>	1	
<i>Do not go fishing and hunting like I used to</i>	1	
<i>Have to be here most of the time</i>	1	
<i>Built a handicap home</i>	1	
<i>Many tasks don't get done because caregiving is important</i>	1	

*Percents do not always add to 100.0 due to multiple responses; N=652.

Demographics

- Approximately 43 percent of caregivers report that it is difficult for them to divide expenses because the care recipient lives with them. However, more than 32 percent of caregivers reported that they spent between \$0 and \$1,000 in the last year caring for the care recipient (Figure 20, Appendix Table 20).

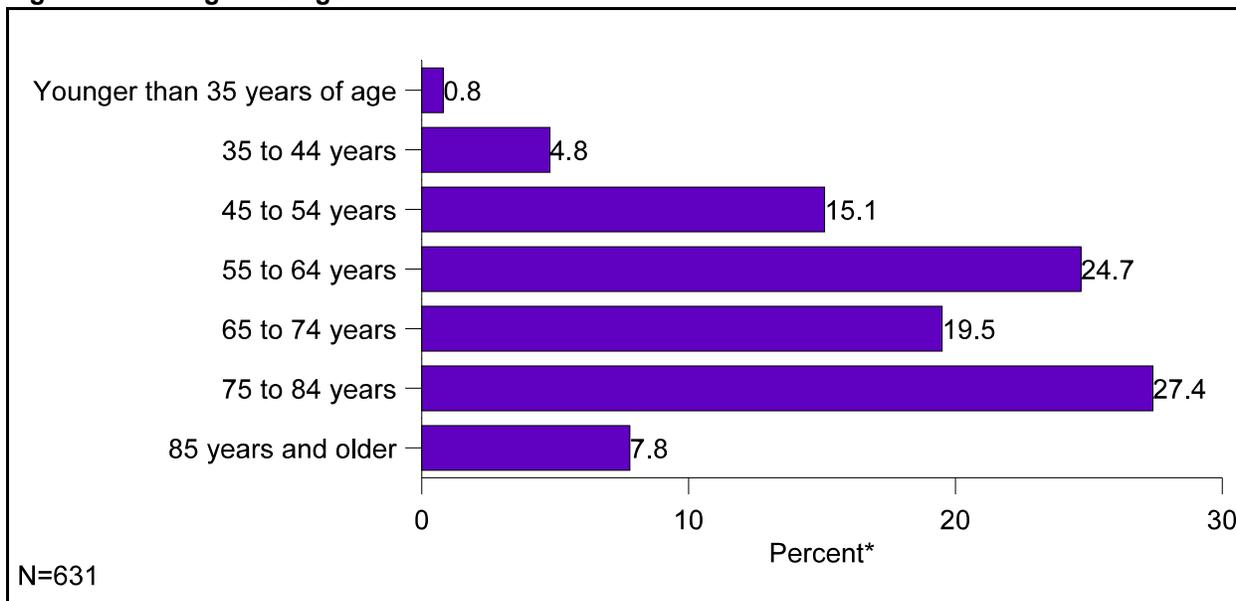
Figure 20. Average Money Spent Within the Last Year Caring for Care Recipient



*Full response category states: "The care recipient lives with me - it's difficult to separate expenses."

- More than half of caregivers are age 65 or older (Figure 21, Appendix Table 21).

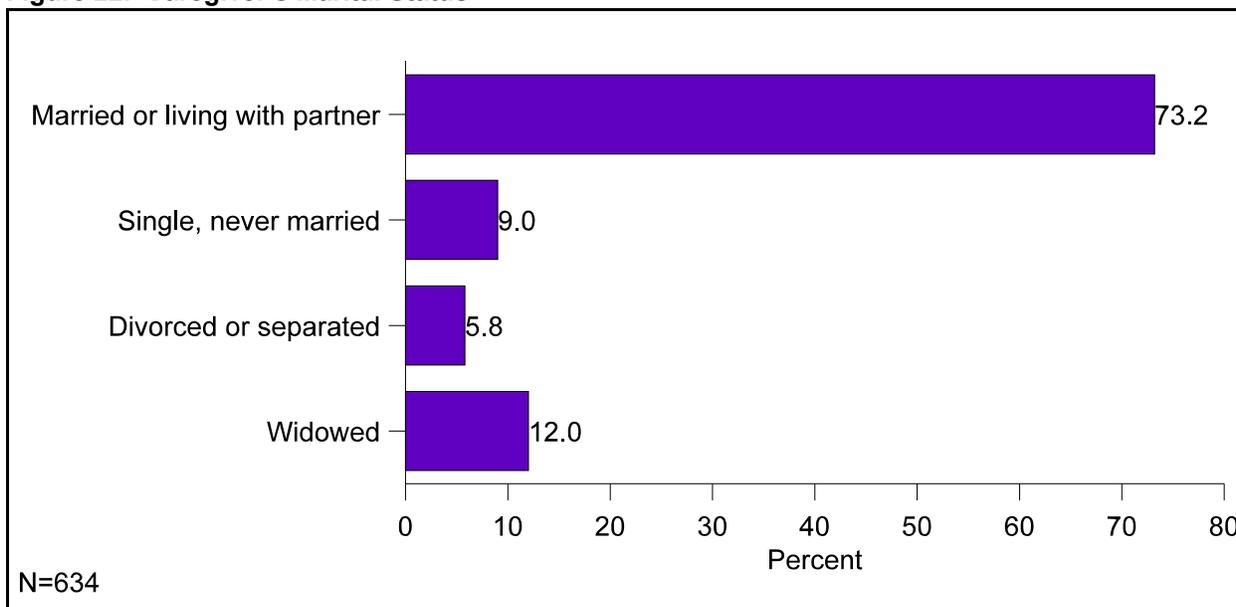
Figure 21. Caregiver's Age



*Percents do not always add to 100.0 due to rounding.

- ▶ Approximately 73 percent of caregivers are married or living with a partner (Figure 22, Appendix Table 22).

Figure 22. Caregiver's Marital Status



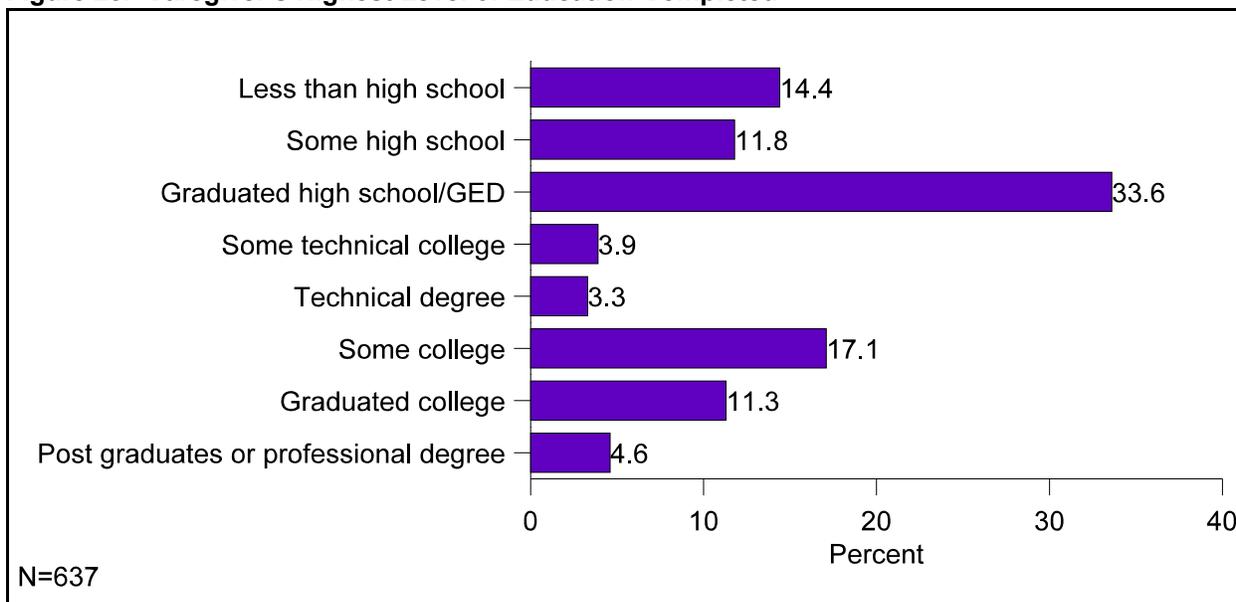
- ▶ A majority of caregivers do not have children residing in their household. However, of caregivers who do have children residing within their household, a majority of them have only one child within their household (Table 18).

Table 18. Age of Children That Reside in Caregiver's Household

Age of Children	Number of Respondents with Children by Number of Children							
	Total Number of Respondents with Children		1 child		2 children		3 children	
	#	%	#	%	#	%	#	%
0 to 4 years old	34	100.0	34	100.0	0	0.0	0	0.0
5 to 9 years old	14	100.0	10	71.4	4	28.6	0	0.0
10 to 14 years old	29	100.0	22	75.9	7	24.1	0	0.0
15 to 18 years old	26	100.0	23	88.5	3	11.5	0	0.0
18 years or older	39	100.0	35	89.7	3	7.7	1	2.6

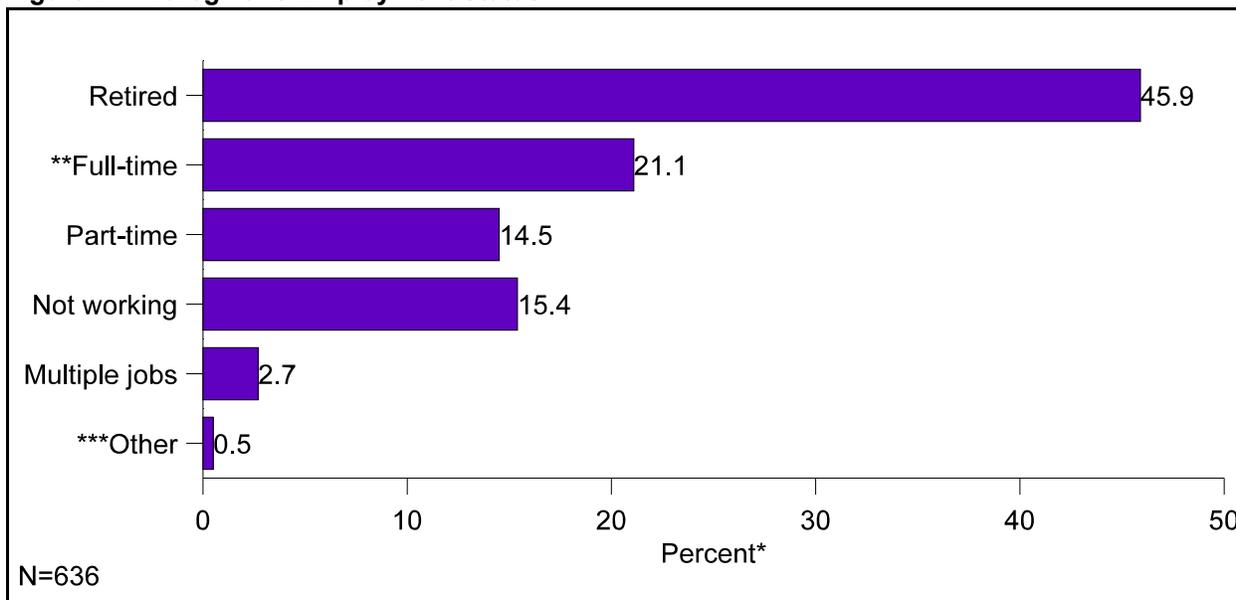
- ▶ Nearly 34 percent of caregivers indicated the highest level of education they had achieved was a high school diploma or GED. An almost equal proportion had completed at least some college or more (Figure 23, Appendix Table 23).

Figure 23. Caregiver’s Highest Level of Education Completed



- ▶ Nearly 46 percent of caregivers are retired. Approximately 21 percent of caregivers work full-time (Figure 24, Appendix Table 24a).
- ▶ For a list of other employment status’, see Appendix Table 24b.

Figure 24. Caregiver’s Employment Status



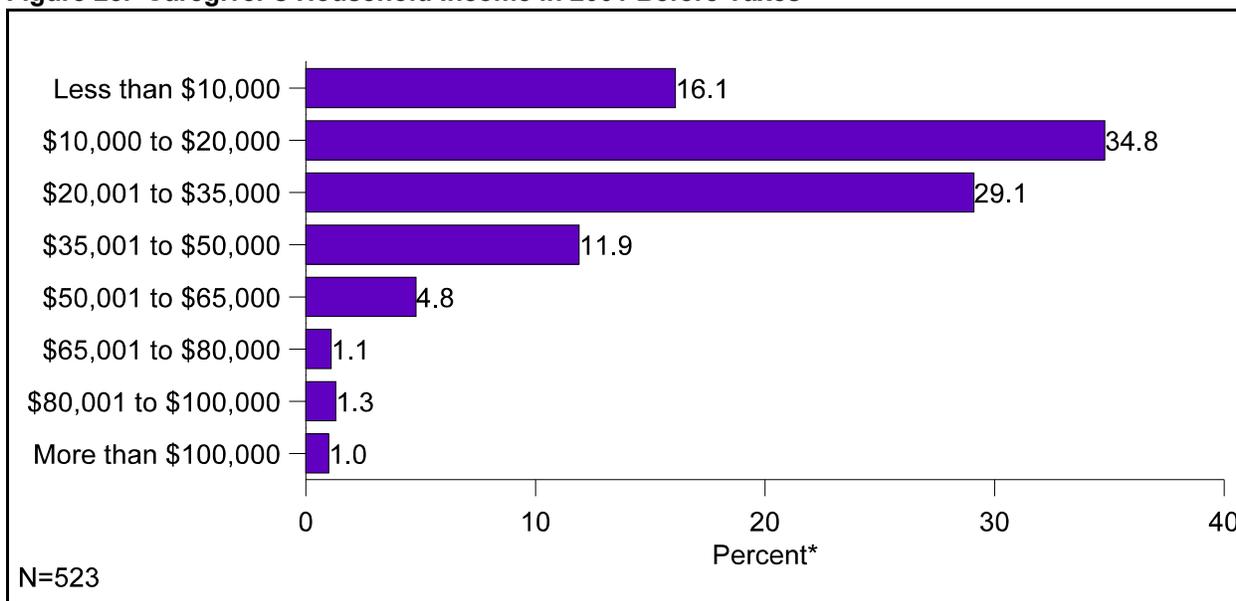
*Percents do not always add to 100.0 due to rounding.

**Full response category states: “Full-time employment (35 hours/week or more).”

***For a list of other employment status’, see Appendix Table 24b.

- ▶ Approximately 29 percent of caregivers had a household income in 2001 before taxes of \$20,001 to \$35,000. More than half of caregivers had a household income in 2001 before taxes of \$20,000 or less (Figure 25, Appendix Table 25).
- ▶ According to the 2000 Census, the median household income in North Dakota was \$34,604 (Source: US Census Bureau, 2000 Census, SF3 Table P53).

Figure 25. Caregiver's Household Income in 2001 Before Taxes**

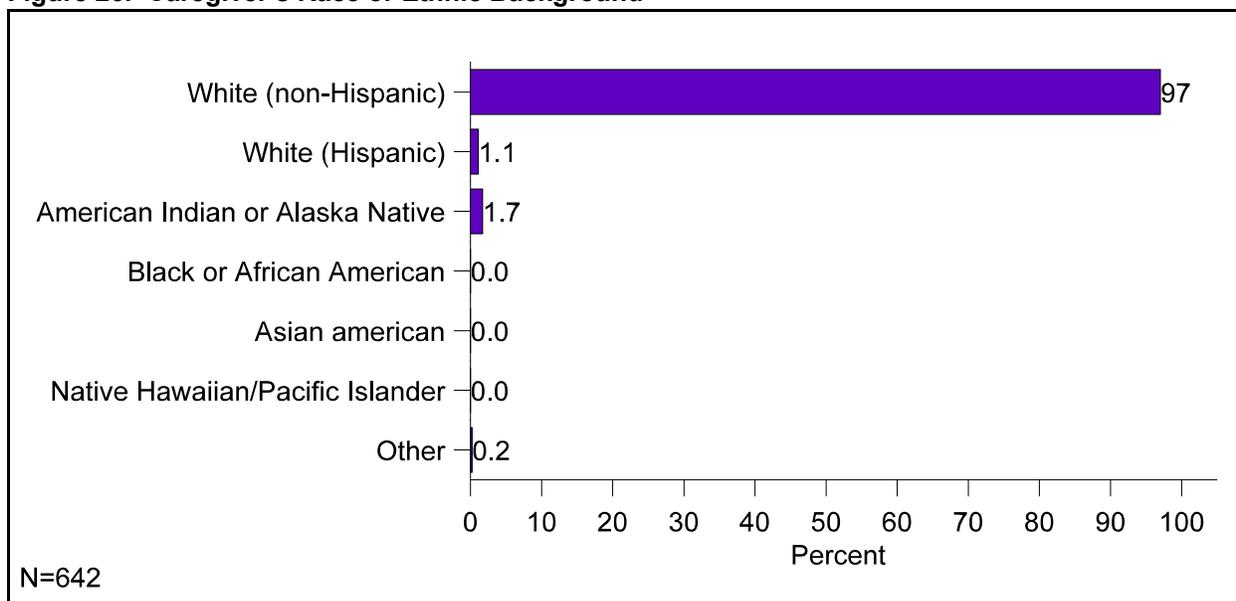


*Percents do not always add to 100.0 due to rounding.

**Including money from jobs, social security, retirement income, public assistance, etc.

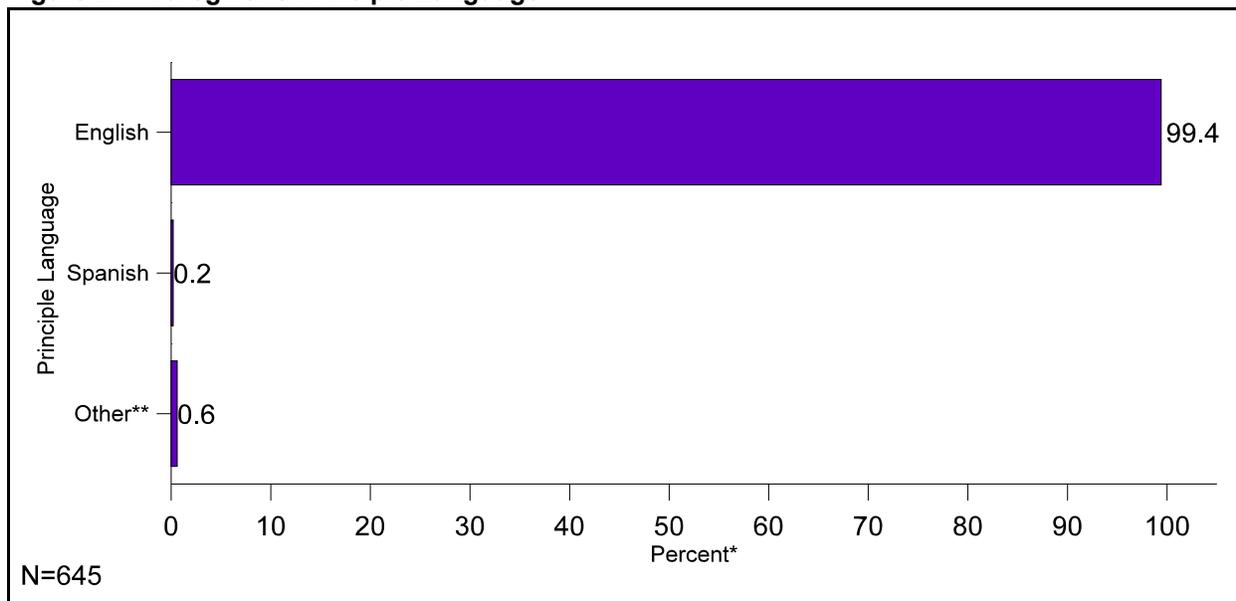
- ▶ The majority of caregivers are white (97.0 percent) (Figure 26, Appendix Table 26).

Figure 26. Caregiver's Race or Ethnic Background



- ▶ The majority of caregivers indicated their principle language is English (99.4 percent) (Figure 27, Appendix Table 27).

Figure 27. Caregiver's Principle Language

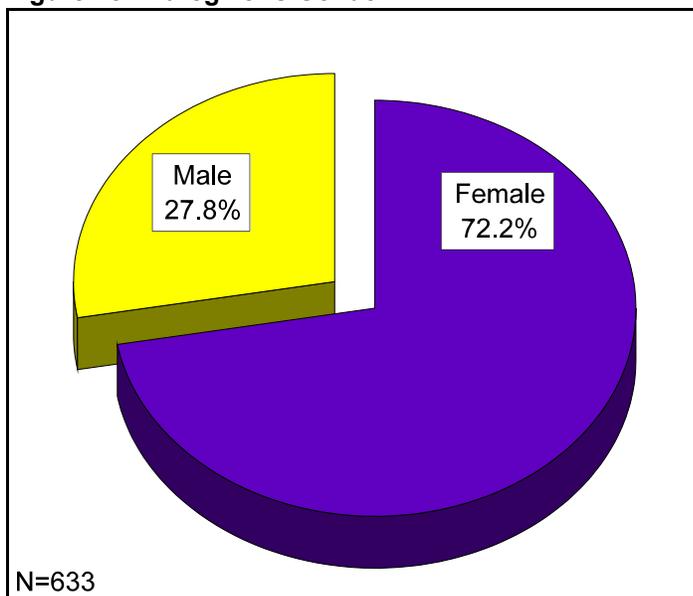


*Percents do not always add to 100.0 due to rounding.

**See Appendix Table 29 for others.

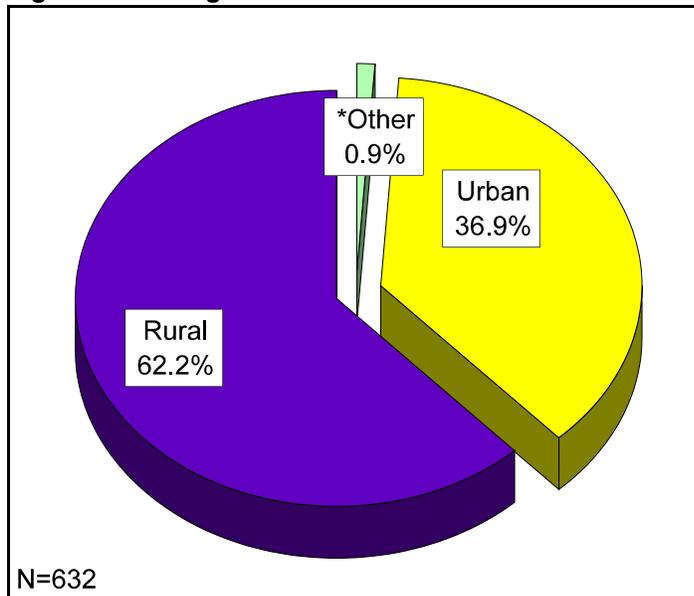
- ▶ Approximately 72 percent of caregivers are female (Figure 28, Appendix Table 28).

Figure 28. Caregiver's Gender



- ▶ More than 62 percent of caregivers indicated their place of residence is rural (Figure 29, Appendix Table 29a).
- ▶ For a list of other places of residence, see Appendix Table 29b.

Figure 29. Caregiver's Place of Residence



*For a list of other places of residence, see Appendix Table 29b.

- ▶ As follows is a table showing the distribution of caregivers by county of residence (Table 19).
- ▶ For a list of caregiver's other places of residence, see Appendix Table 29b.

Table 19. Caregivers by County of Residence

County	Respondents	
	#	%
Adams	37	5.9
Barnes	9	1.4
Benson	2	0.3
Billings	3	0.5
Bottineau	12	1.9
Bowman	14	2.2
Burke	1	0.2
Burleigh	20	3.2
Cass	1	0.2
Cavalier	25	4.0
Dickey	9	1.4
Divide	16	2.5
Dunn	17	2.7
Eddy	0	0.0
Emmons	16	2.5
Foster	8	1.3
Golden Valley	4	0.6
Grand Forks	9	1.4
Grant	16	2.5
Griggs	11	1.7
Hettinger	16	2.5
Kidder	25	4.0
LaMoure	5	0.8
Logan	5	0.8
McHenry	19	3.0
McIntosh	6	0.9

Table 19. Caregivers by County of Residence (continued)

County	Respondents	
	#	%
McKenzie	23	3.6
McLean	22	3.5
Mercer	15	2.4
Morton	20	3.2
Mountrail	5	0.8
Nelson	6	0.9
Oliver	4	0.6
Pembina	12	1.9
Pierce	10	1.6
Ramsey	15	2.4
Renville	0	0.0
Richland	11	1.7
Rolette	16	2.5
Sargent	0	0.0
Sheridan	14	2.2
Sioux	0	0.0
Slope	5	0.8
Stark	27	4.3
Steele	0	0.0
Stutsman	16	2.5
Towner	2	0.3
Traill	0	0.0
Walsh	17	2.7
Ward	21	3.3
Wells	17	2.7
Williams	42	6.6
Total	626	100.0

Tests of Statistical Significance

Significant Differences by Caregiver Relationship

Caregivers were asked to identify their relationship to the person to whom they provided informal care (also known as the care recipient). Due to the small number of persons who indicated they provided care to anyone other than a spouse or parent, all other responses were grouped into a category called additional caregivers.

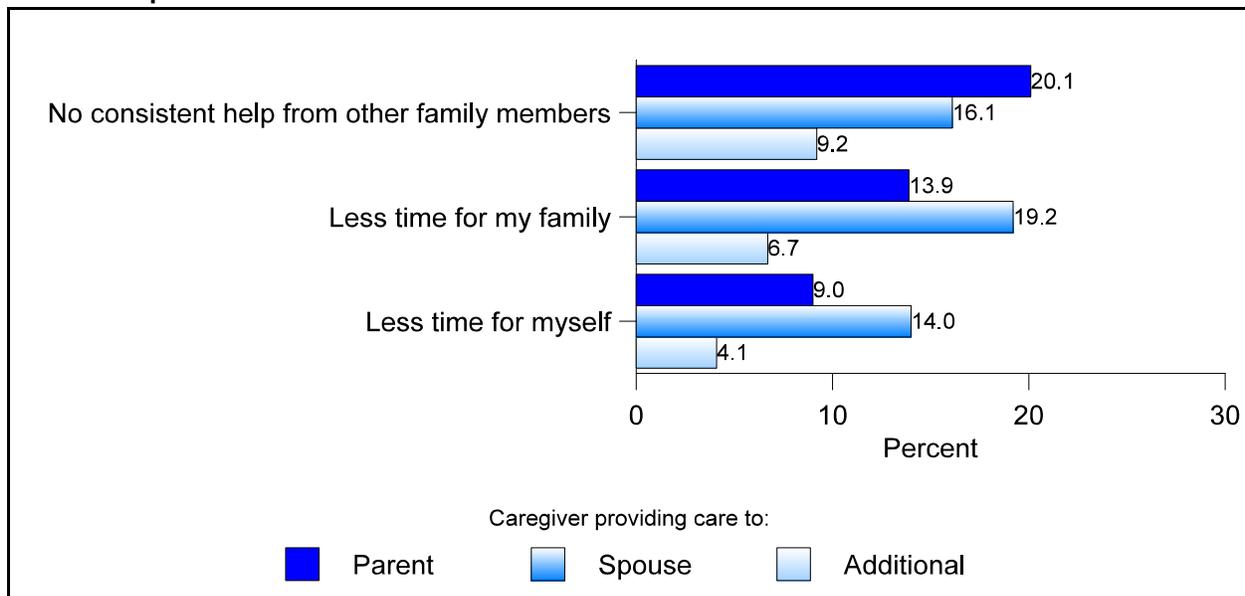
Difficulties

- ▶ The nine types of difficulties noted in the survey that were found to have a statistically significant difference by caregiver relationship are grouped into three categories representing issues related to time and assistance, emotional or social conflicts, and physical and lifestyle changes (Figure 30a, Figure 30b, and Figure 30c, respectively).

Difficulties Relating To Time and Assistance

- ▶ Parental caregivers were twice as likely as additional caregivers to report very serious difficulties in receiving no consistent help from other family members (Figure 30a, Appendix Table 30a).
- ▶ Approximately 19 percent of spousal caregivers said having less time for their family is a very serious difficulty. However, more than twice as many parental caregivers (13.9 percent) than additional caregivers (6.7 percent) reported that having less time for their family is a very serious difficulty (Figure 30a, Appendix Table 30a).
- ▶ Fourteen percent of spousal caregivers indicated that having less time for themselves is a very serious difficulty. More than twice as many parental caregivers (9.0 percent) than additional caregivers (4.1 percent) reported that having less time for themselves is a very serious difficulty (Figure 30a, Appendix Table 30a).

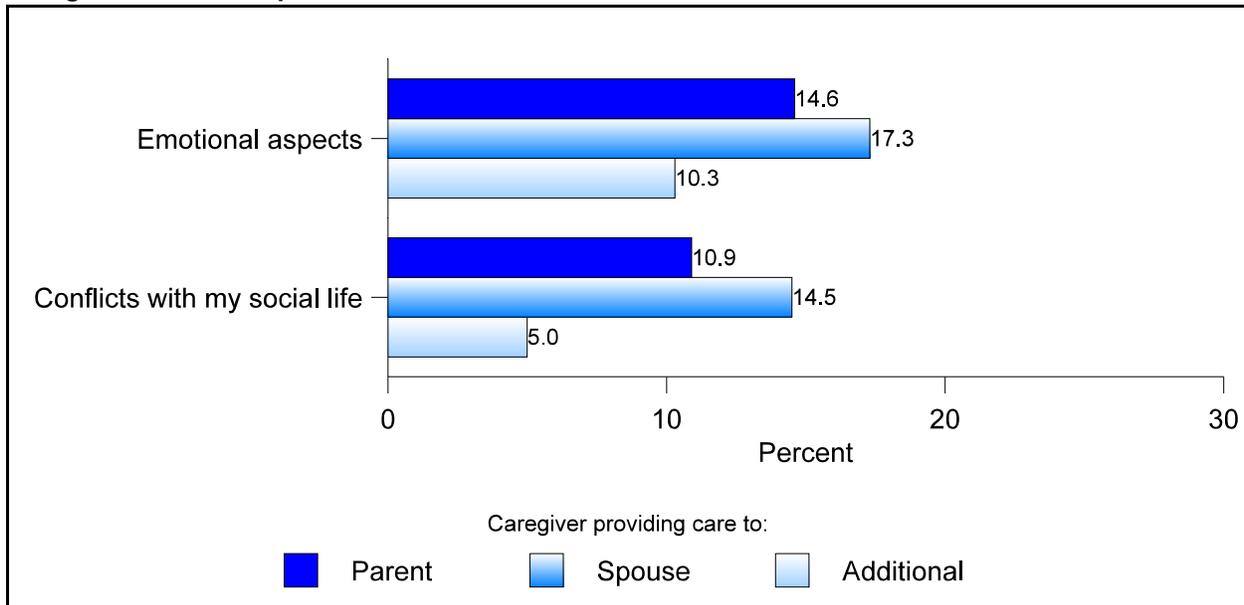
Figure 30a. Difficulties Relating To Time and Assistance Rated As “Very Serious” by Caregiver Relationship



Difficulties Relating To Emotional and Social Conflict

- ▶ Parental and spousal caregivers were more likely than additional caregivers to report that emotional aspects are a very serious difficulty (14.6 percent, 17.3 percent, and 10.3 percent, respectively) (Figure 30b, Appendix Table 30b).
- ▶ Nearly three times as many spousal caregivers (14.5 percent) and twice as many parental caregivers (10.9 percent) than additional caregivers (5.0 percent) were likely to indicate that conflicts with their social lives are a very serious difficulty (Figure 30b, Appendix Table 30b).

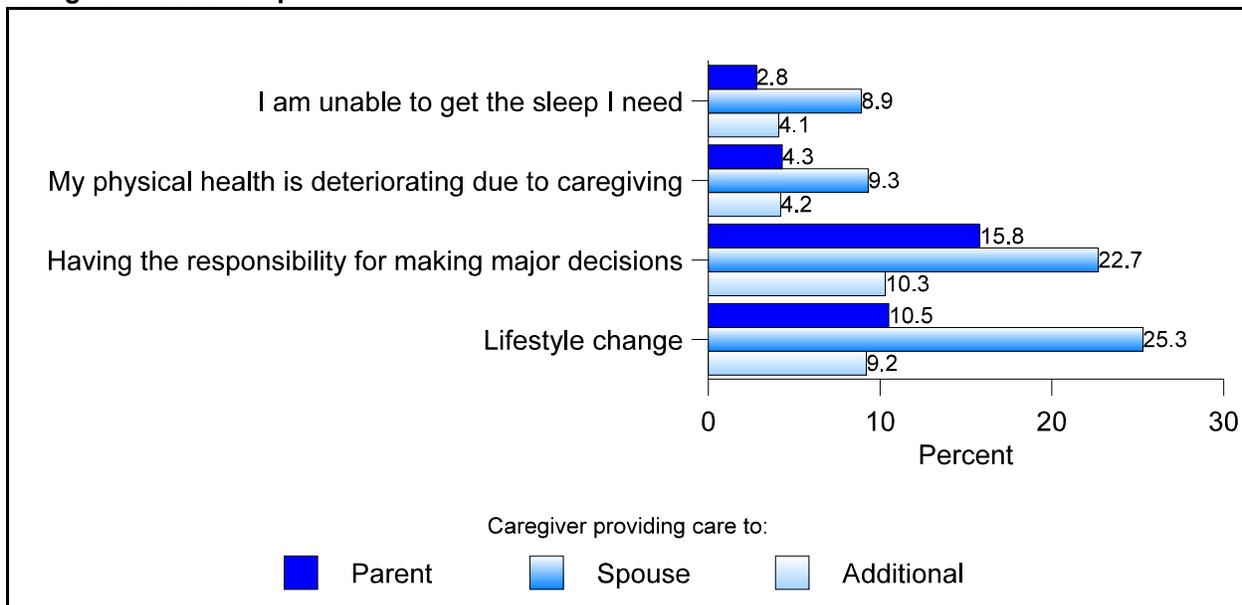
Figure 30b. Difficulties Relating to Emotional and Social Conflict Rated As “Very Serious” by Caregiver Relationship



Difficulties Relating To Physical and Lifestyle Changes

- ▶ Nearly 9 percent of spousal caregivers reported that being unable to get the sleep they need is a very serious difficulty. This proportion is three times the amount of parental caregivers (2.8 percent) and approximately twice the amount of additional caregivers (4.1 percent) (Figure 30c, Appendix Table 30c).
- ▶ More than 9 percent of spousal caregivers reported that deterioration in their physical health due to caregiving is a very serious difficulty. This is nearly twice the proportion of parental and additional caregivers (4.3 percent and 4.2 percent, respectively) (Figure 30c, Appendix Table 30c).
- ▶ Nearly one-fourth of spousal caregivers reported that having the responsibility for making major life decisions for a loved one is a very serious difficulty. Nearly 16 percent of parental caregivers and approximately 10 percent of additional caregivers also reported this to be a very serious difficulty (Figure 30c, Appendix Table 30c).
- ▶ More than a fourth of spousal caregivers reported that a change in lifestyle is a very serious difficulty. Nearly 11 percent of parental caregivers and approximately 9 percent of additional caregivers also reported this to be a very serious difficulty (Figure 30c, Appendix Table 30c).

Figure 30c. Difficulties Relating To Physical and Lifestyle Changes Rated “Very Serious” by Caregiver Relationship



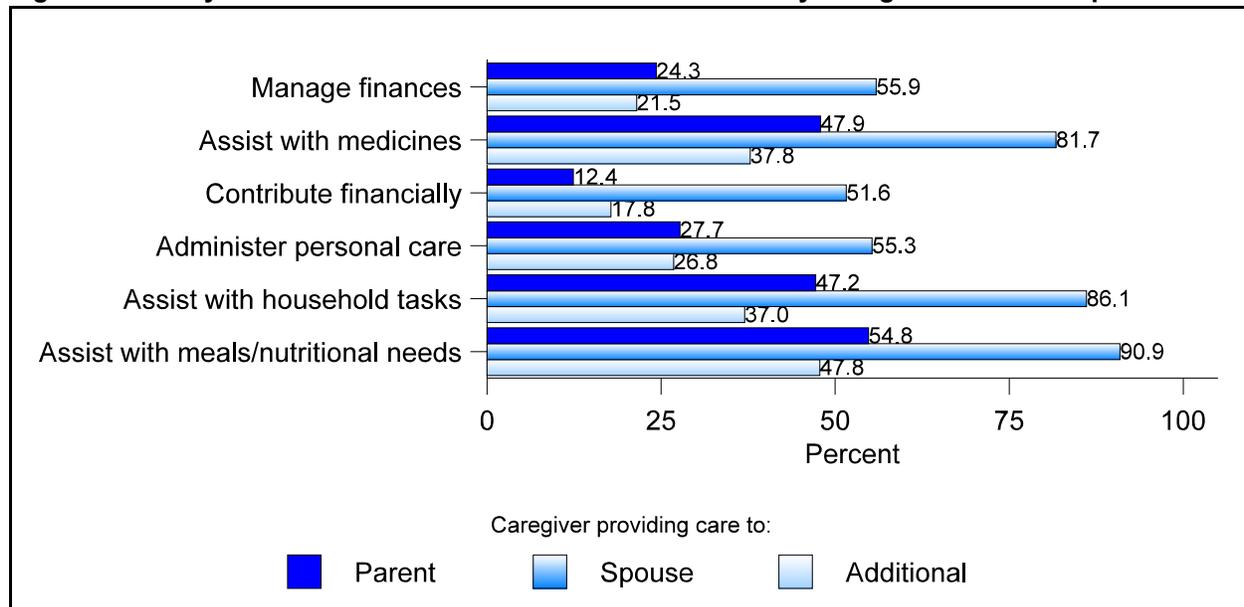
Daily Provision of Services

- ▶ A list of the 16 services typically provided by the caregiver on a daily basis were noted in the survey and 11 were found to have a statistically significant difference by caregiver relationship. Significant results are grouped into three categories representing active/hands-on care, facilitation services, and interpersonal care (Figure 31a, Figure 31b, and Figure 31c).
- ▶ Overall, it was more common for caregivers to report they provide hands-on/active care services than facilitation services or interpersonal care on a daily basis (Figure 31a, Figure 31b, Figure 31c).

Active/Hands-on Care

- ▶ More than 80 percent of spousal caregivers assisted with medicines, household tasks and meals on a daily basis. This was nearly twice the level of additional caregivers (Figure 31a, Appendix Table 31a).
- ▶ Parental and additional caregivers were very similar in the amount of active/hands-on care they provided on a daily basis. However, in all instances it was less than half the proportion of active/hands-on care provided by spousal caregivers on a daily basis (Figure 31a, Appendix Table 31a).

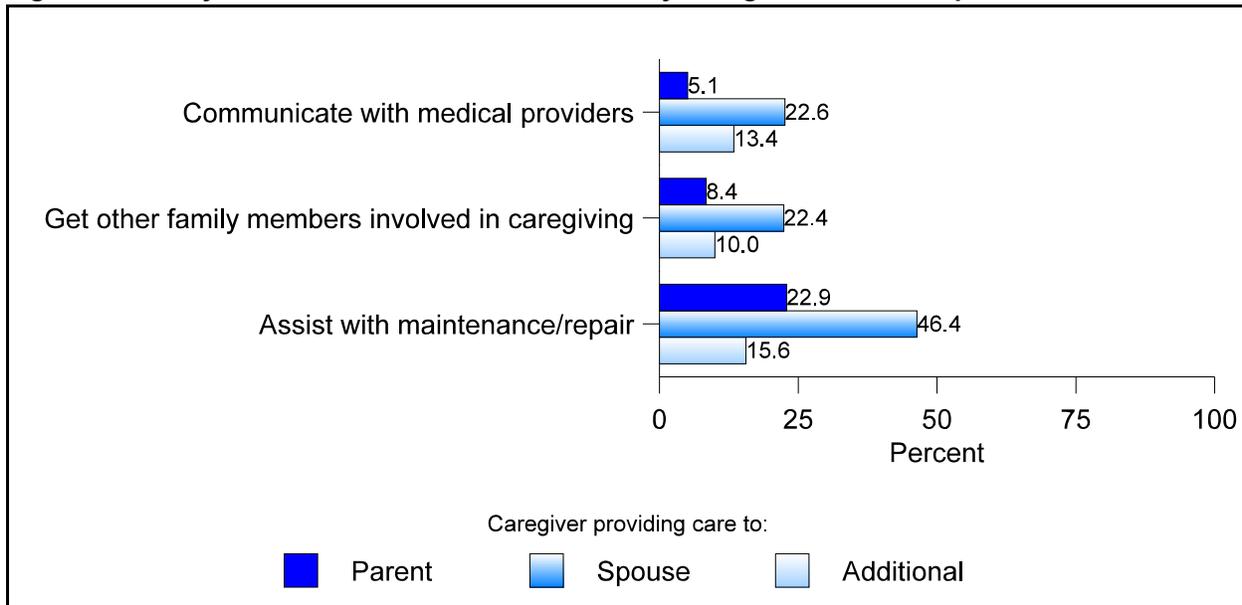
Figure 31a. Daily Provision of Active/Hands-on Care Services by Caregiver Relationship



Facilitation Services

- ▶ It was uncommon for caregivers to provide facilitation services on a daily basis. Nonetheless, spousal caregivers were more likely than parental or additional caregivers to provide such care on a daily basis (Figure 31b, Appendix Table 31b).
- ▶ With the exception of maintenance/repair, parental caregivers were less likely than spousal or additional caregivers to provide facilitation services on a daily basis (Figure 31b, Appendix Table 31b).
- ▶ In general, spousal caregivers provided twice the proportion of facilitation services on a daily basis than did additional caregivers and nearly three times the proportion of parental caregivers (Figure 31b, Appendix Table 31b).

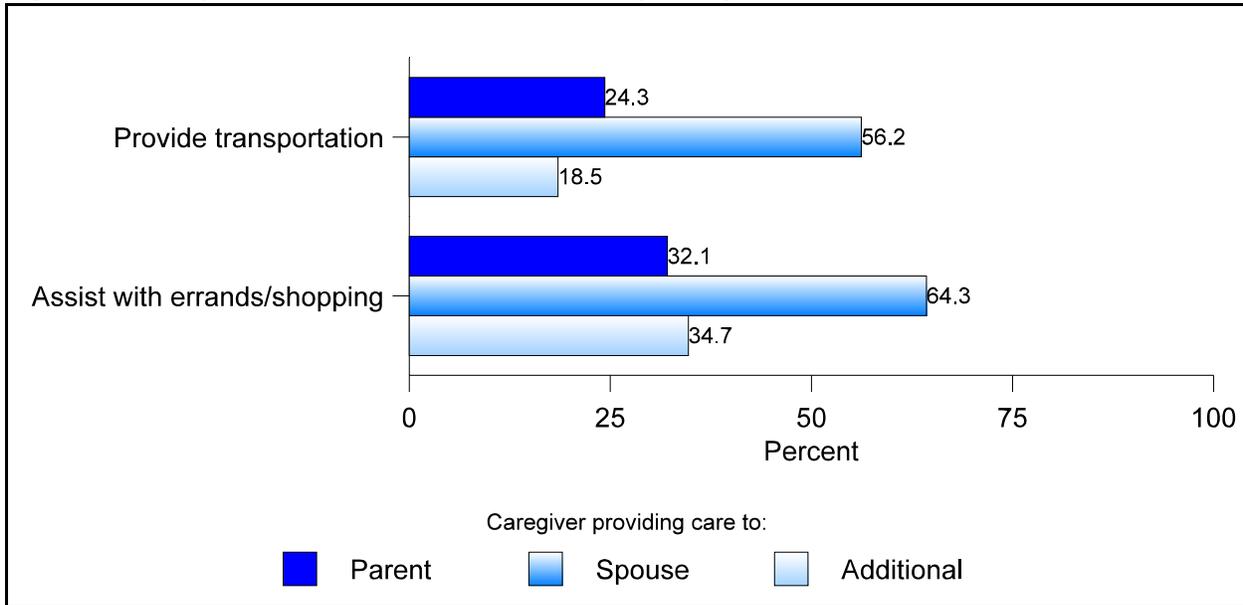
Figure 31b. Daily Provision of Facilitation Services by Caregiver Relationship



Interpersonal Care

- ▶ The majority of spousal caregivers provided interpersonal care on a daily basis (Figure 31c, Appendix Table 31c).
- ▶ Approximately the same proportion of parental and additional caregivers provided daily interpersonal care. However, this proportion was less than half that of interpersonal care provided daily by spousal caregivers (Figure 31c, Appendix Table 31c).

Figure 31c. Daily Provision of Interpersonal Care by Caregiver Relationship



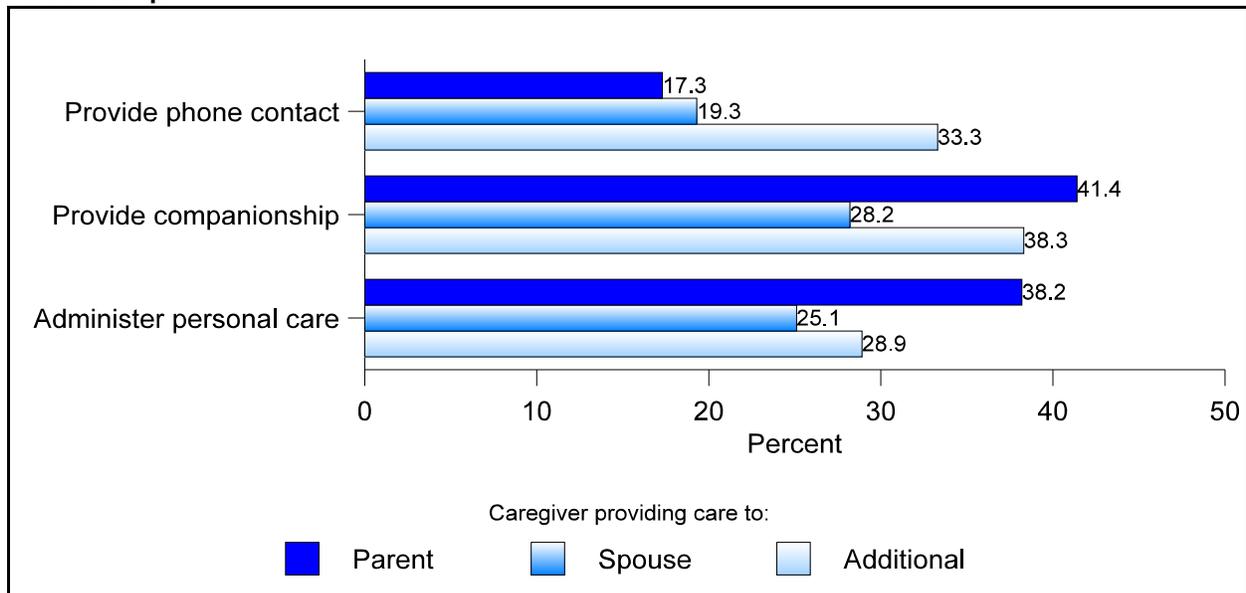
Assistance with Provision of Services

- ▶ Responses to the need for assistance in providing informal care were found to have statistically significant differences by caregiver relationship in only three of the 16 service areas listed in the survey (Figure 32, Appendix Table 32).

Active/Hands-on Care

- ▶ Parental caregivers were more likely to request assistance in providing companionship and administering personal care than additional caregivers. However, less than half of parental caregivers requested such assistance (Figure 32, Appendix Table 32).
- ▶ One-third of the additional caregivers requested assistance in making phone contacts, a proportion twice that of all other caregivers (Figure 32, Appendix Table 32).

Figure 32. Caregivers Who Would Like Help Providing Active/Hands-on Services by Caregiver Relationship



APPENDIX TABLES

Appendix Table 1. Relationship of Care Recipient to Caregiver

Care Recipient	Respondents(N=652)	
	#	%*
Spouse	281	43.1
Mother/Mother-in-law	190	29.1
Father/Father-in-law	71	10.9
Friend	53	8.1
Relative	38	5.8
Currently does not provide care, but has done so within the last year	24	3.7
Sibling/Sibling-in-law	19	2.9
Adult child (60 or older)	9	1.4
Other	21	3.2
<i>Not specified/Blank</i>	6	
<i>Grandparent</i>	3	
<i>Spouse</i>	3	
<i>Grandchild</i>	2	
<i>Parent</i>	2	
<i>Step-parent</i>	1	
<i>Offspring</i>	1	
<i>Non-relative</i>	1	
<i>To all who need help</i>	1	
<i>Currently do not provide care</i>	1	

*Percents do not always add to 100.0 due to multiple responses; N=652.

Appendix Table 2. Reasons Care Recipient Needs Services

Reasons	Respondents (N=652)	
	#	%*
The aging process	424	65.0
Physical disabilities (arthritis, stroke, etc.)	348	53.4
Cognitive impairment (e.g., Alzheimer's/dementia)	150	23.0
Mental illness (depression, panic/anxiety disorder, schizophrenia)	29	4.4
End of life issues (e.g., Hospice)	20	3.1
Developmental disabilities/mental retardation	15	2.3
Head injury	3	0.5
Substance abuse issues	3	0.5
Other:	74	11.3
<i>Blank</i>	12	
<i>Cancer</i>	10	
<i>Vision impairment/Blindness</i>	8	
<i>Diabetes/Kidney problems/Dialysis</i>	6	
<i>Health problems/Medical reasons</i>	5	
<i>Heart problems</i>	4	
<i>Stroke</i>	4	
<i>Parkinson's disease</i>	3	
<i>Heart/Diabetes</i>	3	
<i>MS</i>	2	
<i>Emphysema/Lung problems</i>	2	
<i>Handicapped</i>	2	
<i>Memory</i>	1	
<i>Broken back</i>	1	
<i>Chronic brain syndrome</i>	1	
<i>Polio</i>	1	
<i>Leukemia</i>	1	
<i>Macular degeneration</i>	1	
<i>Surgery</i>	1	
<i>Heart/Diabetes/Gout</i>	1	
<i>Heart/Cancer</i>	1	
<i>Incontinent/Heart</i>	1	
<i>Knee/Hip surgery</i>	1	
<i>Neuropathy/Accident victim/Poor hearing</i>	1	
<i>Place to live</i>	1	

*Percents do not always add to 100.0 due to multiple responses; N=652.

Appendix Table 3. Whether Caregiver Receives Monetary Compensation For Caregiving Services

Response	Respondents	
	#	%*
Yes	42	6.5
No	605	93.4
Other	1	0.2
<i>Yes and no</i>	1	
Total	648	100.1

*Percents do not always add to 100.0 due to rounding.

Appendix Table 4. Where Care Recipient Receives Care

Response	Respondents (N=652)	
	#	%*
Care recipient lives with me	381	58.4
Care recipient's home/apartment	238	36.5
An assisted living facility	15	2.3
An Independent living facility	4	0.6
Other**	15	2.3

*Percents do not always add to 100.0 due to multiple responses; N=652.

**Fifteen caregivers indicated that they provide care in places other than those listed, however, they did not indicate what those places were.

Appendix Table 5. Amount of Care Required For a Care Recipient Living in Caregiver's Home

Amount of Care Required	Respondents	
	#	%*
Around the clock-care recipient cannot be left alone	95	24.4
Around the clock-care recipient can be left alone for a few hours	197	50.6
Around the clock-care recipient can be left alone for most of the day	97	24.9
Total	389	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 6. Distance Caregiver is From Care Recipient if Not Cared For in Caregiver's Home

Distance	Respondents	
	#	%*
Less than 20 minutes away	191	82.3
20 and 59 minutes away	27	11.6
One to two hours away	8	3.4
More than two hours away	6	2.6
Total	232	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 7. Average Hours Spent Caregiving Per Week if Care Recipient is Not Cared For in Caregiver's Home

Average Hours	Respondents	
	#	%
0 to 5 hours/week	62	33.3
6 to 10 hours/week	44	23.7
11 to 15 hours/week	32	17.2
16 to 20 hours/week	14	7.5
More than 20 hours/week	34	18.3
Total	186	100.0

Appendix Table 8. Length of Time Spent Caregiving

Length of Time	Respondents	
	#	%*
Less than 1 year	55	9.3
1 year to 3 years	260	43.8
4 years to 6 years	142	23.9
7 years to 9 years	42	7.1
10 years or more	95	16.0
Total	594	100.1

*Percents do not always add to 100.0 due to rounding.

Note: Lengths of time past 1 year provided by respondent in terms of half years have been rounded up to the nearest whole year; lengths of time provided as a range have been coded as the upper value of the range.

Appendix Table 9a. Whether Caregiver Experiences Other Caregiving Difficulties

Response	Respondents	
	#	%
Yes*	84	14.6
No	493	85.4
Total	577	100.0

*Other caregiving difficulties listed in Appendix Table 9b.

Appendix Table 9b. Other Caregiving Difficulties Experienced by Caregiver

Response	#
Answered yes, but no specific response listed	10
Lifting/physical difficulties	9
Respite care	7
Transportation difficulties	5
Caregiver has much or total responsibility	5
Problems with other family members	5
Lack of personal time for caregiver	5
Maintaining household duties	5
Conflicts with job	4
Financial difficulties	4
Moods of care recipient	4
Memory issues	4
Demands from care recipient	3
Nutrition issues	3
Medical problems	2
Too much paperwork	2
Time problems	2
Personal care for recipient	2
Depression	2
Limited services available	2
Nursing care	1
Lack of emotional support	1
Feel unappreciated	1
No support groups	1

Appendix Table 9b. Other Caregiving Difficulties Experienced by Caregiver (continued)

Response	#
Need escort help	1
Increased stress	1
Hard to deal with someone who will not accept help	1
He needs social outlets	1
Own physical health - eyesight, arthritis, slight stroke	1
Defining her position legally against his family members	1
Difficult to watch her in this situation	1
Frustrating adult child dependant on finance from elder	1
Good thing hospital showed me how to use the machines, no local nurses knew	1
He doesn't enjoy going anywhere so there are no vacations or much going	1
Hearing the radio and TV - deafening to me	1
I took care of my husband for 2 years about 4 years ago when he passed away, he has had a lot of care. He was on home health.	1
If anything happens to me he would not be able to help or get help	1
Need others in town to offer to help with shopping - lifeline respondedes	1
For the 1st 1 ½ years d,f,h,j,k and m were closer to the 3 level. In home care was given for 4 months.	1
Has been in nursing home since February and I spend half the day with him	1
Sometimes feel services of home health could be utilities	1
Spending 2 hours daily out of the home	1
Who do you get in contact with for help	1
Unable to leave alone for long	1
When she lived with us. Her needs and desires always came first with my husband	1
Total	110

Appendix Table 10a. Whether Caregiver Experiences Other Concerns Associated With Caregiving

Response	Respondents	
	#	%
Yes*	53	9.0
No	537	91.0
Total	590	100.0

*Other concerns listed in Appendix Table 10b.

Appendix Table 10b. Other Concerns Associated With Caregiving

Response	#
Answered "yes," but no specific response listed	8
It is expected of me/it is my duty to care for the care recipient	6
Caregivers personal problems/health	5
Respite care - cost and availability	5
Future problems with care recipient	4
Isolation from friends and family	3
Too many responsibilities	3
More services need to be available	2
Transportation	2
Time constraints	1
Personal care issues	1
Emotional stress	1
Health and safety issues	1
Expenses	1
Physical difficulties	1
Care recipient's finances	1
Unsure if care recipient should be living alone or driving	1
Dad did not qualify for hospice or home health even given weeks to live because of kidney dialysis - not considered home bound - very frustrating and angering for family	1
In-home caregiver	1
Check on client's more often	1
I don't like to leave him alone when I am unable to be at home in case that I need medical help - example overnight in hospital	1
If we can get help to fix our car for transporting patient to doctor appointment and elsewhere	1

Appendix Table 10b. Other Concerns Associated With Caregiving (continued)

Response	#
Lack of understanding	1
She has messed in her pants about 3 times and won't change or bathe	1
On weekends there is no support	1
My mother had a heart trouble	1
What is available and what isn't	1
Alcoholism of a relative who resides with the one I provide care for	1
Another nursing home, more openings, weekend help	1
He can't hear [and] it's difficult for me to repeat and explain over and over and he [is a] very controlling person	1
He sometimes takes risks when walking outside and still tries to do things he may not be up to	1
Information on alternative living arrangements	1
Scared of doing something wrong and the dialysis would go wrong. Feeling alone at times.	1
Other family members who stay there and make meals which they leave for me to clean up	1
Senior companion	1
Hearing impairment and abnormal sleeping patterns	1
There are no good senior programs in Walsh County (i.e.: day care). Thank goodness there is [specific people mentioned].	1
Unable to be at home at noon meal time to make sure spouse eats a meal and takes all his medication	1
In community people do appreciate any help	1
Concerned that I am able to help and do the best and not let her down - she is such a good partner	1
Total	69

Appendix Table 11a. Whether There Are Other Informal Caregivers Who Provide Care to Care Recipient

Response	Respondents	
	#	%
Yes*	329	52.1
No**	303	47.9
Total	632	100.0

*Other informal caregivers listed in Appendix Table 11b.

**Reasons why other informal caregivers did not provide care listed in Appendix Table 12.

Appendix Table 11b. Other Informal Caregivers Who Provide Care to Care Recipient

Response	#
Family	63
Sister	54
Daughter	43
Son	39
Friend	31
Brother	27
Children	27
Home health (including homemaker services, caregiver program, private caretaker and personal attendants)	24
Answered yes, but no specific response listed	19
Specific person mentioned	18
Neighbor	17
Spouse	13
Daughter-in-law	11
Granddaughter	10
Husband	10
CHR	10
Siblings	9
Sister-in-law	7
Nurse	7
Brother-in-law	6
Social services	5
Grandchildren	5
Mom	4
Niece	4
Wife	2
Nephew	2
Cousin	2
Partner	2
Dad	1
Grandson	1
Son-in-law	1

Appendix Table 11b. Other Informal Caregivers Who Provide Care to Care Recipient (continued)

Response	#
Extended family	1
In-laws	1
Aunt	1
Siblings' spouse	1
Hospice	1
Respite care	1
IHS	1
Siblings' children	1
Health unit	1
People hired by me	1
Senior companion service	1
Too expensive	1
Very occasional	1
At night spend one patient at Tufty Manor	1
Good Samaritan - in the home now	1
Medication - [illegible]	1
Another agency	1
PT	1
HD meals	1
Senior citizens center	1
Several different people	1
Since [February care recipient is in a] nursing home	1
Tri City Cares	1
We help take care of him	1
Weekly on Wednesday	1
Other private care providers	1
Private person	1
QSP family children	1
Rare occasions, a lady can stay with him	1
Very rare, four times in the last year	1
Total	502

Appendix Table 12. Reasons Why Other Informal Caregivers Do Not Provide Care to Care Recipient

Response	Respondents (N=652)	
	#	%*
Others live farther away	386	44.9
Others have full-time jobs	302	35.2
There are no other immediate family members	230	26.8
Others have less flexible daily schedules	153	17.8
Others have young dependents living with them	127	14.8
Others are unwilling or "just can't"	119	13.9
Recipient doesn't want care from others	112	13
Others are too inexperienced	59	6.9
Others are embarrassed/uncomfortable fulfilling intimate needs (bathing, toileting, etc.)	49	5.7
Others are unaware of needed care (have not been informed-have not been asked to help)	42	4.9
Others are also in need of care	40	4.7
Others do not get along with care recipient	39	4.5
Other reasons	56	6.5
<i>No need</i>	11	
<i>Answered other, but no specific response listed</i>	10	
<i>There is nobody else</i>	5	
<i>Others are too busy</i>	3	
<i>There are no others are around</i>	3	
<i>Others do not care</i>	2	
<i>Caregiver does not want assistance</i>	1	
<i>Family doesn't understand level of care needed</i>	1	
<i>Family if needed</i>	1	
<i>I don't work, I have MS</i>	1	
<i>Priorities are somewhere else</i>	1	
<i>Unreliable family members</i>	1	
<i>Family found out that she really need help with my prodding</i>	1	
<i>He is on disability</i>	1	
<i>Others are helping</i>	1	

*Percents do not always add to 100.0 due to multiple responses; N=652.

Appendix Table 12. Reasons Why Other Informal Caregivers Do Not Provide Care to Care Recipient (continued)

Response	Respondents	
	#	%*
<i>Psychological distress</i>	1	
<i>Take care of each others</i>	1	
<i>They just don't</i>	1	
<i>Feel it's her responsibility</i>	1	
<i>Financially unable to pay others</i>	1	
<i>Grandson - I choose to help with him</i>	1	
<i>I am unable to determine why friends and neighbors hesitate to offer help in caregiving</i>	1	
<i>I will soon be eighty years of age and don't know how long I can. Right now [I am in] pretty good health.</i>	1	
<i>Our son and family help but all [of them are] working, so time is very limited</i>	1	
<i>PHN, refuse to go out because of [an] abusive child [in care recipient's home]</i>	1	
<i>Scared of responsibility</i>	1	

*Percents do not always add to 100.0 due to multiple responses; N=652.

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient

Other Reasons by Type of Service	#
<i>Dietician Services</i>	
Answered other, but no specific response listed	3
Do not need it right now	2
Not necessary	2
Meals on wheels	1
Care recipient using Ensure only	1
Caregiver refused to use	1
Don't care for dietician	1
We [will] call if we need information	1
Can't afford	1
Like to eat	1
My father eats with me and has balanced meals	1
Not available	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
She does not want to use	1
Patient has passed away	1
Will be using	1
Home Delivered Meals	
Caregiver cooks	11
Does not like the food	6
Do not need it	5
Meals are already provided at residence	5
Care recipient uses congregate meals	4
Care recipient uses senior center	4
Can only eat liquids	3
Cost	3
Answered other, but no specific response listed	3
Caregiver cooks	2
Not homebound	2
Distance	2
Caregiver will not use them	1
Do not want [care recipient] on them	1
Do not like [the] time of delivery	1
Food is the least of his worries and needs	1
Haven't applied	1
I guess he's not sick	1
Likes to get out and visit other people	1
May start using soon	1
No one to deliver	1
Not always home during the noon hour	1
Resides in country, uses [illegible] when in town, eats evening meal with family	1
Told not eligible	1
Will start, need them now	1
Difficult to get there	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
<i>Congregate Meal Settings</i>	
Mobility is difficult	37
Receiving home delivered meals	26
Homebound	11
Too difficult to attend	10
Prefer to eat/cook at home	7
Care recipient will not use it	5
Cost	5
Care recipient can not eat the food	4
Poor health	4
Care recipient will not eat the food	3
Answered other, but no specific response listed	2
Can't travel with care recipient	2
Too conscious of his disability	2
Don't feel hungry	1
Do not need it now	1
Can not work	1
Don't know if recipient would use it, haven't crossed that road yet	1
Alzheimer's - difficult to deal with in new setting	1
Using home's	1
Alzheimer's - crowds don't work	1
Choose not to use	1
Recipient embarrassed to eat out	1
Access/time	1
Messy eater	1
Sometimes does not want to	1
The place that had it quit	1
Not practical at this time	1
Stubborn, too much work getting to center	1
Never have used	1
Very seldom	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
Not able to understand difficult to transfer	1
We do use when necessary	1
Time for recipient is difficult	1
Can partake at any time	1
On a feed table	1
Food is same as meals on wheels	1
Can't get her there in the middle of [the] day	1
Adult Day Centers	
Expense	7
Distance	5
Difficult to get the care recipient there	5
Transportation	3
Not available	3
May use in the future	3
Poor health	2
Don't need	1
Answered other, but no specific response listed	1
Husband died one year ago and she won't go without him	1
I'm too stubborn to go for that	1
They said she required too much time given by a nurse - blood sugar checks, prescriptions, etc., used to use it at St. Luke's 1 day per week	1
Could be available on the weekends	1
Not able to - does not remember	1
Outreach Programs	
Answered other, but no specific response listed	1
Visiting Nurse	
Receiving health care elsewhere	11
Do not need this service now	8
Have used this service in the past	5
Cost	4
Answered other, but no specific response listed	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
Care recipient will not use it	1
CHR	1
Will use this service in the future	1
None show up	1
This is inconsistent. Also, quality of care is a question. Another is who does provide this care. Who is the nurse?	1
Have to qualify for home health	1
Home health care intercepted patient/doctor relations and medical negligence lead to seizure	1
Just for emergencies	1
PHN refuse to go to home because of [the recipient's] child	1
Would like to have nurse come see Grandma	1
Didn't like the nurse	1
1 time last year she came and gave flu shots	1
Nurses not capable of caring for him	1
Did not know about it	1
Have not started the service	1
Caregiver will not accept nursing service	1
Just finding out about this service	1
Parish Nurse	
Not available	5
Program is just beginning	2
Inconvenient	2
Answered other, but no specific response listed	1
Just haven't pursued it, not wanting to ask	1
Do not know if it is available through her church	1
Doing fine as we are	1
What services are available?	1
I do not need it at this time	1
Homemaker Services/Home Health Aides	
Cost	20

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
This service is already provided	16
Do not need at this time	8
Do not qualify	6
Have used this service in the past	3
Answered other, but no specific response listed	3
May use this service in the future	3
Have not asked	2
Not available	2
Not sure who does this in this area [specific city listed]. [Specific city listed] - heard complaints by workers about having to go way out to our house. As stated, complaints about distance to go to [the] country [specific city listed]. In [specific city listed] workers are not consistent, seems to be changing.	1
Won't use it	1
Would like to know more about it	1
Aide every two weeks is not practical	1
Interruptions in service due to hospital stays	1
Rescheduling changes by providers made it difficult	1
Client didn't trust aides to help	1
Not trained to do home dialysis	1
It hasn't been arranged	1
Hadn't thought of it	1
They work	
<i>Escort/Transportation Services</i>	
Caregiver drives	19
Family members drive	14
Too difficult for care recipient to use by themselves	11
Do not need it right now	9
Mobility	6
Care recipient is unable to use it	6
Care recipient will not use it	4
Will start using it soon	3
Care recipient drives	2

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

Other Reasons by Type of Service	#
Transportation is taken care of	2
Answered other, but no specific response listed	1
Driveway is too steep for the bus. She is unable to walk to the road, even with assistance	1
Parents do	1
Doesn't like the atmosphere at the senior center where he would go	1
Mother has good comments about her transport and assistance when she has used CHR program. She has asked if there are other services available through them or elsewhere	1
Did not know about	1
Not possible	1
Driver is too mean	1
She is blind and isn't comfortable with anyone. It's a bus - not enough help for each individual	1
Water fluid pills	1
Doesn't need to go out except for a trip to our son's home on occasion	1
Hasn't utilized it yet	1
I feel she would be too confused	1
Does not want to spend money	1
Shopping Assistance	
Caregivers goes shopping	10
Family members go shopping	8
Do not need it right now	3
Care recipient goes shopping	3
Stores deliver	1
She's not strong enough	1
\$2 in gas gets me to town and back	1
Unable to do any shopping	1
When is this done?	1
Does not know what she needs	1
Bus taken to store, unable to walk much	1

Appendix Table 13. Reasons Why Services Are Not Being Used if Services Are Available to Care Recipient (continued)

<i>Pet Services</i>	
No pet	8
Cost	1
Answered other, but no specific response listed	1
Does not care for pets to be indoors	1
We take the dog for grooming	1

Appendix Table 14. Reasons Why Services Are Not Good if Services Available to Care Recipient Are Rated “One” or “Two”

Reasons by Type of Service	#
<i>Dietician Services</i>	
Does not like the food	4
Answered other, but no specific response listed	4
This rates elder meals in [specific city listed]. Delivers are done by ‘at work’ basis. If [it is a] holiday, a funeral, or a tribal leave day, [there are] no deliveries. As a diabetic elder, meals do measure in [specific city listed]! Not in [specific reservation listed].	1
Variety of foods lacked	1
We didn’t get the help in the areas we needed (or very little about our diet)	1
I think when they ask for strawberry Ensure the should get what they want, not have to wait for next months supply	1
Rural area	1
<i>Home Delivered Meals</i>	
Not always the food the care recipient is able to eat	7
Repetitious meals	3
Sometimes the food is overcooked	3
The meals are not good quality	3
The meals are good	2
The meals are too spicy	2
Food is cold on arrival	2
The portions are too small	2
Not consistently good	1
Care recipient does not like the type of food that is served	2
The service delivery is good	1
Care recipient will not eat it	1

Appendix Table 14. Reasons Why Services Are Not Good if Services Available to Care Recipient Are Rated “One” or “Two” (continued)

Reasons by Type of Service	#
[Care recipient] feels the meals are leftovers	1
Answered other, but no specific response listed	1
Would like more raw vegetables and fresh fruit	1
I work and the home delivered meal service is a blessing to me	1
<i>Congregate Meal Settings</i>	
Overcooked meals	2
Hard to get her to eat	1
My patient is not able to talk, so [illegible] as meal at home, and is very happy with it	1
The key word here [is congregate]. People like to visit and see each other. My mother will go to [the] meal site when she can in either [specific city listed] or [specific city listed]. Both places to have adequate site. [Specific city listed] is newer but only really used for meals as far as I know.	1
Answered other, but no specific response listed	1
Too little parking available, no handicapped parking	1
Service is good, but so many places are not east to get into	1
They are very good but they are only once a day Monday-Thursday only	1
Poor gravy - [I] think the potatoes are rewarmmed	1
Balanced meals, but patient does not like all [of the] food	1
<i>Adult Day Centers</i>	
Seems [like there is] limited activity	1
Centers or community centers become dominated by a family (or a worker of a family) or by council member	1
<i>Outreach Programs</i>	
Minimal help	1
Don't like the frozen meals	1
Could be so weekends are available	1
<i>Visiting Nurse</i>	
Inconsistent	2
Services are limited	2
Nurses time is limited	2
Not reliable with schedule	1

Appendix Table 14. Reasons Why Services Are Not Good if Services Available to Care Recipient Are Rated “One” or “Two” (continued)

Reasons by Type of Service	#
I tried to get a visiting nurse in the past and it was difficult to impossible to arrange, so quit trying	1
IHS nurse was forgetful and sometimes undependable	1
Answered other, but no specific response listed	1
Was willing to work with client	1
<i>Parish Nurse</i>	
Answered other, but no specific response listed	1
<i>Homemaker Services/Home Health Aides</i>	
Services are limited	6
Does not clean very well	3
Provider was unreliable and had no transportation	1
Nursing home	1
Monetary [have] been cut [in] half	1
Do not want them there	1
Questions about billing and unit charge - self pay	1
Hire someone	1
<i>Homemaker Services/Home Health Aides</i>	
Services are limited	4
They do not clean very well	4
Monetary's [have] been cut [in half]	1
Don't want them there	1
Services were sporadic. Provider was unreliable and had no transportation	1
Hire someone	1
Have questions about billing and unit charge - self pay	1
Need people to help replace light bulbs, clean windows	1
Nursing home	1
<i>Escort/Transportation Services</i>	
Driver is unpleasant	5
Limited service time available	4
Picks elderly [up] only [the] mail	1
Have to wait too long for [them to] return home	1

Appendix Table 14. Reasons Why Services Are Not Good if Services Available to Care Recipient Are Rated “One” or “Two” (continued)

Not dependable	1
No room for physical disability needs due to seats being taken driver rushes elders when completing their shopping	1
Handicap accessible vehicles for the ladies that are in wheelchairs	1
They say they are too busy or it's not their job	1
Shopping Assistance	
Answered other, but no specific response listed	3
Pet Services	
Answered other, but no specific response listed	1

Appendix Table 15a. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Care Recipient

Response	Respondents	
	#	%
Yes*	53	11.5
No	409	88.5
Total	462	100.0

*Other services listed in Appendix Table 15b.

Appendix Table 15b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Care Recipient

Response	#
Activities for elders	7
Help with medical expenses	7
Transportation services	6
Respite care	5
Beauty services	4
Answered yes, but no specific response listed	3
Maintenance help	3
Help with personal care	3
Chore services	3
Transportation to doctor/nurse	2
Escort services	1

Appendix Table 15b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Care Recipient (continued)

Response	#
Some kind of check-in system for when I'm at work so I don't have to worry so much	1
Services [like] adopted grandchild	1
Better of [the] services [we] do have	1
Counseling to the elderly	1
Would like to see a support group for caregivers - also part-time help caregiving available	1
Congregate exercise setting followed by a social	1
Home bound dental, eye care, etc.	1
Bath rails and a lift helper [and] a chair ramp	1
Would like to be able to have a safe place where my care recipient could stay when I leave town for a few days	1
New elderly home	1
If they can get washer and dryers for the patient so they don't have to go out too much when patient wants to stay home.	1
United way in [specific city listed] had something called Volunteer Caregiver Exchange	1
800 numbers for caregivers to call	1
I want and she needs someone to provide care from 12-8pm, 5 days a week	1
Less expensive care - not Alzheimer's unit	1
Handicapped accessible living quarters	1
Vocational rehab is being overlooked	1
Pets are company. Neutering clinic for pets from traveling pet clinic	1
Possibly a visitation services with more compatible visitors than now available	1
I would like to have nurses come and check grandma	1
Could use legal assistance filling out forms	1
Caregiver services during evening hours	1
Need handrails	1
Budget planning	1
More counseling for anger - bitterness for seniors	1
Help [explaining] things to him	1
Friendly visiting	1
Home health	1

Appendix Table 16. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver

Reasons by Type of Service	#
<i>Information About Available Services</i>	
No need	4
Care recipient refuses to use it	3
Family takes care of needs	2
Have not looked into it	2
Finances	2
Answered yes, but no specific response listed	2
Doesn't want people around	1
Live too far out and can't get in for these services	1
Children S/B finding this out	1
Didn't know it was available until recently	1
<i>Assistance With Accessing Available Services</i>	
Not needed now/may use in the future	3
Answered yes, but no specific response listed	3
Have not looked into it	3
Too expensive	2
Transportation problems	2
Will not use	2
Family takes care of it	2
Hired help	1
Did not want to	1
Did not know what is available	1
<i>Individual Caregiver Counseling</i>	
Answered yes, but no specific response listed	3
Hate meetings	1
Not yet	1
Receives counseling through church	1
Have in the past	1
He refuses	1
Don't know who to contact	1
Just haven't	1

Appendix Table 16. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver (continued)

Reasons by Type of Service	#
Don't need at this time	1
<i>Caregiver Training or Education</i>	
Too busy	5
Distance	3
Care recipient refuses	2
Answered yes, but no specific response listed	2
Unable to go	1
Had some	1
Have not heard what is available	1
Wife [illegible] jobs	1
Don't know where to get training	1
Call medical when needed	1
Don't take time to attend classes	1
Could not get respite care	1
Need time off	1
<i>Respite Care</i>	
Do not need it right now	9
Family/friends provide relief	7
They are looking into it	4
Recipient does not want it	4
Cost	4
Answered yes, but no specific response listed	3
Too far to come, no one in the area	1
Not available	1
Haven't called for it	1
<i>Caregiver Support Groups</i>	
No time	7
Answered yes, but no specific response listed	6
Distance	3
May use in the future	2
Just have never gone	2

Appendix Table 16. Reasons Why Services Are Not Being Used if Services Are Available to Caregiver (continued)

Reasons by Type of Service	#
Did not previously know about this support group	1
We did at first, but haven't for quite a while	1
It is difficult to get to [the] meetings	1
Not set up	1
Haven't had to use it yet	1

Appendix Table 17. Reasons Why Services Are Not Good if Services Available to Caregiver Are Rated "One" or "Two"

Reasons Why Services Were Not Good	#
<i>Information About Available Services</i>	
Not enough information for services needed - poor insurance BCBS	1
No available service. Once in a while brochure will be with senior meals	1
Answered other, but no specific response listed	1
Not well informed	1
Needs more advertising	1
Doesn't get any satisfaction	1
<i>Assistance With Accessing Available Services</i>	
Answered other, but no specific response listed	3
Not well informed	2
Too much red tape	1
Very little	1
It is difficult to contact the correct agency and get the service when I need it	1
More publicized	1
If you qualify	1
<i>Individual Caregiver Counseling</i>	
Hasn't helped much	1
<i>Caregiver Training or Education</i>	
No information	1
Answered other, but no specific response listed	1
<i>Respite Care</i>	
Answered other, but no specific response listed	2
Family provides respite	2

Appendix Table 17. Reasons Why Services Are Not Good if Services Available to Caregiver Are Rated “One” or “Two” (continued)

Reasons Why Services Were Not Good	#
Only problem - my insurance didn't pay all	1
Only because [illegible] opened it's doors to daycare	1
It's hard to have someone all the time or they may quit or have other obligations	1
Paid	1
Caregiver Support Groups	
Answered other, but no specific response listed	2
Sometimes, but it's hard to get away	1
[It was run] different than I expected, but I'm not sure when I expected	1
Only problem - my insurance didn't pay all	1
Only because [illegible] opened it's doors to daycare	1
It's hard to have someone all the time or they may quit or have other obligations	1
Paid	1
Caregiver Support Groups	
Answered other, but no specific response listed	2
Sometimes, but it's hard to get away	1
[It was run] different than I expected, but I'm not sure when I expected	1

Appendix Table 18a. Whether There Are Other Services Not Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver

Response	Respondents	
	#	%
Yes*	39	7.8
No	458	92.2
Total	497	100.0

*Other services listed in Appendix Table 18b.

Appendix Table 18b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver

Services	#
Answered other, but no specific response listed	7
Respite care	6
Financial assistance	4

Appendix Table 18b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver (continued)

Services	#
Help with household chores	3
Adult day care	2
I was told [that] Easter Seals would provide for my husband when I had surgery - but, Because of location they refused - needless to say - I don't support Easter Seals anymore	1
Parenting aide - tutor to help fill out papers	1
What state services are available?	1
Not sure as to all that's available at present	1
Counseling for caregivers	1
Legal advice	1
Telephone availability and/or beeper or something like that for those who cannot afford telephone services	1
More [information] for the caregiver legal benefits for caregiver	1
Insurance - tax deductions	1
Help	1
Training for emergency situations	1
Someone to visit	1
Don't know	1
More advertising on services	1
In-home services	1
[Information] is not readily available on bathing/shampooing help	1
Access safety of living at home	1
Need services available but not so expensive	1
Delivery from Wal-Mart for those who do not drive	1
Resources for caregiver of those with memory loss	1
Better shopping, better transportation in [specific city listed]	1
Physical therapy available in the home	1
Better way of getting around when we can not drive anymore - besides transit	1
Alerting system	1
More activities for elderly - air conditioned bus to see scenery	1
Need more services so we can stay at our home in the country	1
800 number to call for help as nurse program and counseling	1

Appendix Table 18b. Other Services Not Already Mentioned That Caregiver Would Like to Have Available to Them as a Caregiver (continued)

Services	#
Companionship for the caregiver. I feel very isolated.	1
More than one senior companion would be helpful	1
Caregiving for people living in the country	1
Help explaining services etc to him	1

Appendix Table 19a. Whether There Are Other Services Not Mentioned With Which Caregiver Would Like Help

Response	Respondents	
	#	%
Yes*	26	4.7
No	528	95.3
Total	554	100.0

*Other services are listed in Appendix Table 19b.

Appendix Table 19b. Other Services Not Already Mentioned With Which Caregiver Would Like Help

Other Services	#
Respite care	5
Answered yes, but no specific response listed	5
Yard work	1
Physical therapy availability at clinic	1
Need [an] apartment with 2 bedrooms	1
Someone who would take parents to [the] doctor and stay with her during [the] appointment and report on it	1
Rides	1
More in-home physical therapy	1
Legal and financial aid information	1
Help with home maintenance	1
Need a better social life for both of us	1
Adult protection	1
Financial help with medicines	1
Body massage	1
Legal advice	1
Insurance benefits for caregivers - to be able to go to doctors and dentists	1
Simplify and make [information] more available on TV	1
Spiritually - no contact	1
More social activities offered for peer groups	1
Elderly need more than 1 bath a week - bowel/bladder [problems] are on-going and [getting] worse as they get older. Who - in this world today - would settle for 1 bath a week	1

Appendix Table 20. Average Money Spent Within the Last Year Caring For Care Recipient

Response	Respondents	
	#	%
\$0 to \$1,000	197	32.3
\$1,001 to \$2000	23	3.8
\$2,001 to \$3,000	27	4.4
\$3,001 to \$4,000	11	1.8
\$4,001 to \$5,000	2	0.3
More than \$5,000	20	3.3
The care recipient lives with me-it's difficult to separate expenses	263	43.1
I do not know	67	11.0
Total	610	100.0

Appendix Table 21. Caregiver's Age

Age	Respondents	
	#	%*
Younger than 35 years of age	5	0.8
35 to 44 years	30	4.8
45 to 54 years	95	15.1
55 to 64 years	156	24.7
65 to 74 years	123	19.5
75 to 84 years	173	27.4
85 years and older	49	7.8
Total	631	100.1

*Percents do not always add to 100.0 due to rounding.

Appendix Table 22. Caregiver's Marital Status

Marital Status	Respondents	
	#	%
Married or living with partner	464	73.2
Single, never married	57	9.0
Divorced or separated	37	5.8
Widowed	76	12.0
Total	634	100.0

Appendix Table 23. Caregiver's Highest Level of Education Completed

Level of Education	Respondents	
	#	%
Less than high school	92	14.4
Some high school	75	11.8
Graduated high school/GED	214	33.6
Some technical college	25	3.9
Technical degree	21	3.3
Some college	109	17.1
Graduated college	72	11.3
Post graduates or professional degree	29	4.6
Total	637	100.0

Appendix Table 24a. Caregiver's Employment Status

Employment Status	Respondents	
	#	%*
Retired	292	45.9
Full-time employment (35 hours/week or more)	134	21.1
Part-time	92	14.5
Not working	98	15.4
Multiple jobs	17	2.7
Other**	3	0.5
Total	636	100.1

*Percents do not always add to 100.0 due to rounding.

**For a list of other employment status', see Appendix Table 24b.

Appendix Table 24b. Caregiver's Other Employment Status

Caregiver's Other Employment	#
Answered other, but no specific response listed	1
Retired and full-time employment	1
Self-employed	1
Part-time and retired	1
Not working, is a farm wife with a full-time job	1

Appendix Table 25. Caregiver's Household Income in 2001 Before Taxes**

Household Income	Respondents	
	#	%*
Less than \$10,000	84	16.1
\$10,000 to \$20,000	182	34.8
\$20,001 to \$35,000	152	29.1
\$35,001 to \$50,000	62	11.9
\$50,001 to \$65,000	25	4.8
\$65,001 to \$80,000	6	1.1
\$80,001 to \$100,000	7	1.3
More than \$100,000	5	1.0
Total	523	100.1

*Percents do not always add to 100.0 due to rounding.

**Including money from jobs, social security, retirement income, public assistance, etc.

Appendix Table 26. Caregiver's Race or Ethnic Background

Race or Ethnic Background	Respondents	
	#	%
White (non-Hispanic)	623	97.0
White (Hispanic)	7	1.1
American Indians or Alaska Native	11	1.7
Black or African American	0	0.0
Asian American	0	0.0
Native Hawaiian or other Pacific Islander	0	0.0
Other*	1	0.2
Total	642	100.0

*Answered other, but no specific response listed.

Appendix Table 27. Caregiver's Principle Language

Language	Respondents	
	#	%*
English	641	99.4
Spanish	1	0.2
Other	3	0.6
<i>Czech</i>	1	
<i>Swedish and Norwegian</i>	1	
<i>German and English</i>	1	
Total	645	100.2

*Percents do not always add to 100.0 due to rounding.

Appendix Table 28. Caregiver's Gender

Gender	Respondents	
	#	%
Male	176	27.8
Female	457	72.2
Total	633	100.0

Appendix Table 29a. Caregiver's Place of Residence

Residence	Respondents	
	#	%
Rural	393	62.2
Urban	233	36.9
Other*	6	0.9
Total	632	100.0

*For a list of other places of residence, see Appendix Table 29b.

Appendix Table 29b. Caregiver's Other Place of Residence

Residence	Respondents
	#
USA	4
Unknown	1
Williams and Divide, 2 homes	1
Total	6

Appendix Table 30a. Ratings of Difficulties Relating to Time and Assistance by Caregiver Relationship

Type of Difficulty by Caregiver Relationship		Percent of Respondents					
		Not at all serious difficulty 1	2	3	4	Very serious difficulty 5	Total*
<i>No consistent help from other family members</i>							
Caregivers providing care to:	Parent (N=219)	33.8	19.6	11.0	15.5	20.1	100.0
	Spouse (N=255)	39.2	18.4	14.9	11.4	16.1	100.0
	Additional (N=120)	38.3	19.2	24.2	9.2	9.2	100.1
<i>Less time for my family</i>							
Caregivers providing care to:	Parent (N=223)	32.7	21.1	16.6	15.7	13.9	100.0
	Spouse (N=261)	24.5	17.2	21.8	17.2	19.2	100.0
	Additional (N=119)	52.9	17.6	13.4	9.2	6.7	100.0
<i>Less time for myself</i>							
Caregivers providing care to:	Parent (N=222)	23.9	25.7	23.4	18.0	9.0	100.0
	Spouse (N=264)	20.5	16.7	29.2	19.7	14.0	100.1
	Additional (N=123)	35.0	26.8	22.8	11.4	4.1	100.1

*Percents do not always add to 100.0 due to rounding.

Appendix Table 30b. Ratings of Difficulties Relating to Emotional and Social Conflicts by Caregiver Relationship

Type of Difficulty by Caregiver Relationship		Percent of Respondents					
		Not at all serious difficulty 1	2	3	4	Very serious difficulty 5	Total
<i>Emotional aspects</i>							
Caregiver providing care to:	Parent (N=226)	17.3	23.5	23.5	21.2	14.6	100.0
	Spouse (N=266)	17.3	15.0	27.1	23.3	17.3	100.0
	Additional (N=126)	31.0	15.1	28.6	15.1	10.3	100.0
<i>Conflicts with my social life</i>							
Caregiver providing care to:	Parent (N=220)	40.5	18.6	17.7	12.3	10.9	100.0
	Spouse (N=262)	27.9	19.8	22.5	15.3	14.5	100.0
	Additional (N=120)	54.2	17.5	15.0	8.3	5.0	100.0

Appendix Table 30c. Ratings of Difficulties Relating to Physical and Lifestyle Changes by Caregiver Relationship

Type of Difficulty by Caregiver Relationship		Percent of Respondents					
		Not at all serious difficulty 1	2	3	4	Very serious difficulty 5	Total*
<i>I am unable to get the sleep I need due to caregiving</i>							
Caregiver providing care to:	Parent (N=212)	66.5	18.9	6.6	5.2	2.8	100.0
	Spouse (N=258)	36.4	22.1	20.5	12.0	8.9	100.0
	Additional (N=121)	68.6	14.0	9.9	3.3	4.1	100.0
<i>My physical health is deteriorating due to caregiving</i>							
Caregiver providing care to:	Parent (N=209)	67.0	13.9	10.5	4.3	4.3	100.0
	Spouse (N=259)	34.0	22.8	21.2	12.7	9.3	100.0
	Additional (N=120)	63.3	17.5	9.2	5.8	4.2	100.0
<i>Having the responsibility for making major life decisions for a loved one</i>							
Caregiver providing care to:	Parent (N=221)	32.1	16.7	24.0	11.3	15.8	100.0
	Spouse (N=255)	28.6	16.5	18.8	13.3	22.7	100.0
	Additional (N=117)	48.7	12.0	20.5	8.5	10.3	100.0
<i>Lifestyle change</i>							
Caregiver providing care to:	Parent (N=220)	28.2	20.5	27.3	13.6	10.5	100.1
	Spouse (N=261)	17.6	13.4	20.3	23.4	25.3	100.0
	Additional (N=120)	45.8	18.3	15.8	10.8	9.2	99.9

*Percents do not always add to 100.0 due to rounding.

Appendix Table 31a. Provision of Active/Hands-on Care Services by Caregiver Relationship

Caregiver Services by Caregiver Relationship		Percent of Respondents					
		Daily	Weekly	Monthly	On occasion	Never	Total*
<i>Manage finances</i>							
Caregiver providing care to:	Parent (N=218)	24.3	26.1	18.8	19.3	11.5	100.0
	Spouse (N=256)	55.9	13.7	19.1	7.8	3.5	100.0
	Additional (N=121)	21.5	9.9	20.7	20.7	27.3	100.0
<i>Assist with medicines</i>							
Caregiver providing care to:	Parent (N=211)	47.9	16.1	2.8	20.4	12.8	100.0
	Spouse (N=246)	81.7	3.3	0.0	6.1	8.9	100.0
	Additional (N=111)	37.8	8.1	3.6	19.8	30.6	99.9
<i>Contribute financially</i>							
Caregiver providing care to:	Parent (N=193)	12.4	6.2	9.8	32.6	38.9	99.9
	Spouse (N=188)	51.6	5.3	29.3	5.9	8.0	100.1
	Additional (N=107)	17.8	10.3	7.5	16.8	47.7	100.1
<i>Administer personal care</i>							
Caregiver providing care to:	Parent (N=213)	27.7	20.2	5.6	29.6	16.9	100.0
	Spouse (N=246)	55.3	14.6	4.5	13.8	11.8	100.0
	Additional (N=112)	26.8	23.2	5.4	19.6	25.0	100.0
<i>Assist with household tasks</i>							
Caregiver providing care to:	Parent (N=216)	47.2	23.6	6.9	19.4	2.8	99.9
	Spouse (N=245)	86.1	7.3	0.0	5.7	0.8	99.9
	Additional (N=119)	37.0	21.8	5.0	25.2	10.9	99.9
<i>Assist with meals/nutritional needs</i>							
Caregiver providing care to:	Parent (N=217)	54.8	14.7	0.5	17.1	12.9	100.0
	Spouse (N=253)	90.9	4.7	0.0	3.6	0.8	100.0
	Additional (N=115)	47.8	9.6	1.7	22.6	18.3	100.0

*Percents do not always add to 100.0 due to rounding.

Appendix Table 31b. Provision of Facilitation Services by Caregiver Relationship

Caregiver Services by Caregiver Relationship		Percent of Respondents					
		Daily	Weekly	Monthly	On occasion	Never	Total*
<i>Communicate with medical providers</i>							
Caregiver providing care to:	Parent (N=216)	5.1	16.7	30.6	43.5	4.2	100.1
	Spouse (N=243)	22.6	17.3	25.9	31.7	2.5	100.1
	Additional (N=112)	13.4	9.8	13.4	40.2	23.2	100.1
<i>Get other family members involved in caregiving</i>							
Caregiver providing care to:	Parent (N=203)	8.4	17.7	7.4	48.3	18.2	100.0
	Spouse (N=228)	22.4	13.6	3.1	44.7	16.2	100.0
	Additional (N=110)	10.0	9.1	2.7	42.7	35.5	100.0
<i>Assist with maintenance/repair</i>							
Caregiver providing care to:	Parent (N=201)	22.9	21.4	9.0	35.8	10.9	100.0
	Spouse (N=235)	46.4	13.2	5.1	20.4	14.9	100.0
	Additional (N=109)	15.6	14.7	2.8	33.9	33.0	100.0

*Percents do not always add to 100.0 due to rounding.

Appendix Table 31c. Provision of Interpersonal Care by Caregiver Relationship

Caregiver Services by Caregiver Relationship		Percent of Respondents					
		Daily	Weekly	Monthly	On occasion	Never	Total*
<i>Provide transportation</i>							
Caregiver providing care to:	Parent (N=222)	24.3	45.9	5.0	21.6	3.2	100.0
	Spouse (N=251)	56.2	24.7	2.0	12.4	4.8	100.1
	Additional (N=124)	18.5	39.5	7.3	27.4	7.3	100.0
<i>Assist with errands/shopping</i>							
Caregiver providing care to:	Parent (N=221)	32.1	47.1	6.8	12.7	1.4	100.1
	Spouse (N=249)	64.3	30.9	1.2	2.0	1.6	100.0
	Additional (N=124)	34.7	40.3	6.5	14.5	4.0	100.0

*Percents do not always add to 100.0 due to rounding.

Appendix Table 32. Whether the Caregiver Would Like Help Providing Active/Hands-on Services by Caregiver Relationship

Caregiver Services by Caregiver Relationship		Percent of Respondents		
		Yes	No	Total
<i>Provide phone contact</i>				
Caregiver providing care to:	Parent (N=162)	17.3	82.7	100.0
	Spouse (N=145)	19.3	80.7	100.0
	Additional (N=90)	33.3	66.7	100.0
<i>Provide companionship</i>				
Caregiver providing care to:	Parent (N=174)	41.4	58.6	100.0
	Spouse (N=177)	28.2	71.8	100.0
	Additional (N=94)	38.3	61.7	100.0
<i>Administer personal care</i>				
Caregiver providing care to:	Parent (N=170)	38.2	61.8	100.0
	Spouse (N=179)	25.1	74.9	100.0
	Additional (N=83)	28.9	71.1	100.0

SURVEY INSTRUMENT

INFORMAL CAREGIVERS MAIL SURVEY

*An **informal caregiver** provides needed care on a long term basis to a **care recipient**, who is most often a relative, friend, or neighbor. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group), or those who provide care as a career. Long-term care often involves assisting the care receiver with personal hygiene, getting dressed, using the bathroom, or household tasks such as preparing meals. It does not include recovery from an injury after which the recipient no longer needs care. Currently we are interested only in those recipients of care who are at least 60 years of age.*

- Q1. What is your caregiver status? (Check all that apply)
- I provide care to my spouse
 - I provide care to my mother/mother-in-law
 - I provide care to my father/father-in-law
 - I provide care to a friend
 - I provide care to a relative
 - I provide care to a sibling/sibling-in-law
 - I provide care to my adult child (60 years of age or older)
 - I currently do not provide care, but have done so within the last year
 - Other (specify) _____
- Q2. Why does the care receiver need services? (Check all that apply)
- Aging process
 - Cognitive impairment (e.g., Alzheimer's/dementia)
 - Developmental disabilities/Mental retardation
 - Mental illness (depression, panic/anxiety disorder, schizophrenia)
 - Physical disabilities (arthritis, stroke, etc.)
 - Head injury
 - Substance abuse issues
 - End of life issues (e.g., Hospice)
 - Other (specify) _____
- Q3. Do you receive monetary compensation for any of the caregiving services you provide (such as Qualified Service Providers or Guardian Services, where you are compensated because it would cost the state more for formal care)?
- Yes
 - No
- Q4. Where is the caregiving done? (Check all that apply)
- In my home - the care recipient lives with me
 - Care recipient's home/apartment (**skip to Q5**)
 - Assisted living facility (**skip to Q5**)
 - Independent living facility (**skip to Q5**)
 - Other
- Q4a. If the care recipient lives with you, how much care is required?
- Around the clock/care recipient cannot be left alone (**skip to Q6**)
 - Around the clock/care recipient can be left alone for a few hours (**skip to Q6**)
 - Around the clock/care recipient can be left alone for most of the day (**skip to Q6**)

Q5. If the care recipient is not living with you...

5a. How far away do you live from him/her?

- Less than 20 minutes away
- Between 20 and 59 minutes away
- Between one and two hours away
- More than two hours away

5b. How many hours per week, **on average**, are you caregiving?

- 0-5 hours/week
- 6-10 hours/week
- 11-15 hours/week
- 16-20 hours/week
- More than 20 hours/week

Q6. How long have you been providing caregiving services to your care recipient?
_____ (please indicate months or years)

Q7.

Here is a list of caregiving difficulties you may have experienced when providing care. Please tell us the difficulties you have experienced by circling the letters of your choices. Then, on a one to five scale, with one being "Not at all serious" and five being "Very serious", please indicate how serious the difficulty was.

What are the difficulties you experience when providing care to your loved one?	Please rate the seriousness of the difficulties you have experienced
Caregiving difficulties	Rating of seriousness
a. Less time for myself (shopping, hobbies, etc.)	Not at all-1 2 3 4 5-Very serious
b. Less time for my family (shorter vacations, missed events, etc.)	Not at all-1 2 3 4 5-Very serious
c. No consistent help from other family members	Not at all-1 2 3 4 5-Very serious
d. Affects my family relationships	Not at all-1 2 3 4 5-Very serious
e. Conflicts with my social life (eating out, movies, visiting friends, etc.)	Not at all-1 2 3 4 5-Very serious
f. Emotional aspects (frustration, sadness, anxiety, etc.)	Not at all-1 2 3 4 5-Very serious
g. Less privacy	Not at all-1 2 3 4 5-Very serious
h. Interferes with my job	Not at all-1 2 3 4 5-Very serious
i. Financial obligations	Not at all-1 2 3 4 5-Very serious
j. Lifestyle change	Not at all-1 2 3 4 5-Very serious
k. Having the responsibility for making major life decisions for loved ones	Not at all-1 2 3 4 5-Very serious
l. My physical health is deteriorating due to caregiving	Not at all-1 2 3 4 5-Very serious
m. I am unable to get the sleep I need due to caregiving	Not at all-1 2 3 4 5-Very serious

Q7a. Are there other caregiving difficulties you may have experienced when providing care that haven't already been mentioned?

No
 Yes (please specify) _____

Q8. Here is a list of concerns that may have applied to you at some time during your caregiving. Please indicate how much you agree or disagree with each statement.

Concerns	Please rate how much you agree or disagree with the concern
a. It is difficult for me to accept support or assistance when caregiving because it is my duty to provide care	Strongly disagree-1 2 3 4 5- Strongly agree
b. It is difficult for me to find support or assistance when caregiving (I feel like I don't have help)	Strongly disagree-1 2 3 4 5- Strongly agree
c. It is difficult for me to accept financial support or assistance when caregiving because it sometimes carries a negative stigma	Strongly disagree-1 2 3 4 5- Strongly agree
d. It is difficult for me to accept help from others when caregiving because I'm being paid (e.g. Qualified Service Provider)	Strongly disagree-1 2 3 4 5- Strongly agree
e. I'm providing caregiving services because people in my community will think ill of me if I don't	Strongly disagree-1 2 3 4 5- Strongly agree
f. Since I have started caregiving services I've experienced a sense of isolation from others in my community	Strongly disagree-1 2 3 4 5- Strongly agree
g. Since I have started caregiving services I've experienced a lack of understanding from others in my community	Strongly disagree-1 2 3 4 5- Strongly agree

Q8a. Are there other concerns for you as a caregiver that haven't already been mentioned?

No
 Yes (please specify) _____

Q9. Are there other informal caregivers who are providing care to the care recipient?

Yes----->Who is providing care? _____
 No

Q10. If there are other people who are not providing care, why not? (Check all that apply)

- There are no other immediate family members
- Others are also in need of care
- Others are embarrassed/uncomfortable fulfilling intimate needs (bathing, toileting, etc.)
- Others are too inexperienced
- Others live farther away
- Others have full-time jobs
- Others have less flexible daily schedules
- Others have young dependents living with them
- Others do not get along with care recipient
- Others are unaware of needed care (have not been informed - have not been asked to help)
- Others are unwilling or "just can't"
- Recipient doesn't want care from others
- Other reasons _____

The next series of questions addresses services that may or may not be available for your care recipient.

Q11. Are **dietician services** available to your care recipient?

- Yes (**Skip to Q11b**)
 No
 Do not know

Q11a. If you answered "No" or "Do not know", would you like **dietician services** to be available to your care recipient?

- Yes (**skip to Q12**)
 No (**skip to Q12**)

Q11b. If **dietician services** are available to your care recipient, are you using it?

- Yes (**Skip to Q11d**)
 No

Q11c. If you're not using **dietician services**, why not? (**After answering, skip to Q12**)

- Do not need it
 Care recipient won't use it
 Other reason (please specify) _____

Q11d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **dietician services**. Not good at all - 1 2 3 4 5 - Very good

Q11e. If you rated **dietician services** 1 or 2, please tell us why the service was not good.

Q12. Are **home delivered meals (through Meals on Wheels, community volunteering, church, etc.)** available to your care recipient?

- Yes (**Skip to Q12b**)
 No
 Do not know

Q12a. If you answered "No" or "Do not know", would you like **home delivered meals** to be available to your care recipient?

- Yes (**skip to Q13**)
 No (**skip to Q13**)

Q12b. If **home delivered meals** are available to your care recipient, are you using it?

- Yes (**Skip to Q12d**)
 No

Q12c. If you're not using **home delivered meals**, why not? (**After answering, skip to Q13**)

- Do not need it
 Care recipient won't use it
 Other reason (please specify) _____

Q12d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **home delivered meals**. Not good at all - 1 2 3 4 5 - Very good

Q12e. If you rated **home delivered meals** 1 or 2, please tell us why the service was not good.

Q13. Are **congregate meal settings (at Senior centers, restaurants, etc.)** available to your care recipient?

- Yes (**Skip to Q13b**)
 No
 Do not know

Q13a. If you answered "No" or "Do not know", would you like **congregate meal settings** to be available to your care recipient?

- Yes (**skip to Q14**)
 No (**skip to Q14**)

- Q13b. If **congregate meal settings** are available to your care recipient, are you using it?
 Yes (**Skip to Q13d**)
 No
- Q13c. If you're not using **congregate meal settings**, why not? (**After answering, skip to Q14**)
 Do not need it
 Care recipient won't use it
 Other reason (please specify) _____
- Q13d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **congregate meal settings**.
 Not good at all - 1 2 3 4 5 - Very good
- Q13e. If you rated **congregate meal settings** 1 or 2, please tell us why the service was not good.

- Q14. Are **adult day centers** available to your care recipient?
 Yes (**Skip to Q14b**)
 No
 Do not know
- Q14a. If you answered "No" or "Do not know", would you like **adult day centers** to be available to your care recipient?
 Yes (**skip to Q15**)
 No (**skip to Q15**)
- Q14b. If **adult day centers** are available to your care recipient, are you using it?
 Yes (**Skip to Q14d**)
 No
- Q14c. If you're not using **adult day centers**, why not? (**After answering, skip to Q15**)
 Do not need it
 Care recipient won't use it
 Other reason (please specify) _____
- Q14d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **adult day centers**.
 Not good at all - 1 2 3 4 5 - Very good
- Q14e. If you rated **adult day centers** 1 or 2, please tell us why the service was not good.

- Q15. Are **outreach programs (i.e. senior companions)** available to your care recipient?
 Yes (**Skip to Q15b**)
 No
 Do not know
- Q15a. If you answered "No" or "Do not know", would you like **outreach programs** to be available to your care recipient?
 Yes (**skip to Q16**)
 No (**skip to Q16**)
- Q15b. If **outreach programs** are available to your care recipient, are you using it?
 Yes (**Skip to Q15d**)
 No
- Q15c. If you're not using **outreach programs**, why not? (**After answering, skip to Q16**)
 Do not need it
 Care recipient won't use it
 Other reason (please specify) _____
- Q15d. On a one to five scale, with one being "Not good at all" and five being "Very Good", please rate **outreach programs**.
 Not good at all - 1 2 3 4 5 - Very good
- Q15e. If you rated **outreach programs** 1 or 2, please tell us why the service was not good.

Q16. Are **visiting nurse** available to your care recipient?

- Yes (**Skip to Q16b**)
 No
 Do not know

Q16a. If you answered "No" or "Do not know", would you like **visiting nurse** to be available to your care recipient?

- Yes (**skip to Q17**)
 No (**skip to Q17**)

Q16b. If **visiting nurse** are available to your care recipient, are you using it?

- Yes (**Skip to Q16d**)
 No

Q16c. If you're not using **visiting nurse**, why not? (**After answering, skip to Q17**)

- Do not need it
 Care recipient won't use it
 Other reason (please specify) _____

Q16d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **visiting nurse**. Not good at all - 1 2 3 4 5 - Very good

Q16e. If you rated **visiting nurse** 1 or 2, please tell us why the service was not good.

Q17. Are **parish nurses** available to your care recipient?

- Yes (**Skip to Q17b**)
 No
 Do not know

Q17a. If you answered "No" or "Do not know", would you like **parish nurses** to be available to your care recipient?

- Yes (**skip to Q18**)
 No (**skip to Q18**)

Q17b. If **parish nurses** are available to your care recipient, are you using it?

- Yes (**Skip to Q17d**)
 No

Q17c. If you're not using **parish nurses**, why not? (**After answering, skip to Q18**)

- Do not need it
 Care recipient won't use it
 Other reason (please specify) _____

Q17d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **parish nurses**. Not good at all - 1 2 3 4 5 - Very good

Q17e. If you rated **parish nurses** 1 or 2, please tell us why the service was not good.

Q18. Are **homemaker services/home health aides** available to your care recipient?

- Yes (**Skip to Q18b**)
 No
 Do not know

Q18a. If you answered "No" or "Do not know", would you like **homemaker services/home health aides** to be available to your care recipient?

- Yes (**skip to Q19**)
 No (**skip to Q19**)

Q18b. If **homemaker services/home health aides** are available to your care recipient, are you using it?

- Yes (**Skip to Q18d**)
 No

Q18c. If you're not using **homemaker services/home health aides**, why not? **(After answering, skip to Q19)**

- Do not need it
- Care recipient won't use it
- Other reason (please specify) _____

Q18d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **homemaker services/home health aides**.
Not good at all - 1 2 3 4 5 - Very good

Q18e. If you rated **homemaker services/home health aides** 1 or 2, please tell us why the service was not good _____

Q19. Are **escort/transportation services** available to your care recipient?

- Yes **(Skip to Q19b)**
- No
- Do not know

Q19a. If you answered "No" or "Do not know", would you like **escort/transportation services** to be available to your care recipient?

- Yes **(skip to Q20)**
- No **(skip to Q20)**

Q19b. If **escort/transportation services** are available to your care recipient, are you using it?

- Yes **(Skip to Q19d)**
- No

Q19c. If you're not using **escort/transportation services**, why not? **(After answering, skip to Q20)**

- Do not need it
- Care recipient won't use it
- Other reason (please specify) _____

Q19d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **escort/transportation services**. Not good at all - 1 2 3 4 5 - Very good

Q19e. If you rated **escort/transportation services** 1 or 2, please tell us why the service was not good _____

Q20. Are **shopping assistance** available to your care recipient?

- Yes **(Skip to Q20b)**
- No
- Do not know

Q20a. If you answered "No" or "Do not know", would you like **shopping assistance** to be available to your care recipient?

- Yes **(skip to Q21)**
- No **(skip to Q21)**

Q20b. If **shopping assistance** are available to your care recipient, are you using it?

- Yes **(Skip to Q20d)**
- No

Q20c. If you're not using **shopping assistance**, why not? **(After answering, skip to Q21)**

- Do not need it
- Care recipient won't use it
- Other reason (please specify) _____

Q20d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **shopping assistance**. Not good at all - 1 2 3 4 5 - Very good

Q20e. If you rated **shopping assistance** 1 or 2, please tell us why the service was not good. _____

Q21. Are **pet services (grooming, vet needs, etc.)** available to your care recipient?

- Yes (**Skip to Q21b**)
- No
- Do not know

Q21a. If you answered "No" or "Do not know", would you like **pet services** to be available to your care recipient?

- Yes (**skip to Q22**)
- No (**skip to Q22**)

Q21b. If **pet services** are available to your care recipient, are you using it?

- Yes (**Skip to Q21d**)
- No

Q21c. If you're not using **pet services**, why not? (**After answering, skip to Q22**)

- Do not need it
- Care recipient won't use it
- Other reason (please specify) _____

Q21d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **pet services**. Not good at all - 1 2 3 4 5 - Very good

Q21e. If you rated **pet services** 1 or 2, please tell us why the service was not good

Q22. Are there other services that haven't already been mentioned that you would like to have available to your care recipient?

- No
- Yes (please specify) _____

The next series of questions addresses services that may be available to you as a caregiver.

Q23. Is **information about available services** available to you?

- Yes (**Skip to Q23b**)
- No
- Do not know

Q23a. If you answered "No" or "Do not know", would you like **information about available services** to be available to you?

- Yes (**skip to Q24**)
- No (**skip to Q24**)

Q23b. If **information about available services** is available to you, are you using it?

- Yes (**Skip to Q23d**)
- No

Q23c. If you're not using **information about available services**, why not? (**After answering, skip to Q24**)

- Do not need it
- Other reason (please specify) _____

Q23d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **information about available services**.

Not good at all - 1 2 3 4 5 - Very good

Q23e. If you rated **information about available services** 1 or 2, please tell us why the service was not good

Q24. Is **assistance with accessing available services** available to you?

Yes (**Skip to Q24b**)

No

Do not know

Q24a. If you answered "No" or "Do not know", would you like **assistance with accessing available services** to be available to you?

Yes (**skip to Q25**)

No (**skip to Q25**)

Q24b. If **assistance with accessing available services** is available to you, are you using it?

Yes (**Skip to Q24d**)

No

Q24c. If you're not using **assistance with accessing available services**, why not? (**After answering, skip to Q25**)

Do not need it

Other reason (please specify) _____

Q24d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **assistance with accessing available services**.

Not good at all - 1 2 3 4 5 - Very good

Q24e. If you rated **assistance with accessing available services** 1 or 2, please tell us why the service was not good _____

Q25. Is **individual caregiver counseling** available to you?

Yes (**Skip to Q25b**)

No

Do not know

Q25a. If you answered "No" or "Do not know", would you like **individual caregiver counseling** to be available to you?

Yes (**skip to Q26**)

No (**skip to Q26**)

Q25b. If **individual caregiver counseling** is available to you, are you using it?

Yes (**Skip to Q25d**)

No

Q25c. If you're not using **individual caregiver counseling**, why not? (**After answering, skip to Q26**)

Do not need it

Other reason (please specify) _____

Q25d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **individual caregiver counseling**.

Not good at all - 1 2 3 4 5 - Very good

Q25e. If you rated **individual caregiver counseling** 1 or 2, please tell us why the service was not very good _____

Q26. Is **caregiver training or education** available to you?

Yes (**Skip to Q26b**)

No

Do not know

Q26a. If you answered "No" or "Do not know", would you like **caregiver training or education** to be available to you?

Yes (**skip to Q27**)

No (**skip to Q27**)

Q26b. If **caregiver training or education** is available to you, are you using it?

Yes (**Skip to Q26d**)

No

Q26c. If you're not using **caregiver training or education**, why not? (**After answering, skip to Q27**)

Do not need it

Other reason (please specify) _____

Q26d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **caregiver training or education**.

Not good at all - 1 2 3 4 5 - Very good

Q26e. If you rated **caregiver training or education** 1 or 2, please tell us why the service was not good _____

Q27. Is **respite care (someone else provides short-term relief for you)** available to you?

Yes (**Skip to Q27b**)

No

Do not know

Q27a. If you answered "No" or "Do not know", would you like **respite care** to be available to you?

Yes (**skip to Q28**)

No (**skip to Q28**)

Q27b. If **respite care** is available to you, are you using it?

Yes (**Skip to Q27d**)

No

Q27c. If you're not using **respite care**, why not? (**After answering, skip to Q28**)

Do not need it

Other reason (please specify) _____

Q27d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **respite care**.

Not good at all - 1 2 3 4 5 - Very good

Q27e. If you rated **respite care** 1 or 2, please tell us why the service was not very good _____

Q28. Are **caregiver support groups** available to you?

Yes (**Skip to Q28b**)

No

Do not know

Q28a. If you answered "No" or "Do not know", would you like **caregiver support groups** to be available to you?

Yes (**skip to Q29**)

No (**skip to Q29**)

Q28b. If **caregiver support groups** are available to you, are you using it?

Yes (**Skip to Q28d**)

No

Q28c. If you're not using **caregiver support groups**, why not? (**After answering, skip to Q29**)

Do not need it

Other reason (please specify) _____

Q28d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **caregiver support groups**.

Not good at all - 1 2 3 4 5 - Very good

Q28e. If you rated **caregiver support groups** 1 or 2, please tell us why the service was not good. _____

Q29. Are there other services I haven't already been mentioned that you would like to have available to you as a caregiver ?

No
 Yes (please specify _____

Q30. Think about the services that you have provided or are now providing to your care recipient. Please tell us which of the following services you've provided, how often you've provided the service, and if you would have liked help providing the service. For example, if you have phone contact on a weekly basis check the "weekly" box.

Type of Service	How often have you provided this service? (Please fill in the most appropriate box)					Would you have liked help providing this service?	
	Daily	Weekly	Monthly	On Occasion	Never	Yes	No
Manage finances							
Contribute financially							
Administer personal care (bathing, bandaging, nail care, etc.)							
Assist with household tasks (including pet care)							
Assist with maintenance/repair (indoor/outdoor)							
Assist with meals/nutritional needs							
Assist with errands/shopping							
Provide companionship							
Provide phone contact							
Help with worries, anxiety, and emotional needs (i.e., loss of independence, leaving home behind, fear of death, crying, anger, etc.)							
Listen to them - someone for them to talk to							
Provide transportation, getting places							
Assist with medicines (administering, side effects, etc.)							
Communicate with medical providers							
Get other family members involved in caregiving							
Help with legal assistance							

Q31. Are there other services that haven't already been mentioned that you would like to have available to you as a caregiver?

- No
 Yes (please specify) _____

Q32. What kinds of information/services would be valuable to you as a caregiver, now or in the future?

- Information about the care recipient's condition or disability (what to expect as they age, etc.)
 Information on end of life issues
 Information about developments or changes in laws which might affect your situation
 Info-line (central place to call to find out what kind of help is available or where to get it)
 Someone to help you arrange for services, assess your situation
 Someone to talk to/counseling services/support group
 Respite care or adult day care
 Aftercare/grief counseling
 Hotline (for dealing with immediate emotional needs while preserving dignity of care recipient)
 Help in understanding how to select a nursing home/other care facility
 Help in assessing the timing of placement in formal caregiving institutions
 Help in understanding how to pay for nursing homes, adult day care, etc.
 Help in dealing with agencies (bureaucracies) to get services
 Financial support
 Tax break, stipend, government subsidy
 Other (specify) _____
 None of the above

Q33. Because of caregiving have you... (check all that apply)

- Changed locations to accommodate care recipient's needs (e.g. handicap accessibility)
 Sold a home to move in with care recipient
 Stopped working
 Retired early
 Taken a less demanding job
 Changed from full-time to part-time work
 Reduced your official working hours
 Lost some of your employment fringe benefits
 Had time conflicts between working and caregiving
 Used your vacation time to provide care
 Taken a leave of absence to provide care
 Lost a promotion
 Taken off work early or arrived to work late because you provided care
 Other (specify) _____
 None of the above

Q34. Within the past year, on average, how much money have you spent caring for your care recipient?

- 0 to \$1,000
 \$1,001 to \$2,000
 \$2,001 to \$3,000
 \$3,001 to \$4,000
 \$4,001 to \$5,000
 More than \$5,000
 The care recipient lives with me - it's difficult to separate expenses.
 I do not know

Q35. What is your age?

- Younger than 35 years of age
 35 to 44 years old
 45 to 54 years old
 55 to 64 years old
 65 to 74 years old
 75 to 84 years old
 85 or older

Q36. What is your marital status?

- Married or living with partner
 Single, never married
 Divorced or separated
 Widowed

- Q37. If there are children who reside in you household, what are their ages? (Please indicate the number of children in each age category.)
- 0 to 4 years old
 - 5 to 9 years old
 - 10 to 14 years old
 - 15 to 18 years old
 - 18 or older
- Q38. What is your gender?
- Male
 - Female
- Q39. What is the highest level of education you have completed?
- Less than high school
 - Some high school
 - Graduated high school/GED
 - Some technical college
 - Technical degree
 - Some college
 - Graduated college
 - Post graduate or professional degree
- Q40. What is your employment status?
- Full-time employment (35 hours/week or more)
 - Part-time
 - Multiple jobs (including full-time)
 - Retired
 - Not working
- Q41. What was your annual household income in 2001 before taxes (including money from jobs, social security, retirement income, public assistance, etc.)?
- Less than \$10,000
 - \$10,000-\$20,000
 - \$20,001-\$35,000
 - \$35,001-\$50,000
 - \$50,001-\$65,000
 - \$65,001-\$80,000
 - \$80,001-\$100,000
 - More than \$100,000
- Q42. What is your race/ethnic background?
- White (Non-Hispanic)
 - White (Hispanic)
 - Black or African American
 - Asian American
 - American Indian or Alaska Native
 - Native Hawaiian or other Pacific Islander
 - Other race/ethnicity _____
- Q43. What is your principle language?
- English
 - Spanish
 - Other _____
- Q44. What is your zip code? _____

The North Dakota Department of Human Services Aging Services Division is interested in establishing a registry of caregivers in North Dakota. Information gathered from the survey will assist policymakers in developing programs and educational materials to help meet the needs of caregivers such as yourself. If you are willing, please give us your name, address, and phone number so we may add you to the registry.

45. Name: _____
 Address: _____
 Phone: _____

Thank you for taking time to help us with this important study!