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# ***Grandparents as Caregivers in North Dakota, 2002***

*Outreach and Phone Surveys*

## FORWARD

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# EXECUTIVE SUMMARY

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## INTRODUCTION

A survey of grandparent caregivers in North Dakota was conducted during the first half of 2002. The purpose of this study was to gain insight into the barriers and difficulties grandparents have in providing care to grandchildren, and to assist policy makers in exploring ways to improve caregiving and to improve the lives of those who provide informal care. The following, rather broad definition of grandparent caregiver was used when collecting the data:

*A **grandparent caregiver** is a relative caregiver who lives with their grandchild (18 years of age or younger), is the primary caregiver, and has either a legal or an informal relationship with the child.*

A total of 106 interviews of grandparent caregivers are included in the database. These interviews were collected in two ways. First, approximately one in four interviews were obtained through a random telephone survey of households that was conducted in the spring of 2002. The purpose of this initial data collection effort was to gather sufficient data to estimate the overall number of grandparent caregivers in the state. Secondly, a followup data collection effort began in the summer of 2002. Outreach case workers in each of North Dakota's eight planning regions (as defined by the North Dakota Department of Human Services) were asked to conduct face-to-face interviews with grandparent caregivers in their respective service areas.

A survey instrument nearly identical to the one used in the initial telephone data collection process was given to the outreach workers for their data collection effort. Each outreach worker was responsible for finding and interviewing the grandparent caregivers in their area, and the outreach workers were encouraged to interview as many grandparent caregivers as they could find from each of the counties in their service area. The survey instrument was divided into six sections, and information was gathered on the following topical areas: Characteristics of Caregiving, Caregiving Difficulties and Concerns, Services Available to Grandchildren, Services Available to Grandparents, Services Provided by Grandparents, and Demographic Characteristics of Grandparents.

## SURVEY RESULTS

### *Characteristics of Caregiving*

- More than 57 percent of grandparents provide care for just one child. Grandchildren receiving care from their grandparents are fairly equally distributed by age, with 47 percent of grandparents indicating their grandchildren are less than 10 years of age, and 53 percent reporting that their grandchildren are 10 years of age or older.
- The majority of grandparents indicated their grandchildren are white.
- Nearly 52 percent of grandparents indicated they do not currently have legal guardianship of their grandchildren.
- For approximately 67 percent of the grandparents, the mother of the grandchild is the grandparent's offspring. A majority of the time, the grandparent is caring for their grandchild because of issues related to the mother. Nearly 50 percent of grandparents indicated their relationship with the parent of the grandchild is amicable.
- One-fourth of grandparents have spent four to six years caring for their grandchildren. Nearly 45 percent of grandparents indicated their grandchildren require care around the clock (24 hours, 7 days a week), with almost equal percentages of grandparents reporting that their grandchildren can be left alone for a few hours or overnight (23.3 percent and 22.3 percent, respectively).

## EXECUTIVE SUMMARY (continued)

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- Three-fourths of grandparents receive no monetary compensation in caring for their grandchildren. In addition, approximately 59 percent of grandparents reported their grandchildren receive no monetary compensation. More than a third of grandparents indicated their households do receive non-monetary help through the school lunch program or through medical assistance.
- A majority of grandparents indicated the grandchildren for which they are providing care have no special needs. However, for grandparents who reported that their grandchildren do have special needs, the top three needs as reported by grandparents are emotional issues, learning disabilities, and hyperactivity disorders.

### *Caregiving Difficulties and Concerns*

- In general, grandparents experience a variety of difficulties and concerns associated with caregiving. However, overall, grandparents did not rate any of these difficulties as very serious. In addition, grandparents generally did not agree that there were many concerns associated with caring for their grandchild.
  - Approximately one-fourth of grandparents indicated they felt the difficulties in the following areas were serious or very serious: emotional aspects, the financial burden, and the feeling of being more 'tied down'.
  - At least 20 percent of grandparents agreed or strongly agreed with the following statements regarding concerns associated with caregiving: other family members being jealous of the extra care and attention given to grandchildren, difficulties in finding support or assistance when caregiving, and difficulties in accepting support or assistance because they feel it is their duty to provide care.
- If another family member also provides care to the grandchild, it is more common for that person to be a family member *within* the household, rather than a family member outside the household. There are many reasons why others do not provide care, and the top two reasons are because others have full-time jobs or because others live farther away.

### *Services Available to Grandchildren*

- At least three-fourths of grandparents indicated the following services are available to their grandchildren: school lunch programs, extracurricular activities, and special education.
- Nearly 30 percent of grandparents reported the following services are *not* available to their grandchildren: positive role models or mentor program, tutoring or homework assistance, and scholarships. More than half indicated they would like these aforementioned services to be available.

### *Services Available to Grandparents*

- More than 54 percent of grandparents indicated they have access to information about available services.
- At least 40 percent of grandparents indicated that parish nurses, caregiver support groups, and shopping assistance are *not* available to them.

## EXECUTIVE SUMMARY (continued)

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- In instances where the service was not available, the top five services that grandparents would like to have available to them are information about available services, legal assistance or legal aid, assistance with accessing available services, outreach programs, and caregiver support groups.
- If the service was available, more than half of grandparents indicated they are using assistance with accessing available services and information about available services.
- Regardless of the type of service, the most common reason that grandparents do not use the services available to them is because they do not need them.
- At least a third of grandparents indicated that the following information or services would be valuable to them, now or in the future: an info-line; financial support; tax breaks, stipends, or government subsidies; and someone to talk to, counseling services, or support groups.

### *Services Provided by Grandparents*

- At least 90 percent of grandparents indicated they provide a variety of services to their grandchildren: listening to them or being someone for them to talk to; providing companionship; providing discipline; help with worries, anxiety, and emotional needs; contributing financially; providing transportation or help in getting places; assisting with meals and nutritional needs; assisting with household care; and assisting with errands or shopping.
- Although providing cross-cultural education for their grandchildren is the service provided least by grandparents, approximately 66 percent had done so.
- At least 80 percent of grandparents provide the following services on a daily basis: listening to their grandchildren and being someone for them to talk to, providing companionship, assisting with meals or nutritional needs, and assisting with household care.
- While the majority of grandparents reported they do not want help with the caregiving services listed, at least one-fourth indicated they would like help with the following services: contributing financially; providing tutoring and homework assistance; and helping with worries, anxiety, or emotional needs.
- Forty percent of grandparents reported they have experienced no financial difficulties in caring for their grandchildren.
- Approximately one-fourth had taken off work early or arrived to work late because of caregiving (27.4 percent) or had other time conflicts between working and caregiving (23.6 percent).

### *Demographic Characteristics of Grandparents*

- In general, results indicate that grandparents who care for their grandchildren are young, educated, and working.
  - Approximately 67 percent of grandparents are under the age of 65.
  - Approximately 38 percent of grandparents have a post-high school education.
  - Nearly half of grandparents are employed, with one-fourth working full-time.

## EXECUTIVE SUMMARY (continued)

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- The highest proportions of grandparents reported they had either spent more than \$5,000 within the last year caring for their grandchild, or they do not know how much they had spent (27.2 percent and 25.2 percent, respectively).
- Nearly 71 percent of grandparents are married or living with a partner.
- Approximately 79 percent of grandparents do not have children other than grandchildren residing in their household.
- Nearly 63 percent of grandparents have an annual household income of \$35,000 or less. According to the 2000 US Census, North Dakota's median household income is \$34,604 (Source: US Census Bureau, 2000 Census, SF3 Table P53).
- The majority of grandparents reported their race or ethnic background as white.
- Approximately 95 percent of grandparents indicated their principle language is English.
- Nearly 84 percent of grandparents who responded to the survey are female.
- According to the results of this report, approximately 55 percent of grandparents who care for their grandchildren are living in rural areas.

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# INTRODUCTION

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## STUDY OBJECTIVES

The overall purpose of this study was threefold. First, the study was undertaken to gather information that would give policymakers an understanding of both the characteristics of grandparents who are placed in the role of caring for their grandchildren and the barriers that impede their caregiving. Second, the findings from the study are intended to serve as a tool to explore ways to better serve grandparents who provide informal care to their grandchildren in North Dakota. The final purpose of the study is to serve as a baseline to follow the trends in characteristics of grandparent caregivers and to monitor the state's ability in improving the caregiving role of grandparents in North Dakota.

## METHODOLOGY

Data on grandparent caregivers were collected through two separate processes. The first phase of data collection was conducted in order to estimate the prevalence of grandparent caregivers in North Dakota. This was done in conjunction with a parallel study that focused on informal caregivers. In order to calculate prevalence rates, a random survey of North Dakota households was conducted. This was accomplished by using a two-staged stratified sampling design of housing units. First, the state was divided into two categories representing those counties classified as urban (i.e., having a city with at least 2,500 residents) and rural (i.e., without any cities of at least 2,500 residents). Approximately half of the state's households fall into each of these two categories. Thus, half of the sample was apportioned to each of the categories. In the second stage, the urban counties were segmented into the following two components: a) households inside cities greater than 5,000 population, and b) all other households in urban counties. A proportional sample was drawn from these two components, and this comprised the urban county sample. Similarly, a proportional sample of households from each of the rural counties was drawn which comprised the rural sample. This process ensured that a representative sample of households would be contacted from both urban cities and rural areas, and it produced a generalizable sample for the state. Interviewers were drawn from a pool of trained surveyors and were supervised by staff of the North Dakota State Data Center. A computer assisted telephone interviewing (CATI) system was used to reduce coder error and ensure consistency in responses.

A random sample of 10,000 households was used as the sampling frame for data collection, and a total of 2,625 households were successfully contacted. Approximately 6.5 percent of these households reported having informal caregivers, 18 percent of which had grandparent caregivers within the household. This resulted in 26 completed surveys, but since this number was too few to provide a broad coverage of characteristics, a second phase of data collection was initiated. We contacted outreach workers at the county and regional levels who provided us with assistance in collecting the data. The outreach workers conducted face-to-face interviews with grandparent caregivers whom they had identified within their service region. Eighty useable surveys were collected by the outreach workers throughout the summer and fall of 2002. The eighty surveys collected by outreach workers, combined with the 26 telephone surveys, amounted to a total of 106 completed grandparent caregiver surveys.

## SURVEY DESIGN

The survey instruments used in the data collection were designed by the staff of the North Dakota State Data Center (NDSDC) in cooperation with the staff at Aging Services. The instruments were pre-tested through a series of focus groups conducted by the NDSDC staff. Focus groups were conducted in both urban and rural settings, and participants in the focus groups included caregivers, care recipients, health care professionals, and service providers. The interview instrument was divided into six sections and was designed to gather information on the following areas: Characteristics of Caregiving, Caregiving Difficulties and Concerns, Services Available to Grandchildren, Services Available to Grandparents, Services Provided by Grandparents, and Demographic Characteristics of Grandparents.

## INTRODUCTION (continued)

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As mentioned in the introduction of the Executive Summary, the outreach and phone surveys were nearly identical, however, a few slight variations do exist. To aid the reader, a symbol key has been devised to help explain the differences between the two surveys. When a symbol is encountered in the main report or in the appendix tables, please refer to the following symbol key to explain the variations between the outreach and phone survey instruments.

### Symbol Key

†	=	Question asked only in outreach survey
‡	=	Question asked only in phone survey
<hr/>		
○	=	Response option available only to outreach survey respondents
β	=	Response option available only to phone survey respondents

### ANALYSIS

The analysis for the outreach and phone surveys was conducted in a three-step process. Data from the surveys were hand-entered (outreach survey) or directly transferred from CATI (phone survey) into the Statistical Packages for the Social Sciences (SPSS) software program to aid in analyzing the data. Secondly, frequencies for all questions were computed, with incomplete survey items being coded as missing data and being excluded from the results presented in this report. Lastly, data were entered into a word processing program in order to examine and present the results in the form of figures, tables and appendix tables.

### INTERPRETING THE RESULTS

These data were collected for the purpose of establishing prevalence rates of informal caregiving in North Dakota. The results are meant to be used as a guide to the experience of providing informal care in North Dakota. Because of the difficulty in identifying and contacting grandparent caregivers, this sample is not large enough to be generalizable. Furthermore, due to the small number of responses to some questions, caution is advised when interpreting the data in certain cases. When caution is advised, a note is indicated in the text accompanying the figures or tables.

## RECOMMENDATIONS

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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 four 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. Next, 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. In the last section, we offer recommendations and information specifically focused on grandparent caregivers in North Dakota.

### I. BROAD POLICY RECOMMENDATIONS

- The findings 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. (Note: The following paragraph refers to results found in the *Informal Caregivers: 2002* outreach and phone survey reports.)

**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.



## RECOMMENDATIONS (continued)

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- 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 a 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 chart on the following page offers an overview of specific recommendations for policy initiatives organized by three target areas.

## RECOMMENDATIONS (continued)

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

### 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

## RECOMMENDATIONS (continued)

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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 to both 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>).

## RECOMMENDATIONS (continued)

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### 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.
- Creating 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

## IV. GRANDPARENT CAREGIVERS: POLICY RECOMMENDATIONS FOR NORTH DAKOTA

The 2002 North Dakota Family Caregivers Support Project is comprised of several components. In general, findings from the various elements of the project point to the compelling need to address informal caregiving in North Dakota. The recommendations we offer in the following section are specifically focused on grandparent caregivers in North Dakota.

- First, the findings from this research suggest there is a compelling need to institute a sustainable grandparent caregiving initiative in the state.

**Rationale:** Statistics gathered throughout the North Dakota Family Caregivers Support Project indicate that grandparent caregivers represent 18 percent of all informal caregiving households in North Dakota or approximately 3,000 households, with data from the 2000 Census supporting this approximation. A question was asked on the 2000 Census regarding grandparents who had "responsibility for most basic needs of any grandchildren under the age of 18" that live in their household. Findings from the Census indicate there were 2,547 grandparent caregivers in North Dakota in the year 2000. Demographers forecast the number of elderly in the state to sharply rise in the near future and best estimates indicate the proportion of the state's total population of persons 65 years of age and older will exceed 23 percent by the year 2020. More importantly, the uneven distribution of seniors will become compounded. Currently, nearly two-thirds of the state's 39 rural counties already have senior populations that exceed 20 percent. These proportions have been projected to exceed 30 percent by 2020. It is reasonable to expect, therefore, that the proportion of grandparent caregivers will also expand greatly within the near future.

## RECOMMENDATIONS (continued)

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- Second, priority should be directed at two specific areas: financial assistance and support systems.

**Rationale:** Findings from this research indicate that 3 out of 4 grandparent caregivers do not receive any monetary compensation for their services. In addition, most of the grandparent caregivers already have marginal incomes with more than one-third having annual household incomes below \$20,000. Moreover, approximately 59 percent of grandparents indicated that their grandchildren do not receive any form of financial assistance. The research findings also show that grandparent caregivers frequently desire various services but can not attain those services. For example, approximately half of grandparents indicated that information about available services was available to them, but for those who did *not* have that service available, nearly 70 percent wanted such information. Similarly, approximately half of the grandparent caregivers in this study wished to have the following services available to them if services were not already available: legal assistance, outreach services, assistance with accessing available services or involvement in caregiver support groups.

Therefore, the following specific recommendations for policy initiatives are suggested:

**1. Create and sustain an information delivery system**

- utilize the Internet to provide 24-hour access to an information delivery system
- provide detailed information regarding location and type of services available
- provide links to key services (e.g., legal assistance, outreach workers, support groups)
- offer a feedback mechanism to allow grandparents to interact with professionals

**2. Offer statewide or regional legal assistance to best leverage the cost of such services**

- provide legal assistance for custody and guardianship concerns
- create a grandparent caregiver advocacy network
- develop incentives for legal professionals to become involved with grandparent caregivers

**3. Organize integrated outreach/mentoring programs for grandchildren**

- dovetail activities with existing programs such as “Big Brother-Big Sister”
- network with faith-based organizations
- create formal mentoring systems through public schools

**4. Create a statewide advisory group to explore ways to eliminate barriers to accessing resources.**

Specific issues should include:

- transportation
- issues of distance
- employer incentives (e.g., flex hours to allow working grandparents the ability to attend necessary functions)

**5. Organize and sustain caregiver support groups**

- develop a marketing campaign to increase awareness of support groups
- design public relations efforts to reduce stigma associated with support groups
- provide incentives and financial assistance for support groups (including facility use)
- develop mechanisms that will increase access to support groups

**6. Develop integrated system for children with special needs (e.g., emotional problems, learning disabilities, hyperactivity disorders)**

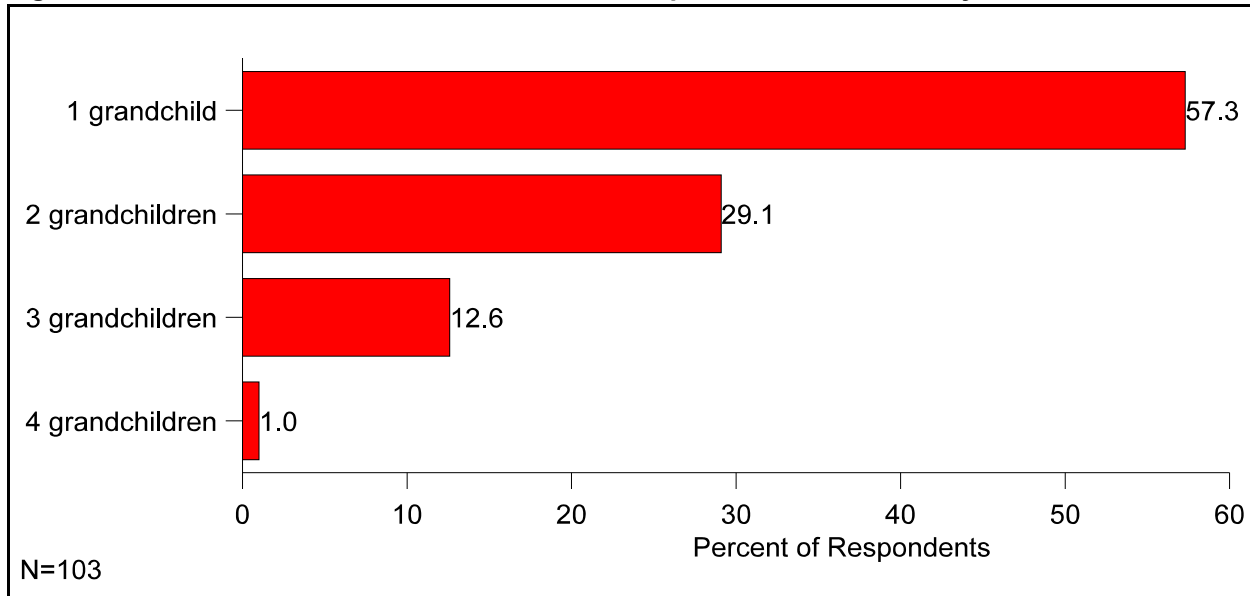
- design a referral system for grandparents, especially for those without legal custody or guardianship
- consider legislation that will allow grandparent caregivers access to insurance or health coverage, especially for those without legal custody or guardianship
- organize an aggressive campaign to ensure that grandparent caregivers understand the options available to them in working with special needs children

## **SURVEY RESULTS**

## CHARACTERISTICS OF CAREGIVING

- ▶ Results indicated that more than 57 percent of grandparents provide care for just one child (Figure 1, Appendix Table 1).

**Figure 1. Number of Grandchildren For Whom Grandparent Provides Primary Care**



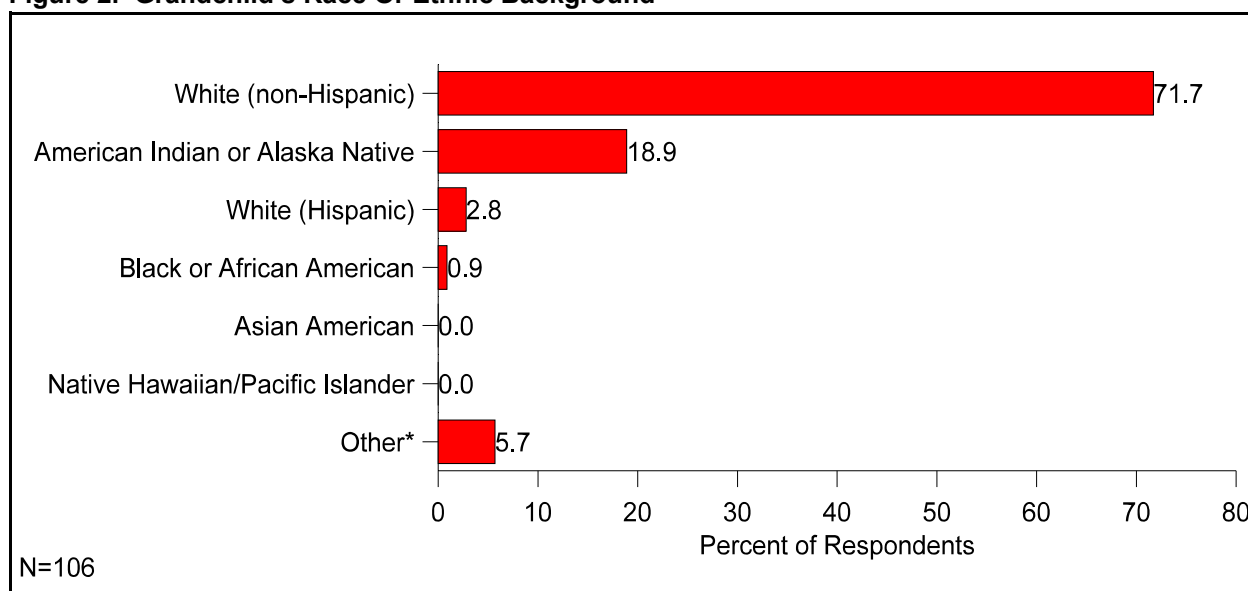
- ▶ The age distribution of grandchildren being cared for by grandparents is fairly equal among all age groups (Table 1).

**Table 1. Number And Age of Grandchildren Receiving Primary Care From Grandparents**

Age of Grandchildren	Grandchildren Receiving Primary Care from Grandparents	
	#	%
0 to 4 years	34	21.5
5 to 9 years	41	25.9
10 to 14 years	44	27.8
15 years of age and above	39	24.7
Total	158	100.0

- ▶ The majority of grandparents reported their grandchildren are white (non-Hispanic and Hispanic) (74.5 percent) (Figure 2, Appendix Table 2).

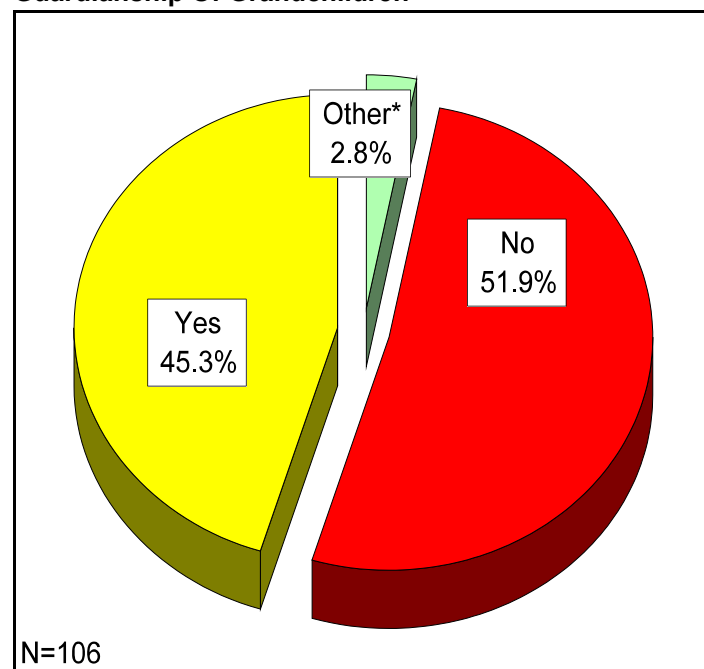
**Figure 2. Grandchild's Race Or Ethnic Background**



\*For a table listing other races or ethnic backgrounds, see Appendix Table 2.

- ▶ A small majority of grandparents reported they currently do not have legal guardianship of their grandchildren (51.9 percent) (Figure 3, Appendix Table 3).

**Figure 3. Whether Grandparent Currently Has Legal Guardianship Of Grandchildren**

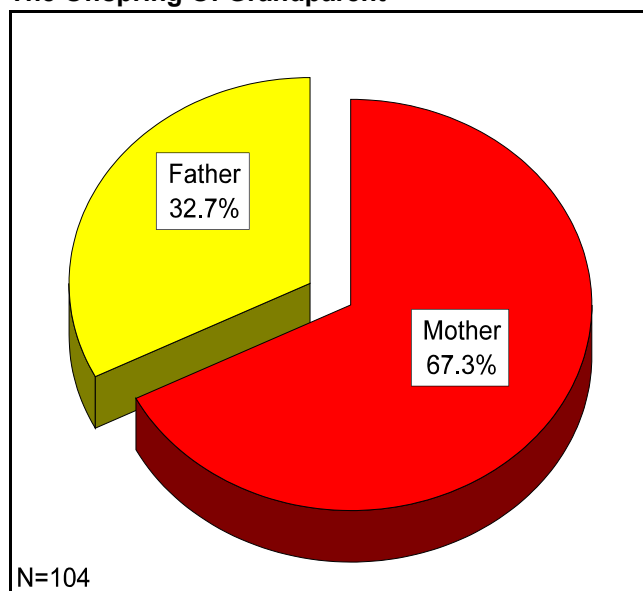


\*For other guardianship situations as reported by grandparents, see Appendix Table 3.  
 Note: Some respondents chose to respond with an other guardianship status, although "other" was not an original response option on the survey.



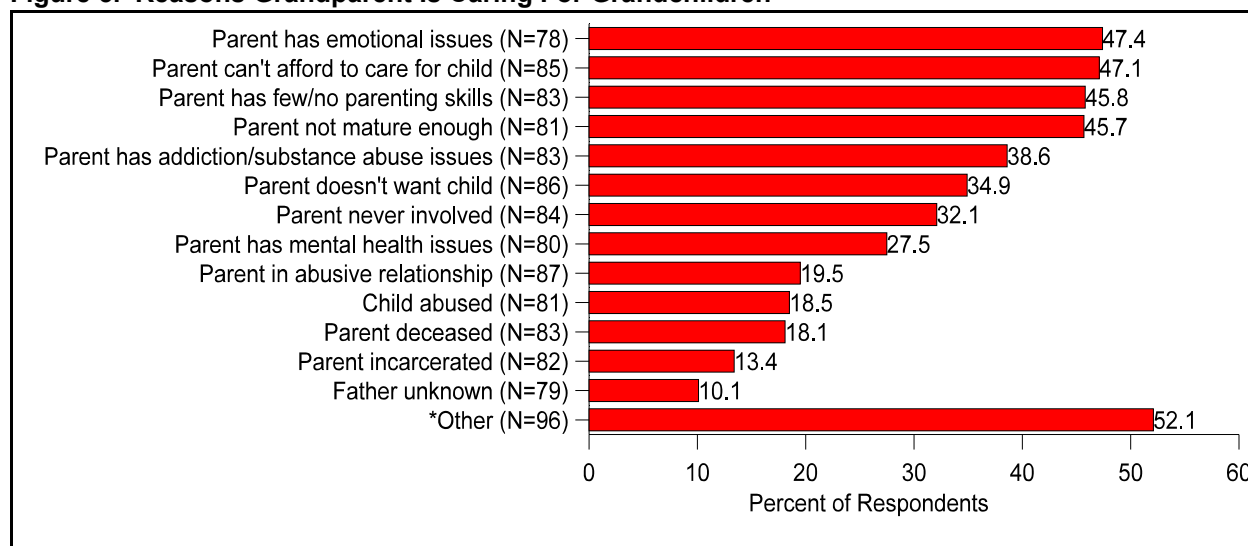
- ▶ Approximately 67 percent of grandparents indicated the grandchild's mother is their offspring (Figure 4, Appendix Table 4).

**Figure 4. Which Of The Grandchild's Parents Is The Offspring Of Grandparent**



- ▶ Nearly half of all respondents are caring for their grandchildren because the parent has emotional issues (47.4 percent), the parent can't afford to care for the child (47.1 percent), the parent has few or no parenting skills (45.8 percent), or the parent is not mature enough (45.7 percent) (Figure 5, Appendix Table 5).
- ▶ Approximately 52 percent of grandparents indicated their grandchildren need care because of other reasons not indicated on the survey (Figure 5).
- ▶ See Appendix Table 5a for other reasons grandparents may be caring for their grandchildren.

**Figure 5. Reasons Grandparent Is Caring For Grandchildren**



\*For other reasons grandparent may be caring for grandchildren, see Appendix Table 5a.

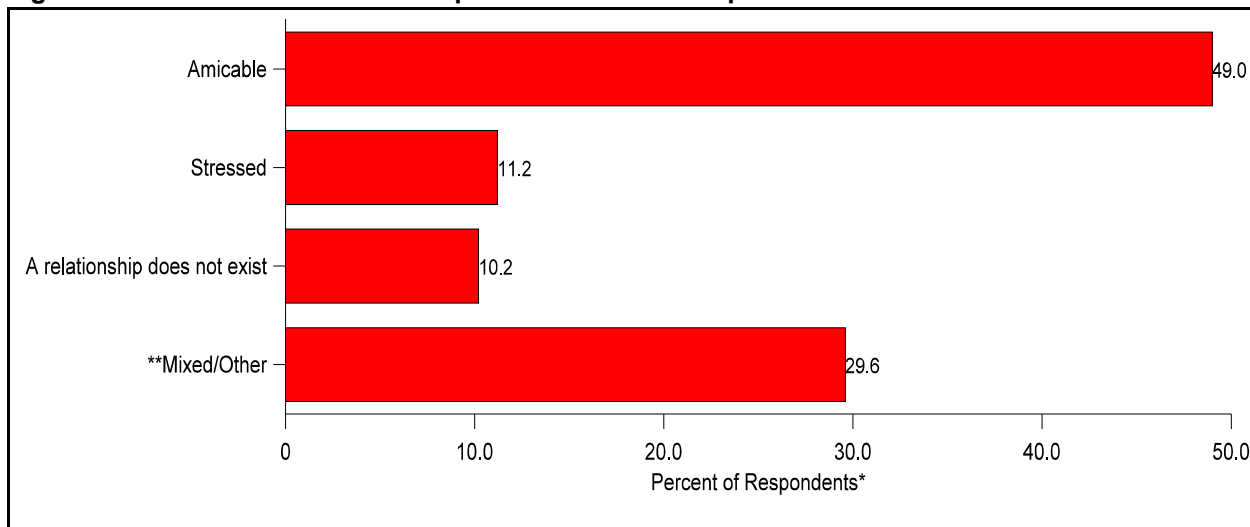
- ▶ Grandparents are caring for their grandchildren mostly due to issues relating to the mother. However, in instances where a parent is not involved in the child's life, a parent is deceased, or a parent is or was incarcerated, approximately 40 percent of respondents related these issues to the father. Caution should be used when interpreting these data due to the small number of respondents (Table 2).

**Table 2. To Which Parent The Statement Refers, When Giving Reasons Why Grandparent Is Caring For Grandchildren**

Reasons	Respondents by Parent of Child							
	Total		Mother		Father		Both	
	#	%	#	%	#	%	#	%
Parent can't afford to care for child	39	100.0	21	53.8	3	7.7	15	38.5
Parent has few/no parenting skills	37	100.0	19	51.4	4	10.8	14	37.8
Parent has emotional issues	36	100.0	25	69.4	2	5.6	9	25.0
Parent is not mature enough (i.e., roles sometimes seemed reversed)	35	100.0	21	60.0	1	2.9	13	37.1
Parent has addiction/substance abuse issues	29	100.0	15	51.7	5	17.2	9	31.0
Parent does not want to be bothered by raising child/does not want child	29	100.0	17	58.6	9	31.0	3	10.3
Parent was never involved in the child's life	26	100.0	7	26.9	12	46.2	7	26.9
Parent has mental health issues	22	100.0	19	86.4	0	0.0	3	13.6
Parent is in an abusive relationship that interferes with raising the child	18	100.0	11	61.1	4	22.2	3	16.7
Parent is deceased	15	100.0	3	20.0	6	40.0	6	40.0
Child was abused	14	100.0	7	50.0	4	28.6	3	21.4
Parent is/was incarcerated	12	100.0	5	41.7	5	41.7	2	16.7
Father is unknown	7	100.0	0	0.0	7	100.0	0	0.0

- ▶ Nearly half of grandparents indicated that the relationship between themselves and the grandchild's parents would be considered amicable (49.0 percent). Nearly 30 percent reported a mixed relationship (29.6 percent). Caution should be used when interpreting these data due to the small number of respondents (Figure 6, Appendix Table 6).
- ▶ See Appendix Table 6 for the status of the relationship by the parent to which it refers. Refer to Table 6a for other relationship statuses as reported by grandparents.

**Figure 6. Status Of The Relationship Between The Grandparent And The Grandchild's Parents**

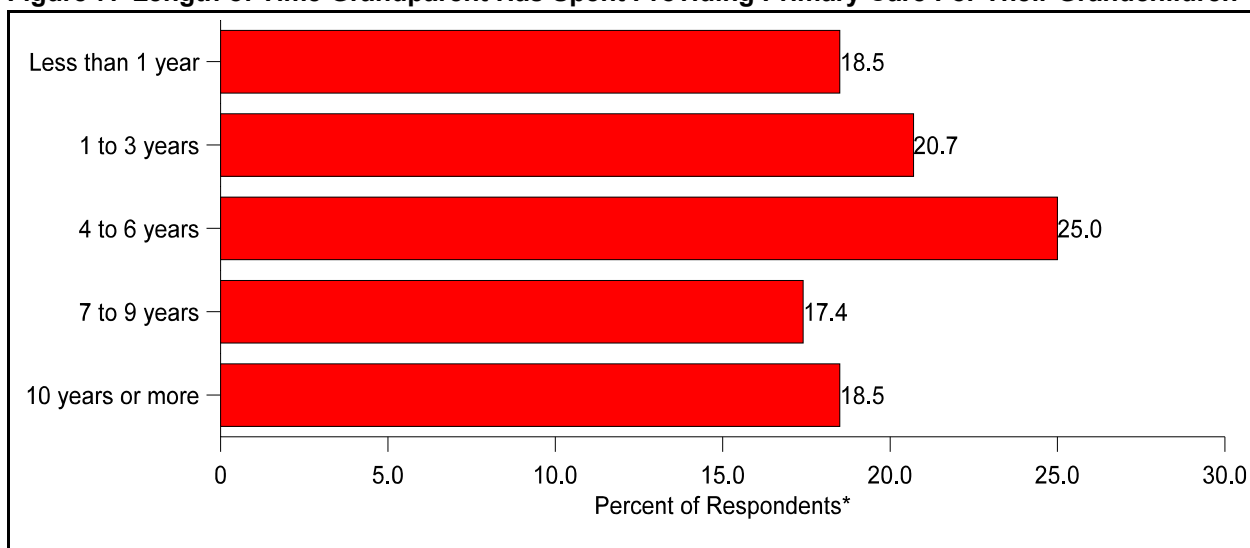


\*Percents do not add to 100.0 due to rounding.

\*\*See Appendix Table 6a for other reported relationship statuses.

- ▶ There is a fairly equal distribution in the number of years that grandparents have been caring for their grandchildren. While approximately 39 percent of respondents have been providing care for less than four years, 25 percent have been providing care for four to six years, and nearly 36 percent have been providing care for more than six years (Table 7, Appendix Table 7).

**Figure 7. Length of Time Grandparent Has Spent Providing Primary Care For Their Grandchildren**

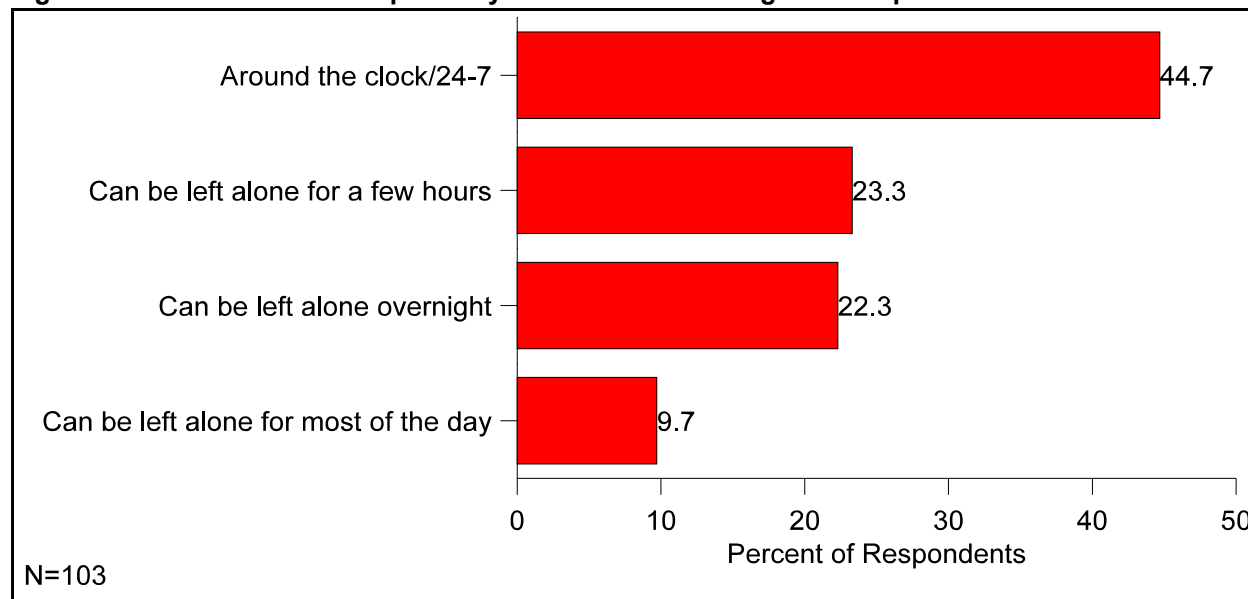


\*Percents do not add to 100.0 due to rounding.

Note: Lengths of time greater than 1 year indicated by grandparent 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.

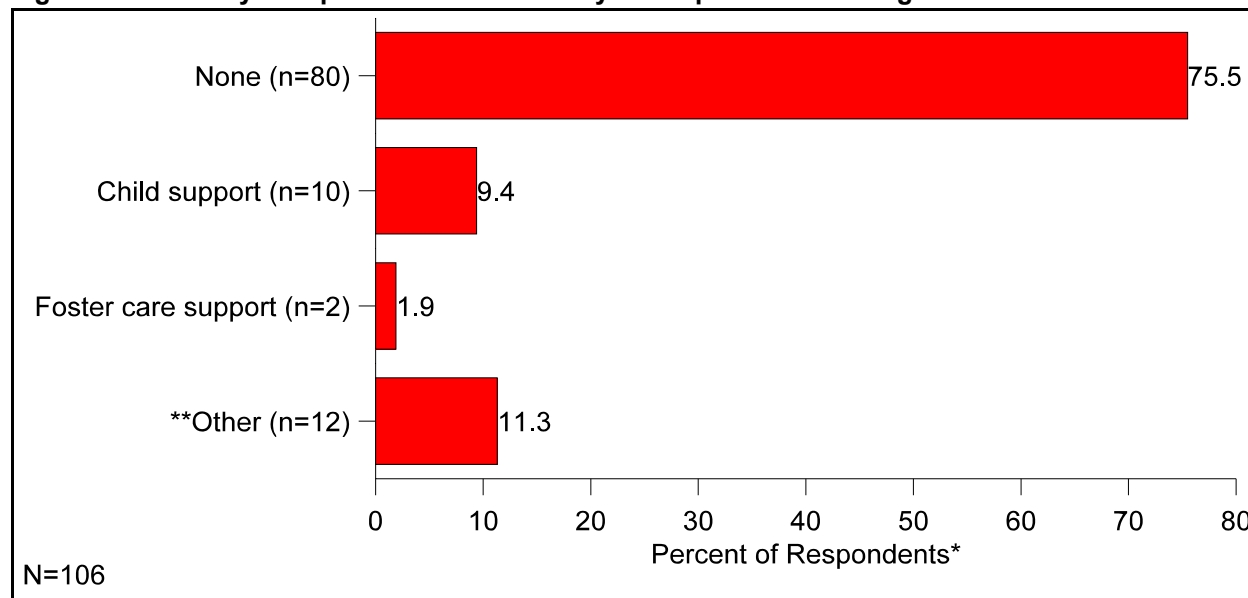
- ▶ Nearly 45 percent of grandparents indicated their grandchildren require care around the clock (24 hours, 7 days a week) while only 10 percent of grandparents indicated their grandchildren can be left alone for most of the day (9.7 percent) (Figure 8, Appendix Table 8).

**Figure 8. Amount Of Care Required By Grandchildren Living In Grandparent’s Home**



- ▶ Three-fourths of grandparents (75.5 percent) receive no monetary compensation in caring for their grandchildren (Figure 9, Appendix Table 9).

**Figure 9. Monetary Compensation Received By Grandparents In Caring For Grandchildren**

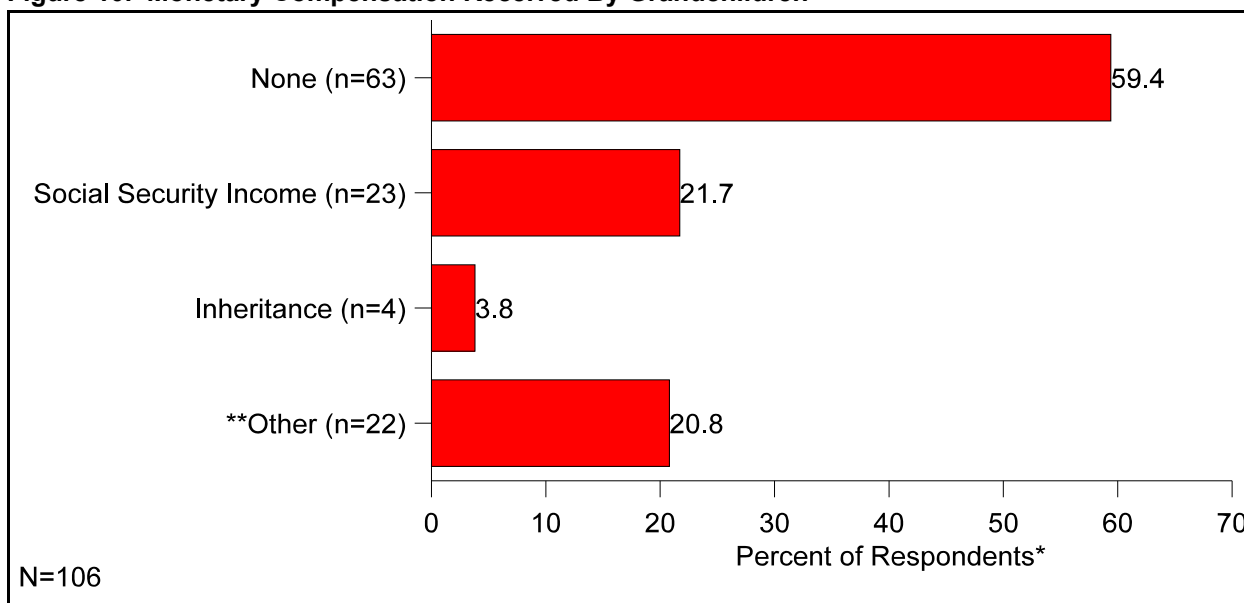


\*Percents do not add to 100.0 due to multiple responses; N=106.

\*\*A list of other monetary compensation received by grandparents is given in Appendix Table 9.

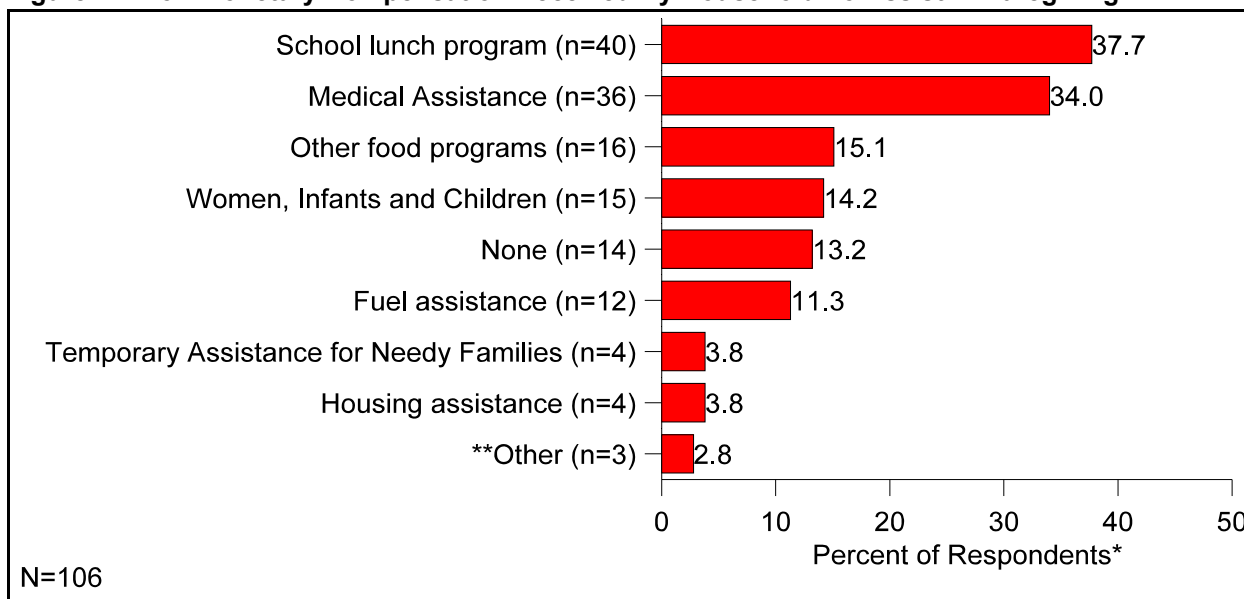
- ▶ More than 59 percent of grandparents reported their grandchildren receive no monetary compensation (Figure 10, Appendix Table 10).

**Figure 10. Monetary Compensation Received By Grandchildren**



- ▶ More than a third of grandparents reported their households receive non-monetary compensation through the school lunch program (37.7 percent) or through medical assistance (34.0 percent) (Figure 11, Appendix Table 11).

**Figure 11. Non-Monetary Compensation Received By Household To Assist In Caregiving**

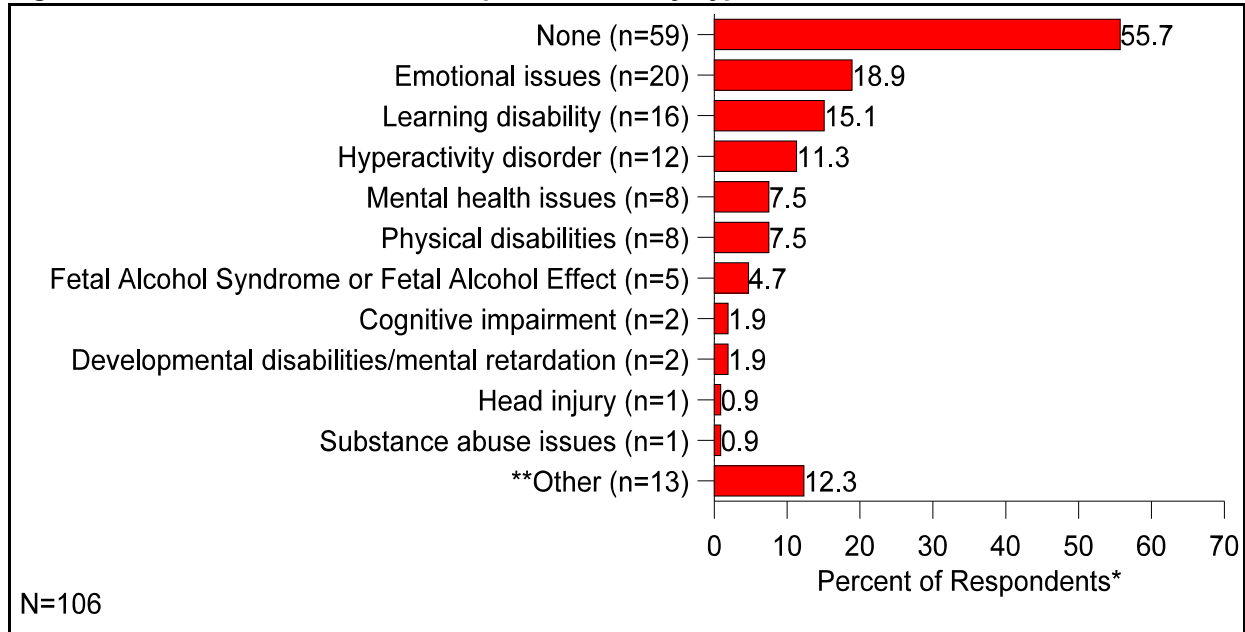


\*Percents do not add to 100.0 due to multiple responses; N=106.

\*\*For other non-monetary compensation received by households, see Appendix Table 11.

- ▶ Approximately 56 percent of grandparents indicated that their grandchildren being cared for require no special needs care. For those grandchildren who have special needs, the top three special needs are as follows: emotional issues (18.9 percent), learning disabilities (15.1 percent) and hyperactivity disorders (11.3 percent) (Figure 12, Appendix Table 12).

**Figure 12. Whether Grandchild Has Special Needs By Type Of Need**



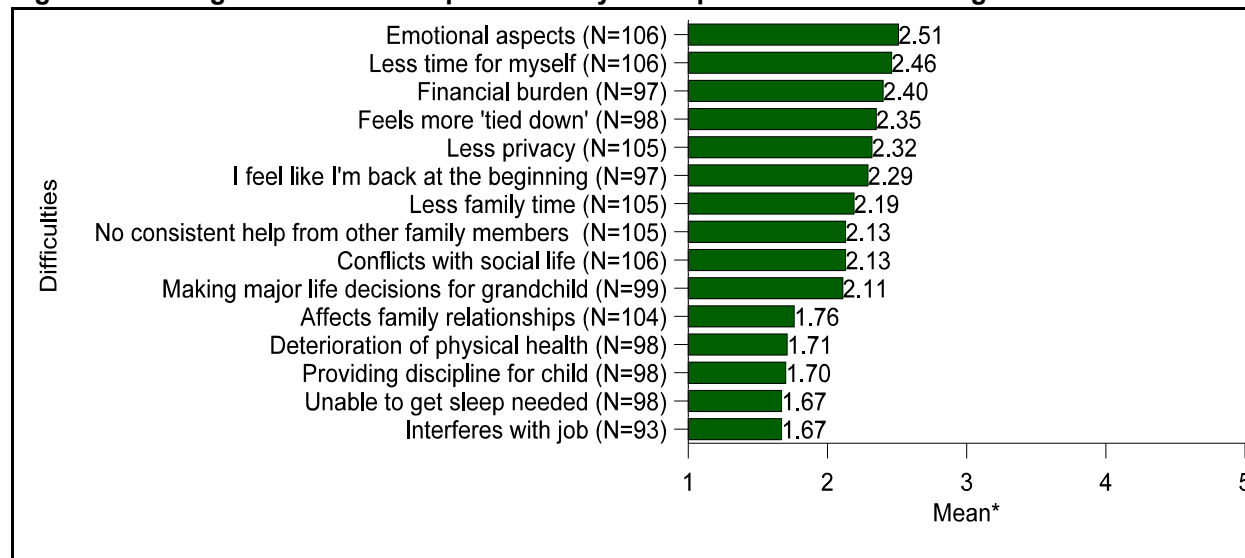
\*Percents do not add to 100.0 due to multiple responses; N=106.

\*\*For other special needs of grandchildren, see Appendix Table 12.

## CAREGIVING DIFFICULTIES AND CONCERNS

- Overall, grandparents rated the seriousness of difficulties experienced when providing care as not very serious. Grandparents rated these difficulties from 1.67 to 2.51 on a scale from one to five, with one being “not at all serious” and five being “very serious” (Figure 13, Appendix Table 13).

**Figure 13. Rating Of Difficulties Experienced By Grandparent When Providing Care**

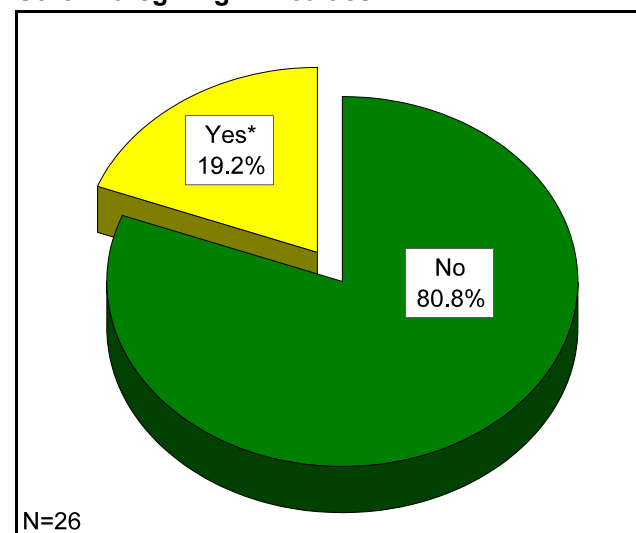


\*Means were based on a one to five scale, with one being “not at all serious” and five being “very serious”.

Note: “Do not know/refused” was excluded from the means and was only available as an option to phone respondents.

- Nearly 81 percent of grandparents do not experience caregiving difficulties other than those difficulties listed in Figure 13. Caution should be used when interpreting these data due to the small number of respondents (Figure 14, Appendix Table 14).
- The responses of grandparents who experience other caregiving difficulties are listed in Appendix Table 14a.

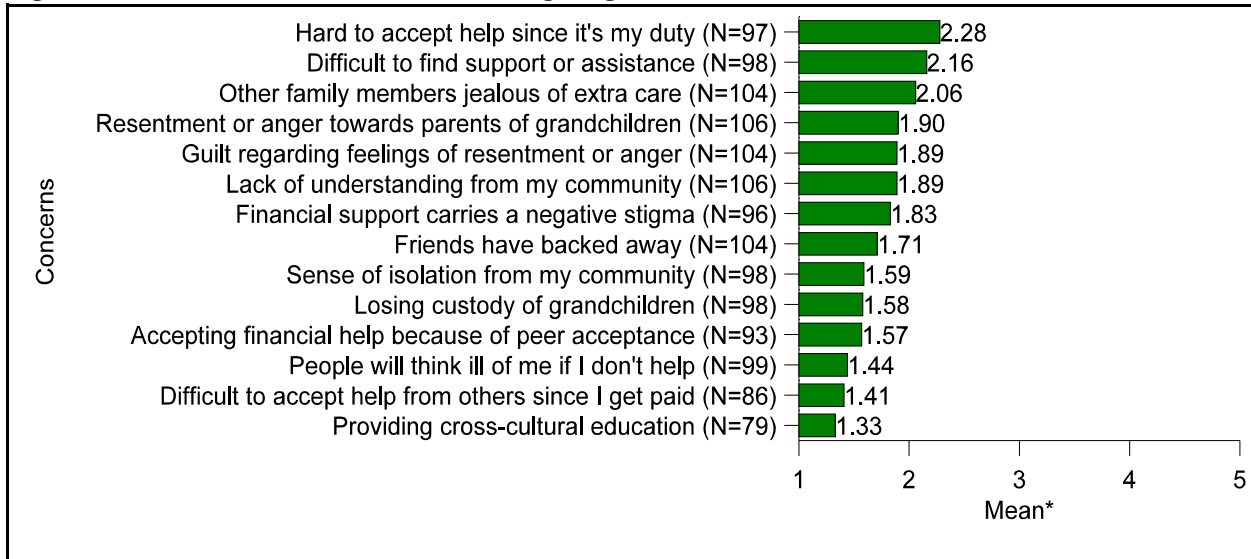
**Figure 14. Whether Grandparent Reported Any Other Caregiving Difficulties †**



†For a list of other caregiving difficulties, see Appendix Table 14a.

- ▶ Grandparents generally disagreed with statements regarding concerns associated with being a caregiver. Mean responses ranged from 1.33 to 2.28 on a scale from one to five, with one being “strongly disagree” and five being “strongly agree” (Figure 15, Appendix Table 15).

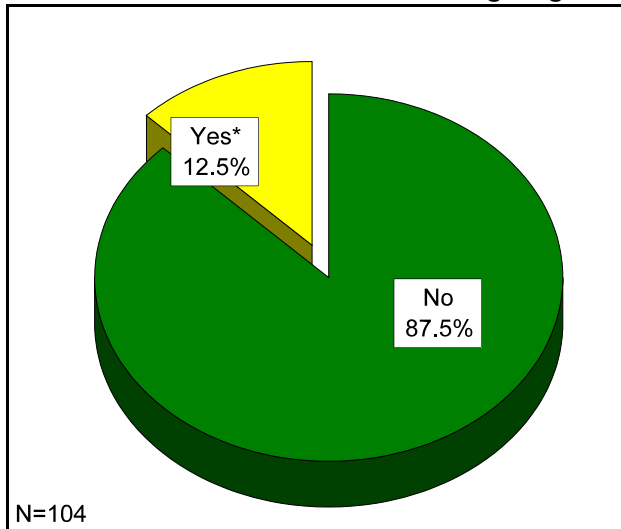
**Figure 15. Concerns Associated With Caregiving**



\*Means were based on a one to five scale, with one being “strongly disagree” and five being “strongly agree”.  
 Note: “Do not know/Refused” was excluded from the means and was only available as an option to phone respondents.

- ▶ Nearly 88 percent of grandparents do not have concerns associated with caregiving other than those concerns mentioned in Figure 15 (Figure 16, Appendix Table 16).
- ▶ The responses of grandparents who have other concerns are listed in Appendix Table 16a.

**Figure 16. Whether Grandparent Experienced Other Concerns Associated With Caregiving**

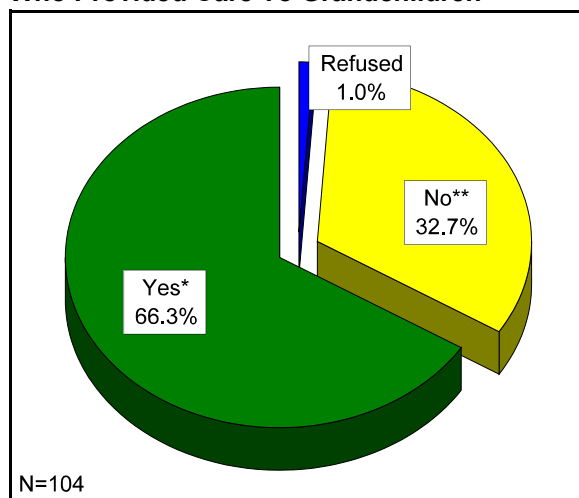


\*See Appendix Table 16a for other concerns associated with caregiving.



- ▶ Approximately 66 percent of grandparents reported there are other family members *within* the household who provide care to grandchildren (Figure 17, Appendix Table 17).
- ▶ See Appendix Table 17a for a list of other family members within the household who provide care to grandchildren. See Figure 19 for reasons why others don't provide care.

**Figure 17. Whether There Were Other Family Members Within Grandparent's Household Who Provided Care To Grandchildren**



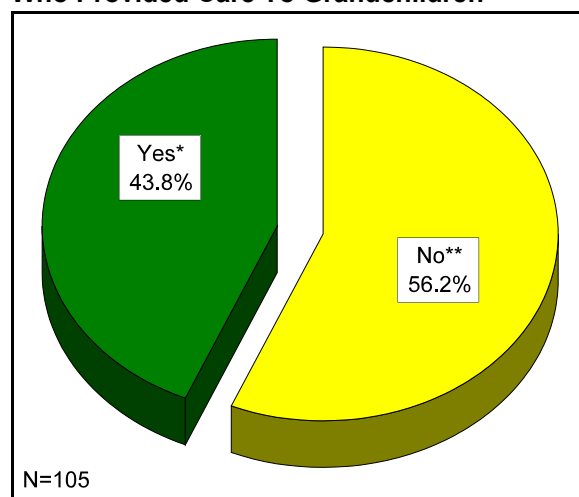
\*See Appendix Table 17a for other family members within the household who provide care to grandchildren.

\*\*See Figure 19 for reasons why others do not provide care.

Note: "Refused" option available only to phone survey respondents.

- ▶ Approximately 56 percent of grandparents indicated there are other family members *outside* the household who provide care to grandchildren (Figure 18, Appendix Table 18).
- ▶ See Appendix Table 18a for a list of other family members outside the household who provide care to grandchildren. See Figure 19 for reasons why others don't provide care.

**Figure 18. Whether There Were Other Family Members Outside Grandparent's Household Who Provided Care To Grandchildren**

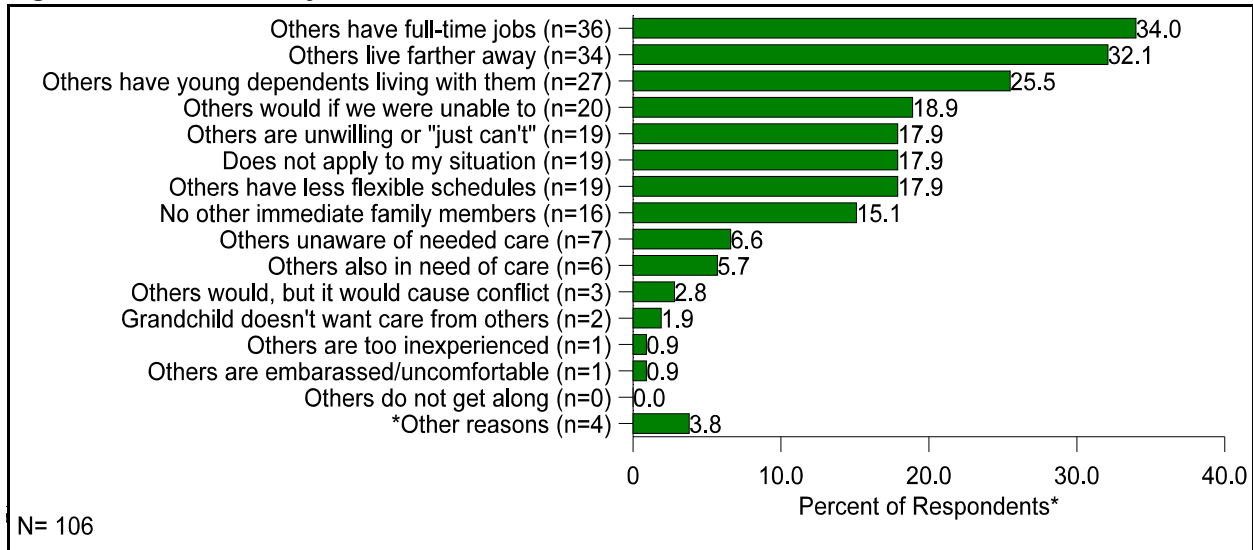


\*See Appendix Table 18a for other family members outside the household who provide care to grandchildren.

\*\*See Figure 19 for reasons why others do not provide care.

- ▶ More than a quarter of grandparents indicated others do not provide care to their grandchildren because others have full-time jobs (34.0 percent), others live farther away (32.1 percent), or others have young dependents living with them (25.5 percent) (Figure 19, Appendix Table 19).
- ▶ For other reasons why others do not provide care, see Appendix Table 19.

**Figure 19. Reasons Why Others Do Not Provide Care To Grandchildren**



\*Percents do not add to 100.0 due to multiple responses; N=106.

\*\*For other reasons why others are not providing care, see Appendix Table 19.

## SERVICES AVAILABLE TO GRANDCHILDREN

- ▶ More than 88 percent of grandparents indicated that a school lunch program is available to their grandchildren. More than half of grandparents indicated that extracurricular activities (82.2 percent), special education (76.2 percent), medical assistance (72.6 percent), counseling services (67.3 percent), and tutoring or homework assistance (55.8 percent) are available to their grandchildren (Table 3).
- ▶ For nearly 30 percent of grandparents, the following services are not available to their grandchildren: positive role models or mentor programs (26.9 percent), tutoring or homework assistance (27.9 percent), and scholarships (29.6 percent) (Table 3).
- ▶ Grandparents are most unaware of scholarship availability (40.8 percent), followed by the availability of positive role models or mentor programs (31.7 percent) (Table 3).

**Table 3. Whether Services Were Available To Grandchildren**

Services for Grandchild	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
School lunch program	91	88.3	11	10.7	1	1	103	100.0
Extracurricular activities	83	82.2	9	8.9	9	8.9	101	100.0
Special education	77	76.2	16	15.8	8	7.9	101	99.9
Medical assistance	77	72.6	20	18.9	9	8.5	106	100.0
Counseling services	70	67.3	13	12.5	21	20.2	104	100.0
Tutoring/homework assistance	58	55.8	29	27.9	17	16.3	104	100.0
Positive role models/mentor program	43	41.3	28	26.9	33	31.7	104	99.9
Scholarships	29	29.6	29	29.6	40	40.8	98	100.0

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

- ▶ More than half of grandparents who indicated their grandchildren do not have scholarships or positive role models or mentor program services available to them reported that they would like these services to be available (Table 4).
- ▶ Approximately one-third or more of grandparents reported they would like all of the remaining services to be available to their grandchildren (Table 4).

**Table 4. If Services Were Not Available To Grandchildren, Whether Grandparent Would Like Them To Be Available**

Services Unavailable To Grandchildren	Respondents by Desire for Services							
	Yes		No		Do not know/ Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%*
Scholarships	41	66.1	19	30.6	2	3.2	62	99.9
Positive role models/mentor program	28	51.9	25	46.3	1	1.9	54	100.1
Medical assistance	12	46.2	14	53.8	0	0.0	26	100.0
Counseling services	15	44.1	19	55.9	0	0.0	34	100.0
Extracurricular activities	6	42.9	8	57.1	0	0.0	14	100.0
Tutoring/homework assistance	15	35.7	26	61.9	1	2.4	42	100.0
Special education	7	31.8	14	63.6	1	4.5	22	99.9
School lunch program	3	30.0	7	70.0	0	0.0	10	100.0

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

- ▶ At least half of grandparents indicated their grandchildren have used the following services: school lunch program (75.6 percent), extracurricular activities (69.9 percent), medical assistance (68.5 percent), positive role models or mentor programs (52.5 percent), and counseling services (51.5 percent) (Table 5).

**Table 5. Whether Services Were Being Used If Services Were Available To Grandchildren**

Services Available to Grandchildren	Respondents by Use of Services					
	Yes		No		Total	
	#	%	#	%	#	%
School lunch program	68	75.6	22	24.4	90	100.0
Extracurricular activities	58	69.9	25	30.1	83	100.0
Medical assistance	50	68.5	23	31.5	73	100.0
Positive role models/mentor program	21	52.5	19	47.5	40	100.0
Counseling services	34	51.5	32	48.5	66	100.0
Tutoring/homework assistance	25	46.3	29	53.7	54	100.0
Scholarships	10	35.7	18	64.3	28	100.0
Special education	24	32.4	50	67.6	74	100.0

- ▶ Regardless of the type of service, the most common reason the grandchild does not use the service is because they do not need it (Table 6).
- ▶ When services are available, two school-related services—extracurricular activities (18.2 percent) and the school lunch program (15.0 percent)—were the top two services that grandparents indicated their grandchild would not use. Caution should be used when interpreting these data due to the small number of respondents. (Table 6).
- ▶ Other reasons why services were not being used by the grandchild are listed in Appendix Table 20 by type of service.

**Table 6. Reasons Why Services Were Not Being Used If Services Were Available To Grandchildren**

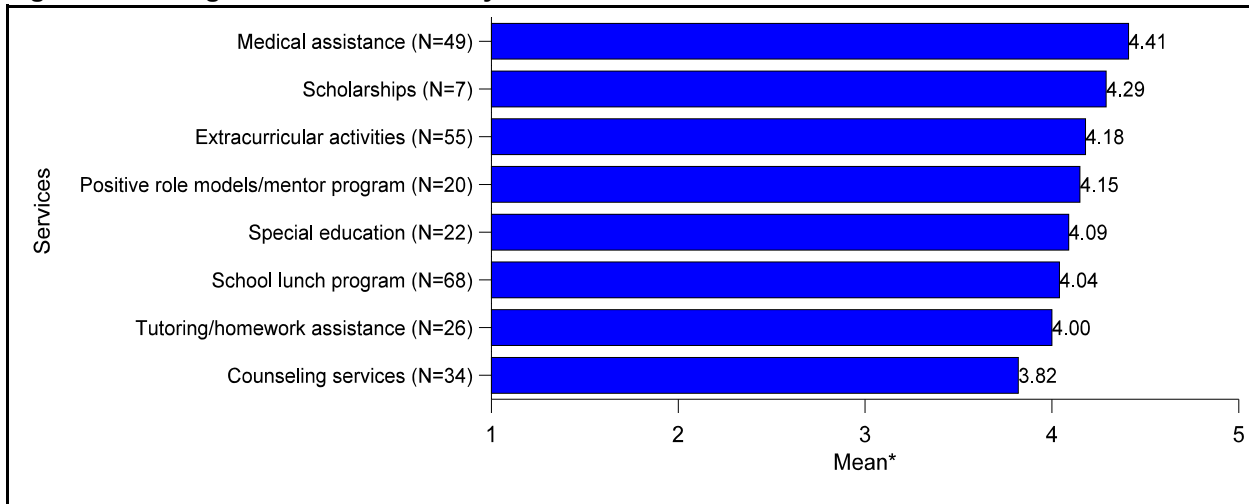
Services Available to Grandchildren	Respondents by Reason for Non-Use of Service									
	Do not need it		Grandchild won't use it		Other reasons**		Do not know/ Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%	#	%*
Special education	43	100.0	0	0.0	0	0.0	0	0.0	43	100.0
Counseling services	28	87.5	1	3.1	2	6.3	1	3.1	32	100.0
Tutoring/homework assistance	23	82.1	3	10.7	2	7.1	0	0.0	28	99.9
Extracurricular activities	7	31.8	4	18.2	11	50.0	0	0.0	22	100.0
Medical assistance	11	52.4	0	0.0	10	47.6	0	0.0	21	100.0
School lunch program	8	40.0	3	15.0	9	45.0	0	0.0	20	100.0
Scholarships	10	55.6	0	0.0	8	44.4	0	0.0	18	100.0
Positive role models/mentor program	11	64.7	1	5.9	4	23.5	1	5.9	17	100.0

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

\*\*See Appendix Table 20 for other reasons services were not being used.

- ▶ Grandparents rated services used by their grandchildren as quite good, from 3.82 to 4.41 on a scale from one to five, with one being “not good at all” and five being “very good” (Figure 20, Appendix Table 21).
- ▶ Comments regarding why grandparents rated certain services lower (by giving the service a score of “one” or “two” on the scale) can be found in Appendix Table 21a.

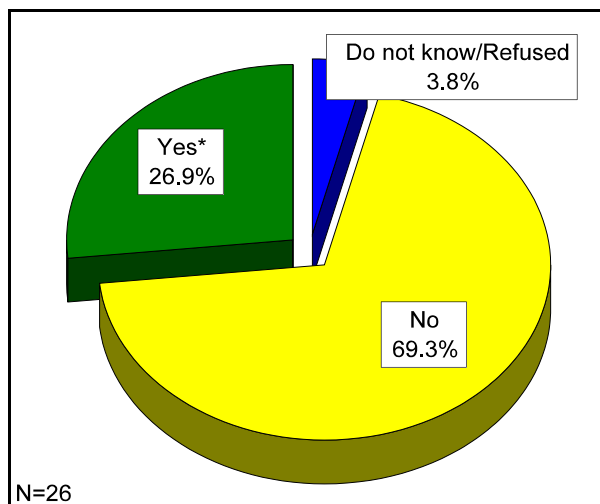
**Figure 20. Ratings of Services Used By Grandchildren**



\*Means were based on a one to five scale, with one being “not good at all” and five being “very good”.  
 Note: “Do not know/Refused” was excluded from the means and was only an option to phone respondents.

- ▶ More than 69 percent of grandparents indicated that there are no services (other than those mentioned in Figure 20) they would like to have available to their grandchildren. Caution should be used when interpreting these data due to the small number of respondents. (Figure 21, Appendix Table 22).
- ▶ The responses of grandparents who would like other services to be available to their grandchildren can be found in Appendix Table 22a.

**Figure 21. Whether There Were Other Services Not Mentioned That Grandparent Would Like To Have Available To Grandchildren ‡**



\*See Appendix Table 22a for other services not mentioned.  
 Note: Do not know/Refused option available only to phone survey respondents.

## SERVICES AVAILABLE TO GRANDPARENTS

- ▶ More than half of grandparents reported that information about available services is available to them as a caregiver (Table 7).
- ▶ Half of grandparents indicated that shopping assistance (49.0 percent) and parish nurses (55.9 percent) are not available to them (Table 7).
- ▶ The top six services grandparents are most unaware of are individual caregiver counseling (43.1 percent), outreach programs (42.9 percent), caregiver training or education (41.7 percent), caregiver support groups (41.0 percent), legal assistance or legal aid (34.3 percent) and assistance with accessing available services (33.0 percent) (Table 7).

**Table 7. Whether Services Were Available To Grandparent**

Grandparent Services	Respondents by Availability of Services							
	Yes		No		Do not know		Total	
	#	%	#	%	#	%	#	%*
Information about available services	56	54.9	18	17.6	28	27.5	102	100.0
Escort/transportation services	49	46.7	37	35.2	19	18.1	105	100.0
Legal assistance/legal aid	46	43.8	23	21.9	36	34.3	105	100.0
Medicine/prescription delivery	46	43.4	39	36.8	21	19.8	106	100.0
Visiting nurse (blood pressure and other vitals)	46	43.4	32	30.2	28	26.4	106	100.0
Assistance with accessing available services	42	42.0	25	25.0	33	33.0	100	100.0
Respite care (someone else who provides short-term relief for you)	41	39.4	40	38.5	23	22.1	104	100.0
Homemaker services/home health aides	40	38.1	40	38.1	25	23.8	105	100.0
Technology assistance (e.g., using the Internet)	39	37.5	40	38.5	25	24.0	104	100.0
Outreach programs (e.g., youth companions)	36	34.3	24	22.9	45	42.9	105	100.1
Individual caregiver counseling	29	28.4	29	28.4	44	43.1	102	99.9
Caregiver training or education	27	26.2	33	32.0	43	41.7	103	99.9
Shopping assistance	27	26.0	51	49.0	26	25.0	104	100.0
Caregiver support groups	19	19.0	40	40.0	41	41.0	100	100.0
Parish nurses	16	15.7	57	55.9	29	28.4	102	100.0

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

- ▶ Regarding services that were not available, the top five services grandparents would like to have available to them are information about available services (69.8 percent), legal assistance or legal aid (51.9 percent), assistance with accessing available services (48.1 percent), outreach programs (47.7 percent), and caregiver support groups (47.2 percent) (Table 8).

**Table 8. If Services Were Not Available To Grandparent, Whether Grandparent Would Like Them To Be Available**

Services Unavailable to Grandparent	Respondents by Desire for Service							
	Yes		No		Do not know/ Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%*
Information about available services	30	69.8	12	27.9	1	2.3	43	100.0
Legal assistance/legal aid	28	51.9	26	48.1	0	0.0	54	100.0
Assistance with accessing available services	25	48.1	27	51.9	0	0.0	52	100.0
Outreach programs (e.g., youth companions)	31	47.7	33	50.8	1	1.5	65	100.0
Caregiver support groups	34	47.2	38	52.8	0	0.0	72	100.0
Technology assistance (e.g., using the Internet)	23	41.8	31	56.4	1	1.8	55	100.0
Caregiver training or education	24	34.3	46	65.7	0	0.0	70	100.0
Individual caregiver counseling	21	32.3	44	67.7	0	0.0	65	100.0
Respite care (someone else who provides short-term relief for you)	19	32.2	40	67.8	0	0.0	59	100.0
Medicine/prescription delivery	15	28.3	38	71.7	0	0.0	53	100.0
Escort/transportation services	13	25.5	38	74.5	0	0.0	51	100.0
Homemaker services/home health aides	13	21.3	46	75.4	2	3.3	61	100.0
Visiting nurse (blood pressure and other vitals)	10	18.9	41	77.4	2	3.8	53	100.1
Parish nurses	14	18.2	62	80.5	1	1.3	77	100.0
Shopping assistance	12	16.9	59	83.1	0	0.0	71	100.0

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



- ▶ When the services were available, more than half indicated that they have used the following services: assistance with accessing available services (61.0 percent) and information about available services (58.2 percent).
- ▶ However, more than half reported they do not use the remaining services listed in Table 9, with more than three-fourths not using homemaker services or home health aides (80.0 percent) and caregiver support groups (84.2 percent) (Table 9).

**Table 9. Whether Services Were Being Used If Services Were Available To Grandparent**

Services Available to Grandparent	Respondents by Use of Service					
	Yes		No		Total	
	#	%	#	%	#	%*
Assistance with accessing available services	25	61.0	16	39.0	41	100.0
Information about available services	32	58.2	23	41.8	55	100.0
Visiting nurse (blood pressure and other vitals)	20	47.6	22	52.4	42	100.0
Parish nurses	7	43.8	9	56.3	16	100.1
Technology assistance (e.g., using the Internet)	16	43.2	21	56.8	37	100.0
Respite care (someone else who provides short-term relief for you)	17	42.5	23	57.5	40	100.0
Outreach programs (e.g., youth companions)	13	39.4	20	60.6	33	100.0
Medicine/prescription delivery	17	38.6	27	61.4	44	100.0
Legal assistance/legal aid	16	36.4	28	63.6	44	100.0
Escort/transportation services	17	34.7	32	65.3	49	100.0
Individual caregiver counseling	10	33.3	20	66.7	30	100.0
Caregiver training or education	9	33.3	18	66.7	27	100.0
Shopping assistance	8	29.6	19	70.4	27	100.0
Homemaker services/home health aides	8	20.0	32	80.0	40	100.0
Caregiver support groups	3	15.8	16	84.2	19	100.0

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

- ▶ Regardless of the type of service, the most common reason why the grandparents are not using the service (if it was available to them) is because they do not need it. Caution should be used when interpreting these data due to the small number of respondents (Table 10).
- ▶ Other reasons why grandparents do not use the services available to them are listed in Appendix Table 23 by type of service.

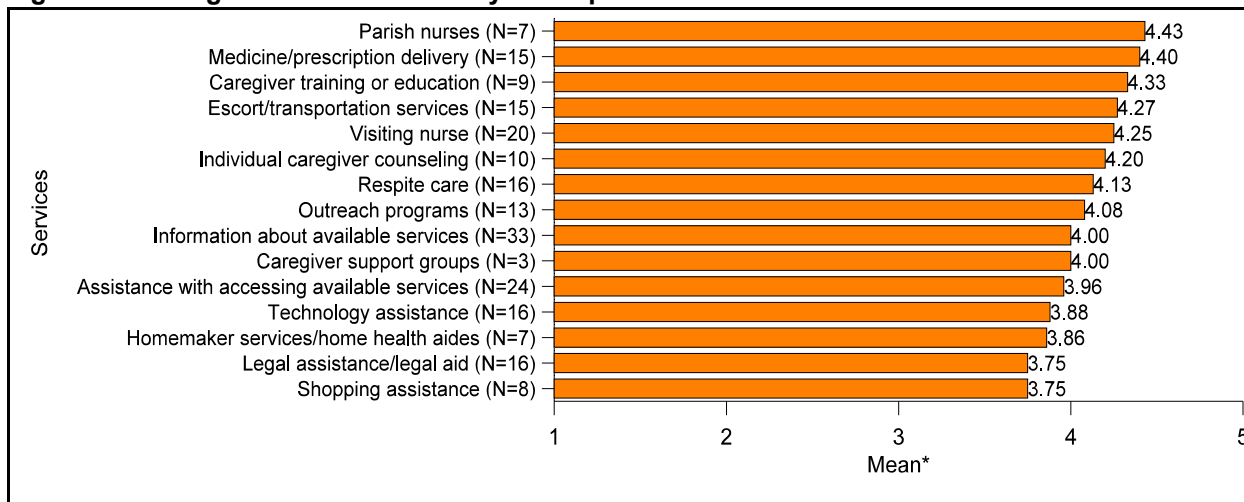
**Table 10. Reasons Why Services Were Not Being Used If Services Were Available To Grandparent**

Services Available to Grandparent	Respondents by Reason for Non-Use of Service							
	Do not need it		Other reasons*		Do not know/ Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%
Homemaker services/home health aides	29	93.5	2	6.5	0	0.0	31	100.0
Escort/transportation services	27	90.0	2	6.7	1	3.3	30	100.0
Medicine/prescription delivery	25	100.0	0	0.0	0	0.0	25	100.0
Legal assistance/legal aid	20	80.0	4	16.0	1	4.0	25	100.0
Visiting nurse (blood pressure and other vitals)	20	95.2	1	4.8	0	0.0	21	100.0
Information about available services	15	71.4	5	23.8	1	4.8	21	100.0
Respite care (someone else who provides short-term relief for you)	15	75.0	5	25.0	0	0.0	20	100.0
Technology assistance (e.g., using the Internet)	14	70.0	6	30.0	0	0.0	20	100.0
Outreach programs (e.g., youth companions)	15	78.9	4	21.1	0	0.0	19	100.0
Shopping assistance	18	100.0	0	0.0	0	0.0	18	100.0
Caregiver training or education	15	83.3	3	16.7	0	0.0	18	100.0
Individual caregiver counseling	17	100.0	0	0.0	0	0.0	17	100.0
Caregiver support groups	13	86.7	2	13.3	0	0.0	15	100.0
Assistance with accessing available services	12	85.7	2	14.3	0	0.0	14	100.0
Parish nurses	9	100.0	0	0.0	0	0.0	9	100.0

\*See Appendix Table 23 for other reasons services were not being used.

- ▶ Grandparents rated the services they use as quite good, from 3.75 to 4.43 on a scale from one to five, with one being “not good at all” and five being “very good”. Caution should be used when interpreting these data due to the small number of respondents (Figure 22, Appendix Table 24).
- ▶ Comments regarding why grandparents rated certain services poorly (by giving the service a score of a “one” or “two”) can be found in Appendix Table 24a.

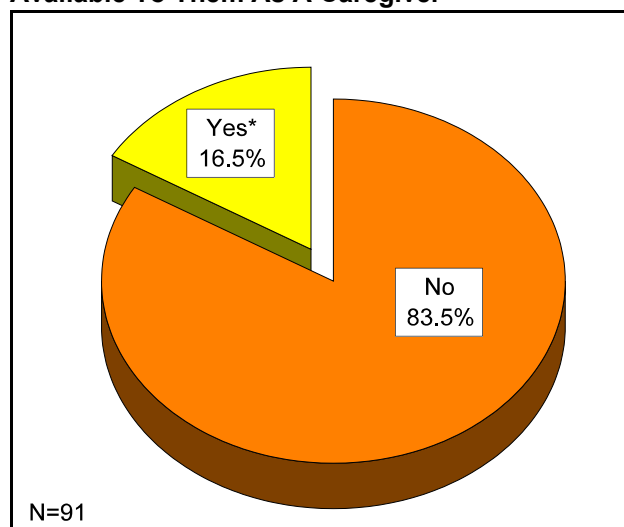
**Figure 22. Ratings Of Services Used By Grandparents**



\*Means were based on a one to five scale, with one being “not good at all” and five being “very good”.  
 Note: “Do not know/Refused” was excluded from the means and was only available as an option for phone respondents.

- ▶ Nearly 84 percent of grandparents reported there are no services (other than those mentioned in Figure 22 or Table 10) that they would like to have available to them as a caregiver (Figure 23, Appendix Table 25).
- ▶ Other services that grandparents would like to have available to them are listed in Appendix Table 25a.

**Figure 23. Whether There Were Other Services Not Mentioned That Grandparent Would Like To Have Available To Them As A Caregiver**



\*See Appendix Table 25a for other services not mentioned.

- ▶ At least a third of grandparents reported that the following information or services would be valuable to them as caregivers, now or in the future: an info-line (47.2 percent); financial support (46.2 percent); tax breaks (37.7 percent); and someone to talk to, counseling services or support groups (35.8 percent) (Table 11).

**Table 11. Information Or Services That Would Be Valuable To Grandparent**

Information or Services	Respondents (N=106)	
	#	%*
Info-line (central place to call and find out what kind of help is available)	50	47.2
Financial support	49	46.2
Tax break, stipend, government subsidy	40	37.7
Someone to talk to/counseling services/support group	38	35.8
Information about developments/changes in laws affecting your situation	34	32.1
Help in dealing with agencies (bureaucracies) to get services	31	29.2
Hotline (for dealing with immediate emotional needs while preserving dignity)	24	22.6
Help in dealing with parents of grandchildren (i.e. mediation/intervention)	22	20.8
Information about your grandchild's condition or disability	21	19.8
Someone to help you arrange for services, assess your situation	20	18.9
Assistance with discipline	17	16.0
Respite care	17	16.0
Assistance with cross-cultural education	8	7.5
Help in understanding how to pay for group homes/other care facilities	7	6.6
Aftercare/grief counseling	6	5.7
Help in assessing the timing of placement in formal caregiving institutions	3	2.8
Help in understanding how to select a group home/other care facility	3	2.8
None of the above	18	17.0
Other	3	2.8
<i>Not at this time</i>	1	
<i>Straighten out daughter</i>	1	
<i>Blank</i>	1	

\*Percents do not add to 100.0 due to multiple responses; N=106.

## SERVICES PROVIDED BY GRANDPARENTS

- ▶ Approximately two-thirds of grandparents reported they have provided one or all of the services listed below (Table 12).
- ▶ At least 95 percent of grandparents reported they have listened to their grandchildren and have been someone for them to talk to (100.0 percent); provided companionship (99.0 percent); provided discipline (98.0 percent); helped with worries, anxiety, and emotional needs (97.9 percent); contributed financially (97.0 percent); provided transportation and help getting places (96.9 percent); assisted with meals or nutritional needs (96.9 percent); and assisted with household care (95.4 percent) (Table 12).

**Table 12. Whether Grandparent Provided Any Of The Following Services\***

Services	Respondents by Provision of Service					
	Yes		No		Total	
	#	%	#	%	#	%
Listen to them-someone for them to talk to	99	100.0	0	0.0	99	100.0
Provide companionship	98	99.0	1	1.0	99	100.0
Provide discipline	96	98.0	2	2.0	98	100.0
Help with worries, anxiety, and emotional needs	93	97.9	2	2.1	95	100.0
Contribute financially	96	97.0	3	3.0	99	100.0
Provide transportation, getting places	93	96.9	3	3.1	96	100.0
Assist with meals/nutritional needs	94	96.9	3	3.1	97	100.0
Assist with household care	83	95.4	4	4.6	87	100.0
Assist with errands/shopping	84	93.3	6	6.7	90	100.0
Get other family members involved in caregiving	80	87.0	12	13.0	92	100.0
Provide tutoring/homework assistance	75	86.2	12	13.8	87	100.0
Assist with medicines (administering, side effects, etc.)	72	83.7	14	16.3	86	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	69	82.1	15	17.9	84	100.0
Manage finances	68	76.4	21	23.6	89	100.0
Provide cross-cultural education	42	65.6	22	34.4	64	100.0

\*Question asked only in phone survey. To obtain equivalent of Yes/No for outreach survey, if respondent checked anything from "Daily" to the "On Occasion" column (see Table 13), that was counted as a "Yes" for Table 12. Since they were able to quantify how often they have provided a service, it was assumed that the respondent has provided or does provide the service mentioned. If outreach survey respondents checked "Never" (see Table 13), that was counted as a "No" for Table 12.

- ▶ More than 87 percent of grandparents provided the following services on a *daily* basis: listening to their grandchildren and being someone for them to talk to (88.9 percent), assisting with meals or nutritional needs (88.7 percent), and providing companionship (87.9 percent) (Table 13).
- ▶ The services which the largest proportion of grandparents were providing *weekly* were assisting with errands and shopping (27.8 percent), managing finances (12.4 percent), and providing transportation or help getting places (11.5 percent) (Table 13).
- ▶ The services which the largest proportion of grandparents were providing *monthly* were the monetary-related issues of managing finances (10.1 percent) and contributing financially (8.1 percent) (Table 13).
- ▶ Approximately 40 percent of respondents involve other family members in caregiving daily (40.2 percent), as well as occasionally (37.0 percent) (Table 13).

**Table 13. Frequency of Service Delivery If Grandparent Provided Service**

Services	Respondents by Frequency of Service Delivery											
	Daily		Weekly		Monthly		On occasion		Dnk/Refused or Never**		Total	
	#	%	#	%	#	%	#	%	#	%	#	%*
Provide companionship	87	87.9	8	8.1	0	0.0	3	3.0	1	1.0	99	100.0
Contribute financially	68	68.7	4	4.0	8	8.1	16	16.2	3	3.0	99	100.0
Listen to them-someone for them to talk to	88	88.9	5	5.1	0	0.0	6	6.1	0	0.0	99	100.1
Provide discipline	70	71.4	5	5.1	0	0.0	21	21.4	2	2.0	98	99.9
Assist with meals/nutritional needs	86	88.7	3	3.1	0	0.0	5	5.2	3	3.1	97	100.1
Provide transportation, getting places	72	75.0	11	11.5	1	1.0	9	9.4	3	3.1	96	100.0
Help with worries, anxiety, and emotional needs	75	78.9	4	4.2	0	0.0	14	14.7	2	2.1	95	99.9
Get other family members involved in caregiving	37	40.2	8	8.7	1	1.1	34	37.0	12	13.0	92	100.0
Assist with errands/shopping	47	52.2	25	27.8	2	2.2	10	11.1	6	6.7	90	100.0
Manage finances	38	42.7	11	12.4	9	10.1	10	11.2	21	23.6	89	100.0
Provide tutoring/homework assistance	51	58.6	8	9.2	1	1.1	15	17.2	12	13.8	87	99.9
Assist with household care	70	80.5	7	8.0	1	1.1	5	5.7	4	4.6	87	99.9
Assist with medicines (administering, side effects, etc.)	46	53.5	3	3.5	0	0.0	23	26.7	14	16.3	86	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	47	56.0	8	9.5	0	0.0	14	16.7	15	17.9	84	100.1
Provide cross-cultural education	26	40.6	1	1.6	0	0.0	15	23.4	22	34.4	64	100.0

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

\*\*"Do not know/Refused" was an option available only to phone respondents, while "Never" was the corresponding response in the outreach survey, available only to outreach respondents. See note on Table 12 for further explanation.

- ▶ A majority of grandparents indicated they would not like help providing any of the services listed in Table 14.
- ▶ At least one-fourth of grandparents would like help contributing financially (32.5 percent); providing tutoring and homework assistance (30.9 percent); and help with worries, anxiety, and emotional needs (26.3 percent) (Table 14).

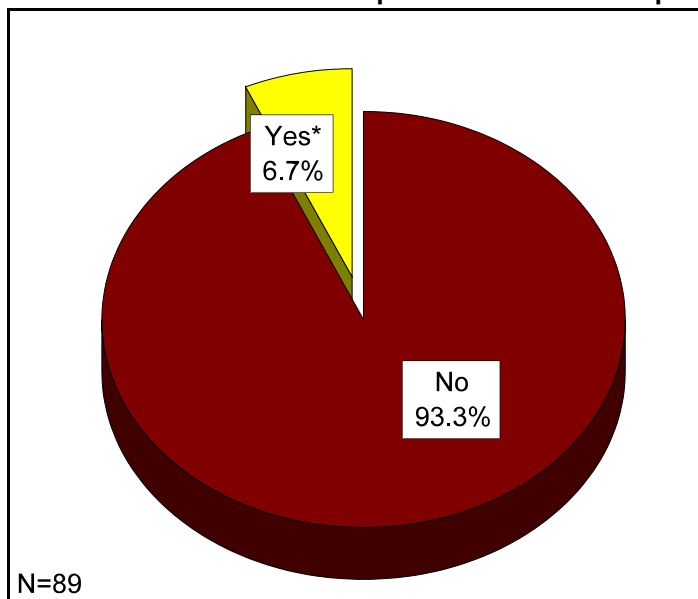
**Table 14. Whether Grandparent Would Like Help Providing The Following Services**

Services	Respondents by Desire for Help							
	Yes		No		Do not know/ Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%*
Contribute financially	27	32.5	56	67.5	0	0.0	83	100.0
Provide tutoring/homework assistance	25	30.9	56	69.1	0	0.0	81	100.0
Help with worries, anxiety, and emotional needs	21	26.3	59	73.8	0	0.0	80	100.1
Listen to them-someone for them to talk to	19	23.2	63	76.8	0	0.0	82	100.0
Provide companionship	18	21.7	65	78.3	0	0.0	83	100.0
Assist with household care	15	18.8	64	80.0	1	1.3	80	100.1
Provide transportation, getting places	15	18.1	68	81.9	0	0.0	83	100.0
Provide discipline	13	16.0	67	82.7	1	1.2	81	99.9
Get other family members involved in caregiving	10	12.5	70	87.5	0	0.0	80	100.0
Assist with meals/nutritional needs	10	12.3	71	87.7	0	0.0	81	100.0
Assist with errands/shopping	9	11.4	70	88.6	0	0.0	79	100.0
Manage finances	8	10.1	71	89.9	0	0.0	79	100.0
Assist with medicines (administering, side effects, etc.)	7	8.8	73	91.3	0	0.0	80	100.1
Provide cross-cultural education	6	8.3	66	91.7	0	0.0	72	100.0
Administer personal care (bathing, bandaging, nail care, etc.)	3	3.7	78	96.3	0	0.0	81	100.0

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

- ▶ Approximately 93 percent of grandparents reported there are no other services (other than those mentioned in Tables 12 through 14) with which they would like help (Figure 24, Appendix Table 26).
- ▶ Comments from grandparents regarding other services with which they would like help can be found in Appendix Table 26a.

**Figure 24. Whether There Were Other Services Not Mentioned With Which Grandparent Would Like Help**



\*See Appendix Table 26a for other services not already mentioned with which grandparent would like help.



- ▶ Nearly 41 percent of grandparents indicated they have not experienced any of the financial difficulties listed in Table 15 as a result of caregiving.
- ▶ Approximately one-fourth of grandparents indicated they had taken off work early or arrived to work late because of caregiving (27.4 percent), or had other time conflicts between working and caregiving (23.6 percent) (Table 15).

**Table 15. Financial Difficulties Grandparent Has Experienced Because Of Caregiving**

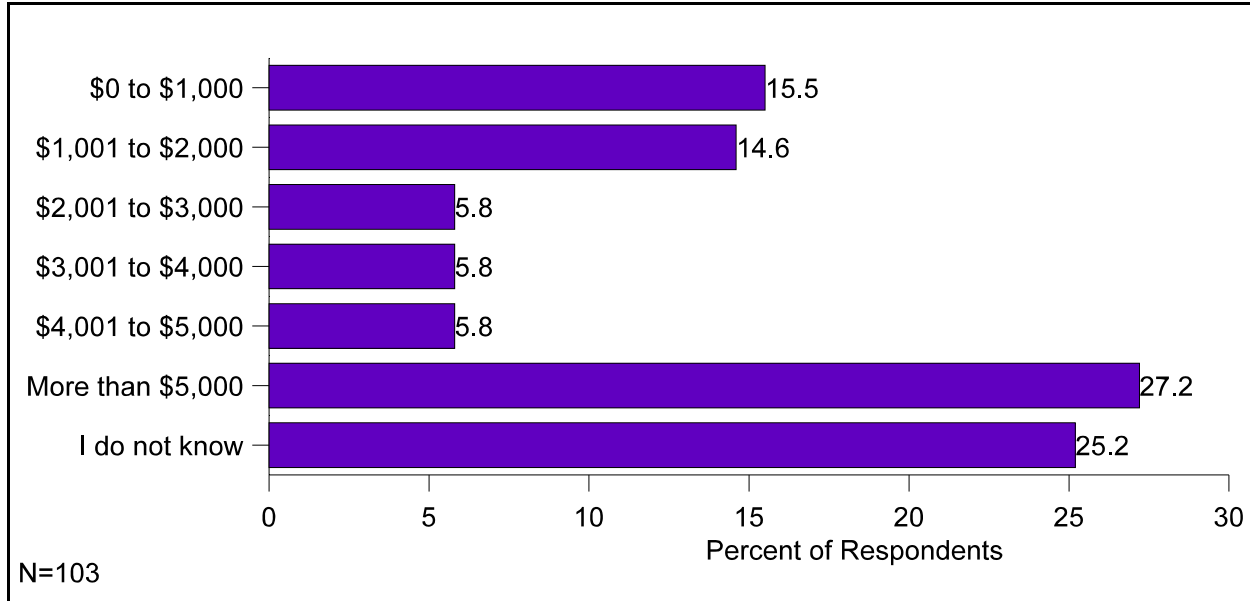
Financial Difficulties	Respondents (N=106)	
	#	%*
None of the difficulties listed below	43	40.6
Taken off work early or arrived to work late	29	27.4
Had time conflicts between working and caregiving	25	23.6
Used your vacation time to provide care	19	17.9
Stopped working	13	12.3
Retired early	12	11.3
Moved or changed locations to be with your grandchildren	8	7.5
Reduced your official working hours	6	5.7
Taken a leave of absence to provide care	6	5.7
Lost some of your employment fringe benefits	4	3.8
Changed from full-time to part-time work	3	2.8
Taken a less demanding job	3	2.8
Sold a home to move in with grandchildren	1	0.9
Lost a promotion	1	0.9
Other	5	4.7
<i>Extended my work time</i>	1	
<i>Husband unable to return due to providing care</i>	1	
<i>Husband retired early</i>	1	
<i>Lose friends because you don't have time to be with them</i>	1	
<i>Work at home</i>	1	

\*Percents do not add to 100.0 due to multiple responses; N=106.

## DEMOGRAPHIC CHARACTERISTICS OF GRANDPARENTS

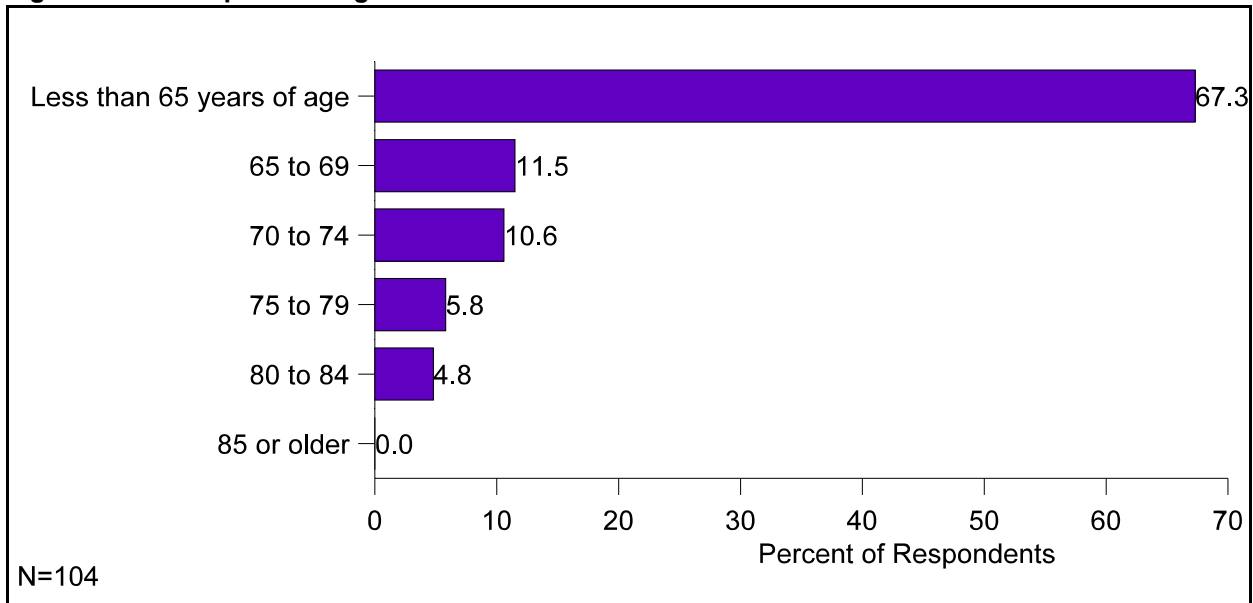
- ▶ A majority of grandparents indicated they either spent more than \$5,000 within the last year in caring for their grandchildren, or they do not know how much they had spent within the previous year (27.2 percent and 25.2 percent, respectively) (Figure 25, Appendix Table 27).

**Figure 25. Average Amount Of Money Spent Within The Last Year In Caring For Grandchildren**



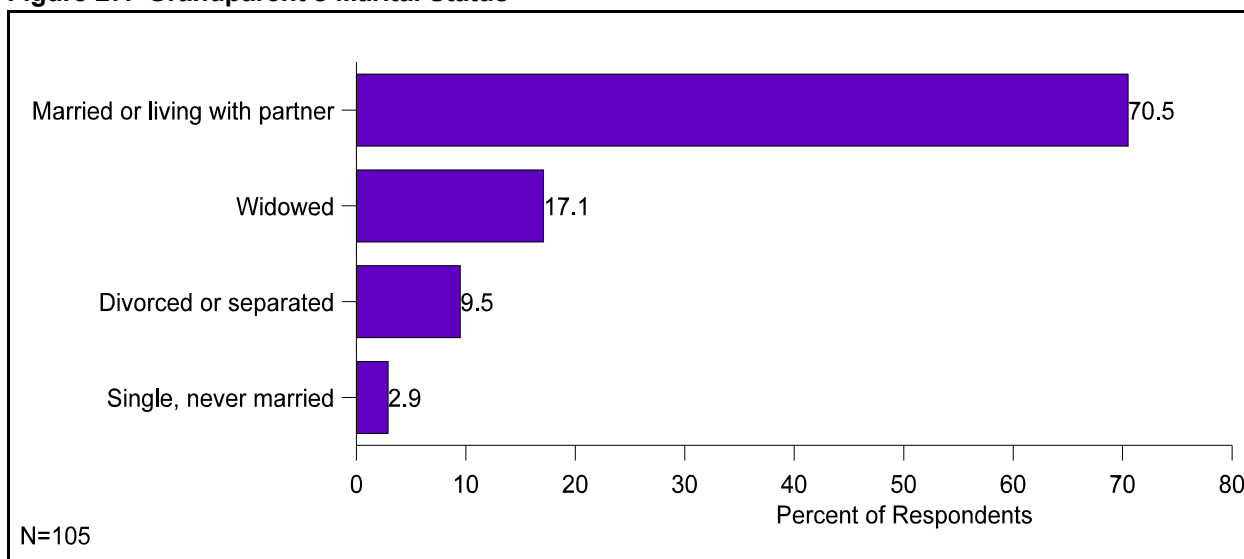
- ▶ More than 67 percent of grandparents are under the age of 65 (Figure 26, Appendix Table 28).

**Figure 26. Grandparent's Age**



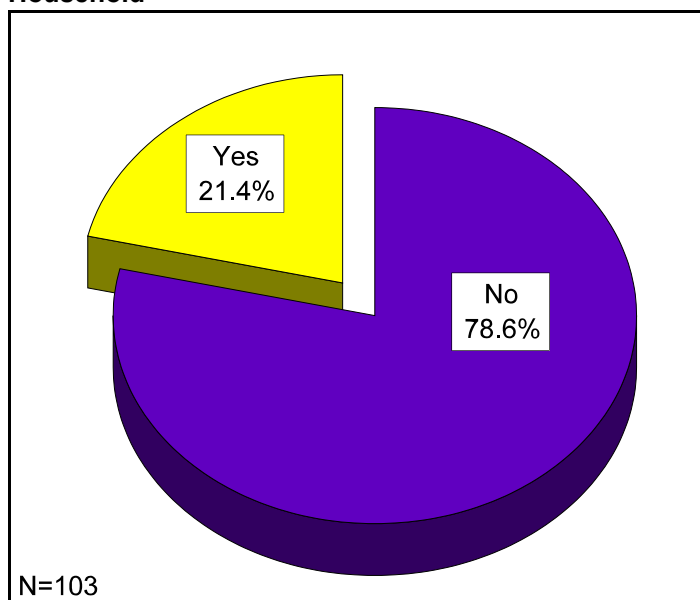
- ▶ Nearly 71 percent of grandparents are married or living with a partner (Figure 27, Appendix Table 29).

**Figure 27. Grandparent's Marital Status**



- ▶ Nearly 79 percent of grandparents do not have children other than grandchildren residing in their household (Figure 28, Appendix Table 30).

**Figure 28. Whether There Were Children, Other Than Grandchildren, That Resided In Grandparent's Household**



\*See Table 16 for number of children, other than grandchildren, residing in grandparent's household by age cohort.

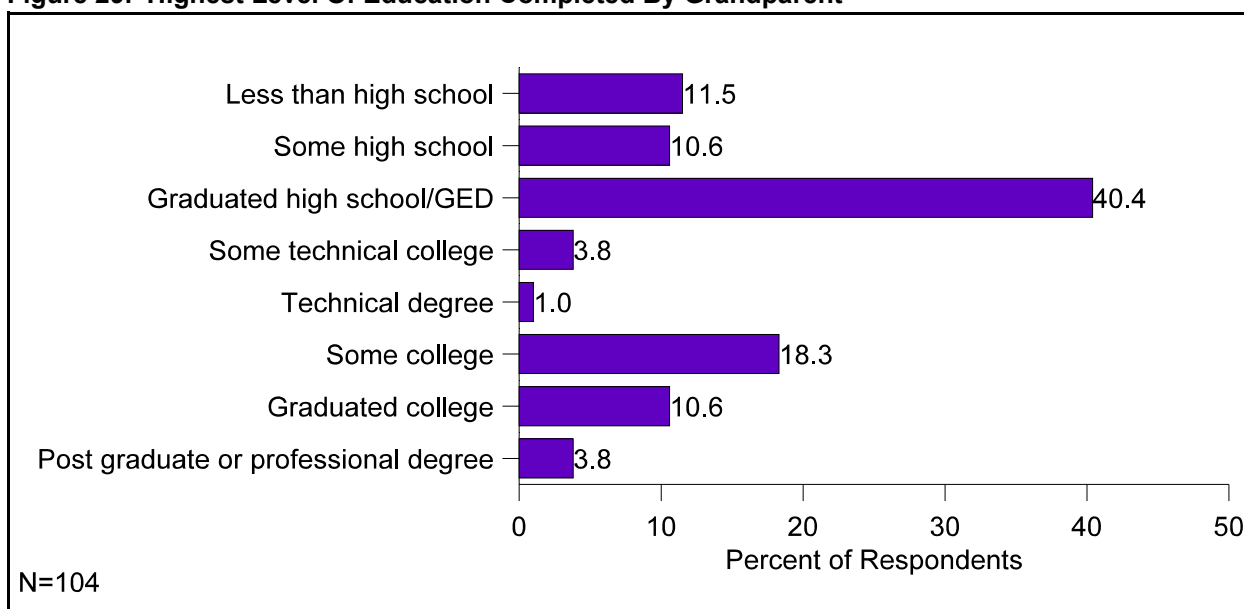
- ▶ Grandparents who reported there were children other than grandchildren in their household indicated that approximately one-fourth were under the age of 10 and nearly three-fourths were older than 10 (Table 16).

**Table 16. Number and Age Of Children, Other Than Grandchildren, That Reside In Grandparent’s Household**

Ages	Children Other Than Grandchildren In Grandparent’s Household	
	#	%
0 to 4 years of age	3	9.1
5 to 9 years of age	6	18.2
10 to 14 years of age	7	21.2
15 years of age and older	17	51.5
Total	33	100.0

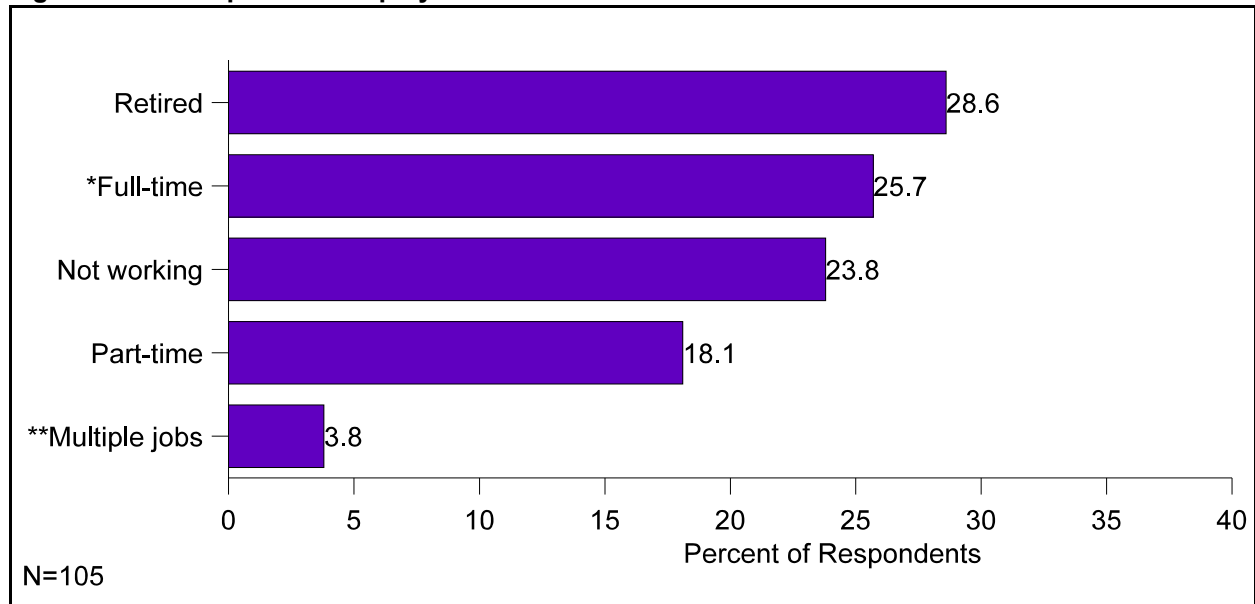
- ▶ Approximately 40 percent of grandparents have graduated high school or have received their GED (40.4 percent), or have a post-high school education (37.5 percent) (Figure 29, Appendix Table 31).

**Figure 29. Highest Level Of Education Completed By Grandparent**



- ▶ While the majority of grandparents are either retired or not working (52.4 percent), nearly half are employed, with approximately one-fourth working full time (25.7 percent) (Figure 30, Appendix Table 32).

**Figure 30. Grandparent's Employment Status**

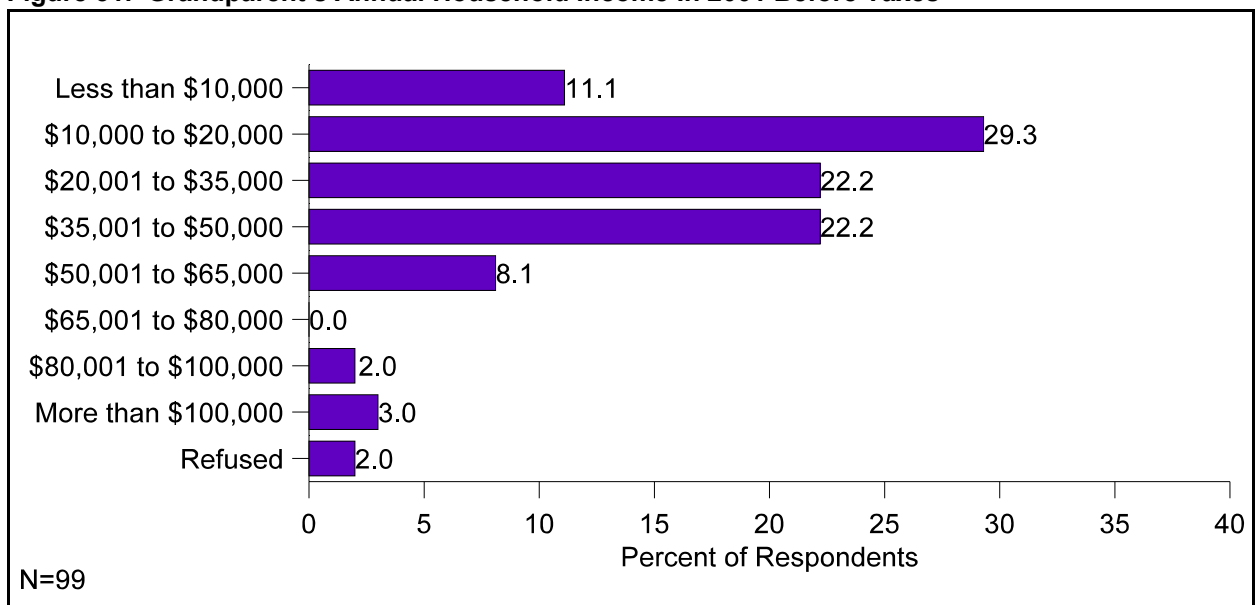


\*Full response category in outreach and phone survey states "Full-time employment (35 hours/week or more)".

\*\*Full response category in outreach survey states "Multiple jobs (including full-time)"; full response category in phone survey states "Multiple jobs".

- ▶ Nearly 63 percent of grandparents have an annual household income of \$35,000 or less (Figure 31, Appendix Table 33).
- ▶ According to the 2000 Census, the median household income in North Dakota was \$34,604 compared to \$41,994 for the United States (Source: US Census Bureau, Census 2000, Summary File 3 (SF3), Table P53).

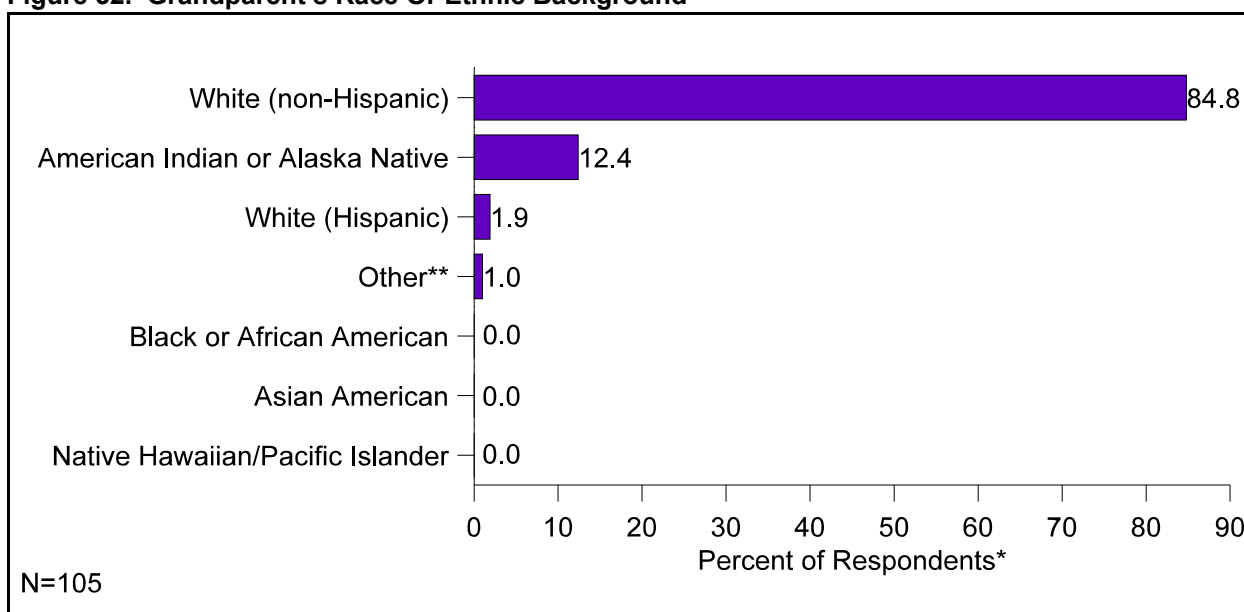
**Figure 31. Grandparent's Annual Household Income In 2001 Before Taxes\***



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

- ▶ Nearly 87 percent of grandparents indicated that their race or ethnic background is white (non-Hispanic and Hispanic) (86.7 percent) (Figure 32, Appendix Table 34).

**Figure 32. Grandparent's Race Or Ethnic Background**

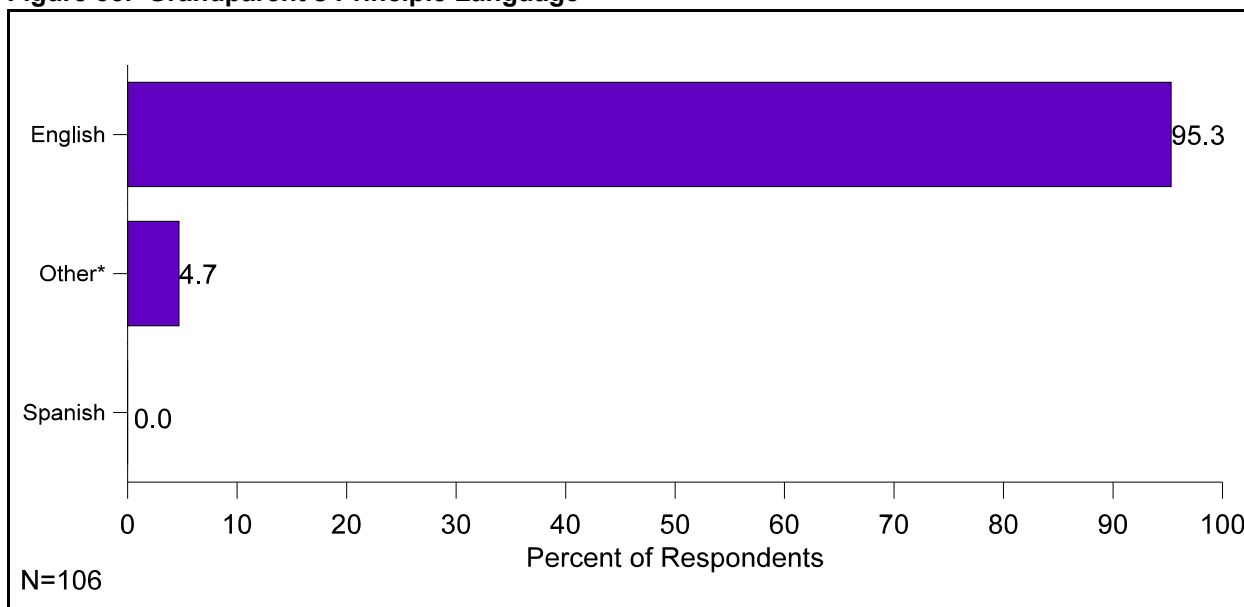


\*Percents do not add to 100.0 due to rounding.

\*\*See Appendix Table 34 for a list of other races or ethnic backgrounds reported by respondents.

- ▶ The majority of grandparents indicated their principle language is English (95.3 percent) (Figure 33, Appendix Table 35).

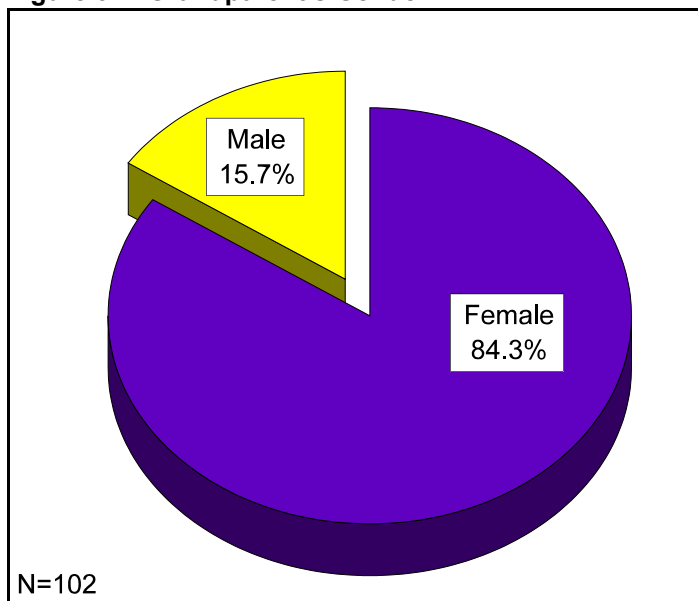
**Figure 33. Grandparent's Principle Language**



\*See Appendix Table 35 for other languages reported by respondents.

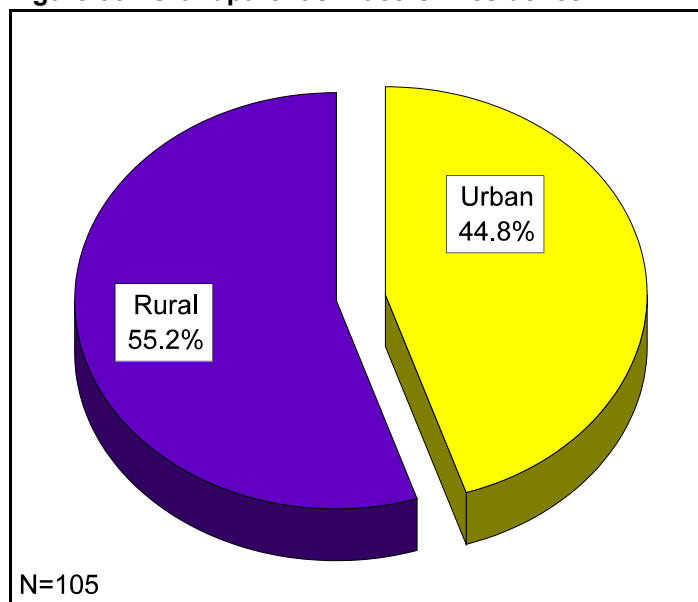
- ▶ The majority of grandparents that responded to this survey are female (84.3 percent) (Figure 34, Appendix Table 36).

**Figure 34. Grandparent's Gender**



- ▶ Results indicated that approximately 55 percent of grandparents who are caring for their grandchildren live in rural areas (Figure 35, Appendix Table 37).
- ▶ See Table 17 for the number and percent of grandparent caregivers in North Dakota by county name in which they reside, according to the results of this study.

**Figure 35. Grandparent's Place Of Residence**



**Table 17. Distribution of Grandparent Caregivers By County\***

County	Respondents		County	Respondents	
	#	%		#	%
Adams	5	6.3	McLean	4	5.1
Barnes	1	1.3	Mercer	0	0.0
Benson	7	8.9	Morton	0	0.0
Billings	0	0.0	Mountrail	0	0.0
Bottineau	0	0.0	Nelson	1	1.3
Bowman	2	2.5	Oliver	0	0.0
Burke	0	0.0	Pembina	0	0.0
Burleigh	4	5.1	Pierce	2	2.5
Cass	0	0.0	Ramsey	0	0.0
Cavalier	0	0.0	Renville	0	0.0
Dickey	0	0.0	Richland	6	7.6
Divide	2	2.5	Rolette	4	5.1
Dunn	1	1.3	Sargent	0	0.0
Eddy	0	0.0	Sheridan	1	1.3
Emmons	3	3.8	Sioux	0	0.0
Foster	1	1.3	Slope	2	2.5
Golden Valley	0	0.0	Stark	3	3.8
Grand Forks	1	1.3	Steele	0	0.0
Grant	3	3.8	Stutsman	0	0.0
Griggs	0	0.0	Towner	0	0.0
Hettinger	2	2.5	Traill	0	0.0
Kidder	9	11.4	Walsh	4	5.1
LaMoure	0	0.0	Ward	1	1.3
Logan	0	0.0	Wells	0	0.0
McHenry	1	1.3	Williams	8	10.1
McIntosh	0	0.0	Total	79	100.0
McKenzie	1	1.3			

\*Data for this table was gathered only from the outreach survey. For the phone survey, telephone interviewers asked respondent for the name of the county in which they resided. The interviewer then recorded a code designating the county as rural or urban, with the actual county name not being recorded.



## APPENDIX TABLES

**Appendix Table 1. Number Of Grandchildren For Whom Grandparent Provides Primary Care**

Number of Grandchildren	Respondents	
	#	%
1 grandchild	59	57.3
2 grandchildren	30	29.1
3 grandchildren	13	12.6
4 grandchildren	1	1.0
Total	103	100.0

**Appendix Table 2. Grandchild's Race Or Ethnic Background**

Race or Ethnic Background of Grandchildren	Respondents		
	#	%	
White (Non-Hispanic)	76	71.7	
American Indian or Alaska Native	20	18.9	
White (Hispanic)	3	2.8	
Black or African American	1	0.9	
Asian American	0	0.0	
Native Hawaiian or other Pacific Islander	0	0.0	
Other	6	5.7	
<i>1 White (non-Hispanic) &amp; 1 White (Hispanic)</i>	<i>1</i>		
<i>½-White and part American Indian or Pacific Islander</i>	<i>1</i>		
<i>2 children: ½ Native American, ½ White; 1 child: ½ White/Black/Native American</i>	<i>1</i>		
<i>Both children: American Indian and White (non-Hispanic)</i>	<i>1</i>		
<i>White (non-Hispanic) and American Indian or Alaska Native</i>	<i>1</i>		
<i>White and American Indian or Alaska Native</i>	<i>1</i>		
Total	106		100.0

**Appendix Table 3. Whether Grandparent Currently Has Legal Guardianship Of Grandchildren**

Response	Respondents	
	#	%
Yes	48	45.3
No	55	51.9
Other	3	2.8
<i>1 granddaughter-legal guardianship; 1 other granddaughter lives in home with mother</i>	1	
<i>No, working on it</i>	1	
<i>Yes, during school year</i>	1	
Total	106	100.0

Note: Some respondents chose to respond with an other guardianship status, although "other" was not an original response option on the survey.

**Appendix Table 4. Which Of The Grandchild's Parents Is The Offspring Of Grandparent**

Response	Respondents	
	#	%
Mother	70	67.3
Father	34	32.7
Total	104	100.0

**Appendix Table 5. Reasons Grandparent Is Caring For Grandchildren**

Reasons	Respondents							
	Yes		No		Refused <sup>β</sup>		Total	
	#	%	#	%	#	%	#	%*
Parent has emotional issues	37	47.4	41	52.6	0	0.0	78	100.0
Parent can't afford to care for child	40	47.1	45	52.9	0	0.0	85	100.0
Parent has few/no parenting skills	38	45.8	45	54.2	0	0.0	83	100.0
Parent is not mature enough (i.e., roles sometimes seemed reversed)	37	45.7	44	54.3	0	0.0	81	100.0
Parent has addiction/substance abuse issues	32	38.6	51	61.4	0	0.0	83	100.0
Parent does not want to be bothered by raising child/does not want child	30	34.9	55	64.0	1	1.2	86	100.1
Parent was never involved in the child's life	27	32.1	57	67.9	0	0.0	84	100.0
Parent has mental health issues	22	27.5	58	72.5	0	0.0	80	100.0
Parent is in an abusive relationship that interferes with raising the child	17	19.5	70	80.5	0	0.0	87	100.0
Child was abused	15	18.5	66	81.5	0	0.0	81	100.0
Parent is deceased	15	18.1	68	81.9	0	0.0	83	100.0
Parent is/was incarcerated	11	13.4	71	86.6	0	0.0	82	100.0
Father is unknown	8	10.1	71	89.9	0	0.0	79	100.0
Other reasons*	50	52.1	46	47.9	0	0.0	96	100.0

\*Percents may not add to 100.0 due to rounding.

\*\*For other reasons grandparent may be caring for grandchildren, see Appendix Table 5a.

**Appendix Table 5a. Other Reasons Grandparent Is Caring For Grandchildren**

Other reasons	#
<i>Any son (father of child) is living with us also</i>	1
<i>Assisting with care</i>	1
<i>Because of publicity, we would not want children in daycare. I am an at-home grandmother.</i>	1
<i>Behavioral problems on the grandchild's part</i>	1
<i>Best for the child</i>	1
<i>Can not afford own place-parent going back to college</i>	1
<i>Child's needs not met day to day</i>	1
<i>Child neglect</i>	1
<i>Child wants/wanted to live with us</i>	2
<i>Children beaten and abused by their mother's mom</i>	1
<i>Concern for stable environment for children</i>	1
<i>Developmentally, special parents were not able to help</i>	1
<i>Divorced parents help son with joint custody</i>	1
<i>Doesn't want to live in small town and he can't please his step dad</i>	1
<i>Father and child live with me and father works so I take care of child while father works</i>	1
<i>Father is sickly and mother is a parent but not a mother</i>	1
<i>Father lives in Greece</i>	1
<i>Father works out of town and returns to home on weekends, mother abandoned children</i>	1
<i>Grandparents are security for the child</i>	1
<i>Grandson decided to live with grandparent instead of parents</i>	1
<i>Granddaughter mother passed, had a hard time with father</i>	1
<i>Had no place to live</i>	1
<i>He wants to live with us, here by choice, mother is in his life</i>	1
<i>Help them get on their feet</i>	1
<i>Her dad has custody and he works</i>	1
<i>I am working with him on learning skills for education</i>	1
<i>Legally adopted</i>	1
<i>Mother borderline mentally handicapped</i>	1

**Appendix Table 5a. Other Reasons Grandparent Is Caring For Grandchildren (continued)**

Other reasons	#
<i>Mother cannot be a mother &amp; is addicted to drugs</i>	1
<i>Mother does not want the mother role-more of a playmate</i>	1
<i>Mother was in college at time of birth</i>	1
<i>Mother was in school</i>	1
<i>Mother works evenings</i>	1
<i>Moved in because of lack of room in home of parents</i>	1
<i>Mutual agreement that we could provide a better life</i>	1
<i>My granddaughter is living with father and stepmother...she says stepmother has addiction</i>	1
<i>Parents moved out of state. Child did not like the school in the new state.</i>	1
<i>Parent needed to get a better job</i>	1
<i>Parents moved to Wyoming, grandchild wanted to finish high school in ND</i>	1
<i>Parents seeking educational licenses/degrees</i>	1
<i>So the father can work</i>	1
<i>Someone needs to be there for them</i>	1
<i>The mother is caring for another child that is handicapped</i>	1
<i>To help parents for a needed break</i>	1
<i>Trouble in Oregon, we are trying to keep him out of it, and school ed.</i>	1
<i>Unwed mother with health problems</i>	1
<i>Very upset after her father passed away</i>	1
<i>Wanted a steady home for grandchild</i>	1
<i>We agreed to take care of her</i>	1
<i>Yes, I love them very much</i>	1
<b>Total</b>	<b>50</b>

**Appendix Table 6. Status Of The Relationship Between Grandparent And The Grandchild's Parents And To Which Parent The Relationship Status Applies**

Relationship Status	Respondents							
	Mother		Father		Both		Total	
	#	%	#	%	#	%	#	%
Amicable	16	39.0	6	75.0	26	53.1	48	49.0
Stressed	6	14.6	1	12.5	4	8.2	11	11.2
A relationship does not exist	5	12.2	0	0.0	5	10.2	10	10.2
Mixed/Other**	14	34.1	1	12.5	14	28.6	29	29.6
Total	41	99.9	8	100.0	49	100.1	98	100.0

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

\*\*See Appendix Table 6a for a list of other mixed relationship statuses.

**Appendix Table 6a. Mixed Relationship Statuses As Reported By Grandparents**

Response	#
<i>A little stressful, amicable</i>	1
<i>Amiable, and stressed with certain behaviors</i>	1
<i>Amicable and a relationship does not exist (with 1 parent of 1 child)</i>	1
<i>Amicable to father, a relationship does not exist for mother</i>	1
<i>Amicable with father, mother hasn't had contact for 12 years</i>	1
<i>Amicable: father; a relationship does not exist: mother</i>	1
<i>Both parents are deceased (murder/suicide)</i>	1
<i>Daughter lives in home-other daughter lives in Minot, ND</i>	1
<i>Father: amicable; mother: relationship does not exist</i>	1
<i>Good</i>	7
<i>Good relationship with our daughter, her mother</i>	1
<i>Great parent/daughter relationship</i>	1
<i>In contact-share holidays</i>	1
<i>Mother: amicable; father: a relationship does not exist</i>	1
<i>No problems</i>	1
<i>Ok</i>	1
<i>Stressed-maternal, amicable-paternal</i>	1
<i>Stressed and amicable</i>	1
<i>Very close mother son relationship both very close to us as parents and grandparents</i>	1
<i>Very good</i>	2
<i>Very good for one, stressed for the other</i>	1
<i>Blank</i>	1
Total	29

**Appendix Table 7. Length of Time Grandparent Has Spent Providing Primary Care For Their Grandchildren**

Length of Time	Respondents	
	#	%*
Less than 1 year	17	18.5
1 year to 3 years	19	20.7
4 years to 6 years	23	25.0
7 years to 9 years	16	17.4
10 years or more	17	18.5
Total	92	100.1

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

Note: Lengths of time greater than 1 year indicated by grandparent 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 8. Amount Of Care Required By Grandchildren Living In Grandparent's Home**

Amount of Care Required	Respondents	
	#	%
Around the clock/24-7	46	44.7
Grandchildren can be left alone for a few hours	24	23.3
Grandchildren can be left alone overnight	23	22.3
Grandchildren can be left alone for most of the day	10	9.7
Total	103	100.0



**Appendix Table 9. Monetary Compensation Received By Grandparents In Caring For Grandchildren**

Response	Respondents (N=106)	
	#	%*
None	80	75.5
Child support (formal or informal)	10	9.4
Foster care support	2	1.9
Other	12	11.3
<i>\$250.00 per month</i>	1	
<i>Daughter helps with monetary expenses</i>	1	
<i>Father for grandson, buys clothes, and some other stuff</i>	1	
<i>Father helps with bills</i>	1	
<i>Food stamps</i>	1	
<i>Parental assistance</i>	1	
<i>Relative care</i>	1	
<i>Social Security &amp; he gets help from state</i>	1	
<i>Social Services-ineligible caretaker</i>	1	
<i>SS-my wife is deceased</i>	1	
<i>SS and SSI</i>	1	
<i>Subsidized adoption</i>	1	

\*Percents do not add to 100.0 due to multiple responses; N=106.

**Appendix Table 10. Monetary Compensation Received By Grandchildren**

Response	Respondents (N=106)	
	#	%*
None	63	59.4
Social Security Income (SSI)	23	21.7
Inheritance	4	3.8
Other	22	20.8
<i>Adoption assistance program</i>	1	
<i>AFDC</i>	1	
<i>Child support</i>	4	
<i>Child support from father</i>	1	
<i>Child support from the father of one of the girls regularly &amp; child support sporadically from the mother for the other girl</i>	1	
<i>Housing 4 days/week</i>	1	
<i>Medical assistance</i>	1	
<i>Mother helps with some support</i>	1	
<i>Only pays for clothing and necessary items</i>	1	
<i>Parent gives money</i>	1	
<i>Personal payments</i>	1	
<i>Relative care</i>	1	
<i>Small child support</i>	1	
<i>Some support to the mother but grandparents don't receive any help</i>	1	
<i>Subsidized adoption</i>	1	
<i>WIC</i>	2	
<i>Blank</i>	2	

\*Percents do not add to 100.0 due to multiple responses; N=106.

**Appendix Table 11. Non-Monetary Compensation Received By Household To Assist In Caregiving**

Response	Respondents (N=106)	
	#	%*
School lunch program	40	37.7
Medical assistance for uninsured or under-insured children	36	34.0
Other food programs (food pantry, food commodities, food stamps, etc.)	16	15.1
Women, Infants, and Children (WIC)	15	14.2
None	14	13.2
Fuel assistance	12	11.3
Housing assistance	4	3.8
Temporary Assistance for Needy Families (TANF)	4	3.8
Other	3	2.8
<i>Indian health services help out</i>	1	
<i>Need a tax break for raising a child on retirement</i>	1	
<i>Parents supply insurance</i>	1	

\*Percents do not add to 100.0 due to multiple responses; N=106.

**Appendix Table 12. Whether Grandchild Has Special Needs By Type Of Need**

Response	Respondents (N=106)	
	#	%*
None	59	55.7
Emotional issues	20	18.9
Learning disability	16	15.1
Hyperactivity disorder	12	11.3
Mental health issues	8	7.5
Physical disabilities	8	7.5
FAS/FAE	5	4.7
Cognitive impairment	2	1.9
Developmental disabilities/mental retardation	2	1.9
Head injury	1	0.9
Substance abuse issues	1	0.9
Other	13	12.3
<i>Anxiety from abuse from father</i>	1	
<i>Attention deficit</i>	1	
<i>Bi-polar disorder</i>	2	
<i>Cerebral Palsy</i>	1	
<i>Needs tubes in ears</i>	1	
<i>Severe allergy, costly meds</i>	1	
<i>Speech problems</i>	1	
<i>Speech</i>	1	
<i>Spina Bifida</i>	1	
<i>This may arise in future and cause problems but hasn't yet (re: FAS/FAE)</i>	1	
<i>Blank</i>	2	

\*Percents do not add to 100.0 due to multiple responses; N=106.

**Appendix Table 13. Rating Of Difficulties Experienced By Grandparent When Providing Care**

Difficulties Experienced	Mean	Respondents													
		Not at all serious 1		2		3		4		Very serious 5		Do not know/ Refused <sup>β</sup> 6		Total	
		#	%	#	%	#	%	#	%	#	%	#	%	#	%*
Emotional aspects	2.51	32	30.2	23	21.7	25	23.6	17	16.0	9	8.5	0	0.0	106	100.0
Less time for myself	2.46	36	34.0	19	17.9	28	26.4	12	11.3	11	10.4	0	0.0	106	100.0
The financial burden	2.40	43	44.3	10	10.3	20	20.6	10	10.3	14	14.4	0	0.0	97	99.9
I feel more tied down	2.35	39	39.4	18	18.2	16	16.2	18	18.2	7	7.1	1	1.0	99	100.1
Less privacy	2.32	41	39.0	21	20.0	21	20.0	12	11.4	10	9.5	0	0.0	105	99.9
I feel like I'm back at the beginning	2.29	50	51.0	5	5.1	20	20.4	8	8.2	14	14.3	1	1.0	98	100.0
Less time for my family	2.19	47	44.8	19	18.1	21	20.0	8	7.6	10	9.5	0	0.0	105	100.0
No consistent help from other family members	2.13	55	52.4	16	15.2	10	9.5	13	12.4	11	10.5	0	0.0	105	100.0
Conflicts with my social life	2.13	55	51.9	13	12.3	16	15.1	13	12.3	9	8.5	0	0.0	106	100.1
Having the responsibility for making major life decisions for grandchildren	2.11	49	49.5	17	17.2	15	15.2	9	9.1	9	9.1	0	0.0	99	100.1
Affects my family relationships	1.76	62	59.6	17	16.3	16	15.4	6	5.8	3	2.9	0	0.0	104	100.0
My physical health is deteriorating due to caregiving	1.71	62	63.3	18	18.4	8	8.2	4	4.1	6	6.1	0	0.0	98	100.1
I have difficulty providing/am not able to provide discipline for my grandchild	1.70	59	59.6	20	20.2	10	10.1	7	7.1	2	2.0	1	1.0	99	100.0
Interferes with my job	1.67	61	65.6	14	15.1	11	11.8	2	2.2	5	5.4	0	0.0	93	100.1
I am unable to get the sleep I need due to caregiving	1.67	63	64.3	15	15.3	10	10.2	9	9.2	1	1.0	0	0.0	98	100.0

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

Note: Do not know/Refused" was excluded from the means and was only given as an option to phone respondents.

**Appendix Table 14. Whether Grandparent Reported Any Other Caregiving Difficulties †**

Response	Respondents	
	#	%
Yes*	5	19.2
No	21	80.8
Total	26	100.0

\*For a list of other caregiving difficulties, see Appendix Table 14a.

**Appendix Table 14a. Other Caregiving Difficulties As Reported By Grandparents †**

Response	#
<i>Bedwetting hypothyroid 9 yr. old</i>	1
<i>I really struggled to get her motivated with homework, she didn't really want to be here...the reasons were because she had flunked her freshman year and had to repeat it and didn't want to go back to school...wanted to quit school.</i>	1
<i>Mother disappeared at first &amp; it was very stressful</i>	1
<i>Stressed before legal guardianship.</i>	1
<i>The 18 &amp; 14 yr. Old have brittle bone disease &amp; one uses crutches &amp; the other uses a wheelchair. Grandma has CA.</i>	1
Total	5

**Appendix Table 15. Concerns Associated With Caregiving**

Concerns	Mean	Respondents													
		Strongly disagree 1		2		3		4		Strongly agree 5		Do not know/ Refused 6		Total	
		#	%	#	%	#	%	#	%	#	%	#	%	#	%*
It is difficult for me to accept support or assistance because it is my duty	2.28	46	47.4	15	15.5	12	12.4	11	11.3	13	13.4	0	0.0	97	100.0
It is difficult for me to find support or assistance when caregiving	2.16	48	49.0	16	16.3	13	13.3	12	12.2	9	9.2	0	0.0	98	100.0
Other family members are jealous of the extra care and attention I give to my grandchildren	2.06	54	51.9	18	17.3	11	10.6	14	13.5	7	6.7	0	0.0	104	100.0
I feel resentment or anger towards the parents of my grandchildren for putting this responsibility on me	1.90	62	58.5	13	12.3	18	17.0	6	5.7	7	6.6	0	0.0	106	100.1
I feel guilty about feelings of resentment or anger that I have	1.89	62	59.6	14	13.5	11	10.6	11	10.6	6	5.8	0	0.0	104	100.1
Since I have started caregiving services I've experienced a lack of understanding from others in my community	1.89	64	60.4	13	12.3	12	11.3	11	10.4	6	5.7	0	0.0	106	100.1
It is difficult for me to accept financial support or assistance because of the negative stigma	1.83	55	56.7	20	20.6	10	10.3	4	4.1	7	7.2	1	1.0	97	99.9
Since I have started caring for my grandchildren, friends have backed away	1.71	67	63.8	15	14.3	11	10.5	7	6.7	4	3.8	1	1.0	105	100.1
Since I have started caregiving services I've experienced a sense of isolation from others in my community	1.59	62	63.3	21	21.4	10	10.2	3	3.1	2	2.0	0	0.0	98	100.0
I have concerns about losing custody of my grandchildren	1.58	70	70.7	12	12.1	7	7.1	5	5.1	4	4.0	1	1.0	99	100.0
It is difficult for me to accept financial support or assistance because my grandchildren fear peer acceptance	1.57	60	62.5	23	24.0	4	4.2	2	2.1	4	4.2	3	3.1	96	100.1
People in my community will think ill of me if I don't provide care	1.44	73	73.7	15	15.2	7	7.1	1	1.0	3	3.0	0	0.0	99	100.0
It is difficult for me to accept help from others when caregiving because I'm being paid	1.41	66	76.7	12	14.0	4	4.7	1	1.2	3	3.5	0	0.0	86	100.1
I do not feel I can provide appropriate cross-cultural education to my multi-racial grandchild	1.33	66	80.5	5	6.1	4	4.9	3	3.7	1	1.2	3	3.7	82	100.1

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

Note: "Do not know/Refused" was excluded from the means and was only an option to those taking the phone survey.

**Appendix Table 16. Whether Grandparent Experienced Other Concerns Associated With Caregiving**

Response	Respondents	
	#	%
Yes*	13	12.5
No	91	87.5
Total	104	100.0

\*For other concerns associated with caregiving, see Appendix Table 16a.

**Appendix Table 16a. Other Concerns Associated With Caregiving**

Response	#
<i>Concern over daughter's threats of taking my grandchild back. If this happens, I would have to pay for all the lawyers &amp; after 6 years (all his life) I'm not about to give him up.</i>	1
<i>Grandparent age and parents age are different.</i>	1
<i>Money-wise could be better</i>	1
<i>Daughter seems to be backsliding in what she understands/or is able to comprehend</i>	1
<i>Emotional status</i>	1
<i>Hard to get insurance if not legal guardian</i>	1
<i>I am a single parent too</i>	1
<i>I worry about my granddaughter but she has really adjusted her senior year</i>	1
<i>Medical costs</i>	1
<i>No one considers we are grandparents on a fixed income raising a grandchild</i>	1
<i>Uninsurance problems</i>	1
<i>Will my grandchildren feel a loss of their parent</i>	1
<i>Blank</i>	1
Total	13



**Appendix Table 17. Whether There Were Other Family Members Within Grandparent's Household Who Provided Care To Grandchildren**

Response	Respondents	
	#	%
Yes*	69	66.3
No**	34	32.7
Refused <sup>β</sup>	1	1.0
Total	104	100.0

\*Other family members within grandparent's household who provided care are listed in Appendix Table 17a.

\*\*Reasons why others did not provide care are listed in Appendix Tables 19.

**Appendix Table 17a. Other Family Members Within Grandparent's Household Who Provided Care to Grandchildren**

Family Member by Relationship to Grandparent*	#
<i>Child's mother-spouse-aunts</i>	1
<i>Children</i>	13
<i>Friend</i>	1
<i>Granddaughter</i>	1
<i>Grandfather-uncles</i>	1
<i>Grandparents</i>	8
<i>Husband and children's mother</i>	1
<i>My fiancée helps with support.</i>	1
<i>My sister and my daughter</i>	1
<i>Parents</i>	1
<i>Spouse-grandfather</i>	1
<i>Spouse</i>	34
<i>Spouse, child (16 yrs. old)</i>	1
<i>Spouse, daughters</i>	2
<i>Spouse, son, mother</i>	1
<i>The child's father</i>	1
Total	69

\*Respondents were asked if there were other family members within their household who provided care to their grandchildren. If the respondent answered yes, they were then prompted with the question "What is their relationship to you?" to identify who those persons were by their relationship to the grandparent. Answers suggest that respondents may not always have identified a family member by the relationship to themselves.

**Appendix Table 18. Whether There Were Other Family Members Outside Grandparent's Household Who Provided Care To Grandchildren**

Response	Respondents	
	#	%
Yes*	46	43.8
No**	59	56.2
Total	105	100.0

\*Other family members outside grandparent's household who provided care are listed in Appendix Table 18a.

\*\*Reasons why others did not provide care are listed in Appendix Table 19.

**Appendix Table 18a. Other Family Members Outside Grandparent's Household Who Provided Care To Grandchildren** <sup>o</sup>

Family Member by Relationship to the Grandparent*	#
<i>Another son</i>	1
<i>Aunts and uncles</i>	6
<i>Aunts, uncles, maternal grandfather</i>	1
<i>Daughter</i>	1
<i>Father</i>	1
<i>Friend</i>	1
<i>Godparents</i>	1
<i>Great aunt</i>	1
<i>Great grandma, aunt</i>	1
<i>Grandparents</i>	4
<i>Husband and daughters</i>	1
<i>Mother</i>	1
<i>No-children's father</i>	1
<i>Parents</i>	3
<i>Sister</i>	1
<i>Sister and sister in laws</i>	1
<i>Sisters/mother</i>	1
<i>Son's girlfriend</i>	1
<i>Son and daycare</i>	1
<i>Son, uncles and aunts</i>	1
<i>Yes, all our family, especially mother</i>	1
<i>Blank</i>	15
Total	46

\*Respondents were asked if there were other family members within their household who provided care to their grandchildren. If the respondent answered yes, they were then prompted with the question "What is their relationship to you?" to identify who those persons were by their relationship to the grandparent. Answers suggest that respondents may not always have identified a family member by the relationship to themselves.

**Appendix Table 19. Reasons Why Others Did Not Provide Care To Grandchildren**

Response	Respondents (N=106)	
	#	%*
Others have full-time jobs	36	34.0
Others live farther away	34	32.1
Others have young dependents living with them	27	25.5
Others would provide care if we were unable to	20	18.9
Others are unwilling or "just can't"	19	17.9
Does not apply to my situation	19	17.9
Others have less flexible daily schedules	19	17.9
There are no other immediate family members	16	15.1
Others are unaware of needed care (have not been informed-have not been asked to help)	7	6.6
Others are also in need of care	6	5.7
Others would provide care, but it would cause conflict in that family	3	2.8
Recipient doesn't want care from others	2	1.9
Others are too inexperienced	1	0.9
Others are embarrassed/uncomfortable fulfilling intimate needs (bathing, toileting, etc.)	1	0.9
Others do not get along with care recipient	0	0.0
Other reasons	4	3.8
<i>Doesn't get along</i>	1	
<i>Emotional complications</i>	1	
<i>Had previously lived with grandfather, but didn't work out there either as there was a disciplinary problem</i>	1	
<i>The grandmother was given care when another relative thought they were going to get them</i>	1	

\*Percents do not add to 100.0 due to multiple responses; N=106.

**Appendix Table 20. Other Reasons Why Services Were Not Being Used If Services Were Available To Grandchildren**

Other Reasons by Type of Service*	#
<b>Counseling Services</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Did for 2 years when children need it</i>	1
<i>Grandchildren won't use it, counselor could not get through to child</i>	1
<b>Tutoring/homework assistance</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>School year has just begun</i>	1
<i>Teachers are excellent with the girls</i>	1
<b>School lunch program</b> <span style="float: right;"><b>Total</b></span>	<b>9</b>
<i>Child is too young</i>	1
<i>Don't qualify</i>	2
<i>Girls want to brown bag it</i>	1
<i>Not in high school yet</i>	1
<i>She comes home for lunch</i>	1
<i>She didn't live with me long enough to receive service</i>	1
<i>Too old</i>	1
<i>Too young</i>	1
<b>Scholarships</b> <span style="float: right;"><b>Total</b></span>	<b>8</b>
<i>Aren't able to get one</i>	1
<i>Do not need it yet</i>	1
<i>Don't want to</i>	1
<i>Not in school</i>	1
<i>Not qualified</i>	1
<i>Not yet</i>	1
<i>Possibly next year</i>	1
<i>Student wants to work a year first</i>	1
<b>Extracurricular activities</b> <span style="float: right;"><b>Total</b></span>	<b>11</b>
<i>Can't afford it</i>	1
<i>Child is too young</i>	1
<i>Health, more art related or music</i>	1
<i>Lived in country, too much driving</i>	1
<i>Money?</i>	1
<i>Not capable of participating in group activities</i>	1
<i>Not interested</i>	1
<i>Not presently, summer vacation</i>	1
<i>Too young</i>	3

**Appendix Table 20. Other Reasons Why Services Were Not Being Used If Services Were Available To Grandchildren (continued)**

<b>Other Reasons by Type of Service*</b>	<b>#</b>
<b>Positive role models/mentor program</b> <span style="float: right;"><b>Total</b></span>	<b>4</b>
<i>Don't need now</i>	1
<i>Haven't applied for it yet</i>	1
<i>Long waiting list</i>	1
<i>Not impressed with mentors' availability</i>	1
<b>Medical assistance</b> <span style="float: right;"><b>Total</b></span>	<b>10</b>
<i>Covered under family insurance, do not need it</i>	1
<i>Exploring other insurance options</i>	1
<i>Have applied for it but was refused</i>	1
<i>Have her on my insurance doesn't qualify for med assist</i>	1
<i>Mother buys insurance</i>	1
<i>Not sure if parent is using this service</i>	1
<i>Use Indian Health Services</i>	1
<i>We do not qualify</i>	1
<i>Would not allow us to use clinic of our choice</i>	1
<i>You know if you qualify being I am not the legal guardian</i>	1

\*If a service is not listed in this table, no respondents indicated there were 'other' reasons why their grandchildren were not using the service.

**Appendix Table 21. Ratings Of Services Used By Grandchildren**

Services for Grandchild	Mean	Respondents													
		Not good at all 1**		2**		3		4		Very good 5		Do not know/ Refused <sup>β</sup> 6		Total	
		#	%	#	%	#	%	#	%	#	%	#	%	#	%*
Medical assistance	4.41	0	0.0	2	4.0	5	10.0	13	26.0	29	58.0	1	2.0	50	100.0
Scholarships	4.29	0	0.0	0	0.0	2	25.0	1	12.5	4	50.0	1	12.5	8	100.0
Extra-curricular activities	4.18	0	0.0	2	3.6	13	23.2	13	23.2	27	48.2	1	1.8	56	100.0
Positive role models/mentor program	4.15	0	0.0	0	0.0	7	35.0	3	15.0	10	50.0	0	0.0	20	100.0
Special education	4.09	0	0.0	1	4.5	5	22.7	7	31.8	9	40.9	0	0.0	22	99.9
School lunch program	4.04	1	1.5	6	8.8	16	23.5	11	16.2	34	50.0	0	0.0	68	100.0
Tutoring/homework assistance	4.00	0	0.0	1	3.8	9	34.6	5	19.2	11	42.3	0	0.0	26	99.9
Counseling services	3.82	2	5.9	0	0.0	12	35.3	8	23.5	12	35.3	0	0.0	34	100.0

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

\*\*Reasons why services were not good (rated a "1" or a "2") are listed in Appendix Table 21a.

Note: "Do not know/Refused" was excluded from the means and was only an option to those taking the phone survey.

**Appendix Table 21a. Reasons Why Services Were Not Good If Services Available To Grandchildren Were Rated Poorly\***

<b>Reasons Why Services Were Not Good by Type of Service*</b>	<b>#</b>
<b>Counseling services</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Counselor didn't help with real emotional problems</i>	1
<i>Did not change attitude or actions</i>	1
<b>Tutoring/homework assistance</b> <span style="float: right;"><b>Total</b></span>	<b>1</b>
<i>But not enough, because these kids don't have parents</i>	1
<b>School lunch program</b> <span style="float: right;"><b>Total</b></span>	<b>7</b>
<i>Food is not very good</i>	1
<i>Food is tasteless, pizza rubbery, seldom tastes good</i>	1
<i>Food is terrible</i>	1
<i>Food not as good as could be</i>	1
<i>Kids don't like food</i>	1
<i>Quality poor nutrition</i>	1
<i>Too greasy, salty, starch</i>	1
<b>Special education</b> (1 respondent rated services low, but 2 gave responses) <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Not sure how much</i>	1
<i>Not well educated regarding bipolar children</i>	1
<b>Extracurricular activities</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Sat on the bench</i>	1
<i>What's there besides sports</i>	1
<b>Medical assistance</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Insurance pays first then medicaid pays the rest</i>	1
<i>Slow in getting help</i>	1

\*Only services that respondents rated poorly (with a "1" or a "2" on a five-point scale with "1" being "not good at all" and "5" being "very good") are listed in this table. If a service is not listed, no respondents rated it poorly.

**Appendix Table 22. Whether There Were Other Services Not Mentioned That Grandparent Would Like To Have Available To Grandchildren †**

Response	Respondents	
	#	%
Yes*	7	26.9
No	18	69.3
Do not know/Refused	1	3.8
Total	26	100.0

\*See Appendix Table 22a for other services not mentioned.

**Appendix Table 22a. Other Services Not Mentioned That Grandparent Would Like To Have Available To Grandchildren †**

Response	#
<i>Dental services are 40 miles away</i>	1
<i>Dental work is important we don't receive help with.</i>	1
<i>Medical &amp; Dental Services</i>	1
<i>More child psychologists around Western ND Dickinson</i>	1
<i>Transportation to after school activities</i>	1
<i>Blank</i>	2
Total	7



**Appendix Table 23. Other Reasons Why Services Are Not Being Used If They Are Available To Grandparent**

Other Reasons by Type of Service*	#
<b>Outreach programs (e.g., youth companions) Total</b>	<b>4</b>
<i>Boys-girls club just started</i>	1
<i>Do not know how to connect with this program/Big Brother</i>	1
<i>Haven't applied</i>	1
<i>Just never had them available</i>	1
<b>Visiting nurse (blood pressure and other vitals) Total</b>	<b>1</b>
<i>Left blank</i>	1
<b>Homemaker services/home health aides Total</b>	<b>2</b>
<i>Not eligible</i>	1
<i>We can not afford them</i>	1
<b>Escort/transportation services Total</b>	<b>2</b>
<i>I give transportation to school</i>	1
<i>Isn't any around</i>	1
<b>Information about available services Total</b>	<b>5</b>
<i>Don't qualify</i>	1
<i>I wouldn't qualify</i>	1
<i>Not at this time! Maybe in the future.</i>	1
<i>Not available as far as I know</i>	1
<i>Left blank</i>	1
<b>Assistance with accessing available services Total</b>	<b>2</b>
<i>Didn't qualify</i>	1
<i>Don't know of any</i>	1
<b>Caregiver training or education Total</b>	<b>3</b>
<i>No time</i>	1
<i>Too many medical problems right now</i>	1
<i>Left blank</i>	1
<b>Respite care (someone else who provides short-term relief for you) Total</b>	<b>5</b>
<i>Because they wouldn't take my grandchildren plus my 2 children</i>	1
<i>Don't need yet</i>	1
<i>Gone most of the time</i>	1
<i>Never been approached with this as to being available.</i>	1
<i>Not eligible</i>	1

**Appendix Table 23. Other Reasons Why Services Are Not Being Used If They Are Available To Grandparent (continued)**

Other Reasons by Type of Service*	#
<b>Caregiver support groups</b> <span style="float: right;"><b>Total</b></span>	<b>2</b>
<i>Never been offered as a service to me</i>	1
<i>No time &amp; to find a sitter for the kids would be tough</i>	1
<b>Legal assistance/legal aid</b> <span style="float: right;"><b>Total</b></span>	<b>4</b>
<i>Because it still costs money do not have</i>	1
<i>Not able to get involved not legal guardian</i>	1
<i>Not eligible</i>	1
<i>Too hard to get help from</i>	1
<b>Technology assistance (e.g., using the Internet)</b> <span style="float: right;"><b>Total</b></span>	<b>6</b>
<i>No computer, do not need it</i>	1
<i>Don't have computer at home</i>	1
<i>Don't have it hooked up yet</i>	1
<i>Have no desire to use computer</i>	1
<i>I don't think the Internet is that good of a thing to do</i>	1
<i>Medical problems</i>	1

\*If a service is not listed in this table, no respondents indicated there were 'other' reasons why they were not using the service.

**Appendix Table 24. Ratings Of Services Used By Grandparents**

Grandparent Services	Mean	Respondents													
		Not good at all 1**		2**		3		4		Very Good 5		Do not know/ Refused 6 <sup>β</sup>		Total	
		#	%	#	%	#	%	#	%	#	%	#	%	#	%*
Parish nurses	4.43	0	0.0	0	0.0	1	14.3	2	28.6	4	57.1	0	0.0	7	100.0
Medicine/ prescription delivery	4.40	0	0.0	0	0.0	3	18.8	3	18.8	9	56.3	1	6.3	16	100.2
Caregiver training or education	4.33	0	0.0	0	0.0	2	22.2	2	22.2	5	55.6	0	0.0	9	100.0
Escort/ transportation services	4.27	0	0.0	0	0.0	3	18.8	5	31.3	7	43.8	1	6.3	16	100.2
Visiting nurse (blood pressure and other vitals)	4.25	1	5.0	0	0.0	2	10.0	7	35.0	10	50.0	0	0.0	20	100.0
Individual caregiver counseling	4.20	0	0.0	0	0.0	2	20.0	4	40.0	4	40.0	0	0.0	10	100.0
Respite care (someone else provides short- term relief for you)	4.13	0	0.0	0	0.0	5	31.3	4	25.0	7	43.8	0	0.0	16	100.1
Outreach programs (e.g., youth companions)	4.08	1	7.7	0	0.0	2	15.4	4	30.8	6	46.2	0	0.0	13	100.1
Information about available services	4.00	0	0.0	0	0.0	11	33.3	11	33.3	11	33.3	0	0.0	33	99.9
Caregiver support groups	4.00	0	0.0	0	0.0	1	33.3	1	33.3	1	33.3	0	0.0	3	99.9
Assistance with accessing available services	3.96	0	0.0	0	0.0	9	37.5	7	29.2	8	33.3	0	0.0	24	100.0
Technology assistance (e.g., using the Internet)	3.88	1	5.9	0	0.0	6	35.3	2	11.8	7	41.2	1	5.9	17	100.1
Homemaker services/ home health aides	3.86	0	0.0	0	0.0	3	42.9	2	28.6	2	28.6	0	0.0	7	100.1
Shopping assistance	3.75	0	0.0	1	12.5	2	25.0	3	37.5	2	25.0	0	0.0	8	100.0
Legal assistance/ legal aid	3.75	1	6.3	0	0.0	6	37.5	4	25.0	5	31.3	0	0.0	16	100.1

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

\*\*Reasons why service was not good (rated a "1" or "2") are listed in Appendix Table 24a.

Note: "Do not know/Refused" was excluded from the means and was only an option to those taking the phone survey.

**Appendix Table 24a. Reasons Why Services Were Not Good If Services Available To Grandparent Were Rated Poorly\***

Reasons Why Services Were Not Good by Type of Service	#
<b>Outreach programs (e.g., youth companions) Total</b>	<b>1</b>
<i>Poorly advertised!</i>	<i>1</i>
<b>Visiting nurse (blood pressure and other vitals) Total</b>	<b>1</b>
<i>Blank</i>	<i>1</i>
<b>Shopping assistance Total</b>	<b>1</b>
<i>Just drops us off</i>	<i>1</i>
<b>Legal assistance/legal aid Total</b>	<b>1</b>
<i>They don't do anything to help-only refer me to someone else</i>	<i>1</i>
<b>Technology assistance (e.g., using the Internet) Total</b>	<b>1</b>
<i>Poor advertising</i>	<i>1</i>

\*Only services that respondents rated poorly (with a "1" or a "2" on a five-point scale with "1" being "not good at all" and "5" being "very good") are listed in this table. If a service is not listed, no respondents rated it poorly.

**Appendix Table 25. Whether There Are Other Services Not Mentioned That Grandparent Would Like To Have Available To Them As A Caregiver**

Response	Respondents	
	#	%
Yes*	15	16.5
No	76	83.5
Total	91	100.0

\*Other services listed in Appendix Table 25a.

**Appendix Table 25a. Other Services Not Already Mentioned That Grandparent Would Like To Have Available To Them As A Caregiver**

Services	#
<i>A support group of people raising grandkids</i>	1
<i>Big Brother-Big Sister program. The list is so long &amp; there is concern over how well they screen people</i>	1
<i>Daycare</i>	1
<i>Daycare asst. costs are \$400 a month</i>	1
<i>Family retreats or get-aways</i>	1
<i>Home repair services, can not afford</i>	1
<i>Medicaid insurance</i>	1
<i>Medical for the care giver's kids. There are no food stamps, no assistance for her own children.</i>	1
<i>More drug &amp; alcohol counseling and family life issues taught in school, i.e. family taught in school</i>	1
<i>More funding to help pay expense; survey the grandchildren and their opinions</i>	1
<i>Most of these [illegible] are for older children ours is 5</i>	1
<i>Support group for grandchildren being raised by grandparents</i>	1
<i>Time to sleep</i>	1
<i>Wife gets from the internet with children's medical issues. Wife works at a pharmacy.</i>	1
<i>Blank</i>	1
Total	15

**Appendix Table 26. Whether There Were Other Services Not Mentioned With Which Grandparent Would Like Help**

Response	Respondents	
	#	%
Yes*	6	6.7
No	83	93.3
Total	89	100.0

\*Other services are listed in Appendix Table 26a.

**Appendix Table 26a. Other Services Not Already Mentioned With Which Grandparent Would Like Help**

Other Services	#
<i>For child to learn a variety of techniques</i>	1
<i>Legal assistance for child</i>	1
<i>Locating friends, socializing</i>	1
<i>Money</i>	1
<i>Needs crib</i>	1
<i>Blank</i>	1
Total	6

**Appendix Table 27. Average Amount Of Money Spent Within The Last Year In Caring For Grandchildren**

Response	Respondents	
	#	%*
0 to \$1,000	16	15.5
\$1,001 to \$2000	15	14.6
\$2,001 to \$3,000	6	5.8
\$3,001 to \$4,000	6	5.8
\$4,001 to \$5,000	6	5.8
More than \$5,000	28	27.2
I do not know	26	25.2
Total	103	99.9

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

**Appendix Table 28. Grandparent's Age**

Age of Grandparent	Respondents	
	#	%
Less than 65 years of age	70	67.3
65 to 69 years	12	11.5
70 to 74 years	11	10.6
75 to 79 years	6	5.8
80 to 84 years	5	4.8
85 years of age and above	0	0.0
Total	104	100.0

**Appendix Table 29. Grandparent's Marital Status**

Marital Status	Respondents	
	#	%
Married or living with partner	74	70.5
Widowed	18	17.1
Divorced or separated	10	9.5
Single, never married	3	2.9
Total	105	100.0

**Appendix Table 30. Whether There Were Children, Other Than Grandchildren, That Reside In Grandparent's Household**

Response	Respondents	
	#	%
Yes*	22	21.4
No	81	78.6
Total	103	100.0

\*See Table 16 for number of children, other than grandchildren, residing in grandparent's household by age cohort.

**Appendix Table 31. Highest Level Of Education Completed By Grandparent**

Level of Education	Respondents	
	#	%
Less than high school	12	11.5
Some high school	11	10.6
Graduated high school/GED	42	40.4
Some technical college	4	3.8
Technical degree	1	1.0
Some college	19	18.3
Graduated college	11	10.6
Post graduate or professional degree	4	3.8
Total	104	100.0

**Appendix Table 32. Grandparent's Employment Status**

Employment Status	Respondents	
	#	%
Retired	30	28.6
Full-time employment (35 hours/week or more)	27	25.7
Not working	25	23.8
Part-time	19	18.1
Multiple jobs (including full-time)	4	3.8
Total	105	100.0

**Appendix Table 33. Grandparent's Annual Household Income In 2001 Before Taxes\*\***

Household Income	Respondents	
	#	%*
Less than \$10,000	11	11.1
\$10,000 to \$20,000	29	29.3
\$20,001 to \$35,000	22	22.2
\$35,001 to \$50,000	22	22.2
\$50,001 to \$65,000	8	8.1
\$65,001 to \$80,000	0	0.0
\$80,001 to \$100,000	2	2.0
More than \$100,000	3	3.0
Refused <sup>β</sup>	2	2.0
Total	99	99.9

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

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



**Appendix Table 34. Grandparent's Race Or Ethnic Background**

Race or Ethnic Background	Respondents	
	#	%*
White (non-Hispanic)	89	84.8
American Indian or Alaska Native	13	12.4
White (Hispanic)	2	1.9
Black or African American	0	0.0
Asian American	0	0.0
Native Hawaiian or other Pacific Islander	0	0.0
Other	1	1.0
<i>Native American and White</i>	1	
Total	105	100.1

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

**Appendix Table 35. Grandparent's Principle Language**

Language	Respondents	
	#	%
English	101	95.3
Spanish	0	0.0
Other	5	4.7
<i>Dakotah and English</i>	1	
<i>English and Sioux</i>	3	
<i>German</i>	1	
Total	106	100.0

**Appendix Table 36. Grandparent's Gender**

Gender	Respondents	
	#	%
Male	16	15.7
Female	86	84.3
Total	102	100.0

**Appendix Table 37. Grandparent's Place Of Residence**

Residence	Respondents	
	#	%
Rural	58	55.2
Urban	47	44.8
Total	105	100.0

## **SURVEY INSTRUMENTS**

## Grandparent Survey Tool

A **relative caregiver** is a grandparent who lives with the child (18 years of age or younger), is the primary caregiver, and has either a legal or informal relationship with the child.

- Q1. How many grandchildren do you provide primary care for? \_\_\_\_\_  
Q1a. What are their ages? Please indicate the number of children for each age category.
- 0 to 4
  - 5 to 9
  - 10 to 14
  - 15 to 18
  - 18 and above
- Q2. What is the child's 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 \_\_\_\_\_
- Q3. How long have you provided primary care for your grandchild(ren)? (including the time before you might have become a legal guardian or foster parent)  
\_\_\_\_\_(Please specify months or years)
- Q4. Do you currently have legal guardianship of your grandchild(ren)?
- Yes
  - No
- Q5. Which of the child's parents is your offspring?
- Mother
  - Father
- Q6. Why are you caring for your grandchild(ren)? (Check all that apply)
- a. Parent is in an abusive relationship that interferes with raising the child  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - b. Parent is/was incarcerated  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - c. Parent can't afford to care for child  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - d. Parent was never involved in the child's life  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - e. Parent does not want to be bothered by raising child/does not want child  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - f. Parent has few/no parenting skills  
 No  
 Yes----->Does this apply to:  Mother  Father  Both

- g. Parent has addiction/substance abuse issues  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - h. Parent is not mature enough (i.e., roles sometimes seemed reversed)  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - i. Parent has emotional issues  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - j. Parent has mental health issues  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - k. Child was abused  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - l. Father is unknown  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
  - m. Parent is deceased  
 No  
 Yes----->Does this apply to:  Mother  Father  Both
- Q6b. Are there other reasons why you're caring for your grandchild(ren) that were not already mentioned?  
 No  
 Yes (please specify)\_\_\_\_\_

- Q7. What is the status of the relationship between the child's parents and yourself?  
 Stressed  
 Amicable  
 A relationship does not exist  
 Other (please specify)\_\_\_\_\_

- Q7a. Which parent does this apply to?  
 Mother  
 Father  
 Both

- Q8. Which, if any, of the following monetary compensations does your grandchild(ren) receive?  
 [check all that apply]  
 Social Security Income (SSI)  
 Inheritance  
 Other (specify)\_\_\_\_\_  
 None

- Q9. Which, if any, of the following monetary compensations do you receive in caring for your grandchild(ren)? [check all that apply]  
 Child support (formal or informal)  
 Foster care support  
 Other (specify)\_\_\_\_\_  
 None

- Q10. Which, if any, of the following non-monetary compensations does your household receive to assist in caring for your grandchild(ren)?
- Women, Infants, and Children (WIC)
  - School lunch program
  - Other food programs (food pantry, food commodities, food stamps, etc.)
  - Medical Assistance for uninsured or under-insured children
  - Temporary Assistance for Needy Families (TANF)
  - Housing assistance
  - Fuel Assistance
  - Other (specify) \_\_\_\_\_
  - None

- Q11. Does your grandchild(ren) have any special needs? (Check all that apply)
- Hyperactivity disorder
  - Learning disability
  - Fetal Alcohol Syndrome or Fetal Alcohol Effect (FAS/FAE)
  - Cognitive impairment
  - Developmental disabilities/Mental retardation
  - Mental health issues (depression, panic/anxiety disorder, schizophrenia)
  - Physical disabilities
  - Emotional issues
  - Head injury
  - Substance abuse issues
  - Other (specify) \_\_\_\_\_
  - None

- Q12. How much care is required by your grandchild(ren)?
- Grandchild(ren) can be left alone overnight
  - Grandchild(ren) can be left alone for most of the day
  - Grandchild(ren) can be left alone for a few hours
  - Around the clock/24-7

Q13. Here is a list of caregiving difficulties you may have experienced when you provided care to your grandchild(ren). Please indicate if you have experienced that difficulty. On a scale from one to five, 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, stress, 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

What are the difficulties you experience when providing care to your loved one?	Please rate the seriousness of the difficulties you have experienced
h. Interferes with my job	Not at all-1 2 3 4 5-Very serious
i. The financial burden (may have to do without things due to extra spending)	Not at all-1 2 3 4 5-Very serious
j. Having the responsibility for making major life decisions for grandchild(ren)	Not at all-1 2 3 4 5-Very serious
k. My physical health is deteriorating due to caregiving	Not at all-1 2 3 4 5-Very serious
l. I am unable to get the sleep I need due to caregiving	Not at all-1 2 3 4 5-Very serious
m. I feel more tied down	Not at all-1 2 3 4 5-Very serious
n. I have difficulty providing/am not able to provide discipline for my grandchild	Not at all-1 2 3 4 5-Very serious
o. I feel like I'm back at the beginning (help with homework, parent/teacher conferences, etc.)	Not at all-1 2 3 4 5-Very serious

Q14. Here is a list of concerns that may have applied to you at some time during your caregiving. On a one to five scale, with one being "Strongly disagree" and five being "Strongly agree", 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 financial support or assistance when caregiving because my grandchild(ren) fear(s) peer acceptance	Strongly disagree-1 2 3 4 5- Strongly agree
e. It is difficult for me to accept help from others when caregiving because I'm being paid (e.g., Licensed Foster Care, etc.)	Strongly disagree-1 2 3 4 5- Strongly agree
f. 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
g. 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

Concerns	Please rate how much you agree or disagree with the concern
h. 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
i. Since I have started caring for my grandchild(ren), friends have backed away because of a loss of common interests and my new responsibilities	Strongly disagree-1 2 3 4 5- Strongly agree
j. I have concerns about losing custody of my grandchild(ren)	Strongly disagree-1 2 3 4 5- Strongly agree
k. I feel resentment or anger towards the parents of my grandchild(ren) for putting this responsibility on me	Strongly disagree-1 2 3 4 5- Strongly agree
l. I feel guilty about feelings of resentment or anger that I have	Strongly disagree-1 2 3 4 5- Strongly agree
m. I do not feel I can provide appropriate cross-cultural education to my multi-racial grandchild	Strongly disagree-1 2 3 4 5- Strongly agree
n. Other family members are jealous of the extra care and attention I give to the grandchild that lives with me	Strongly disagree-1 2 3 4 5- Strongly agree

Q14-a. Are there other concerns for you as a caregiver that I have not mentioned?

No  
 Yes (please specify) \_\_\_\_\_

Q15. Are there other family members **within** your household who are providing care to your grandchild(ren) (i.e., spouse)?

Yes-----> What is their relationship to you? \_\_\_\_\_  
 No

Q16. Are there other family members **outside** of your household who are providing care to your grandchild(ren) (i.e., aunt, uncle, neighbor, etc.)?

Yes-----> What is their relationship to you? \_\_\_\_\_  
 No

Q17. 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, 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
- Others would provide care, but it would cause conflict in that family
- Others would provide care if we were unable to provide care
- Does not apply to my situation
- Other reasons \_\_\_\_\_

The next series of questions addresses services that may or may not be available to your grandchild(ren).

Q18. Are **counseling services** available to your grandchild(ren)?

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

Q18a. If you answered "No" or "Do not know", would you like **counseling services** to be available to your grandchild(ren)?

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

Q18b. If **counseling services** are available to your grandchild(ren), are you using it?

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

Q18c. If you're not using **counseling services**, why not? (**After answering, skip to Q19**)

- Do not need it  
 grandchild(ren) 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 **counseling services**. Not good at all - 1 2 3 4 5 - Very good

Q18e. If you rated **counseling services** 1 or 2, please tell us why the service was not good.  
\_\_\_\_\_

Q19. Is **tutoring/homework assistance** available to your grandchild(ren)?

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

Q19a. If you answered "No" or "Do not know", would you like **tutoring/homework assistance** to be available to your grandchild(ren)?

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

Q19b. If **tutoring/homework assistance** is available to your grandchild(ren), are you using it?

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

Q19c. If you're not using **tutoring/homework assistance**, why not? (**After answering, skip to Q20**)

- Do not need it  
 grandchild(ren) 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 **tutoring/homework assistance**.  
Not good at all - 1 2 3 4 5 - Very good

Q19e. If you rated **tutoring/homework assistance** 1 or 2, please tell us why the service was not good.  
\_\_\_\_\_



Q20. Is **school lunch program** available to your grandchild(ren)?

Yes (**Skip to Q20b**)

No

Do not know

Q20a. If you answered "No" or "Do not know", would you like **school lunch program** to be available to your grandchild(ren)?

Yes (**skip to Q21**)

No (**skip to Q21**)

Q20b. If **school lunch program** is available to your grandchild(ren), are you using it?

Yes (**Skip to Q20d**)

No

Q20c. If you're not using **school lunch program**, why not? (**After answering, skip to Q21**)

Do not need it

grandchild(ren) 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 **school lunch program**.

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

Q20e. If you rated **school lunch program** 1 or 2, please tell us why the service was not good.

\_\_\_\_\_

Q21. Are **scholarships** available to your grandchild(ren)?

Yes (**Skip to Q21b**)

No

Do not know

Q21a. If you answered "No" or "Do not know", would you like **scholarships** to be available to your grandchild(ren)?

Yes (**skip to Q22**)

No (**skip to Q22**)

Q21b. If **scholarships** are available to your grandchild(ren), are you using it?

Yes (**Skip to Q22d**)

No

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

Do not need it

grandchild(ren) 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 **scholarships**.

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

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

\_\_\_\_\_

Q22. Is **special education** available to your grandchild(ren)?

Yes (**Skip to Q22b**)

No

Do not know

Q22a. If you answered “No” or “Do not know”, would you like **special education** to be available to your grandchild(ren)?  
 Yes (**skip to Q23**)  
 No (**skip to Q23**)

Q22b. If **special education** is available to your grandchild(ren), are you using it?  
 Yes (**Skip to Q22d**)  
 No

Q22c. If you're not using **special education**, why not? (**After answering, skip to Q23**)  
 Do not need it  
 grandchild(ren) won't use it  
 Other reason (please specify) \_\_\_\_\_

Q22d. On a one to five scale, with one being “Not good at all” and five being “Very good”, please rate **special education**.  
Not good at all - 1    2    3    4    5 - Very good

Q22e. If you rated **special education** 1 or 2, please tell us why the service was not good.  
\_\_\_\_\_

Q23. Are **extracurricular activities** available to your grandchild(ren)?  
 Yes (**Skip to Q23b**)  
 No  
 Do not know

Q23a. If you answered “No” or “Do not know”, would you like **extracurricular activities** to be available to your grandchild(ren)?  
 Yes (**skip to Q24**)  
 No (**skip to Q24**)

Q23b. If **extracurricular activities** are available to your grandchild(ren), are you using it?  
 Yes (**Skip to Q23d**)  
 No

Q23c. If you're not using **extracurricular activities**, why not? (**After answering, skip to Q24**)  
 Do not need it  
 grandchild(ren) won't use 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 **extracurricular activities**.  
Not good at all - 1    2    3    4    5 - Very good

Q23e. If you rated **extracurricular activities** 1 or 2, please tell us why the services were not good.  
\_\_\_\_\_

Q24. Are **positive role models/mentor programs** available to your grandchild(ren)?  
 Yes (**Skip to Q24b**)  
 No  
 Do not know

Q24a. If you answered “No” or “Do not know”, would you like **positive role models/mentor programs** to be available to your grandchild(ren)?  
 Yes (**skip to Q25**)  
 No (**skip to Q25**)

Q24b. If **positive role models/mentor programs** are available to your grandchild(ren), are you using it?

Yes (**Skip to Q24d**)

No

Q24c. If you're not using **positive role models/mentor programs**, why not? (**After answering, skip to Q25**)

Do not need it

grandchild(ren) won't use 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 **positive role models/mentor program**.

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

Q24e. If you rated **positive role models/mentor program** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q25. Is **medical assistance** available to your grandchild(ren)?

Yes (**Skip to Q25b**)

No

Do not know

Q25a. If you answered "No" or "Do not know", would you like **medical assistance** to be available to your grandchild(ren)?

Yes (**skip to Q26**)

No (**skip to Q26**)

Q25b. If **medical assistance** is available to your grandchild(ren), are you using it?

Yes (**Skip to Q25d**)

No

Q25c. If you're not using **medical assistance**, why not? (**After answering, skip to Q26**)

Do not need it

grandchild(ren) won't use 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 **medical assistance**.

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

Q25e. If you rated **medical assistance** 1 or 2, please tell us why the service was not good.

\_\_\_\_\_

The next series of questions addresses services that may or may not be available to you as a caregiver.

Q26. Are **outreach programs (e.g., youth companions)** available to you as a caregiver?

Yes (**Skip to Q26b**)

No

Do not know

Q26a. If you answered "No" or "Do not know", would you like **outreach programs (e.g., youth companions)** to be available to you?

Yes (**skip to Q27**)

No (**skip to Q27**)

Q26b. If **outreach programs (e.g., youth companions)** are available to you, are you using it?

Yes (**Skip to Q26d**)

No

Q26c. If you're not using **outreach programs (e.g., youth companions)**, 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 **outreach programs (e.g., youth companions)**.

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

Q26e. If you rated **outreach programs (e.g., youth companions)** 1 or 2, please tell us why the service was not good.

\_\_\_\_\_

Q27. Are **visiting nurses (blood pressure and other vitals)** available to you as a caregiver?

Yes (**Skip to Q27b**)

No

Do not know

Q27a. If you answered "No" or "Do not know", would you like **visiting nurses (blood pressure and other vitals)** to be available to you?

Yes (**skip to Q28**)

No (**skip to Q28**)

Q27b. If **visiting nurses (blood pressure and other vitals)** is available to you, are you using it?

Yes (**Skip to Q27d**)

No

Q27c. If you're not using **visiting nurses (blood pressure and other vitals)**, 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 **visiting nurses (blood pressure and other vitals)**.

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

Q27e. If you rated **visiting nurses (blood pressure and other vitals)** 1 or 2, please tell us why the service was not good.

\_\_\_\_\_

Q28. Are **homemaker services/home health aides** available to you as a caregiver?

Yes (**Skip to Q28b**)

No

Do not know

Q28a. If you answered "No" or "Do not know", would you like **homemaker services/home health aides** to be available to you?

Yes (**skip to Q29**)

No (**skip to Q29**)

Q28b. If **homemaker services/home health aides** are available to you, are you using it?

Yes (**Skip to Q28d**)

No

Q28c. If you're not using **homemaker services/home health aides**, 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 **homemaker services/home health aides**.  
Not good at all - 1    2    3    4    5 - Very good

Q28e. If you rated **homemaker services/home health aides** 1 or 2, please tell us why the services were not good. \_\_\_\_\_

Q29. Are **escort/transportation services** available to you as a caregiver?  
 Yes **(Skip to Q29b)**  
 No  
 Do not know

Q29a. If you answered "No" or "Do not know", would you like **escort/transportation services** to be available to you?  
 Yes **(skip to Q30)**  
 No **(skip to Q30)**

Q29b. If **escort/transportation services** are available to you, are you using it?  
 Yes **(Skip to Q29d)**  
 No

Q29c. If you're not using **escort/transportation services**, why not? **(After answering, skip to Q30)**  
 Do not need it  
 Other reason (please specify) \_\_\_\_\_

Q29d. 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

Q29e. If you rated **escort/transportation services** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q30. Is **shopping assistance** available to you as a caregiver?  
 Yes **(Skip to Q30b)**  
 No  
 Do not know

Q30a. If you answered "No" or "Do not know", would you like **shopping assistance** to be available to you?  
 Yes **(skip to Q31)**  
 No **(skip to Q31)**

Q30b. If **shopping assistance** is available to you, are you using it?  
 Yes **(Skip to Q30d)**  
 No

Q30c. If you're not using **shopping assistance**, why not? **(After answering, skip to Q31)**  
 Do not need it  
 Other reason (please specify) \_\_\_\_\_

Q30d. 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

Q30e. If you rated **shopping assistance** 1 or 2, please tell us why the service was not good.

---

Q31. Are **parish nurses** available to you as a caregiver?

Yes (**Skip to Q31b**)

No

Do not know

Q31a. If you answered "No" or "Do not know", would you like **parish nurses** to be available to you?

Yes (**skip to Q32**)

No (**skip to Q32**)

Q31b. If **parish nurses** are available to you, are you using them?

Yes (**Skip to Q31d**)

No

Q31c. If you're not using **parish nurses**, why not? (**After answering, skip to Q32**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q31d. 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

Q31e. If you rated **parish nurses** 1 or 2, please tell us why the service was not good.

---

Q32. Is **information about available services** available to you as a caregiver?

Yes (**Skip to Q32b**)

No

Do not know

Q32a. If you answered "No" or "Do not know", would you like **information about available services** to be available to you?

Yes (**skip to Q33**)

No (**skip to Q33**)

Q32b. If **information about available services** is available to you, are you using it?

Yes (**Skip to Q32d**)

No

Q32c. If you're not using **information about available services**, why not? (**After answering, skip to Q33**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q32d. 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



Q35. Is **caregiver training or education** available to you as a caregiver?

Yes (**Skip to Q35b**)

No

Do not know

Q35a. If you answered “No” or “Do not know”, would you like **caregiver training or education** to be available to you?

Yes (**skip to Q36**)

No (**skip to Q36**)

Q35b. If **caregiver training or education** is available to you, are you using it?

Yes (**Skip to Q35d**)

No

Q35c. If you're not using **caregiver training or education**, why not? (**After answering, skip to Q36**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q35d. 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

Q35e. If you rated **caregiver training or education** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q36. Is **respite care (someone else provides short-term relief for you)** available to you as a caregiver?

Yes (**Skip to Q36b**)

No

Do not know

Q36a. If you answered “No” or “Do not know”, would you like **respite care (someone else provides short-term relief for you)** to be available to you?

Yes (**skip to Q37**)

No (**skip to Q37**)

Q36b. If **respite care (someone else provides short-term relief for you)** is available to you, are you using it?

Yes (**Skip to Q36d**)

No

Q36c. If you're not using **respite care (someone else provides short-term relief for you)**, why not? (**After answering, skip to Q37**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q36d. On a one to five scale, with one being “Not good at all” and five being “Very good”, please rate **respite care (someone else provides short-term relief for you)**.

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

Q36e. If you rated **respite care (someone else provides short-term relief for you)** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q37. Are **caregiver support groups** available to you as a caregiver?

Yes (**Skip to Q37b**)

No

Do not know



Q37a. If you answered “No” or “Do not know”, would you like **caregiver support groups** to be available to you?

Yes (**skip to Q38**)

No (**skip to Q38**)

Q37b. If **caregiver support groups** are available to you, are you using them?

Yes (**Skip to Q37d**)

No

Q37c. If you're not using **caregiver support groups**, why not? (**After answering, skip to Q38**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q37d. 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

Q37e. If you rated **caregiver support groups** 1 or 2, please tell us why the services were not good. \_\_\_\_\_

Q38. Is **legal assistance/legal aid** available to you as a caregiver?

Yes (**Skip to Q38b**)

No

Do not know

Q38a. If you answered “No” or “Do not know”, would you like **legal assistance/legal aid** to be available to you?

Yes (**skip to Q39**)

No (**skip to Q39**)

Q38b. If **legal assistance/legal aid** is available to you, are you using it?

Yes (**Skip to Q38d**)

No

Q38c. If you're not using **legal assistance/legal aid**, why not? (**After answering, skip to Q39**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q38d. On a one to five scale, with one being “Not good at all” and five being “Very good”, please rate **legal assistance/legal aid**.

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

Q38e. If you rated **legal assistance/legal aid** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q39. Is **technology assistance (e.g., using the Internet)** available to you as a caregiver?

Yes (**Skip to Q39b**)

No

Do not know

Q39a. If you answered “No” or “Do not know”, would you like **technology assistance (e.g., using the Internet)** to be available to you?

Yes (**skip to Q40**)

No (**skip to Q40**)

Q39b. If **technology assistance (e.g., using the Internet)** is available to you, are you using it?

Yes (**Skip to Q39d**)

No

Q39c. If you're not using **technology assistance (e.g., using the Internet)**, why not? (**After answering, skip to Q40**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q39d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **technology assistance (e.g., using the Internet)**.

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

Q39e. If you rated **technology assistance (e.g., using the Internet)** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q40. Is **medicine/prescription delivery** available to you as a caregiver?

Yes (**Skip to Q40b**)

No

Do not know

Q40a. If you answered "No" or "Do not know", would you like **medicine/prescription delivery** to be available to you?

Yes (**skip to Q41**)

No (**skip to Q41**)

Q40b. If **medicine/prescription delivery** is available to you, are you using it?

Yes (**Skip to Q40d**)

No

Q40c. If you're not using **medicine/prescription delivery**, why not? (**After answering, skip to Q40**)

Do not need it

Other reason (please specify) \_\_\_\_\_

Q40d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **medicine/prescription delivery**.

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

Q40e. If you rated **medicine/prescription delivery** 1 or 2, please tell us why the service was not good. \_\_\_\_\_

Q41. Are there other services not already mentioned that you would like to have available to you as a caregiver?

No

Yes (please specify) \_\_\_\_\_

Q42. Think about the services that you have provided or are now providing to your grandchild(ren). Please indicate 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 help with personal care every day, check the "daily" 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 care							
Assist with meals or nutritional needs							
Assist with errands and shopping							
Provide companionship							
Help with worries/anxiety/emotional needs							
Listen to them -someone for them to talk to							
Provide transportation - getting places							
Assist with medicines (administering, side effects, etc.)							
Get other family members involved in caregiving							
Provide cross-cultural education							
Provide discipline							
Provide tutoring/homework assistance							

Q42a. Are there other services not already mentioned that you would have liked help with?

No

Yes (please specify) \_\_\_\_\_

Q43. What kinds of information/services would be valuable to you as a caregiver, now or in the future?

- Info-line (central place to call to find out what kind of help is available)
- Hotline (for dealing with immediate emotional needs while preserving dignity)
- Someone to talk to/counseling services/support group
- Someone to help you arrange for services, assess your situation
- Information about your grandchild's condition or disability
- Information about developments or changes in laws affecting your situation
- Financial support
- Respite care
- Aftercare/grief counseling
- Tax break, stipend, government subsidy
- Help in assessing the timing of placement in formal caregiving institutions
- Help in understanding how to select a group home/other care facility
- Help in understanding how to pay for group homes or other care facilities
- Help in dealing with agencies (bureaucracies) to get services
- Help in dealing with parent of grandchild(ren) (i.e. mediation, intervention)
- Assistance with cross-cultural education
- Assistance with discipline
- Other (specify) \_\_\_\_\_
- None of the above

Q44. Because of caregiving, have you...(check all that apply)

- Moved or changed locations to be with your grandchild(ren)
- Sold a home to move in with grandchild(ren)
- 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

Q45. Within the past year, how much money have you spent caring for your grandchild(ren)?

- 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
- (I do not know)

Q46. What is your age?

- Less than 65 years old
- 65 to 69 years old
- 70 to 74 years old
- 75 to 79 years old
- 80 to 84 years old
- 85 or older

- Q47. What is your marital status?  
 Married or living with partner  
 Single, never married  
 Divorced or separated  
 Widowed
- Q48. Are there children other than your grandchild(ren), that reside within your household?  
 No (**Skip to Q49**)  
 Yes
- Q48a. What are their ages? Please indicate the number of children for each age category.  
 0 to 4  
 5 to 9  
 10 to 14  
 15 to 18  
 18 and above
- Q49. What is your gender?  
 Male  
 Female
- Q50. 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
- Q51. What is your employment status?  
 Full-time employment (35 hours/week or more)  
 Part-time  
 Multiple jobs (including full-time)  
 Retired  
 Not working
- Q52. 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
- Q53. 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\_\_\_\_\_

Q54. What is your principle language?

- English
- Spanish
- Other \_\_\_\_\_

Q55. What county do you live in? \_\_\_\_\_

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

Q56. Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_

## Script for Telephone Interviewers (Grandparent Caregivers' Study)

Hello, my name is \_\_\_\_\_ and I'm calling from the Center for Social Research at North Dakota State University. We are conducting a study, sponsored by the North Dakota Department of Human Services Aging Services Division, on caregivers in North Dakota. Do you have a few moments to answer some questions?

The purpose of the study is to develop a service delivery system that responds to the needs of North Dakota's caregivers. The survey is voluntary and you are free to quit at any time. The information you provide will be recorded without your name or any other identifying information.

If you have any questions about the study you may call Aging Services at (701) 328-8910. If you have any questions about the rights of human research subjects please contact the North Dakota State University IRB office at (701) 231-8908.

Let's begin with a discussion of relative caregivers.

*A **relative caregiver** is a grandparent who lives with a child and is the primary caregiver for that child, because of either a legal or informal relationship with the child.*

1. Are you at least 60 years of age and caring for a child 18 years of age or younger?  
 Yes (continue with Senior Caregiver Tool)  
 No
2. If no, do you know a relative, friend, or neighbor who is a senior caregiver?  
 Yes (if yes, please list name, address, and phone number on sheet)  
 No----If no, go on to ask about informal caregivers

Next let's talk about informal caregivers.

*An **informal caregiver** provides needed care on a long term basis to a someone 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 person 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 person no longer needs care.*

2. Are you an informal caregiver (as defined above) of someone who is least 60 years of age?  
 Yes (continue with Informal Caregiver Tool)  
 No
- C. If you are not an informal caregiver, are you *receiving* informal care (as we defined) and at least 60 years of age?  
 Yes (if yes, could you please tell me the name and phone number of your **primary caregiver** and skip to QD)  
 No
4. Do you know a relative, friend, or neighbor in your community who either gives or receives informal care?  
 Yes (if yes, could you please tell me their name and phone number/address so we may contact them to add them to the registry)  
 No

END: Thank you for taking the time to help us with this important survey. Goodnight.

*Grandparent Caregiver Phone Tool*  
April, 2002

ID

The purpose of the study is to develop a service delivery system that responds to the needs of North Dakota's caregivers. The survey will take about 25 minutes [can restart]. The survey is voluntary and you are free to quit at any time. The information you provide will be recorded without your name or any other identifying information. If you have questions about the study, you may call Aging Services at 701-328-8910. If you have questions about the rights of human research subjects, you may call the NDSU Institutional Review Board at 701-231-8908.

Q: defn

A relative caregiver is a grandparent who lives with the child (18 years of age or younger), is the primary caregiver, and has either a legal or informal relationship with the child.

Q1

How many grandchildren are you providing primary care for?

Q1a

How many children are between 0 and 4 years of age?

Q1b

How many children are between 5 and 9 years of age?

Q1c

How many children are between 10 and 14 years of age?

Q1d

How many children are between 15 and 18 years of age?

Q1e

How many children are 18 or older?

Q2

What is the child's race or ethnic background?

- 1 White (non-Hispanic)
- 2 White (Hispanic)
- 3 Black or African American
- 4 Asian American
- 5 American Indian or Alaska Native
- 6 Native Hawaiian or other Pacific Islander
- 7 Other
- 8 [Refused]

Q3

How long have you provided primary care for your grandchild (ren)? (including the time before you became legal guardian or foster parent)

[please specify MONTHS or YEARS]

Q4

Do you currently have legal guardianship of your grandchild (ren)?

- 1 Yes
- 2 No
- 3 [Refused]



Q5

Which of the child's parents is your offspring?

- 1 Mother
- 2 Father
- 3 [Refused]

Q6

Why are you caring for your grandchild (ren)?

- Parent is in an abusive relationship that interferes with raising the child
- Parent is/was incarcerated
- Parent can't afford to care for child
- Parent was never involved in the child's life
- Parent does not want to be bothered by raising child/doesn't want child
- Parent has few/no parenting skills
- Parent has addiction/substance abuse issues
- Parent is not mature enough (roles sometimes seem reversed)
- Parent has emotional issues
- Parent has mental health issues
- Child was abused
- Father is unknown
- Parent is deceased

- 1 Yes
- 2 No
- 3 [Refused]

Q6a

Which parent does this apply to?

- 1 Mother
- 2 Father
- 3 Both
- 4 [Refused]

Q6b

Are there other reasons why you're caring for your grandchild (ren) that I haven't already mentioned?

- 1 Yes
- 2 No
- 3 [Don't know/refused]

Q7

What is the status of the relationship between the child's parents and yourself?

- 1 Stressed
- 2 Amicable
- 3 A relationship does not exist
- 4 Other
- 5 [Refused]

Q7a

Which parent does this relationship apply to.

- 1 Mother
- 2 Father
- 3 Both
- 4 [Refused]

Q8

Which, if any, of the following monetary compensations does your grandchild (ren) receive? [check all that apply]

- Social security
- Inheritance
- Other
- None

Q9

Which, if any, of the following monetary compensations do you receive in caring for your grandchild (ren)?

- Child support (formal or informal)
- Foster care support
- Other
- None

Q10

Which, if any, of the following non-monetary compensations does your household receive to assist in caring for your grandchild (ren)?

- Women, Infants, and Children (WIC)
- School lunch program
- Other food programs (food pantry, food commodities, food stamps, etc.)
- Medical assistance for un-insured or under-insured children
- Temporary Assistance for Needy Families (TANF)
- Housing assistance
- Fuel assistance
- Other
- None

Q11

Does your grandchild (ren) have any special needs? [check all that apply]

- Hyperactive disorder
- Learning disability
- Fetal alcohol syndrome or Fetal alcohol effect (FAS/FAE)
- Cognitive impairment
- Developmental disabilities/mental retardation
- Mental health issues (depression, panic/anxiety disorder, schizophrenia)
- Physical disabilities
- Emotional issues
- Head injury
- Substance abuse issues
- Other
- None

Q12

How much care is required by your grandchild (ren)?

- 1 Grandchild (ren) can be left alone overnight
- 2 Grandchild (ren) can be left alone for most of the day
- 3 Grandchild (ren) can be left alone for a few hours
- 4 Around the clock/24-7
- 5 [Refused]

Q13

Next, I will read you a list of caregiving difficulties you may have experienced when providing care to your grandchild (ren). On a one to five scale, with one being "not at all serious" and five being "very serious", please tell me how serious the difficulty was.

- Less time for myself (shopping, hobbies, etc.)
- Less time for my family (shorter vacations, missed events, etc.)
- No consistent help from other family members
- Affects my family relationships
- Conflicts with my social life (eating out, movies, visiting friends, etc.)
- Emotional aspects (frustration, stress, sadness, anxiety, etc.)
- Less privacy
- Interferes with my job
- The financial burden (may have to do without things due to extra spending)
- Having the responsibility for making major life decisions for grandchild(ren)
- My physical health is deteriorating due to caregiving
- I am unable to get the sleep I need due to caregiving
- I feel more tied down
- I have difficulty providing/am not able to provide discipline for my grandchild
- I feel like I'm back at the beginning (help w/ homework, P/T conferences)

- 1 Not at all serious
- 2
- 3
- 4
- 5 Very serious
- 6 [DNK/refused]

Q13a

Were there other difficulties you experienced when caring for your grandchild (ren) than I haven't already mentioned?

- 1 Yes
- 2 No
- 3 [Refused]

Set\_upa

Now I will read you a list of concerns that may have applied to you at some time during your caregiving. On a one to five scale, with one being "strongly disagree" and five being "strongly agree", please tell me how much you disagree or agree with each statement.

[press any key to continue]

Q14a

It is difficult for me to accept support or assistance when caregiving because it is my duty to provide care. Do you...

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14b

It is difficult for me to find support or assistance when caregiving. (I feel like I don't have help)

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14c

It is difficult for me to accept financial support or assistance when caregiving because it sometimes carries a negative stigma.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14d

It is difficult for me to accept financial support or assistance when caregiving because my grandchild (ren) fear (s) peer acceptance.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14e

It is difficult for me to accept help from others when caregiving because I'm being paid (e.g., Licensed Foster Care, etc.)

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14f

I'm providing caregiving services because people in my community will think ill of me if I don't.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14g

Since I have started caregiving services I've experienced a sense of isolation from others in my community.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14h

Since I have started caregiving services I've experienced a lack of understanding from others in my community.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14i

Since I have started caregiving for my grandchild (ren), friends have backed away because of a loss of common interests and my new responsibilities.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14j

I have concerns about losing custody of my grandchild (ren).

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14k

I feel resentment or anger towards the parents of my grandchild (ren) for putting this responsibility on me.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14l

I feel guilty about feelings of resentment or anger that I have

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14m

I do not feel I can provide appropriate cross-cultural education to my multi-racial grandchild

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14n

Other family members are jealous of the extra care and attention I give to the grandchild that lives with me.

- 1 Strongly disagree
- 2
- 3
- 4
- 5 Strongly agree
- 6 [DNK/refused]

Q14o

Are there other concerns for you as a caregiver that I have not mentioned?

- 1 Yes
- 2 No

Q15

Are there other family members within your household who are providing care to your grandchild (ren) (i.e., spouse)?

- 1 Yes
- 2 No
- 3 [Refused]

Q15a

What is their relationship to you? (spouse, child, etc.)

Q16

Are there other family members outside of your household who are providing care to your grandchild (ren) (i.e., aunt, uncle, neighbor, etc.)?

- 1 Yes
- 2 No
- 3 [Refused]

Q17

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)
- 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 (haven't been informed or asked to help)
- Others are unwilling or "just can't"
- Recipient doesn't want care from others
- Others would provide care, but it would cause conflict in that family
- Others would provide care if we were unable to provide care
- Does not apply to my situation
- Other reason

Set\_up\_b

Next I will read you a list of services. Please tell me if that service is available to your care recipient.

[press any key to continue]

Q18

Is this service available to your grandchild (ren)?

- Counseling
- Tutoring/homework assistance
- School lunch program
- Scholarships
- Special education
- Extracurricular activities
- Positive role models/mentor program
- Medical assistance

- 1 Yes
- 2 No
- 3 [DNK]

Q18a

Are you using this service?

- 1 Yes
- 2 No

Q18b

On a one to five scale, please rate the service.

- 1 Not good at all
- 2
- 3
- 4
- 5 Very good
- 6 [DNK/Refused]

Q18c

Why wasn't the service good?

Q18d

Why aren't you using the service?

- 1 Do not need it
- 2 Grandchild won't use it
- 3 Other
- 4 [DNK/refused]

Q18e

Would you like it to be available to your grandchild?

- 1 Yes
- 2 No
- 3 [DNK/refused]

Q18f

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

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Set\_up\_c

Now I will read you another list of services. Please tell me if that service is available to you as a caregiver.

[press any key to continue]

Q19

Is this service available to you as a care giver?

Outreach programs (e.g., youth companions)  
Visiting nurse (blood pressure and other vitals)  
Homemaker services/home health aides  
Escort/transportation services  
Shopping assistance  
Parish nurse  
Information about available services  
Assistance with accessing available services  
Individual caregiver counseling  
Caregiver training or education  
Respite care (someone else provides short-term relief for you)  
Caregiver support groups  
Legal assistance/Legal aid  
Technology assistance (e.g., using the Internet)  
Medicine/Prescription delivery

- 1 Yes
- 2 No
- 3 [DNK]

Q19a

Are you using this service?

- 1 Yes
- 2 No



Q19b

On a one to five scale, please rate the service.

- 1 Not good at all
- 2
- 3
- 4
- 5 Very good
- 6 [DNK/Refused]

Q19c

Why wasn't the service good?

Q19d

Why aren't you using the service?

- 1 Do not need it
- 2 Other
- 3 [DNK/refused]

Q19e

Would you like it to be available to you as a care giver?

- 1 Yes
- 2 No
- 3 [DNK/refused]

Q19f

Are there other services I haven't already mentioned that you would like to have available to you as a care giver?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Set\_up\_d

Think about the services that you have provided or are now providing to your grandchild (ren). Please tell me 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.

[press any key to continue]

Q20

Have you in the past or do you now...

- Manage finances
- Contribute financially
- Administer personal care (bathing, bandaging, nail care, etc.)
- Assist with household care
- Assist with meals or nutritional needs
- Assist with errands and shopping
- Provide companionship
- Help with worries/anxiety/emotional needs
- Listen to them - someone for them to talk to
- Provide transportation - getting places
- Assist with medicines (administering/side effects, etc.)
- Get other family members involved in caregiving
- Provide cross-cultural education
- Provide discipline
- Provide tutoring/homework assistance

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Q20a

How often have you provided this service?

- 1 Daily
- 2 Weekly
- 3 Monthly
- 4 On occasion
- 5 [Do not know/refused]

Q20b

Regardless of whether or not you have provided this service, would you have liked, or would you now like help providing the service?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Q20c

Are there other services I haven't already mentioned that you would have liked help with?

- 1 Yes
- 2 No
- 3 [Do not know/refused]

Q21

Please tell me what kinds of information/services would be valuable to you as a caregiver, now or in the future. [read list - check all that apply]

- Info-line (central place to call & find out what kind of help is available)
- Hotline (for dealing with immediate emotional needs while preserving dignity)
- Someone to talk to/counseling services/support group
- Someone to help you arrange for services, assess your situation
- Information about your grandchild's condition or disability
- Information about developments/changes in laws affecting your situation
- Financial support
- Respite care
- Aftercare/grief counseling
- Tax break, stipend, government subsidy
- Help in assessing the timing of placement in formal caregiving institutions
- Help in understanding how to select a nursing home/other care facility
- Help in understanding how to pay for group homes or other care facilities
- Help in dealing with agencies (bureaucracies) to get services
- Help in dealing with parent of grandchild (i.e., mediation, intervention)
- Assistance with cross-cultural education
- Assistance with discipline
- Other
- None of the above

Q22

Because of caregiving have you...  
[read list - check all that apply]

- Moved or changed locations to be with your grandchild (ren)
- Sold a home to move in with grandchild (ren)
- 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
- None of the above

Q23

Within the last year, on average, how much money have you spent caring for your grandchild (ren)?

- 1 0 to \$1,000
- 2 \$1,001 to \$2,000
- 3 \$2,001 to \$3,000
- 4 \$3,001 to \$4,000
- 5 \$4,001 to \$5,000
- 6 More than \$5,000
- 7 I do not know

Q24

Would you mind telling me your age?

- 1 Younger than 65 years of age
- 2 65 to 69
- 3 70 to 74
- 4 75 to 79
- 5 80 to 84
- 6 85 or older
- 7 [Refused]

Q25

What is your marital status?

- 1 Married or living with partner
- 2 Single, never married
- 3 Divorced or separated
- 4 Widowed
- 5 [Refused]

Q26

Are there children other than your grandchild (ren) that reside within your household?

- 1 Yes
- 2 No
- 3 [Refused]

Q26a

How many children are between 0 and 4 years of age?

Q26b

How many children are between 5 and 9 years of age?

Q26c

How many children are between 10 and 14 years of age?

Q26d

How many children are between 15 and 18 years of age?

Q26e

How many children are 18 or older?

Q27

What is the highest level of education you have completed?

- 1 Less than high school
- 2 Some high school
- 3 Graduated high school/GED
- 4 Some technical college
- 5 Technical degree
- 6 Some college
- 7 Graduated college
- 8 Post graduate or professional degree
- 9 [Refused]

Q28

What is your employment status?

- 1 Full-time employment (35 hours/week or more)
- 2 Part-time
- 3 Multiple jobs
- 4 Retired
- 5 Not working
- 6 [Refused]

Q29

What was your annual household income in 2001 before taxes (including money from jobs, social security, retirement income, public assistance, etc.)

- 1 Less than \$10,000
- 2 \$10,000 to \$20,000
- 3 \$20,001 to \$35,000
- 4 \$35,001 to \$50,000
- 5 \$50,001 to \$65,000
- 6 \$65,001 to \$80,000
- 7 \$80,001 to \$100,000
- 8 More than \$100,000
- 9 [Refused]

Q30

What is your race or ethnic background?

- 1 White (non-Hispanic)
- 2 White (Hispanic)
- 3 Black or African American
- 4 Asian American
- 5 American Indian or Alaska Native
- 6 Native Hawaiian or other Pacific Islander
- 7 Other
- 8 [Refused]

Q31

What is your principle language?

- 1 English
- 2 Spanish
- 3 Other
- 4 [Refused]

Q32

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.

End

That concludes our survey. Thank you for taking the time to help us with this important study. Good night.

Q33

Record gender based on voice.

- 1 Male
- 2 Female

Q34

Record county code from calling sheet.

- 1 Rural
- 2 Urban