

**NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM:
NORTH DAKOTA'S AMERICAN INDIAN CAREGIVERS**



**Center for Rural Health
UND School of Medicine and Health Sciences**

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Forward

This report contains the American Indian Caregivers from five reservations in North Dakota as part of the National Family Caregivers Support Program. The report parallels data collected on the general population and uses the statewide survey as a benchmark. Both informal and grandparent caregivers are analyzed describing their characteristics, access to, attitudes toward and use of services in an effort to define avenues that will improve the quality of family caregivers.

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**National Family Caregiver Support Program:
North Dakota's American Indian Caregivers**

Project Goals and Methods

The following report contains information reflecting the responses of caregivers from the North Dakota American Indian populations. The research represents an effort to ensure adequate inclusion of the American Indian population living on the 4 reservations in North Dakota and the Trenton service area (hereafter also referred to as a reservation). The reservations were included as part of a statewide research effort, in collaboration with the State Data Center and the Department of Child Development and Family Life at North Dakota State University, to examine the needs for support services for family caregivers, identify patterns of service use and ascertain with barriers to accessing support services. The separate data collection effort was designed to focus and over sample the five reservation communities. Although the American Indian population represents approximately five percent of the state's population, the reservations are rural, relatively isolated and underserved by most long term care programs such as skilled nursing homes, assisted living and home and community based services. Consequently, reliance on their strong traditions of extended family supports often represents the primary option for providing care to elders or for providing child care utilizing grandparents. The data collected for this report and analyzed in this document were developed in recognition of this special context in order to ensure that adequate information is produced representing our reservation residents.

An additional goal for the information reflected in this report is to satisfy the need for data on caregiver characteristics, needs and barriers specific to each reservation in separate reports containing their data and to providing these five communities with community specific data for use in their local family caregiving program development. Four of North Dakota's

reservations applied for and received independent program support from the Administration on Aging under the National Family Caregiver Support Program for the current fiscal year. The results of this survey will also satisfy their needs for conducting an assessment of their service populations.

Strategy to Locate Caregivers

Locating family caregivers is an elusive task as no comprehensive lists of informal caregivers normally exist. Families engage in the caregiving process often without considering their day to day family interactions as caregiving until asked to reflect on the nature of their contributions. This of course makes sampling in a traditional statistical sense very complicated. In the five reservation communities, the task of identifying caregivers was delegated to the Title VI Native Elder Nutrition directors. The small rural environments facilitated knowledge of families and family circumstances making identification of family caregivers a much easier task for the reservations than was the case for the statewide non-Indian samples. Each reservation was given a goal of identifying and interviewing 100 family caregivers, with both informal caregivers and grandparent caregivers included in the total. The mix was determined by the number of caregivers identified and available. The goal of 100 respondents per reservation was thought to represent a very large proportion of these two categories of caregivers in each community and while not a probability sample, because of its exhaustive nature it can be considered representative.

Data received from the five reservations contained 383 useable surveys which represented an accomplishment of 76.6% of the goal. In this survey, as in the bulk of the statewide survey, the sampling strategy did not attempt to employ a probability sample, but rather sought to obtain a convenience sample, using persons identified locally by Title VI staff

and other caregivers. In the absence of experience with this population and issue, we did not know at the onset how many could actually be expected in the population. Given the experience of this effort and the corresponding statewide effort, we now believe that the interviewers were able to gather data from a majority of the caregivers.

The American Indian sample ultimately contained 231 informal caregivers and 152 grandparent caregivers, which suggests a proportion of 60% informal and 40% grandparent caregivers. By contrast, the statewide data resulted in a ratio of 86% informal and 14% grandparent caregivers. More grandparent caregivers were obtained from the five reservation sites than from the remainder of the state, which is quite likely a result of a combination of greater need and strong value placed on extended family relationships. In spite of limitations in the sampling design for these surveys, the disparity is large and one must conclude that grandparent caregiving is much more common among American Indians in North Dakota.

The Survey Tools

Two survey instruments were developed to characterize caregivers in the state and to represent their service needs and issues related to accessibility of support services. These tools correspond with the following two categories of caregivers:

1. **Family Caregivers:** those who serve as informal caregivers to individuals 60 years of age and older.
2. **Older Relative Caregivers:** individuals 60 years of age and older who serve as caregivers to persons 18 years of age and younger.

Primary responsibility for developing the survey instruments resided with the State Data Center. The instruments were the result of an exhaustive literature search and included many items derived from surveys conducted around the nation. Additionally, focus groups were

conducted to identify both appropriate questions and language. A more detailed discussion of this process will be found in a separate report submitted by the State Data Center. The resulting instruments were pre-tested in the Fargo area and subsequently reviewed by the staff of the National Resource Center for Native American Aging at the University of North Dakota (UND) Center for Rural Health to ensure that they would be appropriate for use with the reservation populations. A caveat is important here in that the topic of this research is relatively new and consequently the experience of other investigators was not substantial. Both survey instruments were quite detailed and lengthy and following this analysis, any future survey tools would be streamlined. In this effort, the goal was to ensure the inclusion of all potentially useful information and this contributed to the length of the two instruments.

The survey instrument for informal caregivers is attached as Appendix A. This questionnaire contained items reflecting caregiver characteristics, reasons for caregiving, location of care, difficulties experienced by caregivers, availability and use of other informal caregivers, a series of items on specific services indicating availability, use, desire for access and evaluation of available services, characteristics of care supplied, types of information or services desired, impacts of caregiving on caregiver's lives, and an invitation to become part of a caregiver registry.

A second instrument for use with grandparents (older relative caregivers) is presented in Appendix B. The content of this instrument also characterized the caregivers and reasons for caregiving. It then developed major categories of information on services that targeted the child such as tutoring and children's special needs and information on services that related directly to the caregivers themselves such as respite. It also contains information on the impacts of being a caregiver on the lives of the older relatives along with questions on availability, use and

evaluation of services for services directed at both the child and the caregiver. This instrument also invited respondents to add their names to a registry and to receive information from the caregiver support program.

Data Collection

Data collection on the five reservations was conducted on a face-to-face basis with data collectors trained by the project staff on administering the instrument. Staff involved in the data collection involved a combination of local personnel from the Title VI staff and university graduate students. The data were collected over a eight month period from July 1, 2002 to Feb. 28, 2003. The length of this data collection period was necessitated by substantial delays in being able to obtain tribal authorization and local personnel changes during the data collection process. All data collection required tribal authorization and while the tribes were highly receptive to the project, the process of getting on the agenda for a meeting of each council and receiving approval required patience. Fortunately, we can report that approval was granted by all five tribes and that the data collection was a success. We received 383 usable questionnaires, with adequate representation from each tribe.

Results

The findings from these two survey instruments will be discussed in independent sections. Prior to engaging that analysis, it may be appropriate to entertain questions of whether there are indeed differences between the general population and the reservations and whether there might also be differences between reservations. The answer to these questions helps provide a context to looking at the findings.

1. Are there socially significant differences in the patterns observed between the reservation sample and the general population? The answer is a qualified yes. That is, there are significant differences along with many similarities. The conclusion is first derived from some direct comparisons of the descriptive findings. Many of the comparisons yielded different patterns for the reservation samples when compared with the state. These differences were displayed as different priorities or different ratings of importance for some services or information types. Researchers conclude from the descriptive comparisons that one needs to look at the data from the reservation sample in order to adequately design activities or programs that will meet their needs.

Secondly, a number of factor analyses were conducted that sought to cluster items into meaningful groups using some of the questions that presented 5 point scales for responses. Using the items from questions 7 and 8 in the Informal Caregivers survey, dealing with difficulties experienced and sources of concern, the results from a factor analysis yielded three factors for the general population and four for the reservation sample. Additionally, the items related to independent factors were different for the two populations. Similar results were obtained using item 30 related to the types of services provided. In this case, the same number of dimensions was present, but the content of each dimension was different. Similar results were

obtained from the Grandparent Survey using items 13 and 14. In this case, the general population produced 7 factors or dimensions while the reservation sample produced 5 and once again, the distribution of items to factors differed. While the results of these factor analyses may be a foundation for later exploration of this data, they are useful in this context to document the underlying theme that differences do exist between the social world found on the reservations and those found in North Dakota's towns and cities.

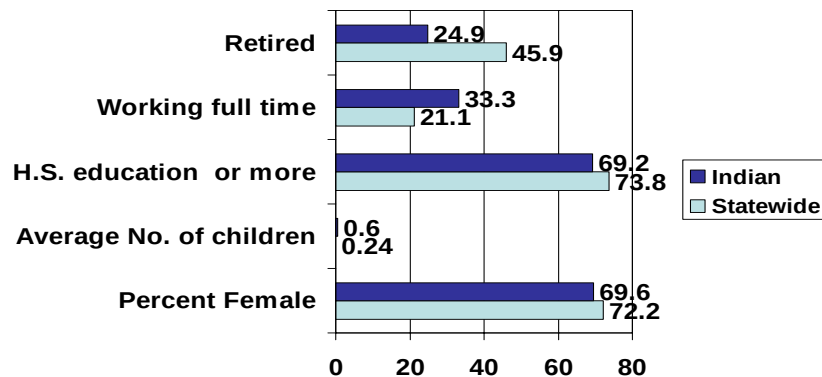
2. Are there differences of note between the five reservations?

Here the answer is no – there were no statistically significant differences observed on a large number of comparisons. Scales developed on the amount of difficulty experienced and the amount of concerns people expressed regarding personal implications of becoming a caregiver were contrasted using analysis of variance. The result produced no differences. The meaning attached to this absence of differences is that tribes should feel free to use the results of the expanded data base as representative of their situations. When small populations yield small samples, it is often difficult to make detailed comparisons or conduct some types of analyses. Solutions to this seek methods of expanding the data base to include a larger number of respondents either through combining data from repeated points in time or expanding a geographic area. Using the combined file is consistent with the latter and justified by the evidence.

INFORMAL CAREGIVERS

Informal caregivers include those persons providing care on a long term basis to a person or persons over age 60 as a volunteer. The following contains a series of descriptive findings from the surveys conducted the North Dakota American Indian reservations. Comparisons are drawn between the American Indian sample and the statewide general population, using the statewide sample as a benchmark for purposes of interpretation. A detailed comparison table is included in the appendix that contains comparisons for each question on the survey that provided useable information.

Figure 1
THE CAREGIVERS

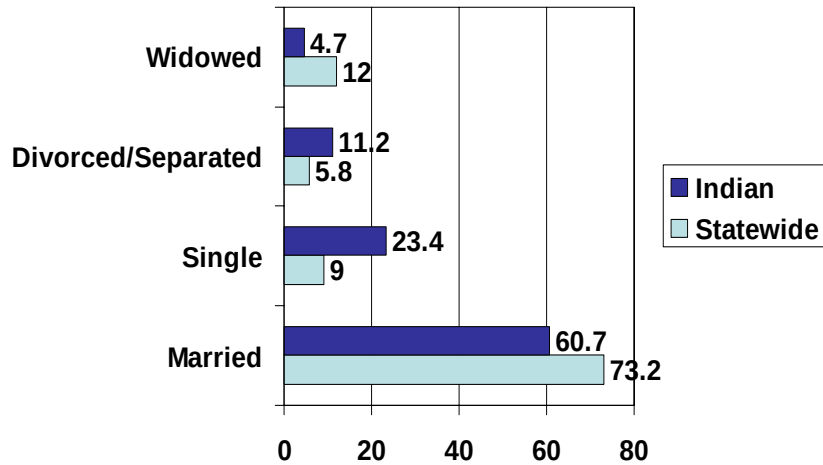


Caregivers among the American Indian population on North Dakota reservations are more likely to be working full-time and less likely to be retired than the North Dakota general population. Similar data for the nation suggests that North Dakota caregivers, both Indian and non-Indian are less likely to be working and more likely to be retired. Nationally, according to the Pandya and Coleman (2000), 52% of the caregivers work full time and 16% are retired.

American Indian caregivers in North Dakota are quite similar to the general population with respect to gender and education and are more likely to have children in the household. Also, according to the Family Caregiver Alliance the proportion of caregivers who are female nationally is 73% - quite close to the proportions reported for North Dakota Indian and non-Indian caregivers in North Dakota. (Pandya and Coleman, 2000) North Dakota American Indian informal caregivers are also less likely to be widowed or married and more likely to be single or separated than the general population. Marital status relates to the existence of in household support for the caregiver and the presence of multiple caregivers under one roof. The task is simply more likely to fall on one individual among the American Indian caregivers. It is also of note that both the general population and American Indian caregivers were more likely to be married than was found in a Robert Wood Johnson study of informal caregivers for the nation. (FACCT, 2001).

Both the North Dakota general population and the American Indian respondents reported educational levels that were lower than the nation. Nationally, the Robert Wood Johnson survey reported 30% with high school or less, while in North Dakota both samples reported above 50% of caregivers with high school or less.

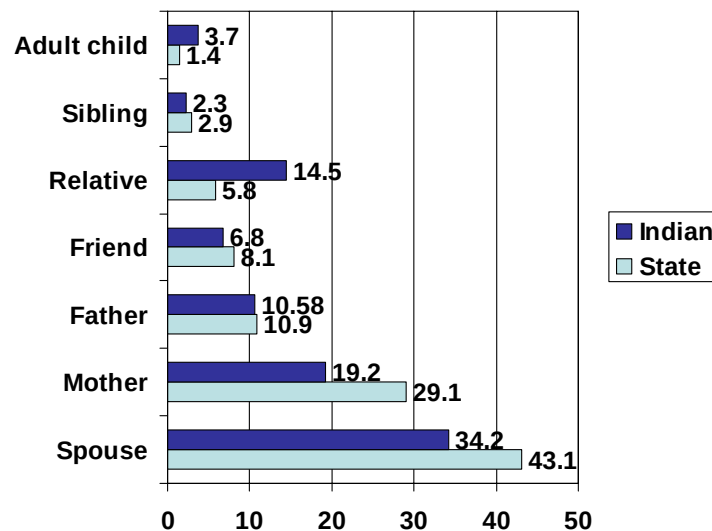
Figure 1
CAREGIVERS: CONT.



The recipients of care also present difference in terms of the profiles. All informal caregivers are most likely to provide care to spouses and mothers, but the proportions for each of these are less among the American Indian sample and the presence of caregiving for other relatives such as aunts and uncles is greater for the American Indian respondents. (See figure 2) Spousal care appears to be higher than found nationally by the National Alliance for Caregiving (Wagner, 1997) although they used recipients over age 50 while this study employed age 60 as the target age for recipients. According to this national data, mothers were the highest in terms of receiving care nationally. The portrait of caregivers produced by the Robert Wood Johnson Foundation also found a majority of care being provided by children of the recipient, again leaving the age of recipients open to all ages. (FAACT, 2001) Nonetheless, our data lead to a suggestion that North Dakota caregivers and the state's American Indian informal caregivers for

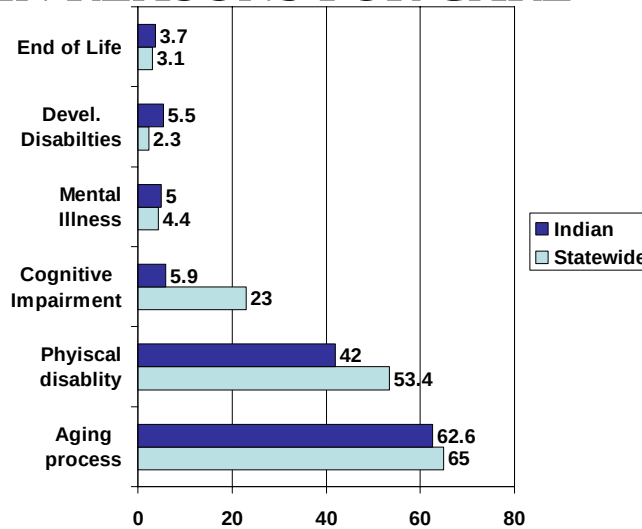
the elderly are more likely to be dependent on spouses, with the Indian caregivers slightly less likely to depend on spouses than the general population.

Figure 2
CAREGIVER RECIPIENTS



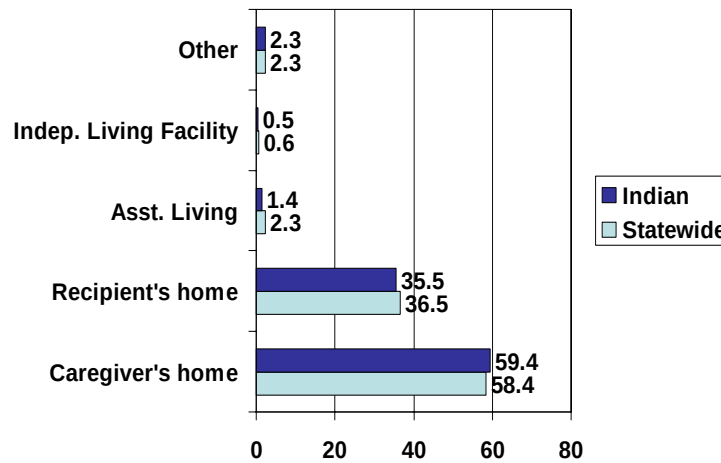
Numerous reasons for informal care are given by the respondents, with the most common reasons being a general aging process, physical disability and cognitive impairment. It is of note that cognitive impairment is reported less frequently among the American Indian respondents than for the general population. This is probably a function of the differences in age structure, as the American Indian elders are clustered in the relatively young cohorts, with few in the 80's or at an age where the risk of Alzheimer's disease increases dramatically. Developmental disabilities are slightly higher among the American Indian respondents and end of life issues and mental illness are quite similar in the two populations.

Figure 3
MAIN REASONS FOR CARE



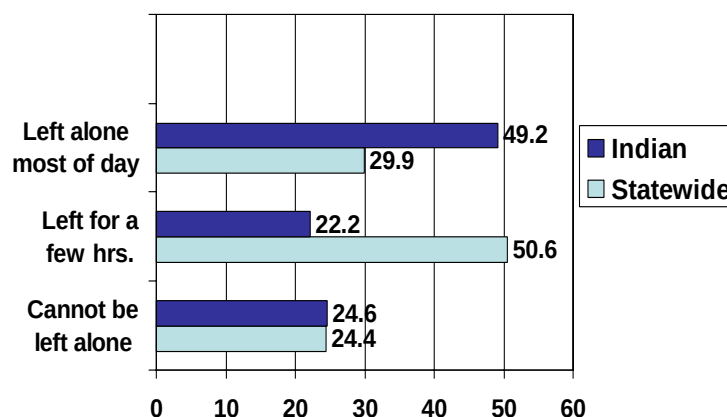
As evident in figure 4, most care is provided either in the caregiver's home or the home of the recipient. Taking an elder into one's home in order to provide the necessary care is the most common practice among all respondents, with few differences. This is a reversal from the data reported by the National Alliance for Caregiving. (Wagner 1997) According to their data reflecting a broader population of recipients, the most common location is in the independent home of the recipient. In North Dakota, for elders, it appears that the more common practice is to bring the recipient into the caregiver's home as the place for providing care. This is true for both Indian and non-Indian populations in the state.

Figure 4
LOCATION OF CARE



The amount of care required was indicated by the amount of time the recipient could be left alone. The proportion that could not be left alone at all was uniform at about 24%, but the proportion that could be left alone for most of the day was much higher for the American Indian respondents. This observation suggests again that the relative youth of the American Indian elders also brings disabilities that are not as severe as those found in the older general population. These results are interpreted as a function of age and can be expected to change with improved survival rates among the American Indian elders.

Figure 5
AMOUNT OF CARE REQUIRED



Length of Caregiving Experience

A smaller proportion of the informal caregivers on the reservations have been caregivers for less than a year (9.3% vs 22%) than the general population and they were more likely to spend over 20 hours a week caregiving (28.6% vs 18.3%). These two indicators suggest that the time committed to informal caregiving is indeed greater among the reservation caregivers even though their recipients could be left alone for greater lengths of time.

Difficulties Resulting from Caregiving

The potential for strain in providing informal care is always present, but many studies tend to document the possibilities for strain rather than measuring actual experiences of difficulty. An example of this is found in the National Institute of Medicine book on improving long term care. They describe a range of activities, many of which contain low stress, but emphasize that caring for a person with severe impairments can drastically alter a persons life and cause considerable stress. (National Institute of Medicine, 2001) In this study, difficulties

potentially resulting from caregiving were measured using a five point scale reflecting the seriousness of each listed difficulty for the respondent with a score of 5 indicate very serious difficulties. The results are listed in table 1. All items produced very low scores for difficulty, with none of the scores for either the reservation sample or the statewide general population reaching the neutral midpoint score of 3. All scores are also substantially lower among the reservation respondents, suggesting that they experience informal caregiving with less difficulty than their counterparts in the general population.

Table 1
DIFFICULTIES EXPERIENCED BY INFORMAL CAREGIVERS

	Statewide General	Reservations
Less time for self	2.67	1.85
Less time for family	2.60	1.65
No consistent help from other family	2.52	1.87
Affects family relationships	1.92	1.52
Conflicts with social life	2.41	1.79
Emotional aspects (anxiety)	2.92	1.95
Less privacy	2.00	1.60
Interferes with job	1.61	1.47
Financial obligations	2.01	1.61
Lifestyle change	2.79	1.91
Having responsibility for decisions	2.64	1.89
Own physical health	1.99	1.49
Unable to sleep	1.92	1.44

A similar set of “concerns” were measured that related more to one’s experience in accepting support services or assistance from others. These items were measured on a scale of 1 (strongly disagree) to 5 strongly agree, indicating the extent to which each respondent experienced each concern. Table 2 presents the results of these items. Again, most of the concerns were rated very low and were somewhat lower among the reservation respondents. Differences tended to be very small.

Table 2
CONCERNS RESULTING FROM CAREGIVING

	Statewide General	Reservations
Difficult to accept support because of a sense of duty	2.35	2.23
Difficult to find support	2.32	1.85
Difficult to accept financial help because of stigma	1.98	1.93
Difficult to accept help because of being a QSP	1.38	1.48
Providing care because others will think ill of me if I don't	1.55	1.69
Experience a sense of isolation	1.88	1.56
Experience a lack of understanding	1.73	1.49

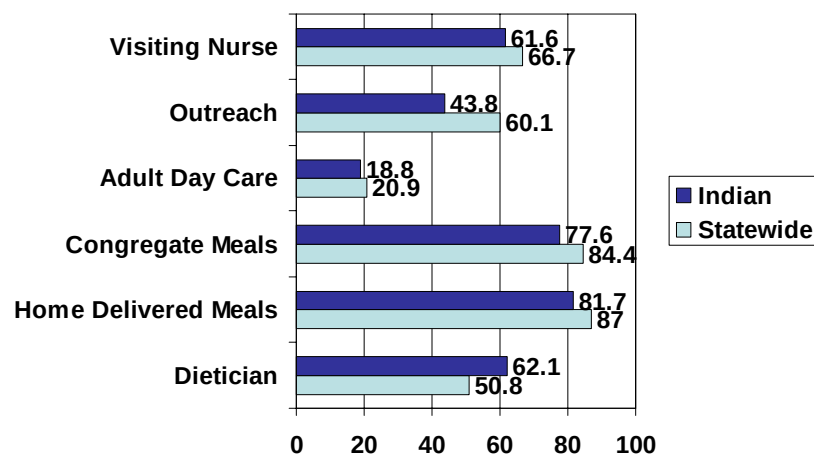
Access to Other Informal Caregivers

A substantial proportion of informal caregivers reported other informal caregivers also providing care. The proportion is lower in the reservation sample with 52% of the statewide general sample reporting other caregivers and 41% among the reservation respondents, which means that the task of providing care is more likely to be one caregiver's burden for those on reservations. The reasons for a lack of others are numerous, with the most common reasons including that others have full time job commitments, less flexible schedules and have young dependents. Distance is also an issue for many as is a lack of other immediate family. The most important aspect of this observation, however, is that the burden of care tends to fall on a single person, making support services even more critical.

Availability of Services

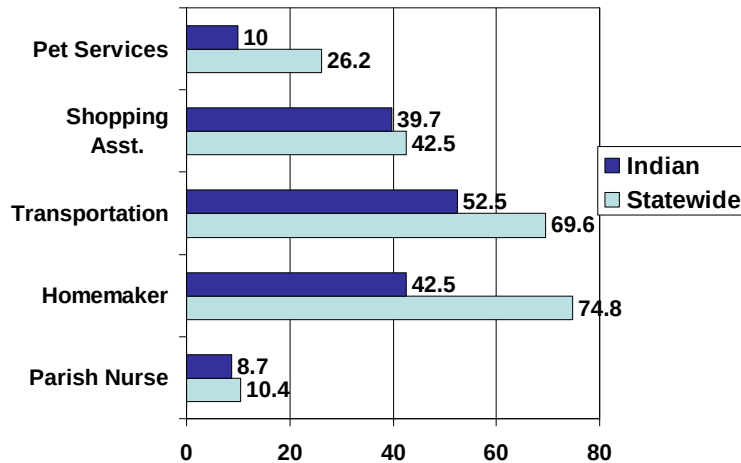
The availability of services is not uniform. Most services are less often available to reservation elders as shown in figure 6. An exception is with the services of dieticians, reflecting a response to the need to manage diabetes among American Indians.

Figure 6
AVAILABILITY:
SERVICES FOR RECIPIENT



The list of services continues for figure 6, continuing to illustrate the case that services are less accessible for the state's American Indian elders living on reservations. In the case of transportation and homemaker services, the disparities are quite large. Pet services, while also less available are considered relatively low in the hierarchy of needs with respect to the array of services. It is, however, clear that the availability of services for reservations in North Dakota remain in need of development.

Figure 6 cont.
 AVAILABILITY:
 SERVICES FOR RECIPIENT cont.



Service Wants

Which of these services are most desired by informal caregivers? The respondents were asked for each service that was not recognized by the respondent as available whether they would like to have the service. Table 3 contains the top six desires for services among those lacking access. The lists are quite similar, with one item different on each column. The order of priority placed visiting nurses and homemaker services as the top two for both the general sample and for the American Indian caregivers. The list suggested similar priorities in terms of the need for new programs.

Table 3
SERVICE WANTS FOR ELDERS AMONG THOSE LACKING THEM

Statewide General	Reservations
Outreach	Visiting nurse
Visiting nurse	Homemaker
Day centers	Outreach
Homemaker	Transportation
Transportation	Congregate meals
Congregate meals	Shopping asst.

Use Rates for Services

Use rates indicate the receptivity to services likely to be experienced when services are made available. It is not automatic that services, once created, will be fully utilized. Table 4 contains the results of a question reflecting use of services for services presently available to over 50% of the informal caregivers for American Indian elders in North Dakota. The Indian elders used available services at a higher rate than the general population for all services and the differences are dramatic. It is clear that receptivity to services is stronger among the state's Indian caregivers, with the implication that a ready clientele awaits the development of these services.

Table 4
USE RATES FOR AVAILABLE SERVICES

	Statewide	Reservations
Dietician	37.7%	61.3%
Home Delivered Meals	54.1%	63.1%
Congregate Meals	38.6%	42.5%
Visiting Nurse	54.0%	69.5%
Homemaker Services	39.7%	42.3%
Transportation	32.8%	51.5%

Quality Ratings of Services

Each of the services received were rated by the respondents on a scale of 1 to 5 with a score of 5 representing “very good”. Some services were available to such a small number of respondents that a meaningful average could not be computed. These were listed as NA or not available. All ratings produced very high scores, suggesting that the quality of existing services was high. (See Table 5) The scores were also quite close between the reservation samples and the statewide general population. Only transportation produced a large difference with the reservation sample much less pleased with the quality of transportation services. The statewide general population scored nearly all services slightly higher than the American Indian caregivers from the reservations. It would appear that the greater availability of services in non-Indian communities also produced a higher quality score.

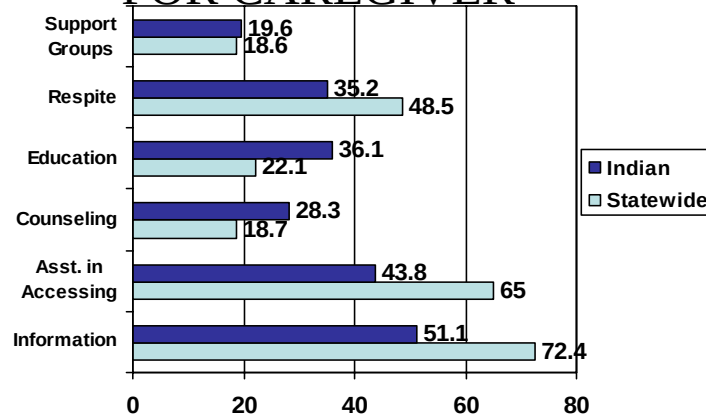
Table 5
RATINGS OF SERVICES

	Statewide	Reservations
Dietitian	3.96	3.85
Home delivered meals	4.24	3.93
Congregate meals	4.42	4.05
Day centers	3.95	NA
Outreach Programs	4.41	4.04
Parish nurse	NA	NA
Homemaker services	4.20	4.24
Transportation	4.36	3.47
Shopping assistance	4.22	4.12
Pet services	NA	NA

Availability of Caregiver Support Services

Support services targeting direct support of the informal caregiver are available at different rates for the general and reservation caregivers. Reservation respondents reported less access to respite care, less assistance in accessing care and less information about services. They reported more counseling, education and about the same access to support groups. (See Figure 7)

Figure 7
**AVAILABILITY OF SERVICES
 FOR CAREGIVER**



Which of the services not available do the respondents give priority? Again, each service not available was measured in terms of the respondents desire to have it become locally available. Table 6 contains the results, listing each service and the proportion of those lacking access who expressed a desire to have it available. The priorities differ between the general population and the reservation respondents, with reservations placing support groups as their lowest service want, while the statewide general population expressed their lowest support for counseling. A direct comparison of the proportions expressing a desire for services produces uneven differences. The reservation respondents were highest on information about services, caregiver education, assistance with accessing services and counseling. The general population was highest on respite care and support groups, but the margin of differences for these was small. Overall, the reservations again appeared the most interested in service development.

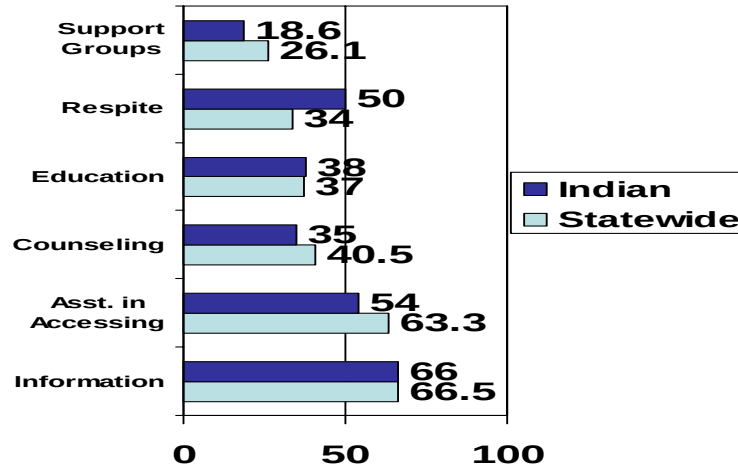
Table 6
SERVICE WANTS AMONG THOSE LACKING CURRENT ACCESS

	Statewide	Reservations
Information about services	68.5	68.2
Assistance in accessing services	48.4	55.6
Caregiver counseling	30.1	39.2
Training or education	33.7	65.5
Respite care	51.1	46.0
Support groups	38.2	37.9

Use of Caregiver Services

The use of caregiver services by North Dakota caregivers is low for both the general population and reservation caregivers. Part of the reluctance to use services may stem from the lack of access historically found in the state. Service availability rarely exceeded 50% and then only for the general population for assistance in accessing services and information. The lack of access is reflected in Figure 8 where only assistance in accessing services and information are used when available at a rate of greater than 50%. While the promise of such support services for postponing institutional care may be recognized, the actual use of such services remains low. The differences are not great for the use of services and only the use of respite care stands out with a difference, but this is based on a very small number who reported access to this service.

Figure 8
USE OF AVAILABLE SERVICES
BY CAREGIVERS



Quality Ratings for Services for Caregivers

Services directed specifically to caregivers were also rated on a 5 point scale with a score of 5 representing “very good”. All ratings were well above the neutral point of 3, but nearly all ratings were also lower among the reservation respondents than the statewide general population. Caregiver support groups were not sufficiently available to the reservations to justify computing an average score. One might conclude from this data in table 7 that while services are doing well, there is greater room for improvement on the reservations.

Table 7
RATINGS OF SERVICES FOR CAREGIVERS

	Statewide	Reservation
Information about services	4.15	3.79
Assistance in accessing services	4.24	3.82
Counseling	4.33	4.03
Caregiver education	4.16	3.97
Respite care	4.35	4.14
Support groups	3.76	NA

Services Provided by Caregivers

In order to characterize the range of services provided by informal caregivers, respondents who provided a service at least monthly were considered as providing the service. Occasional service and never were combined into the negative response with the data in table 8 resulting. It is evident that the majority of caregivers in each group are providing a wide range of services and that improved assistance is in need. Reservation respondents reported that they were more likely to provide transportation services and were more likely to want assistance with providing those services. In most service categories, the reservation respondents reported slightly fewer providing the service and fewer who wanted assistance in providing the service. A close inspection of table 5 will permit one to determine which services were the most frequently provided and which resulted in the highest expression of interest in obtaining help. Again, all services were provided at very high rates. The statewide general population averaged 9.6 services per caregiver, while the reservation sample averaged 8.6 services per caregiver. Both of these represent a large number of services that are provided by the voluntary contributions of informal caregivers.

Table 8
SERVICES PROVIDED AND DESIRE FOR ASSISTANCE:
STATEWIDE AND RESERVATION POPULATIONS

	Statewide		Reservation	
	Percent providing	Percent wanting help	Percent providing	Percent wanting help
Manage finances	74.1%	7.2%	63.4%	10.8%
Contribute finance	52.3%	22.0%	48.9%	16.4%
Personal care	62.9%	31.0%	48.5%	19.4%
Household tasks	81.6%	35.3%	78.2%	22.4%
Maintenance	54.1%	37.9%	42.7%	27.8%
Meals/nutrition	79.0%	30.2%	79.4%	15.9%
Errands/shopping	89.4%	26.0%	81.8%	23.4%
Companionship	96.0%	35.0%	90.8%	15.0%
Phone contact	82.1%	21.7%	69.4%	14.7%
Emotional support	76.3%	27.3%	62.1%	17.4%
Listening	99.8%	35.5%	92.0%	17.1%
Transportation	76.4%	32.3%	80.8%	24.5%
Assist with medicine	71.3%	19.5%	64.9%	18.3%
Communicate with medical providers	55.0%	14.4%	53.0%	18.5%
Get family involved	33.5%	20.0%	38.9%	19.9%
Legal assistance	17.3%	18.5%	17.3%	14.4%

Valued Information

Each respondent was asked to indicate the types of information they would find valuable as informal caregivers. The results are presented in table 9, which compares the reservation responses to the state. Generally, the reservation respondents produced lower proportions indicating a sense of value for the types of information listed. While this may give the appearance of people who demand or expect less, it may be a reflection of the scarcity they now experience with respect to services. Information is of less importance than actually having access to services.

Table 9
INFORMATION CONSIDERED VALUABLE

	Statewide	Reservations
About Conditions	38.2%	32.9%
End of Life	27.0%	20.1%
Legal Challenges	37.6%	15.1%
Info-Line access	36.8%	18.3%
Someone to arrange services	29.1%	16.4%
Counseling/support group	29.1%	22.4%
Respite/Day care	39.1%	19.6%
Grief counseling	15.5%	12.8%
Hotline for emotional needs	14.4%	10.5%
Nursing home selection advice	22.3%	11.0%
Help with nursing home placement	23.8%	10.0%
Understanding payment for nursing care	31.3%	11.4%
Help dealing with agencies	31.0%	19.2%
Financial support	31.7%	19.6%
Tax breaks, subsidies	27.5%	11.9%

Impacts of Caregiving

The range of potential impacts informal caregivers may experience covers residential location and work issues. The actual impacts are numerous and as evident in table 10 are somewhat less consequential among reservation respondents. Part of this may be attributed to the level of care required. As indicated earlier, the statewide general population was more likely to require care that prohibited the caregiver from leaving them alone. The observation most likely results from the relative age of recipients in the general population where higher percentages of very old exist. The care requirements of the frail old are simply more intense and this is reflected in the impacts. One might also suggest that the pattern presented for the statewide impacts represents the future for the state's Indian population as they continue to live

longer but with more chronic disease. This may also account for the differences observed in the number of tasks or services provided by informal caregivers.

Informal adjustments in the workplace were much less in this survey than found by a national survey conducted by Metropolitan Life and reported by the AARP where over 66% of caregivers reported taking time off and arriving late or leaving early to manage caregiving responsibilities. (Pandya and Coleman, 2000) The Metropolitan Life analysis was of a subset of employed caregivers, and leads to a suggestion that our data may understate workplace impacts as an adjustment because they effect only part of the caregiving population.

Table 10
IMPACTS OF INFORMAL CAREGIVING

	Statewide	Reservations
Changed location	15.2%	9.6%
Sold home/moved in with recipient	4.0%	1.4%
Stopped working	7.2%	8.7%
Retired early	6.4%	2.3%
Took less demanding job	3.1%	2.7%
Changed to part-time work	4.9%	2.7%
Reduced official work hours	5.7%	4.6%
Lost fringe benefits	3.5%	4.1%
Time conflicts: work/caregiving	14.7%	11.9%
Used vacation	14.0%	13.2%
Took leave of absence	3.8%	7.3%
Lost promotion	.5%	1.4%
Left work early or arrived late	17.2%	13.7%

Grandparent Caregivers

Grandparent caregivers are defined as either grandparents or older relatives who live with a dependent child and provide care as the primary caregiver. They may have legal custody, but this is not a requirement. It is important to note in these instances that the focus on the elder is not as a recipient of care, but as a provider and the service needs of older providers of care to children is the focus. The descriptive results of this survey are found in detail in a comparison sheet in appendix D. While grandparents or elders caring for children is part of the family caregiver program, far less study has been undertaken of this category of caregivers. This may be due to the focus on long term elderly care issues that tends to drive public interest in informal caregiving.

In addition to the observation regarding the higher rate of grandparent caregiving in American Indian communities, the numbers of children per caregiver is substantially higher. The average number of children per caregiver in the statewide general population was 1.09 while the average for American Indian grandparent caregivers on reservations was 1.62. This is a large difference. As a consequence of the large numbers of children, a question regarding the length of caregiving experience failed to work with the American Indian sample. The question produced a string of responses each representing a different child and rendered the appearance of considerable length of caregiving spread over multiple children.

Reasons for Caregiving

Thirteen reasons for grandparents providing care to their grandchildren were provided in the questions along with an open ended “other” response. The detailed responses for these are contained in appendix D. The top reasons for providing care as shown in table 11, found that the reservation respondents presented three issues that were on the statewide list and two that were

different. Substance abuse led the list for both, but a lack of maturity and emotional issues were not found in the top five for reservation respondents. The difference in terms of percentages was large, with the general population much more focused on these issues. The lack of involvement on the part of parents appeared to be a greater issue for the reservation respondents. The reader is invited to examine the data in appendix D for greater detail on these items. Respondents reported multiple reasons for caregiving, and this set of questions aids one in identifying the most common reasons as well as allowing us to compare reservation responses on each item with the statewide general population.

Table 11
TOP FIVE REASONS FOR GRANDPARENT CAREGIVING

Statewide	Reservations
Substance abuse	Substance abuse
Lack of maturity	Lack of parenting skills
Emotional issues	Parent doesn't want to be bothered
Lack of parenting skills	Parent never involved
Parents can't afford	Parents can't afford

Given the most common reasons that leading to grandparents undertaking the care of their grandchildren, the relationship with the child's parent may be an important consideration. Parents who have relinquished involvement with their children may also have relationship difficulties with the grandparent. Indeed, a statistically significant relationship occurs with parents who have never been involved or do not want to be bothered with the care of their children having substantially higher stressed relationships with the grandparent caregiver and much higher rates of completely severed relationships. This observation is very important in that it suggests a need to identify creative ways to engage the parents of children in positive relationships with both their children and their child's caregiver.

Monetary and Non-monetary Support

Monetary support directed to the children in the care of grandparents is rare for both the general population and the reservations with approximately 60% reporting no sources of financial support given to the child. Monetary support directed to the caregiver was also present in a minority of cases for both samples, but was somewhat more common among the reservation respondents, especially with foster care support.

Non-monetary supports including WIC, school lunch programs, other food programs, medical assistance, TANF, housing assistance, and fuel assistance were all present at higher levels for the reservation grandparents, but only school lunch programs exceeded 50%.

Overall, the impression obtained from these data suggest that a substantial effort is undertaken on the part of reservation grandparent caregivers without extensive support. It is also of note that a large proportion of the caregivers indicated in their “other” reasons for giving care were founded in their love for their grandchildren. This love translates into expenses and may create barriers to seeking assistance.

Special Needs in Children

The survey instrument contained a question soliciting reports of ten special needs children might present. Table 12 presents the main special needs reported by the respondents and greater detail can be found in the appendix. Emotional issues, learning disabilities and hyperactivity lead the list for both the statewide general population and the reservations. The rates at which these special needs are present are not the same and 65% of the reservation caregivers reported “none” as compared to 55% in the statewide general population. Caution should be exercised regarding any interpretation of this finding as the special needs result from

diagnosis and mental health diagnoses may not be uniformly accessible. If this is the case, the data may understate the true level of special needs for the relatively isolated reservations.

Table 12
MAIN SPECIAL NEEDS PRESENT IN CHILDREN

Statewide	Reservations
Emotional issues (18.9%)	Emotional issues (13.5%)
Learning disabilities (15.1%)	Learning disabilities (9.9%)
Hyperactivity disorder (11.3%)	Hyperactivity disorder (12.8%)
Physical disabilities (7.5%)	Fetal alcohol (6.6%)
Mental health issues (7.5%)	Substance abuse (5.1%)
Fetal alcohol (4.7%)	

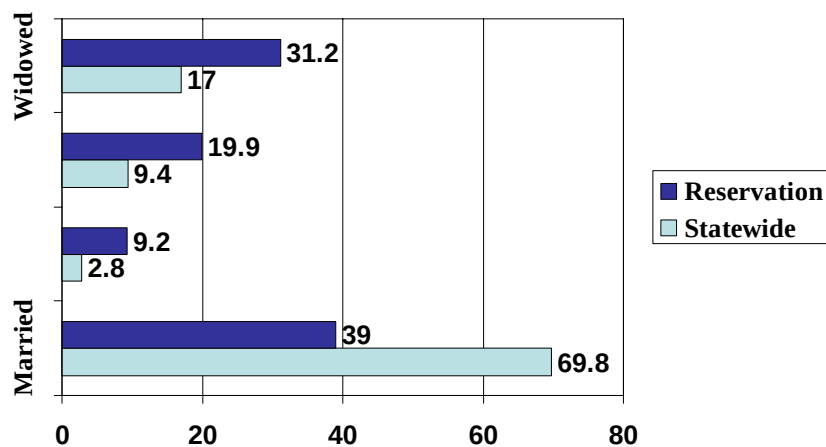
The amount of care required was measured in terms of whether the child could be left overnight, most of the day, part of the day or not at all. Approximately 43% require 24 hour supervision in both the reservation and general samples. Fewer of the reservation caregivers indicated that they could leave the child overnight (9.9% vs 21.7%), perhaps reflecting the large numbers of young children.

Caregiver Characteristics

Grandparent caregivers tended to be young in both samples, with the reservation sample being somewhat younger and included very few over 75 years of age (1.4% vs 10.4%). Marital status of the grandparent caregivers helps to define the household characteristic and the extent of support normally associated with one's spouse. Marital status did differ between the statewide general population and the reservation sample as shown in figure 9. Substantially fewer grandparent caregivers on the reservations were married, with more in each category of the unmarried. The implications of this are substantial. Not only would one expect married

caregivers to have greater supports from their spouse, but normally incomes and living conditions improve among the married.

Figure 9
Marital Status of Grandparents

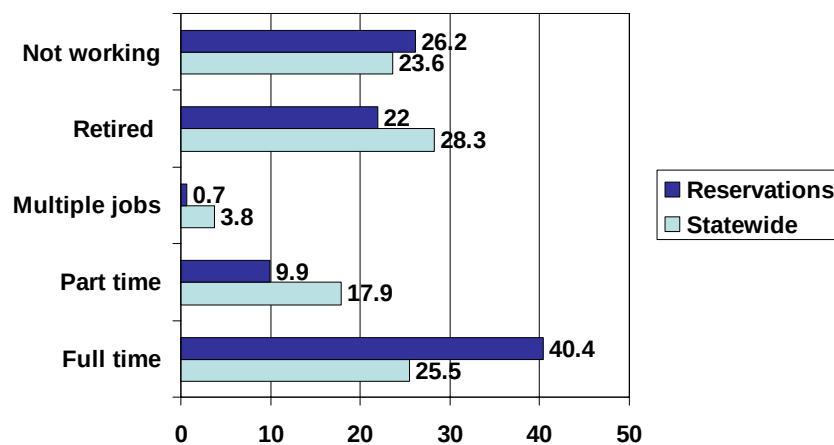


Grandparent caregivers occasionally also have other children in their household in addition to the grandchildren. Once again, the average number for these children is higher for the reservation respondents as they reported an average of .6 additional children as compared with .29 children in the general population.

Educational levels for grandparent caregivers were very similar in the two samples, with slightly fewer of the reservation caregivers having less than high school education (21.7% vs 17.7%). More of the general population reported high school educations while a slightly higher proportion of the reservation sample reported education beyond high school. There is a substantial distribution over a large range in both populations and one should not assume high educational levels as the norm in either.

Employment status of the grandparent caregivers corresponds to the relative ages. More of the reservation caregivers are working full time suggesting that it is normal to be a working grandparent caregiver, especially for reservation respondents. Respondents in the statewide general sample are more likely to be retired, reflecting their relative age, but also suggests that there may be greater age gaps between children and grandparent. Reservation residents were less likely to report part-time work or multiple jobs, which may be a function of local economies, but does present an impact on coordinating care and work.

Figure 10
Employment Status of Grandparents



Income levels were low in both samples and were lowest for the reservation respondents. Among the statewide general sample 37.8% had incomes under \$20,000. This rose to 56.8% for the reservation sample and creates a financial context for providing care that is very austere. If one considers the low level of financial and non-financial support reported earlier, a need clearly exists to ensure that the lower income families gain access to available supports. Significantly more programs are accessed by those with annual incomes under \$20,000 than by those with

higher incomes (3.8 vs 2.5 services accessed), but the overall number of supports accessed remains low.

Caregiver Difficulties

Two sets of questions were asked in the survey about difficulties caregivers may have experienced. The first set of items focused on personal issues such as time conflicts, emotions and such while the second set of items attended to situational aspects that were cause for concern such as being unable to find or accept support or consequences of being paid. There is not a clear division between the two sets, but rather some subtle differences. The first set of items were measured using a five point scale rating seriousness of the difficulty to the respondent with a score of 1 reflecting “not at all serious” and a score of 5 reflecting “very serious”. Table 13 presents the mean score for each item in this difficulty measure. It should be observed that all items present average scores that are very low, suggesting that difficulties in being a caregiver tend to be low. These items did form a reliable scale of difficulty ($\text{Alpha}=.92$) and while the difficulty level for the reservation respondents was lower than that of the general population, both were very low (1.85 and 2.12 respectively).

Table 13
DIFFICULTIES EXPERIENCED BY GRANDPARENT CAREGIVERS

	Statewide	Reservations
Less time for self	2.46	2.14
Less time for family	2.19	1.86
No consistent help from family	2.13	1.99
Affects my family relationships	1.76	1.82
Conflicts with my social life	2.13	1.89
Emotional aspects – frustration	2.51	1.91
Less privacy	2.32	1.94
Interferes with job	1.67	1.62
Financial burden	2.40	2.13
Responsibility for major decisions	2.11	1.75
Deteriorating physical health	1.71	1.40
Unable to sleep due to caregiving	1.67	1.47
Feel more tied down	2.35	1.91
Difficulty providing discipline	1.70	2.02
Feel like I’m back at the beginning	2.29	2.31

The second measure focusing on concerns of a situational nature also used a 5 point scale ranging from (1) strongly disagree to (5) strongly agree. Thus a high score would indicate a problem. As was the case with the previous measure, all scores are presented in table 14 and are at the low end of the scale, suggesting that the concerns listed are not great among either the statewide or reservation grandparent caregivers. These items also formed a reliable scale (Alpha = .891) and can be used to create an overall concern measure. The scale did not produce significant differences and both the statewide general population and the reservation respondents produced very low scores (1.79 and 1.82 respectively). It does not appear that providing care to a grandchild produces awkward circumstances for the caregiver and that any sensitivity over being a grandparent caregiver is relatively minor.

Table 14
CONCERNS OF GRANDPARENT CAREGIVERS

	Statewide	Reservations
Difficult to accept support – duty	2.28	2.11
Difficult to find support	2.16	2.04
Difficult to accept support because of negative stigma	1.83	1.92
Difficult to accept financial support because grandchild fears peer’s response	1.57	1.69
Difficult to accept support because of being paid	1.41	1.61
Providing care because of community pressure	1.44	1.83
Experience of isolation	1.59	1.69
Lack of community understanding	1.89	1.50
Friends back off because of caregiving	1.71	1.68
Concerns about losing custody	1.58	1.82
Anger toward parents of child	1.90	2.00
Guilt over feelings of resentment	1.89	1.96
Cannot provide cross cultural education for mixed racial child	1.33	1.52
Other family members are jealous of the care given	2.06	1.96

Family Supports

The presence of family supports has been alluded to in the discussion of caregiver characteristics. Having other members of the family assisting with providing care contributes both to reducing one’s personal load and to providing moral support. The extent of family support from within the household is less for reservation respondents than the general population. Lower levels of support within the household for reservation caregivers is consistent with the relatively high proportions of single, divorced and widowed caregivers on the reservations. Less than half (44.7%) of the reservation respondents reported the presence of other caregivers in the household, while 67% of the statewide general population reported having other family members within the household assisting with care.

The same pattern prevails for securing support from other family members outside the household with 31.2% of the reservation respondents reporting support from other family outside the household while 43.4% of the statewide general population reported such assistance. It is important to note that when the combined presence of family support from both within and outside of the household was examined, only 36% of the reservation households had support. While this may appear at odds with the cultural norm of extended family responsibility, it may be a response on the part of other family members that simply fails to recognize that providing care for children consumes a great deal of time and energy and assumes all is well.

Reasons for not having others involved in providing care to the children differed between the statewide general population and the reservation respondents. (See table 15) The list of reasons characterized the rationale for excusing others from coming forward to help. In this sense, they employ a model that places responsibility on the individual. These responses systematically produced smaller proportions among the reservation respondents. They were evidently less willing to pass the blame for a lack of support to their family. Rather, they responded more frequently that this simply did not apply to their situation. Distance and work related factors appear less influential among the reservation respondents.

Table 15
REASONS THAT OTHERS DON'T PROVIDE CARE

	Statewide	Reservation
No other immediate family	43.4%	31.2%
Others also need care	14.1%	7.8%
Others too embarrassed with tasks	.9%	0.0%
Others too inexperienced	.9%	.7%
Others live further away	32.1%	12.1%
Others have full time jobs	34.0%	22.0%
Others have less flexibility	17.9%	12.1%
Others have young dependents	25.5%	16.3%
Others don't get along with child		0.7%
Others not aware of need	6.6%	2.1%
Others unwilling or can't	17.9%	17.0%
Recipient doesn't want others	1.9%	1.4%
Care would cause conflict in family	2.8%	3.5%
Others would provide if needed	18.9%	5.7%
Does not apply to my situation	17.9%	28.4%

Services for the Child

When asked whether they had access to services for the dependent child, the reservations respondents reported systematically less access to services. Most services were oriented toward education including counseling, tutoring, school lunch, scholarships, special education, extracurricular activities and role models. All of these were less available to the grandchildren under the care of grandparents on the reservations. Medical assistance was slightly higher. It may be wise to emphasize the importance of these educational services for grandchildren in this arrangement for care. One might assume that extra supportive efforts take on increased significance when the parent is not the primary caregiver. Children need love, attention and

validation and in the absence of parents, this need must be filled by others, including educational services.

Table 16
SERVICE AVAILABILITY: PROPORTIONS WITH ACCESS

	Statewide	Reservation
Counseling	66.0%	41.1%
Tutoring	54.7%	44.7%
School lunch	85.8%	80.1%
Scholarships	27.4%	12.1%
Special Education	72.6%	53.9%
Extracurricular	78.3%	70.2%
Role model/mentor	40.6%	24.8%
Medical asst.	72.6%	79.4%

The proportion of those who presently lack each service, but would like to have it available is presented in table 17. Among those lacking each service, the relative desire to have them available appears mixed and is stronger for the reservation population for tutoring, scholarships and role models/mentors. It is important, however, to note that significant proportions (for both samples) expressed a desire for services in all cases.

Table 17
PROPORTIONS WITHOUT ACCESS WHO WOULD LIKE SERVICES AVAILABLE

	Statewide	Reservation
Counseling	44.1%	36.8%
Tutoring	36.6%	56.1%
School lunch	30.0%	14.3%
Scholarships	66.1%	75.8%
Special Education	33.3%	22.0%
Extracurricular	42.9%	30.8%
Role model/mentor	52.8%	62.2%
Medical asst.	46.2%	42.9%

The use of services that are available once again is very high among reservation respondents.

Table 18 contains the results of the questions regarding the use of available services and it is clearly evident that services made available to the reservation grandparent caregivers' children are used extensively.

Table 18
PROPORTIONS USING AVAILABLE SERVICES

	Statewide	Reservation
Counseling	51.5%	50.9%
Tutoring	46.3%	75.0%
School lunch	75.6%	100.0%
Scholarships	35.7%	58.8%
Special Education	32.4%	45.1%
Extracurricular	69.9%	81.9%
Role model/mentor	52.5%	76.5%
Medical asst.	68.5%	94.5%

The service wants for their grandchildren are high across both samples and tend to focus on academic supports and character building programs. Table 19 contains the results of the responses regarding which services were desired. Over half of the respondents in both samples expressed a desire for scholarship support and role model/mentoring programs. Over half of the reservation respondents also expressed a desire for tutoring. This is a strong expression of family support for education among grandparent caregivers, suggesting that this critical element for success is in place and that such programs would indeed pay dividends. Grandparents with caregiving responsibilities for both samples appear to present a good foundation for educational support programs.

Table 19
CHILD SERVICE WANTS: GRANDPARENT CAREGIVERS

	Statewide	Reservation
Counseling	44.1%	36.8%
Tutoring	36.6%	56.1%
School lunch	30.0%	14.3%
Scholarships	66.1%	75.8%
Special Education	33.3%	22.0%
Extracurricular	42.9%	30.8%
Role model/mentor	52.8%	62.2%
Medical asst.	46.2%	42.9%

When those reporting access to each service were asked to rate the service on a scale of 1 to 5 with a score of 5 reflecting “very good”, the ratings were uniformly high. In this distribution, a 3 would be considered neutral and all scores were well above the neutral point. (See table 20)

Reservation respondents were slightly lower in their support for most services.

Table 20
RATINGS OF SERVICES FOR CHILDREN

	Statewide	Reservations
Counseling	3.82	3.48
Tutoring	4.00	3.56
School lunch	4.04	4.10
Scholarships	4.29	4.45
Special Education	4.09	3.85
Extracurricular	4.08	3.81
Role model/mentor	4.15	3.88
Medical asst.	4.41	3.96

Services for the Caregiver

In addition to examining services that targeted the child, a series of services targeting the grandparent caregiver were investigated following the same pattern of questioning. The list of services is more extensive and includes services directed at the household and the person providing care. Table 21 contains the responses regarding availability. Services for grandparent caregivers are uniformly less available among the reservation caregivers and in some cases the differences are quite dramatic. Many of the services are available at less than half the rate for those found in the statewide general population. These comparisons implicitly argue for a goal of improved equity in providing support services and recognize that geographic and population density factors play a role. Nonetheless, the need is greater on the reservations and the data appear to support a goal of improving access to these services or those ranked as most important.

Table 21
PROPORTION OF GRANDPARENT CAREGIVERS WITH SERVICES AVAILABLE

	Statewide	Reservations
Outreach programs	34.4%	22.7%
Visiting nurse	43.4%	19.9%
Homemaker services/home health aid	37.7%	9.9%
Escort/transportation	46.2%	23.4%
Shopping assistance	25.5%	7.1%
Parish nurses	15.1%	2.1%
Information about services	52.8%	41.8%
Assistance in accessing services	39.6%	27.0%
Individual caregiver counseling	27.4%	11.3%
Caregiver training/education	25.5%	18.4%
Respite care	28.7%	18.4%
Caregiver support group	17.9%	5.7%
Legal assistance	43.4%	24.8%
Technology assistance	36.8%	7.8%
Medicine/prescription delivery	43.4%	20.6%

The desire for services not presently available was not uniformly higher among the reservation respondents; however, the impression derived from table 22 is one of high receptivity to supportive services. While availability was relatively low for the reservation respondents, the interest in having access to the programs not presently available was very high. If one uses the list of services with the highest proportions to establish priorities, (the list for the reservations) would respectively include: assistance in accessing services, caregiver training, information about services, technology assistance and respite care. All the non-available services rated highly in terms of people's desire to have them locally available, suggests that a plan to eventually provide each of them may be in order.

Table 22
PROPORTION OF GRANDPARENT CAREGIVERS WITHOUT SERVICES
WHO EXPRESSED A DESIRE TO HAVE THEM

	Statewide	Reservations
Outreach programs	48.4%	46.7%
Visiting nurse	19.6%	44.4%
Homemaker services/home health aid	22.0%	32.7%
Escort/transportation	25.5%	40.9%
Shopping assistance	16.9%	27.4%
Parish nurses	18.4%	25.6%
Information about services	71.4%	55.9%
Assistance in accessing services	48.1%	56.8%
Individual caregiver counseling	32.3%	34.0%
Caregiver training/education	34.3%	56.3%
Respite care	32.2%	50.0%
Caregiver support group	47.2%	35.1%
Legal assistance	51.9%	33.8%
Technology assistance	42.6%	53.8%
Medicine/prescription delivery	28.3%	31.4%

The use of available services by grandparent caregivers on the reservations was exceptionally high when compared to the statewide general population. The degree of use is presented in table 23 and clearly reflects a high measure of receptivity to services. If one employs use rates as an indicator of popularity for programs, then medicine delivery, visiting nurses, information about services, outreach, respite care, caregiver training or education, and respite care emerge as the most popular.

Table 23
PROPORTION OF GRANDPARENT CAREGIVERS USING AVAILABLE SERVICES

	Statewide	Reservations
Outreach programs	39.4%	78.6%
Visiting nurse	47.6%	79.2%
Homemaker services/home health aid	20.0%	66.7%
Escort/transportation	34.7%	56.3%
Shopping assistance	29.6%	72.7%
Parish nurses	43.8%	60.0%
Information about services	58.2%	78.6%
Assistance in accessing services	61.0%	67.6%
Individual caregiver counseling	33.3%	43.8%
Caregiver training/education	33.3%	76.9%
Respite care	42.5%	77.8%
Caregiver support group	15.8%	40.0%
Legal assistance	36.4%	59.4%
Technology assistance	43.2%	40.0%
Medicine/prescription delivery	38.6%	80.0%

Services provided to grandparent caregivers were rated highly by those receiving them. Each service was rated on a scale from 1 to 5 with 5 representing very good. All of the services rated at the high end of the scale for both the reservation and non-reservation statewide population. The ratings presented in table 24 do not present a consistent pattern for reservation respondents being relatively pleased or displeased as compared to the statewide general population. While individual scores may be used to identify those with the lowest or highest ratings, the range is small and all ratings are in the positive domain. Essentially, it appears that when services are organized and provided, they are well received and rated highly by the users regardless of location.

Table 24
RATINGS OF SERVICES PROVIDED TO GRANDPARENT CAREGIVERS

	Statewide	Reservations
Outreach programs	4.08	3.68
Visiting nurse	4.25	4.23
Homemaker services/home health aid	3.86	4.00
Escort/transportation	4.27	4.29
Shopping assistance	3.75	3.88
Parish nurses	4.43	3.40
Information about services	4.00	3.67
Assistance in accessing services	3.96	3.52
Individual caregiver counseling	4.20	3.78
Caregiver training/education	4.33	3.94
Respite care	4.13	4.52
Caregiver support group	4.00	4.00
Legal assistance	3.75	4.18
Technology assistance	3.88	4.50
Medicine/prescription delivery	4.40	3.86

Services Provided by Grandparent Caregivers

A list of 15 services that might be provided by grandparent caregivers was presented to each respondent, asking them to indicate which services they provided to their grandchild or grandchildren. As is evident in table 25, grandparent caregivers in both the general population and on the reservations tend to be “all things” to their grandchildren! Essentially, grandparent caregivers provide all imaginable services to their grandchildren as they seek to meet the needs of the child. They undertake a complete mix of childrearing tasks wherever they are located, reservation or not.

Table 25
PROPORTION OF GRANDPARENT CAREGIVERS PROVIDING SERVICES

	Statewide	Reservations
Managing finances	65.2%	87.0%
Contributing financially	80.8%	89.5%
Administer personal care	82.1%	81.9%
Assist with household care	65.5%	84.5%
Assist with meals/nutrition	91.8%	92.2%
Assist with errands/shopping	82.2%	87.0%
Provide companionship	96.0%	94.6%
Help with emotional needs	83.2%	74.6%
Listen to them	93.9%	94.8%
Provide transportation	87.5%	92.4%
Assist with medicine	57.0%	50.9%
Get other family members involved	50.0%	37.7%
Provide cross cultural education	42.2%	39.0%
Provide discipline	76.5%	88.6%
Provide tutoring/homework assistance	69.0%	74.2%

Respondents were asked which kinds of information would be valuable to them as caregivers either now or in the future. The results are found in table 26. The reservation respondents placed less value on information overall than did the general population, with 36% indicating that none of the information types were of value. However, these results should be interpreted in the context of reservation life where many of the services about which information might be offered were simply not available. Items assessing information about assistance with institutional placement when no institutions are available, or with taxation, when one has no taxable income, tend to generate a negative response. Nonetheless, these items do help identify areas in which information needs are most valued and in some cases the values are indeed perceived higher among the reservation respondents. Information providing assistance with

discipline, for example, appeared to be valued more on the reservations. A close inspection of Table 24 will help define priorities for information programs targeting the reservation caregivers.

Table 26
KINDS OF INFORMATION VALUED BY GRANDPARENT CAREGIVERS

	Statewide	Reservations
Info-line	47.2%	15.6%
Hotline (for immediate needs)	22.6%	9.2%
Someone to talk to	35.8%	15.6%
Someone to help arrange services	18.9%	14.9%
Information on child's condition	19.8%	9.2%
Information about law changes	32.1%	11.3%
Financial support	46.2%	36.9%
Respite care	46.2%	12.3%
Aftercare counseling	5.7%	5.0%
Tax break, stipends	38.7%	17.0%
Help in institutional placement	2.8%	4.3%
Help in understanding payment system	6.6%	5.0%
Help in dealing with agencies	29.2%	9.9%
Help in dealing with parent of child	20.8%	12.8%
Assistance with cross cultural education	7.5%	9.9%
Assistance with discipline	16.0%	22.0%
None of the above	17.0%	36.2%

Impacts of Caregiving

The impacts of being a grandparent caregiver are reflected in table 27. The most striking observation in this table is that significantly more of the reservation grandparents reported “none of the above” to the question on changes, which was the largest response for both the reservations and the statewide general population. Although higher among the reservation’s respondents, significant changes remain in the work related items. Adapting work to childcare demands is difficult for grandparent caregivers who are still in the labor force and this remains true regardless of residence.

Table 27
CHANGES MADE AS A RESULT OF CAREGIVING

	Statewide	Reservations
Moved – changed location	7.5%	5.0%
Sold home to move in with child	.9%	0.0%
Stopped working	12.3%	5.0%
Retired early	11.3%	5.7%
Took less demanding job	2.8%	2.8%
Changed to part-time work	2.8%	2.8%
Reduced working hours	5.7%	.7%
Lost fringe benefits	3.8%	1.4%
Had time conflicts with work and child care	23.6%	10.6%
Used vacation for care	17.9%	11.3%
Took leave of absence to provide care	5.7%	11.3%
Lost a promotion	.9%	2.8%
Arrived late or took off early at work	27.4%	16.3%
None of the above	40.6%	60.3%

Results Summary

Informal Caregivers	Grandparent Caregivers
Characteristics of caregivers	
• 25% retired • 33% work full-time • 69% female • 61% married	• 23% retired • 40% work full-time • 86% female • 39% married
Intensity of care	
• The intensity of care is relatively low because of the age of the American Indian elders. • Care is of short duration but very time consuming.	• Grandparent caregivers have a high proportion of children requiring 25 hour, 7 day a week care. • Moderate amounts of special needs are present.
Caregiver burden	
• Low sense of burden - 13 items all scored below 2.0 on a 5 point scale where 5 indicated serious difficulty. • Highest concern reflected conflict between a sense of duty to provide care and accepting help. (Score was still very low) • Conclusion – Burden is not a major problem	• Low sense of burden, but slightly higher than for informal caregivers. • As with informal caregivers, all items produced low scores. • Duty was also the highest concern and a barrier to accepting help – but it also produced a low score. • Conclusion – Burden is not a major problem.
Support from other caregivers	
• 41% of the American Indian respondents had other caregivers compared to 51% in the general population	• 44.7% of the American Indian grandparent caregivers had other family members helping compared to 67% in the general population.
The cultural value of familism on reservations appears to assure informal and grandparent care when needed, but does not extend to supporting the caregivers, especially for grandparent caregivers.	
Availability of formal services	
For recipients of care • Almost all services are less available to Indian elders than to the general population. • Over ½ of the services were available to less than 50% of the Indian respondents.	For the Children • Lower availability was found on 7 of 8 services when compared to the general population • Counseling, tutoring, scholarships and mentoring were available to less than 50%
For caregivers • Caregiver education is more readily	For caregivers • Uniformly less in support services

Informal Caregivers	Grandparent Caregivers
available to reservation respondents than others, but recall that informal care is the main local option. • Respite care is less available. • Information about services and assistance in accessing services were low reflecting the low volume of services locally available.	is available to Indian grandparent caregivers. • All grandparent caregivers, Indian and non-Indian, reported low levels of availability for support services.
What they want – the top priorities.	
For recipients • Visiting nurses • Homemaker services • Outreach	For the children • Scholarships • Role models/mentors • Tutors
For caregivers • Information • Caregiver training • Assistance in accessing services	For the caregivers • Information • Assistance in accessing services • Respite • Assistance with technology
Use of available services.	
Recipient services • When services were available, Indian caregivers used them at high rates.	Child services • Use rates are uniformly high for available services
Caregiver services • Services targeting caregivers are used at relatively low rates. • Some services appear to target a sense of burden which was observed to be low.	Caregiver services • Respondents report very high use rates for most services that were available.
Quality ratings for services	
• All ratings were at the positive end of a 5 point rating scale • Services were not rated as highly by American Indian caregivers when compared to the general population.	• Quality ratings for services directed to both the children and the caregivers were all rated at the positive end of a 5 point scale. • The Indian grandparent caregivers were slightly less positive than the general population.

Services caregivers provide	
• They do it all! Especially socio-emotional support, household tasks and transportation. • Legal assistance and help getting other family involved were lowest	• Also “all things” to the child. Especially meals, transportation, companionship and discipline. • Getting other family members involved and cross cultural education were low.
Most valued information	
• Information generally was less valued by North Dakota’s American Indian respondents. • Information questions often referred to services not locally available. • Top categories ○ Information about conditions ○ Counseling/support programs ○ Financial support ○ Assistance in dealing with agencies	• Resistance to information was found – 36% wanted none. • Again, the absence of local services made information about services difficult to appreciate. • Top categories ○ Financial support ○ Discipline
The impacts on caregivers	
• Relatively low impacts were observed among American Indian caregivers, probably as a result of the relatively young ages of the caregivers and recipients. • Dementia is less of a problem in this population. • Work conflicts are the most common impacts.	• Also very low – 60% reported no changes! • Again, work conflicts were the dominant impacts – getting to work late, leaving early, adjusting schedules etc.

The fit between North Dakota’s American Indian caregivers and data produced by a variety of national studies suggests that the caregivers on reservations in North Dakota are not simply a microcosm of the nation. One of the risks evident in this study is that the reservation communities struggle to “catch up” with respect to support services while the concerns at the national level deal more with issues of cost containment (how to limit services) and dealing with

a shrinking labor force pool that is producing fewer potential long term care workers. (Spillman and Pezzin, 2000; Robin Stone, 2000; Nora Super, 2002; Coburn, 2002) While these are valid national issues, they are not germane to reservations. Other issues appear at the national level render assumptions about service availability that do not fit with the reservation environment. For example, concern over the recruitment and retention of health care personnel in long term care requires the presence of long term care services and institutions. The difficulty emerges as a result of the national focus. When a fit between rural reservations and the nation creates different sets of issues, the national policy makers are less likely to attend to the relatively small numbers of people living in isolated rural communities and reservations.

Neil Bull (2003) lists major barriers to rural services that apply to reservations as well. Economic deprivation produces a weak market and leaves services to public programs, geographic isolation and a lack of public transportation produces a strain on access to regional services and service infrastructure is slowly eroding in sparsely populated regions. He also reports an oversupply of rural nursing home beds that combines with an undersupply of home and community based services, leaving rural elderly little choice when confronting activity limitations. Ironically, this oversupply of skilled nursing home beds is absent for reservation communities, leaving only the undersupply of support services.

While some national programs such as PACE (Program for All-inclusive Care for the Elderly) assume the availability of a wide array of services that need to be managed or integrated, reservation communities are struggling to develop an essential array of services. The support services needed to assure optimal quality for family caregivers are derived from the same array of home and community based services that support long-term care generally, but may be

more limited. The data presented above suggest the following list of key services as necessary to support family caregiving.

- Home health
- Personal care
- Nutrition
 - o Dietician
 - o Home delivered meals
 - o Congregate meals
- Homemaker services
- Chore services
- Transportation
- Respite care
- Outreach

Information and training and educational services are central to supporting caregivers in all settings. The means of providing information and education in the 21st century tends to rely increasingly on technology. (Wagner and Niles, 2003; Redford and Goins, 2003) Reliance on internet technology or interactive televideo improve our ability to reach people, but rely on a new infrastructure and perhaps as importantly, a new set of skills in the population. The data in this study suggested that assistance with technology is a need, especially for grandparent caregivers. As information services develop content, it will be important to prepare a mix of traditional means of distribution with the newer high tech modes in order to reach those most in need.

Family caregiving for North Dakota's reservations is consistent both with the general belief that the extended family support system continues to function as it has in previous generations for American Indians and the absence of a complete array of support services or institutional options. Goins, Mitchell and Wu (2003) argue that a gap between the values and reality may exist and our data suggest that the extended family does undertake the caregiving role, but that once this need has been satisfied, support for the caregiver from others in the family is not strong and that they do not expend much effort on increasing the involvement of other family members. Improving the availability of support services is critical to assuring quality in family caregiving.

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INFORMAL CAREGIVERS MAIL SURVEY

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

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

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

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

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

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

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

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

Q7.

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

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

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

☐ No

☐ Yes (please specify) _____

Q8.

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

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

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

☐ No

☐ Yes (please specify) _____

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

☐ Yes----->Who is providing care? _____

☐ No

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

☐ There are no other immediate family members

☐ Others are also in need of care

☐ Others are embarrassed/uncomfortable fulfilling intimate needs (bathing, toileting, etc.)

☐ Others are too inexperienced

☐ Others live farther away

☐ Others have full-time jobs

☐ Others have less flexible daily schedules

☐ Others have young dependents living with them

☐ Others do not get along with care recipient

☐ Others are unaware of needed care (have not been informed - have not been asked to help)

☐ Others are unwilling or "just can't"

☐ Recipient doesn't want care from others

☐ Other reasons _____

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

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

☐ Yes (**Skip to Q11b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q12**)

☐ No (**skip to Q12**)

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

☐ Yes (**Skip to Q11d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes (**Skip to Q12b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q13**)

☐ No (**skip to Q13**)

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

☐ Yes (**Skip to Q12d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes (**Skip to Q13b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q14**)

☐ No (**skip to Q14**)

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

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

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

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

☐ Yes (**Skip to Q16b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q17**)

☐ No (**skip to Q17**)

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

☐ Yes (**Skip to Q16d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes (**Skip to Q17b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q18**)

☐ No (**skip to Q18**)

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

☐ Yes (**Skip to Q17d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes (**Skip to Q18b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q19**)

☐ No (**skip to Q19**)

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

☐ Yes (**Skip to Q18d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

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

☐ Yes **(Skip to Q19b)**

☐ No

☐ Do not know

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

☐ Yes **(skip to Q20)**

☐ No **(skip to Q20)**

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

☐ Yes **(Skip to Q19d)**

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes **(Skip to Q20b)**

☐ No

☐ Do not know

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

☐ Yes **(skip to Q21)**

☐ No **(skip to Q21)**

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

☐ Yes **(Skip to Q20d)**

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ Yes (**Skip to Q21b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q22**)

☐ No (**skip to Q22**)

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

☐ Yes (**Skip to Q21d**)

☐ No

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

☐ Do not need it

☐ Care recipient won't use it

☐ Other reason (please specify) _____

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

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

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

☐ No

☐ Yes (please specify) _____

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

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

☐ Yes (**Skip to Q23b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q24**)

☐ No (**skip to Q24**)

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

☐ Yes (**Skip to Q23d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

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

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

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

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

☐ Yes (**Skip to Q24b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q25**)

☐ No (**skip to Q25**)

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

☐ Yes (**Skip to Q24d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

Q24d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **assistance with accessing available services**.
Not good at all - 1 2 3 4 5 - Very good

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

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

☐ Yes (**Skip to Q25b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q26**)

☐ No (**skip to Q26**)

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

☐ Yes (**Skip to Q25d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

Q25d. On a one to five scale, with one being "Not good at all" and five being "Very good", please rate **individual caregiver counseling**.
Not good at all - 1 2 3 4 5 - Very good

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

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

☐ Yes (**Skip to Q26b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q27**)

☐ No (**skip to Q27**)

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

☐ Yes (**Skip to Q26d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

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

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

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

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

☐ Yes (**Skip to Q27b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q28**)

☐ No (**skip to Q28**)

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

☐ Yes (**Skip to Q27d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

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

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

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

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

☐ Yes (**Skip to Q28b**)

☐ No

☐ Do not know

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

☐ Yes (**skip to Q29**)

☐ No (**skip to Q29**)

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

☐ Yes (**Skip to Q28d**)

☐ No

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

☐ Do not need it

☐ Other reason (please specify) _____

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

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

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

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

☐ No

☐ Yes (please specify _____)

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

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

- Q31. Are there other services that I haven't already been mentioned that you would like to have available to you as a caregiver ?
☐ No
☐ Yes (please specify) _____
- Q32. What kinds of information/services would be valuable to you as a caregiver, now or in the future?
☐ Information about the care recipient's condition or disability (what to expect as they age, etc.)
☐ Information on end of life issues
☐ Information about developments or changes in laws which might affect your situation
☐ Info-line (central place to call to find out what kind of help is available or where to get it)
☐ Someone to help you arrange for services, assess your situation
☐ Someone to talk to/counseling services/support group
☐ Respite care or adult day care
☐ Aftercare/grief counseling
☐ Hotline (for dealing with immediate emotional needs while preserving dignity of care recipient)
☐ Help in understanding how to select a nursing home/other care facility
☐ Help in assessing the timing of placement in formal caregiving institutions
☐ Help in understanding how to pay for nursing homes, adult day care, etc.
☐ Help in dealing with agencies (bureaucracies) to get services
☐ Financial support
☐ Tax break, stipend, government subsidy
☐ Other (specify) _____
☐ None of the above
- Q33. Because of caregiving have you... (check all that apply)
☐ Changed locations to accommodate care recipient's needs (e.g. handicap accessibility)
☐ Sold a home to move in with care recipient
☐ Stopped working
☐ Retired early
☐ Taken a less demanding job
☐ Changed from full-time to part-time work
☐ Reduced your official working hours
☐ Lost some of your employment fringe benefits
☐ Had time conflicts between working and caregiving
☐ Used your vacation time to provide care
☐ Taken a leave of absence to provide care
☐ Lost a promotion
☐ Taken off work early or arrived to work late because you provided care
☐ Other (specify) _____
☐ None of the above
- Q34. Within the past year, on average, how much money have you spent caring for your care recipient?
☐ 0 to \$1,000
☐ \$1,001 to \$2,000
☐ \$2,001 to \$3,000
☐ \$3,001 to \$4,000
☐ \$4,001 to \$5,000
☐ More than \$5,000
☐ The care recipient lives with me - it's difficult to separate expenses.
☐ I do not know
- Q35. What is your age?
☐ Younger than 35 years of age
☐ 35 to 44 years old
☐ 45 to 54 years old
☐ 55 to 64 years old
☐ 65 to 74 years old
☐ 75 to 84 years old
☐ 85 or older
- Q36. What is your marital status?
☐ Married or living with partner
☐ Single, never married
☐ Divorced or separated
☐ Widowed

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

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

45. Name: _____
 Address: _____
 Phone: _____

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

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: _____

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

INFORMAL CAREGIVER RESULTS STATEWIDE GENERAL POPULATION COMPARED WITH NORTH DAKOTA'S INDIAN POPULATION*		
	Statewide General	Indian Population
1. Caregiver recipient:		
Spouse	43.1%	34.2%
Mother (or in-law)	29.1%	19.2%
Father (or in-law)	10.9%	10.5%
Friend	8.1%	6.8%
Relative	5.8%	15.5%
Sibling (or in-law)	2.9%	2.3%
Adult Child over 60	1.4%	3.7%
Not currently providing	3.7%	10.0%
2. Why services were needed:		
Aging process	65.0%	62.6%
Cognitive impairment	23.0%	5.9%
Developmental disabilities	2.3%	5.5%
Mental illness	4.4%	5.0%
Physical disabilities	53.4%	42.0%
Head injury	.5%	1.4%
Substance abuse issues	.5%	1.8%
End of life issues (hospice)	3.1%	3.7%
3. Percent compensated for informal care	6.4%	15.1%
4. Location of caregiving		
Caregivers home (living with)	58.4%	59.4%
Recipients home	36.5%	35.5%
Assisted Living Facility	2.3%	1.4%
Independent Living Facility	.6%	.5%
Other	2.3%	2.3%
4a. Care required		
Cannot be left alone	24.4%	24.6%
Left alone a few hours	50.6%	22.2%
Left alone most of the day	29.9%	49.2%
5a. Distance from caregiver's home to recipient	<u>82.3%</u> Less than 20 min <u>11.6%</u> 20 – 59 min <u>3.4%</u> 1 to 2 hours <u>2.6%</u> over 2 hours	<u>88.7%</u> Less than 20 min <u>9.7%</u> 20 – 59 min <u>1.6%</u> 1 to 2 hours <u> </u> over 2 hours

* The survey of North Dakota's Indian caregivers was conducted in the Fort Berthold, Spirit Lake, Standing Rock, and Turtle Mountain reservations and in the Trenton Service Area

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
5b. Hours per week caregiving	<u>33.3%</u> 0 – 5 <u>23.7%</u> 6 – 10 <u>17.2%</u> 7 – 15 <u>7.5%</u> 16 – 20 <u>18.3%</u> over 20	<u>21.4%</u> 0 – 5 <u>28.6%</u> 6 – 10 <u>5.4%</u> 7 – 15 <u>16.1%</u> 16 – 20 <u>28.6%</u> over 20
6. Length of caregiving experience	22% under 1 yr	9.3% under 1 yr
7. Seriousness of difficulties(5 pt scale)		
Less time for self	2.67	1.85
Less time for family	2.60	1.65
No consistent help from other family	2.52	1.87
Affects family relationships	1.92	1.52
Conflicts with social life	2.41	1.79
Emotional aspects (sadness, anxiety)	2.92	1.95
Less privacy	2.0	1.60
Interferes with job	1.61	1.47
Financial obligations	2.01	1.61
Lifestyle change	2.79	1.91
Having responsibility for decisions	2.64	1.89
Own physical health	1.99	1.49
Unable to sleep	1.92	1.44
8. Strength of concerns		
Difficult to accept support because of a sense of duty	2.35	2.23
Difficult to find support (help)	2.32	1.85
Difficult to accept financial help because of stigma.	1.98	1.93
Difficult to accept help because I'm being paid. (QSPs)	1.38	1.48
I provide care because my community will think ill of me if I don't	1.55	1.69
Experience of a sense of isolation	1.88	1.56
Experience of a lack of understanding	1.73	1.49
9. Are other informal caregivers also providing care? (% yes)	52.1%	41%
10. Reasons for lack of others		
No other immediate family	28.2%	22.9%
Others also in need of care	4.4%	5.0%
Others embarrassed by intimate needs	4.0%	10.5%
Others too inexperienced	4.9%	12.8%
Others live too far away	52.3%	21.5%
Others have full time jobs	36.2%	30.6%
Others have less flexible schedules	19.3%	12.8%
Others have young dependents	12.1%	21.9%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Others do not get along with recipient	4.1%	5.5%
Others are unaware of needed care	3.8%	8.2%
Others are unwilling or just can't	12.1%	18.7%
Recipient doesn't want care by others	11.0%	18.7%
SERVICES FOR RECIPIENT OF CARE		
Availability of services		
Dietician services	50.8%	62.1%
Home delivered meals	87.0%	82.7%
Congregate meals	84.4%	77.6%
Adult day centers	20.9%	17.8%
Outreach programs	60.1%	43.8%
Visiting nurse	66.7%	61.6%
Parish nurse	10.4%	8.7%
Homemaker services	74.8%	42.5%
Escort/transportation services	69.6%	52.5%
Shopping assistance	42.5%	39.7%
Pet services	26.2%	10.0%
Other services desired?		
Proportion of those with services lacking who would like them available.		
Dietician services	17.6%	27.9%
Home delivered meals	23.7%	26.5%
Congregate meals	33.8%	34.6%
Adult day centers	41.5%	32.5%
Outreach programs	54.3%	45.4%
Visiting nurse	47.2%	52.6%
Parish nurse	28.5%	30.5%
Homemaker services	40.2%	46.5%
Escort/transportation services	36.0%	45.0%
Shopping assistance	32.8%	32.7%
Pet services	6.5%	19.6%
Proportion of those with services available that use them.		
Dietician services	37.7%	60.9%
Home delivered meals	54.1%	61.5%
Congregate meals	38.6%	40.7%
Adult day centers	13.6%	34.9%
Outreach programs	66.1%	55.8%
Visiting nurse	54.0%	68.9%
Parish nurse	32.5%	24.1%
Homemaker services	39.7%	40.0%
Escort/transportation services	32.8%	49.0%
Shopping assistance	32.2%	36.4%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Pet services	18.2%	17.9%
Reasons for not using available services		
Dietician services	<u>80.2%</u> Not needed <u>12.6%</u> Recipient won't use <u>7.1%</u> Other	<u>81.0%</u> Not needed <u>11.9%</u> Recipient won't use <u>13.2%</u> Other
Home delivered meals	<u>64.8%</u> Not needed <u>14.6%</u> Recipient won't use <u>20.6%</u> Other	<u>83.0%</u> Not needed <u>3.8%</u> Recipient won't use <u>13.2%</u> Other
Congregate meals	<u>33.4%</u> Not needed <u>23.4%</u> Recipient won't use <u>43.1%</u> Other	<u>65.5%</u> Not needed <u>8.0%</u> Recipient won't use <u>26.4%</u> Other
Adult day centers	<u>62.7%</u> Not needed <u>11.0%</u> Recipient won't use <u>22.1%</u> Other	<u>95.5%</u> Not needed <u>4.5%</u> Recipient won't use <u>0.0%</u> Other
Outreach programs	<u>63.6%</u> Not needed <u>35.4%</u> Recipient won't use <u>1.0%</u> Other	<u>90.6%</u> Not needed <u>9.4%</u> Recipient won't use <u>0.0%</u> Other
Visiting nurse	<u>74.6%</u> Not needed <u>8.3%</u> Recipient won't use <u>18.1%</u> Other	<u>68.6%</u> Not needed <u>8.6%</u> Recipient won't use <u>22.9%</u> Other
Parish nurse	<u>70.2%</u> Not needed <u>8.5%</u> Recipient won't use <u>21.3%</u> Other	<u>66.7%</u> Not needed <u>11.1%</u> Recipient won't use <u>22.2%</u> Other
Homemaker services	<u>66.5%</u> Not needed <u>11.2%</u> Recipient won't use <u>22.3%</u> Other	<u>79.1%</u> Not needed <u>9.3%</u> Recipient won't use <u>11.6%</u> Other
Escort/transportation services	<u>58.9%</u> Not needed <u>16.4%</u> Recipient won't use <u>24.7%</u> Other	<u>59.1%</u> Not needed <u>27.3%</u> Recipient won't use <u>13.6%</u> Other
Shopping assistance	<u>78.2%</u> Not needed <u>8.6%</u> Recipient won't use <u>13.2%</u> Other	<u>80.4%</u> Not needed <u>6.5%</u> Recipient won't use <u>13.0%</u> Other

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Pet services	<u>91.5%</u> Not needed _____ Recipient won't use <u>8.5%</u> Other	<u>100 %</u> Not needed _____ Recipient won't use _____ Other
Rating of services (5 point scale 5 = very good)		
Dietician services	3.96	3.86
Home delivered meals	4.24	3.90
Congregate meals	4.42	3.99
Adult day centers	3.95	3.44
Outreach programs	4.38	4.13
Visiting nurse	4.42	4.02
Parish nurse	4.41	4.13
Homemaker services	4.20	4.20
Escort/transportation services	4.36	3.43
Shopping assistance	4.22	4.10
Pet services	4.43	3.83
SERVICES FOR CAREGIVERS		
Availability of services		
Information about services	72.4%	51.1%
Assistance in accessing services	65.0%	43.8%
Individual caregiver counseling	18.7%	28.3%
Caregiver training or education	22.1%	36.1%
Respite care	48.5%	35.6%
Caregiver support groups	18.6%	19.6%
Those who would like each service among those who lack it.		
Information about services	68.5%	68.2%
Assistance in accessing services	48.4%	55.6%
Individual caregiver counseling	30.1%	39.2%
Caregiver training or education	33.7%	65.5%
Respite care	51.1%	46.0%
Caregiver support groups	38.2%	37.9%
Proportion using available services		
Information about services	66.5%	66.0%
Assistance in accessing services	63.3%	54.0%
Individual caregiver counseling	40.5%	35.0%
Caregiver training or education	37.0%	38.0%
Respite care	34.0%	50.0%
Caregiver support groups	26.1%	18.6%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Service ratings (5 point scale 5 = very good)		
Information about services	4.15	3.82
Assistance in accessing services	4.24	3.80
Individual caregiver counseling	4.33	4.04
Caregiver training or education	4.16	3.97
Respite care	4.35	4.13
Caregiver support groups	3.73	4.22
Frequency of providing finance management	<u>37.3%</u> Daily <u>17.5%</u> Weekly <u>19.3%</u> Monthly <u>14.6%</u> On Occasion <u>11.3%</u> Never	<u>18.8%</u> Daily <u>11.8%</u> Weekly <u>32.3%</u> Monthly <u>15.6%</u> On Occasion <u>21.5%</u> ever
Proportion who would have liked help providing finance management.	7.2%	11.3%
Frequency of contributing financially	<u>28.7%</u> Daily <u>6.8%</u> Weekly <u>16.8%</u> Monthly <u>18.9%</u> On Occasion <u>28.9%</u> Never	<u>19.4%</u> Daily <u>10.6%</u> Weekly <u>19.4%</u> Monthly <u>33.9%</u> On Occasion <u>16.7%</u> Never
Proportion who would have liked help providing finances.	22.0%	16.0%
Frequency of administering personal care.	<u>39.4%</u> Daily <u>18.4%</u> Weekly <u>5.1%</u> Monthly <u>20.8%</u> On Occasion <u>16.3%</u> Never	<u>32.6%</u> Daily <u>14.1%</u> Weekly <u>2.2%</u> Monthly <u>25.0%</u> On Occasion <u>26.1%</u> Never
Proportion who would have liked help providing personal care.	31.0%	18.9%
Frequency of assisting with household tasks.	<u>61.6%</u> Daily <u>16.4%</u> Weekly <u>3.6%</u> Monthly <u>14.8%</u> On Occasion <u>3.6%</u> Never	<u>54.8%</u> Daily <u>21.6%</u> Weekly <u>1.6%</u> Monthly <u>12.2%</u> On Occasion <u>10.1%</u> Never
Proportion who would have liked help with household tasks.	35.3%	21.5%
Frequency of assisting with home maintenance or repairs.	<u>31.6%</u> Daily <u>16.5%</u> Weekly <u>6.1%</u> Monthly <u>28.8%</u> On Occasion <u>17.1%</u> Never	<u>25.8%</u> Daily <u>8.9%</u> Weekly <u>5.8%</u> Monthly <u>37.4%</u> On Occasion <u>22.1%</u> Never
Proportion who would have liked help providing home maintenance.	37.9%	27.2%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Frequency of providing assistance with meals.	<u>69.1%</u> Daily <u>9.4%</u> Weekly <u>.5%</u> Monthly <u>12.3%</u> On Occasion <u>8.7%</u> Never	<u>71.1%</u> Daily <u>6.8%</u> Weekly <u>1.6%</u> Monthly <u>12.6%</u> On Occasion <u>7.4%</u> Never
Proportion who would have liked help providing meals.	30.2%	15.7%
Frequency of providing assistance with errands/shopping.	<u>46.1%</u> Daily <u>38.9%</u> Weekly <u>4.4%</u> Monthly <u>8.6%</u> On Occasion <u>2.0%</u> Never	<u>38.8%</u> Daily <u>40.4%</u> Weekly <u>3.2%</u> Monthly <u>10.1%</u> On Occasion <u>7.4%</u> Never
Proportion who would have liked help with errands/shopping.	26.0%	22.4%
Frequency of providing companionship.	<u>82.3%</u> Daily <u>13.3%</u> Weekly <u>.3%</u> Monthly <u>3.0%</u> On Occasion <u>1.0%</u> Never	<u>83.2%</u> Daily <u>7.6%</u> Weekly <u>1.1%</u> Monthly <u>4.3%</u> On Occasion <u>3.8%</u> Never
Proportion who would have liked help providing companionship.	35.5%	14.4%
Frequency of providing phone contact.	<u>69.0%</u> Daily <u>11.8%</u> Weekly <u>1.2%</u> Monthly <u>9.3%</u> On Occasion <u>8.7%</u> Never	<u>55.2%</u> Daily <u>9.8%</u> Weekly <u>3.8%</u> Monthly <u>20.8%</u> On Occasion <u>10.4%</u> Never
Proportion who would have liked help providing phone contact.	21.7%	13.3%
Frequency of providing help with worries, anxiety or emotions.	<u>65.1%</u> Daily <u>9.9%</u> Weekly <u>1.2%</u> Monthly <u>18.2%</u> On Occasion <u>5.6%</u> Never	<u>47.9%</u> Daily <u>11.7%</u> Weekly <u>2.7%</u> Monthly <u>29.3%</u> On Occasion <u>8.5%</u> Never
Proportion who would have liked help with emotional issues.	27.3%	16.9%
Frequency of being a listener	<u>85.5%</u> Daily <u>10.2%</u> Weekly <u>4.2%</u> Monthly <u>.6%</u> On Occasion <u>_____</u> Never	<u>85.2%</u> Daily <u>6.3%</u> Weekly <u>.5%</u> Monthly <u>4.8%</u> On Occasion <u>3.2%</u> Never
Proportion who would have liked help with the task of listening.	35.5%	15.9%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Frequency of providing transportation.	<u>36.5%</u> Daily <u>35.7%</u> Weekly <u>4.2%</u> Monthly <u>18.9%</u> On Occasion <u>4.7%</u> Never	<u>39.9%</u> Daily <u>38.3%</u> Weekly <u>3.1%</u> Monthly <u>13.6%</u> On Occasion <u>5.2%</u> Never
Proportion who would have liked help providing transportation.	32.3%	23.6%
Frequency of providing assistance with medicines.	<u>60.6%</u> Daily <u>9.0%</u> Weekly <u>1.8%</u> Monthly <u>14.1%</u> On Occasion <u>14.6%</u> Never	<u>57.8%</u> Daily <u>6.8%</u> Weekly <u>1.0%</u> Monthly <u>24.5%</u> On Occasion <u>9.9%</u> Never
Proportion who would have liked help providing assistance with medicines.	19.5%	17.8%
Frequency of providing assistance for communicating with medical personnel.	<u>14.2%</u> Daily <u>15.6%</u> Weekly <u>25.2%</u> Monthly <u>37.8%</u> On Occasion <u>7.2%</u> Never	<u>20.7%</u> Daily <u>16.0%</u> Weekly <u>17.0%</u> Monthly <u>38.8%</u> On Occasion <u>7.4%</u> Never
Proportion who would have liked help with communicating with medical people.	14.4%	<u>18.1%</u>
Frequency of providing assistance to get other family members involved.	<u>14.6%</u> Daily <u>14.2%</u> Weekly <u>4.6%</u> Monthly <u>45.7%</u> On Occasion <u>20.9%</u> Never	<u>24.6%</u> Daily <u>10.9%</u> Weekly <u>3.8%</u> Monthly <u>41.5%</u> On Occasion <u>19.1%</u> Never
Proportion who would have liked help in getting other family members involved.	20.0%	19.4%
Frequency of providing assistance with legal matters.	<u>11.0%</u> Daily <u>2.0%</u> Weekly <u>4.3%</u> Monthly <u>47.8%</u> On Occasion <u>34.9%</u> Never	<u>9.7%</u> Daily <u>5.6%</u> Weekly <u>2.3%</u> Monthly <u>28.0%</u> On Occasion <u>54.3%</u> Never
Proportion who would have liked help in assisting with legal matters.	18.5%	13.7%
Proportion considering the following types of information valuable.		
Information about conditions or disabilities	38.2%	32.9%
End of life issues	27.0%	20.1%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Legal changes affect one	37.6%	15.1%
Info-line access	36.8%	18.3%
Someone to arrange services	29.1%	16.4%
Someone to talk to/counseling or support group	29.1%	22.4%
Respite or adult day care	39.1%	19.6%
Aftercare/grief counseling	15.5%	12.8%
Hotline – for immediate emotional needs	14.4%	10.5%
Nursing home selection advice	22.2%	11.0%
Help in assessing timing for placement in a nursing home.	23.8%	10.0%
Help in understanding how to pay for nursing home care.	31.3%	11.4%
Help in dealing with agencies to get services.	31.0%	19.2%
Financial support	31.7%	19.6%
Tax break, stipend, govt. subsidy	27.5%	11.9%
Other	1.8%	1.8%
None of the above	12.4%	32.0%
Impacts of caregiving		
Changed locations to meet care recipient's needs.	15.2%	9.6%
Sold a home to move in with recipient	4.0%	1.4%
Stopped working	7.2%	8.7%
Retired early	6.4%	2.3%
Taken a less demanding job	3.1%	2.7%
Changed from full to part-time work.	4.9%	2.7%
Reduced official working hours.	5.7%	4.6%
Lost some employment fringe benefits.	3.5%	4.1%
Had time conflicts between work and Caregiving	14.7%	11.9%
Used vacation time for caregiving.	14.0%	13.2%
Took leave of absence for caregiving.	3.8%	7.3%
Lost a promotion	.5%	1.4%
Left work early or arrived late.	17.2%	13.7%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Amounts spent on recipients from personal funds.	<u>36.3%</u> 0 - \$1,000 <u>4.2%</u> \$1,001-2,000 <u>5.0%</u> \$2,001-3,000 <u>2.0%</u> \$3,001-4,000 <u>.4%</u> \$4,001-5,000 <u>3.7%</u> Over \$5,000 <u>48.4%</u> Live together, can't separate.	<u>38.8%</u> 0 - \$1,000 <u>7.9%</u> \$1,001-2,000 <u>3.9%</u> \$2,001-3,000 <u>2.6%</u> \$3,001-4,000 <u> </u> \$4,001-5,000 <u>3.9%</u> Over \$5,000 <u>42.8%</u> Live together, can't separate.
Caregiver's age	<u>.8%</u> under 35 <u>4.8%</u> 35 to 44 <u>15.1%</u> 45 to 54 <u>24.7%</u> 55 to 64 <u>19.5%</u> 65 to 74 <u>27.4%</u> 75 to 84 <u>7.8%</u> 85 & over	<u>18.7%</u> under 35 <u>16.4%</u> 35 to 44 <u>15.9%</u> 45 to 54 <u>24.3%</u> 55 to 64 <u>18.7%</u> 65 to 74 <u>5.6%</u> 75 to 84 <u>.5%</u> 85 & over
Caregiver's marital status	<u>73.2%</u> Married <u>9.0%</u> single, never married <u>5.8%</u> Divorced/Separated <u>12.0%</u> Widowed	<u>60.7%</u> Married <u>23.4%</u> single, never married <u>11.2%</u> Divorced/Separated <u>4.7%</u> Widowed
Children under 18 in household	<u>87.1%</u> None <u>10.3%</u> One <u>2.3%</u> Two <u>.3%</u> Three <u>0%</u> Four	<u>45.4%</u> None <u>34.3%</u> One <u>4.5%</u> Two <u>4.3%</u> Three <u>1.4%</u> Four
Caregiver's gender.	<u>27.8%</u> Male <u>72.2%</u> Female	<u>30.4%</u> Male <u>69.6%</u> Female
Caregiver's education	<u>14.4%</u> less than High School <u>11.8%</u> Some High School <u>33.6%</u> High School <u>3.9%</u> Some Tech College <u>3.3%</u> Tech. degree <u>17.1%</u> Some college <u>11.3%</u> Graduated college <u>4.6%</u> Post grad/ Professional	<u>10.7%</u> less than High School <u>20.1%</u> Some High School <u>24.8%</u> High School <u>5.1%</u> Some Tech College <u>3.7%</u> Tech. degree <u>24.8%</u> Some college <u>8.9%</u> Graduated college <u>1.9%</u> Post grad/ Professional

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Caregiver's employment status	<u>21.1%</u> Full time work <u>14.5%</u> Part time work <u>2.7%</u> Multiple jobs <u>45.9%</u> Retired <u>15.4%</u> Not working	<u>33.3%</u> Full time work <u>7.5%</u> Part time work <u>2.3%</u> Multiple jobs <u>24.9%</u> Retired <u>31.9%</u> Not working
Household income	<u>16.1%</u> less than \$10,000 <u>34.8%</u> \$10,001 – \$20,000 <u>29.1%</u> \$20,001 – \$35,000 <u>11.9%</u> \$35,001 - \$50,000 <u>4.8%</u> \$50,001 - \$65,000 <u>1.1%</u> \$65,001 - \$80,000 <u>1.3%</u> \$80,001 - \$100,000 <u>1.0%</u> over \$100,000	<u>43.0%</u> less than \$10,000 <u>28.5%</u> \$10,001 – \$20,000 <u>18.7%</u> \$20,001 – \$35,000 <u>6.2%</u> \$35,001 - \$50,000 <u>3.6%</u> \$50,001 - \$65,000 ____ \$65,001 - \$80,000 ____ \$80,001 - \$100,000 ____ over \$100,000

GRANDPARENT CAREGIVER SURVEY RESULTS STATEWIDE GENERAL POPULATION COMPARED WITH NORTH DAKOTA'S INDIAN POPULATION		
	Statewide General	Indian Population
Number provided with care		
0 to 4	34	58
5 to 9	41	74
10 to 14	44	54
15 to 18	31	41
18 and above	7	34
Average number of children per caregiver	1.09	1.62
Child's race/ethnic background		
White (Non-Hispanic)	71.7%	
American Indian/Alaskan Native	18.9%	86.8%
Native Hawaiian/Pacific Islander		1.6%
Other (Black or mixed racial)	3.7%	11.7%
Length of caregiving		
Legal guardianship	45.3%	44.7%
Which of parents is your offspring?		
Mother	66.0%	70.1%
Father	32.1%	24.4%
Both	1.9%	5.5%
Reasons for caregiving		
Parent in abusive relationship	<u>16.0%</u> of cases <u>61.1%</u> daughters <u>22.2%</u> sons <u>16.7%</u> both	16.3% of cases 47.6% daughters 14.3% sons 38.1% both
Parent incarcerated	10.4% of cases 41.7% daughters 41.7% sons 16.7% both	13.5% of cases 33.3% daughters 55.6% sons 11.1% both
Parent can't afford child	37.7% of cases 53.8% daughters 7.7% sons 38.5% both	43.3% of cases 31.6% daughters 10.5% sons 57.9% both
Parent was never involved	25.5% of cases 26.9% daughters 46.2% sons 26.9% both	32.6% of cases 39.5% daughters 23.3% sons 37.2% both
Parent doesn't want to be bothered	28.6% of cases 58.6% daughters 31.0% sons 10.3% both	31.2% of cases 40.9% daughters 11.4% sons 47.7% both

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Parent has no parenting skills	35.8% of cases 51.4% daughters 10.8% sons 37.8% both	26.2% of cases 37.1% daughters 17.1% sons 45.7% both
Parent had substance abuse problem	30.2% of cases 51.7% daughters 17.2% sons 31.0% both	34.8% of cases 37.8% daughters 17.8% sons 44.4% both
Parent is not mature enough	34.9% of cases 60.0% daughters 2.9% sons 37.1% both	17.0% of cases 47.8% daughters 13.0% sons 39.1% both
Parent has emotional issues	34.9% of cases 69.4% daughters 5.6% sons 25.0% both	14.2% of cases 63.2% daughters 21.1% sons 15.8% both
Parent has mental health issues	20.8% of cases 86.4% daughters sons 13.6% both	7.1% of cases 60.0% daughters 20.0% sons 20.0% both
Child was abused	14.2% of cases 50.0% daughters 28.6% sons 21.4% both	8.5% of cases 41.7% daughters 25.0% sons 33.3% both
Father unknown	7.5% of cases daughters 100% sons both	9.2% of cases 100% daughters sons both
Parent deceased	14.2% of cases 20.0% daughters 40.0% sons 40.0% both	5.0% of cases 14.3% daughters 57.1% sons 28.6% both
Other (love children, parent away at school, service or work)	52.1%	36.6%
Relationship with child's parent		
Stressed	10.4%	24.1%
Amicable	47.2%	20.6%
Relationship does not exist	9.4%	14.2%
None/other	28.3%	27.7%
Monetary compensation to child		
SSI	21.7%	8.5%
Inheritance	3.8%	
None	59.4%	60.3%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Monetary compensation to caregiver		
Child support	9.4%	4.3%
Foster care	1.9%	21.3%
None	75.5%	53.2%
Non-monetary support to household		
WIC	14.2%	26.2%
School lunch program	37.7%	58.9%
Other food programs	15.1%	35.5%
Medical assistance for uninsured	34.0%	48.2%
TANF	3.8%	28.4%
Housing assistance	3.8%	5.0%
Fuel Assistance	11.3%	29.8%
None	42.5%	12.8%
Special needs present.		
Hyperactivity disorder	11.3%	12.8%
Learning disability	15.1%	9.9%
Fetal alcohol syndrome	4.7%	6.4%
Cognitive impairment	1.9%	0.0%
Developmental disabilities	1.9%	.7%
Mental Health issues	7.5%	1.4%
Physical disabilities	7.5%	0.0%
Emotional issues	18.9%	13.5%
Head injury	.9%	0.0%
Substance abuse	.9%	5.0%
None	55.7%	65.2%
Amount of care required		
Can be left overnight	21.7%	9.9%
Can be left most of day	9.4%	13.5%
Can be left a few hours	22.6%	27.0%
Around the clock care/24-7	43.4%	42.6%
Difficulties experienced (average on 5 point scale – 5=serious)		
Less time for self	2.46	2.14
Less time for my family	2.19	1.86
No consistent help from other family	2.13	1.99
Affects my family relationships	1.76	1.82
Conflicts with my social life	2.13	1.89
Emotional aspects – frustration	2.51	1.91
Less privacy	2.32	1.94
Interferes with job	1.67	1.62
Financial burden	2.40	2.13
Responsibility for major decisions	2.11	1.75
Deteriorating physical health	1.71	1.40

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Unable to sleep due to caregiving	1.67	1.47
Feel more tied down	2.35	1.91
Difficulty providing discipline	1.70	2.02
Feel like I'm back at the beginning	2.29	2.31
Concerns experienced (average on 5 point scale – 5=serious)		
Difficult to accept support – duty	2.28	2.11
Difficult to find support	2.16	2.04
Difficult to accept because of negative stigma	1.83	1.92
Difficult to accept financial support because grandchild fears peer support	1.57	1.69
Difficult to accept support because of being paid	1.41	1.61
Providing care because of community pressure	1.44	1.83
Experience of isolation	1.59	1.69
Lack of community understanding	1.89	1.50
Friends back off because of caregiving	1.71	1.68
Concerns about losing custody	1.58	1.82
Anger toward parents of child	1.90	2.00
Guilt over feelings of resentment	1.89	1.96
Cannot provide cross cultural education for mixed racial child	1.33	1.52
Other family members are jealous of the care given	2.06	1.96
Other concerns	1.88	1.96
Presence of other family within household providing care	67.0%	44.7%
Presence of family outside household providing care	43.4%	31.2%
Reasons others are not providing care		
No other immediate family	14.1%	7.8%
Others also need care	5.7%	7.8%
Others too embarrassed with tasks	.9%	0.0%
Others too inexperienced	.9%	.7%
Others live further away	32.1%	12.1%
Others have full time jobs	34.0%	22.0%
Others have less flexibility	17.9%	12.1%
Others have young dependents	25.5%	16.3%
Others do not get along with child		.7%
Others are not aware of need	6.6%	2.1%
Others are unwilling or can't	17.9%	17.0%
Recipient doesn't want others	1.9%	1.4%
	Statewide General	Indian Population

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Care would cause conflict in family	2.8%	3.5%
Others would provide if needed	18.9%	5.7%
Does not apply to my situation	17.9%	28.4%
Other reasons	3.8%	2.9%
SERVICES FOR RECIPIENT OF CARE		
Proportion with service available		
Counseling	66.0%	41.1%
Tutoring	54.7%	44.7%
School lunch	85.8%	80.1%
Scholarships	27.4%	12.1%
Special education	72.6%	53.9%
Extracurricular activities	78.3%	70.2%
Positive role model/mentor	40.6%	24.8%
Medical assistance	72.6%	79.4%
Proportion that would like to have service available		
Counseling	44.1%	36.8%
Tutoring	36.6%	56.1%
School lunch	30.0%	14.3%
Scholarships	66.1%	75.8%
Special education	33.3%	22.0%
Extracurricular activities	42.9%	30.8%
Positive role model/mentor	52.8%	62.2%
Medical assistance	46.2%	42.9%
Proportion using available services		
Counseling	51.5%	50.9%
Tutoring	46.3%	75.0%
School lunch	75.6%	100%
Scholarships	35.7%	58.8%
Special education	32.4%	45.1%
Extracurricular activities	69.9%	81.9%
Positive role model/mentor	52.5%	76.5%
Medical assistance	68.5%	94.5%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Rating of services – scale of 1-5 5 representing very good		
Counseling	3.82	3.48
Tutoring	4.0	3.56
School lunch	4.04	4.10
Scholarships	4.29	4.45
Special Education	4.09	3.85
Extracurricular activities	4.18	3.81
Positive role model/mentor	4.15	3.88
Medical assistance	4.41	3.96
SERVICES FOR CAREGIVER		
Proportion with service available		
Outreach programs	34.0%	22.7%
Visiting nurse	43.4%	19.9%
Homemaker services/home health aid	37.7%	9.9%
Escort/transportation services	46.2%	23.4%
Shopping assistance	25.5%	7.1%
Parish nurses	15.1%	2.1%
Information about services	52.8%	41.8%
Assistance in accessing services	39.6%	27.0%
Individual caregiver counseling	27.4%	11.3%
Caregiver training or education	25.5%	18.4%
Respite care	28.7%	18.4%
Caregiver support group	17.9%	5.7%
Legal assistance	43.4%	24.8%
Technology assistance	36.8%	7.8%
Medicine/prescription delivery	43.4%	20.6%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Proportion that would like to have service available		
Outreach programs	48.4%	46.7%
Visiting nurse	19.6%	44.4%
Homemaker services/home health aid	22.0%	32.7%
Escort/transportation services	25.5%	40.9%
Shopping assistance	16.9%	27.4%
Parish nurses	18.4%	25.6%
Information about services	71.4%	55.9%
Assistance in accessing services	48.1%	56.8%
Individual caregiver counseling	32.3%	34.0%
Caregiver training or education	34.3%	56.3%
Respite care	32.2%	50.0%
Caregiver support group	47.2%	35.1%
Legal assistance	51.9%	33.8%
Technology assistance	42.6%	53.8%
	Statewide General	Indian Population
Medicine/prescription delivery	28.3%	31.4%
Proportion using available services		
Outreach programs	39.4%	78.6%
Visiting nurse	47.6%	79.2%
Homemaker services/home health aid	20.0%	66.7%
Escort/transportation services	34.7%	56.3%
Shopping assistance	29.6%	72.7%
Parish nurses	43.8%	60.0%
Information about services	58.2%	78.6%
Assistance in accessing services	61.0%	67.6%
Individual caregiver counseling	33.3%	43.8%
Caregiver training or education	33.3%	76.9%
Respite care	42.5%	77.8%
Caregiver support group	15.8%	40.0%
Legal assistance	36.4%	59.4%
Technology assistance	43.2%	40.0%
Medicine/prescription delivery	38.6%	80.0%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Reasons for non-use of services		
Ratings of services – scale of 1 to 5 5 representing very good		
Outreach programs	4.08	3.68
Visiting nurse	4.25	4.23
Homemaker services/home health aid	3.86	4.00
Escort/transportation services	4.27	4.29
Shopping assistance	3.75	3.88
Parish nurses	4.43	3.40
Information about services	4.00	3.67
Assistance in accessing services	3.96	3.52
Individual caregiver counseling	4.20	3.78
Caregiver training or education	4.33	3.94
Respite care	4.13	4.52
Caregiver support group	4.00	4.00
Legal assistance	3.75	4.18
Technology assistance	3.88	4.50
Medicine/prescription delivery	4.40	3.86
Proportion providing service daily, weekly or monthly		
Managing finances	65.2%	87.0%
Contributing financially	80.8%	89.5%
Administer personal care	82.1%	81.9%
Assist with household care	65.5%	84.5%
Assist with meals/nutritional needs	91.8%	92.2%
Assist with errands & shopping	82.2%	87.0`%
Provide companionship	96.0%	94.6%
	Statewide General	Indian Population
Help with emotional needs	83.2%	74.6%
Listen to them	93.9%	94.8%
Provide transportation	87.5%	92.4%
Assist with medicine	57.0%	50.9%
Get other family members involved	50.0%	37.7%
Provide cross cultural education	42.2%	39.0%
Provide discipline	76.5%	88.6%
Provide tutoring/homework assistance	69.0%	74.2%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Proportion that would like help with services		
Managing finances	10.1%	17.4%
Contributing financially	32.5%	40.2%
Administer Personal Care	3.7%	15.3%
Assist with household care	3.7%	15.3%
Assist with meals/nutritional needs	19.0%	23.7%
Assist with errands & shopping	12.3%	20.0%
Provide companionship	11.4%	21.3%
Help with emotional needs	21.7%	18.4%
Listen to them	26.3%	23.1%
Provide transportation	23.2%	19.4%
Assist with medicine	18.1%	35.5%
Get other family members involved	8.8%	16.1%
Provide cross cultural education	12.5%	15.3%
Provide discipline	8.3%	21.2%
Provide tutoring/homework assistance	16.3%	40.0%
Other services listed?	30.9%	50.0%
Kinds of information valued		
Info-line	47.2%	15.6%
Hotline (for immediate needs)	22.6%	9.2%
Someone to talk too (support group)	35.8%	15.6%
Someone to help arrange services	18.9%	14.9%
Information on child's conditions	19.8%	9.2%
Information about law changes	32.1%	11.3%
Financial support	46.2%	36.9%
Respite care	46.2%	12.3%
Aftercare counseling	5.7%	5.0%
Tax break, stipends	37.7%	17.0%
Help in institutional placement	2.8%	4.3%
Help in understanding payment system	6.6%	5.0%
Help in dealing with agencies	29.2%	9.9%
Help in dealing with parent of child	20.8%	12.8%
Assistance in cross cultural education	7.5%	9.9%
Assistance with discipline	16.0%	22.0%
None of the above	17.0%	36.2%

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Changes made due to caregiving		
Moved – changed location	7.5%	5.0%
Sold home to move in with child	.9%	
Stopped working	12.3%	5.0%
Retired early	11.3%	5.7%
Taken less demanding job	2.8%	2.8%
Changed to part-time work	2.8%	2.8%
Reduced official working hours	5.7%	.7%
Lost fringe benefits	3.8%	1.4%
Had time conflicts between work and care	23.6%	10.6%
Used vacation for care	17.9%	11.3%
Taken leave of absence to provide care	5.7%	11.3%
Lost a promotion	.9%	2.8%
Arrived late or taken off early at work	27.4%	16.3%
None of the above	40.6%	60.3%
Amounts spent on care		
\$0 to \$1,000	15.1%	13.5%
\$1001 to \$2,000	14.2%	6.4%
\$2001 to \$3,000	5.7%	6.4%
\$3001 to \$4,000	5.7%	5.7%
\$4001 to \$5,000	5.7%	1.4%
More than \$5,000	26.4%	14.2%
Don't know	24.5%	43.3%
Caregiver's age		
Less than 65	66.0%	61.0%
65 to 69	11.3%	27.7%
70 to 74	10.4%	6.4%
75 to 79	5.7%	.7%
80 to 84	4.7%	.7%
85 and over		

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Caregiver's Marital status		
Married or living with partner	69.8%	39.0%
Single, never married	2.8%	9.2%
Divorced or separated	9.4%	19.9%
Widowed	17.0%	31.2%
Proportion with children in addition to grandchildren in household	21%	36.5%
Their ages		
0 to 4	3	7
5 to 9	6	7
10 to 14	7	13
15 to 18	8	22
18 and above	7	34
Average number of children per caregiver	.29	0.60
Caregiver's gender		
Male	15.1%	13.5%
Female	81.1%	85.8%
Caregiver's education		
Less than high school	11.3%	8.5%
Some high school	10.4%	9.2%
Graduated HS/GED	39.6%	28.4%
Some tech college	3.8%	9.2%
Technical degree	.9%	5.0%
Some college	17.9%	22.5%
College graduate	10.4%	10.6%
Post graduate or professional degree	3.8%	2.1%
Caregiver's employment status		
Full-time employment	25.5%	40.4%
Part-time employment	17.9%	9.9%
Multiple jobs	3.8%	.7%
Retired	28.3%	22.0%
Not working	23.6%	26.2%
Caregiver's household income		
Less than \$10,000	10.4%	27.0%
\$10,000 to \$20,000	27.4%	29.8%
\$20,001 to \$35,000	20.8%	19.9%
\$35,001 to \$50,000	20.8%	8.5%
\$50,001 to \$65,000	7.5%	2.8%
\$65,001 to \$80,000	1.9%	1.4%
\$80,001 to \$100,000	2.8%	1.4%
More than 100,000		

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

	Statewide General	Indian Population
Caregiver's race/ethnicity		
White (Non-Hispanic)	84.0%	.7%
White (Hispanic)	1.9%	
Black or African American		
Asian American		
American Indian or Alaska Native	12.3%	99.3%
Native Hawaiian or Pacific Islander		
Other	.9%	
Caregiver's principle language		
English	95.3%	81.6%
Spanish		
Other	4.7%	18.4%