

III. PROFILE OF FAMILY CAREGIVERS

This chapter profiles informal caregivers and the individuals they assist. An understanding of caregiver characteristics and needs informs program planning and development. As a result, the information presented might be of greater interest to planners and program developers than to others in the aging network. The data compare alternative estimates of the total number of caregivers and relies on the best available sources for describing the target population of the National Family Caregiver Support Program (NFCSP). No single data source captures all the aspects necessary to characterize this population.

Developing a new caregiver support program, or revisiting an existing one, requires a clear understanding of:

- The potential number of caregivers,
- Their characteristics and how these correspond to legislative requirements,
- The characteristics of the individuals to whom they provide care,
- The effects of caregiving on caregivers, and
- Meeting the needs of caregivers.

NUMBER OF CAREGIVERS

Overall Caregiver Estimates

As *Exhibit III.1* indicates, estimates of the number of caregivers range from 7 million (3.4 percent) to 54 million (26.6 percent) individuals. Although the exhibit reflects only some of the reasons for differences in caregiver estimates, differences can result from variations in:

- **Population for whom assistance was provided** (age range for the population to whom assistance was provided [e.g., all ages or age 65 and over] and whether the care recipient population considered needed to have a specific level of impairment);
- **Population providing care** (restrictions in terms of the relationship of the caregiver to the care recipient [e.g., relatives versus others] and the caregiver and care recipient living together);
- **Degree of help** (providing any assistance at all versus providing regular assistance, as well as a primary caregiver designation);
- **Timeframe considered for having provided care** (questions structured in terms of a timeframe [e.g., past month or past year] with longer timeframes resulting in more caregivers);

- **Data collection methods** (1) identification of caregivers by asking individuals with a disability or their proxies about all people who provide assistance [care recipient identified] and 2) identification of caregivers by asking a general sample if they provide assistance [self-identified]; and
- **Unit of observation** (counting households rather than individuals).

Using the two main data collection methods—care recipient identification and self-identified caregivers—surveys have approached estimates of caregivers. Estimates that rely on care recipient identification could double count individuals because some caregivers provide assistance for more than one individual. Data from the Survey of Income and Program Participation (SIPP) suggests this overlap might be as much as 15 percent. In addition, the numbers of helpers the care recipient can identify can affect estimates. In contrast, self-identification might undercount caregivers because it fails to capture some individuals who do not consider themselves caregivers, even though they provide substantial assistance.

Other things being equal, counting households rather than individuals results in smaller estimates because fewer households exist and some households have more than one individual providing care. But, because only one individual in a household would have to provide care for the whole household to be counted, counting households can also increase prevalence estimates (the percentage providing care).

Grandparents Caring for Grandchildren

None of the data sources presented in *Exhibit III.1* fully accounts for older grandparents caring for their grandchildren because most data sources fail to consider care provided to children and the estimates that include child recipients also require that the care recipient have a disability. *Exhibit III.2*, however, presents estimates of the number of grandparents caring for grandchildren from tabulations of the March 1997 and March 2001 Current Population Survey (CPS) and the Census 2000 Supplementary Survey (C2SS). Key distinctions in grandparent caregiver estimates parallel some of those for the broader caregiver estimate, 1) whether the grandchild must be a minor and then whether those age 18 are considered minors, 2) age requirements for the grandparent caregiver, 3) whether the grandparent must be the primary caregiver and how that status is defined (e.g., absence of parents or grandparent currently assuming responsibility for most of the child's basic needs), 4) whether the household must be headed by a grandparent, 5) permanence of the primary caregiver role (e.g., temporarily primary caregiver due to incarceration of the parent), and 6) timeframe and unit of observation. Although the CPS estimates require a grandparent-headed household, the C2SS did not make that stipulation but asked whether the grandparent took responsibility for the minor grandchildren. These approaches resulted in differing estimates, with the lack of the grandparent-headed requirement of the C2SS and the direct question about grandparent responsibility resulting in higher estimates relative to the CPS (2.35 million versus 1.28 million).

**Exhibit III.1
Alternative Estimates of Caregivers**

	1987 NAC	1997 NAC/AARP	1992 NSFH	1982 NLTCS	1984 NLTCS	1994 NLTCS	1999 NLTCS	1997, 1996 SIPP Wave 5	1998, 1996 SIPP Wave 7	1997 NCOA/Pew	2000 NFCA
Caregivers (in millions)	7.0 4.4 primary 1.1 long distance (20+ min.)	22.4 8.6 primary 5.0 long distance (20+ min.)	52.0	7.6	7.3	7.1	7.0 2.8 primary	13.0	9.5 6.7 primary	7.0 long distance (1+ hr.)	54.0
Unit of observation	Households		Individuals	Individuals				Individuals	Individuals	Individuals	Individuals
Prevalence	7.8%	23.0%	31.0%	4.3%	4.0%	3.6%	3.4%	6.2%	4.5%	3.5%	26.6%
Degree of help	Assistance with 2+ IADLs or 1+ ADLs	Any unpaid care	Any help	Who regularly helps?				Who generally helps?	Provide regular assistance?	Provide or manage care services or financial or legal assistance	Provide support services or personal care
Care Recipient Characteristics											
Age	50+	50+	All ages	65+				15+	All ages	55+	All ages
Functional status	2+ IADLs or 1+ ADLs	Need help to take care of self	Physical or mental condition, illness or disability	ADL or IADL impairments of 3+ months				ADL or IADL impairment	Long-term illness or disability	Unspecified	Disability or chronic illness
Methodological Considerations											
Timeframe for reporting	Past 12 months	Past 12 months	Past 12 months	Not specified				Not specified	Past month	NA	NA
Caregiver designation	Self-identified	Self-identified	Self-identified	Care recipient identified up to 5 helpers				Care recipient identified up to 2 helpers	Self-identified	Self-identified	Self-identified

**Exhibit III.1
Alternative Estimates of Caregivers, continued**

	1987 NAC	1997 NAC/AARP	1992 NSFH	1982 NLTCS	1984 NLTCS	1994 NLTCS	1999 NLTCS	1997, 1996 SIPP Wave 5	1998, 1996 SIPP Wave 7	1997 NCOA/Pew	2000 NFCA
Methodological Considerations, cont.											
Mode of interview	Telephone	Telephone	1 hour 40 minutes in person	2 hours in person for care recipient; in 1982 and 1999, generally, 30 minutes in person if caregiver lived with care recipient, by phone if not			2 hours in person	2 hours in person	Telephone	Telephone	
Sample size	754 Caregivers	1,509 Caregivers	10,005 Individuals about 3,000 caregivers	About 6,000 age 65+ individuals with disabilities			36,700 Households about 60,000 individuals about 2,500 with ADLs or IADLs	36,700 Households about 60,000 individuals 2,829 caregivers	200 Caregivers	1000 Individuals 266 caregivers	

1987 National Alliance for Caregiving (NAC) – Wagner, D. (1997). *Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997*.

1997 NAC and AARP (1997). *Family Caregiving in the U.S., Findings from a National Survey, 1997*. Washington, DC: AARP.

1992 National Survey of Families and Households (NSFH) – Administration on Aging (AoA) and Office of the Assistant Secretary for Planning and Evaluation (ASPE). (1998). *Informal Caregiving: Compassion in Action*. Available at <http://aspe.hhs.gov/daltcp/reports/carebro2.pdf>.

1982 National Long Term Care Survey (NLTCS) – Stone, R., Cafferata, G.L., and Sangl, J., (1987). Caregivers of the Frail Elderly: A National Profile. *The Gerontologist*, 27: 616–626.

1984 NLTCS – Stone, R. and Kemper, P. (1989). Spouses of Disabled Elderly: How Large a Constituency for Long-Term Care Reform? *The Milbank Quarterly*, 67: 485–506.

1994 NLTCS – AoA and ASPE (1998). *Informal Caregiving: Compassion in Action*. Available at <http://aspe.hhs.gov/daltcp/reports/carebro2.pdf>.

1999 NLTCS – tabulated by The Lewin Group.

1997, 1996 Survey of Income and Program Participation (SIPP), Wave 5, Adult Disability Topical Module – tabulated by The Lewin Group.

1998, 1996 SIPP, Wave 7, Home Care (Caregiver) Topical Module – tabulated by The Lewin Group.

1997, National Council on Aging and Pew Charitable Trusts – Wagner, D. (1997). Long-Distance Caregiving for Older Adults. *Healthcare and Aging*, National Council on the Aging, Spring 1997.

2000, National Family Caregivers Association (NFCA). (2000). Caregiver Survey-2000. Kensington, MD: NFCA.

Over time, the CPS estimates show significant increases in the number of grandparents taking on the role of primary caregiver for their grandchildren. In 1990, parents were absent in 691,000 grandparent-headed households compared to 904,000 in 1997 and 1.26 million in 2001— an increase of more than 80 percent.¹

Exhibit III.2
Estimates of Grandparents Caring for Grandchildren

	Number (in millions)	Grandparent- Headed Households	Minor Grandchildren Only
Current Population Survey			
1997	3.69	Yes	No
2001			
All grandchildren	4.18	Yes	No
Minor grandchildren	3.61	Yes	Yes
Minor grandchildren and parents absent	1.28	Yes	Yes
Census 2000 Supplementary Survey			
Minor grandchildren	5.60	Not required	Yes
Grandparent responsible	2.35	Not required	Yes

Source: 1997 CPS data from Bryson, K. and Casper, L. (1999). *Co-resident Grandparents and Grandchildren*, Current Population Reports, Special Studies, P23-198, Washington DC: U.S. Bureau of the Census; 2001 CPS data based on unpublished tabulations by The Lewin Group; Census 2000 Supplementary Survey data from the Bureau of the Census Web site summary tables, QT-02 Profile of Selected Social Characteristics: 2000.

Exhibit III.3 shows the impact of the NFCSP requirements regarding grandparents. At the broadest level, the 2001 data indicated 2.81 million households headed by a grandparent where at least one grandchild lives in the same household. Restricting to where the grandparent took on the primary caregiver role by only considering households where the parents of the grandchild were absent reduced the number of households to 1.26 million. The further condition that the grandchild be a minor resulted in 825,000 households. Finally, the NFCSP requirement that the grandparent be age 60 or older produced 327,000 households, or 456,000 grandparents. These data indicate that both the minor grandchild and the older grandparent restrictions significantly narrow the grandparent caregivers for whom NFCSP funds can be used. **Exhibit III.4** indicates that about one-half of older grandparents cared for non-minor grandchildren, and nearly two-thirds of grandparents caring for minor grandchildren were under age 60.

¹ Casper, L. and Bryson, K. (1998). *Co-resident Grandparents and Their Grandchildren: Grandparent Maintained Families*. Population Division Working Paper No. 26: Washington, DC: U.S. Bureau of the Census.

**Exhibit III.3
Narrowing to the NFCSP Definition of Grandparents
Caring for Grandchildren**

Grandparent-Headed Households	Considerations	Grandparents
2.81 million	Grandparent-headed households	4.18 million
1.26 million	Parents absent	1.84 million
0.82 million	Minor grandchildren (age 0–18)	1.28 million
0.33 million	Older grandparents (age 60+)	0.46 million

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

**Exhibit III.4
Estimates of the Number of Grandparent Households and
Grandparents Caring for Grandchildren (Parents Absent),
by Grandchild Minor Status and Grandparent Age, 2001**

	Total	Grandchild < age 19	Grandchild 19+	Total	Grandchild < age 19	Grandchild 19+
Households						
Total	1,260,216	824,958	435,258	100.0%	65.5%	34.5%
Grandparent age 60+	722,589	326,621	395,968	57.3%	25.9%	31.4%
Grandparent < age 60	537,627	498,337	39,290	42.7%	39.5%	3.1%
Individuals						
Total	1,844,968	1,281,004	563,964	100.0%	69.4%	30.6%
Grandparent age 60+	951,192	455,692	495,500	51.6%	24.7%	26.9%
Grandparent < age 60	893,776	825,312	68,464	48.4%	44.7%	3.7%

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

Some portion of grandparents and possibly other older relatives and non-relatives provide assistance to children with mental retardation or developmental disabilities (MR/DD). Based on data from the 1984 National Health Interview Survey Disability Supplement (NHIS-D), approximately 120,000 children under age 18 with MR/DD lived with other relatives.^{2 3} The number of caregivers associated with these children would be greater because in some households more than one individual would provide assistance. However, just as with the grandparent estimates, we would expect that a significant portion of these non-relatives were under age 60.

² Non-relative living arrangements were negligible.

³ Larson, S., Lakin, C., Anderson, L., and Kwak, N. (2001). Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or with Family Members: NHIS-D Analysis. *MR/DD Data Brief*. University of Minnesota: Minneapolis, MN. Institute on Community Integration, 3(2).

NFCSP Caregivers

No single data source lends itself to an estimate of the number of caregivers potentially covered by NFCSP definitions. Our best estimate of approximately 8.2 million combines SIPP data for the number of caregivers for individuals age 60 and older with functional limitations (7.7 million) with the CPS data for the number of grandparents age 60 and older caring for grandchildren under age 19 (456,000). This estimate used the absence of parents to define the primary caregiver role, and it lacks non-relative caregivers age 60 and older caring for someone under age 19, but non-relatives age 60 and older caring for minors would be expected to be small. In addition, it fails to consider long-distance caregivers of individuals age 60 and older, who likely exceed 5.0 million.

SUAs and AAAs lacking sufficient resources for a survey-based needs assessment might use 2000 Census data and prevalence estimates of caregivers to approximate the total number of NFCSP caregivers in their area (state, county, city, or census tract). The characteristics of age, sex, and race/ethnicity in *Exhibit III.5* were chosen because, 1) data from the 2000 Census are available for many geographic levels for age by sex by race/ethnicity, and 2) the prevalence of caregiving differs by these characteristics. The prevalence estimates for caregivers of older individuals focus on primary caregivers of those with disabilities who are age 65 and older. Additional factors to consider in customizing an estimate for a geographic area include the mobility of the population (e.g., in areas with military bases, this highly mobile population would suggest fewer caregivers) and urban/rural status (central city urban areas are much more likely to have grandparents meeting the NFCSP requirements as a caregiver). While the caregiver prevalence rates for race and ethnicity groups other than those provided in *Exhibit III.5* may differ from these broader groups, the national data sources used to estimate the rates did not support statistically reliable estimates for these groups. SUAs and AAAs with high concentrations of Asian, Hispanics, Native Americans or other minorities may wish to supplement any estimates derived based on *Exhibit III.5* with their own data collection efforts.

Exhibit III.5 Estimating the Number of Caregivers in an Area

Step 1: Obtain 2000 Census Estimates of Population by Age, Sex, and Race/Ethnicity.

These data can be found using the Bureau of the Census Web site’s American Factfinder tool at <http://factfinder.census.gov> (*Appendix B* includes screen shots for these instructions). First, select “Advanced National Summary File 1”. In the bottom paragraph of the resulting page, click “detailed tables”. On the new page, choose “list” as the selection method, and choose “State” as the geographic type. Next, select the state for which you want data and click “Add”. Then click “Next”. On the resulting page, select “show all tables” as the search. Select the following tables:

- PCT12-Sex by Age (Total Population)
- PCT12I-Sex by Age (White Alone, Not Hispanic or Latino)
- PCT12J-Sex by Age (Black Alone, Not Hispanic or Latino)

Click “Add” and then click “Show Table”. Copy the tables into Excel. To calculate “Other,” subtract Hispanic, White Alone, and Black Alone from Total. For the White, Black, Hispanic, and Other race categories, sum the ages into the same age groups provided in the matrix below.

Step 2: Multiply the Census data by the prevalence matrix below for each of the corresponding cells. Non-relatives should be multiplied by the total population by age.

Caregivers of Older Individuals						
Age	Male			Female		
	Relative		Non-Relative	Relative		Non-Relative
	White Non-Hispanic	Non-White and Hispanic		White Non-Hispanic	Non-White and Hispanic	
18–34	0.17%	0.09%	0.04%	0.34%	0.21%	0.22%
35–44	0.34%	0.16%	0.08%	0.65%	0.39%	0.24%
45–54	0.45%	0.18%	0.09%	1.52%	1.26%	0.51%
55–64	1.06%	0.28%	0.16%	3.14%	2.19%	0.80%
65–74	2.32%	2.11%	0.40%	3.30%	2.97%	0.36%
75+	4.99%	1.70%	0.16%	2.61%	1.85%	0.74%
Older Grandparents Caring for Minor Grandchildren						
Age	White	Black	Hispanic	Other		
60–64	0.9%	6.3%	4.2%	0.9%		
65–69	0.3%	3.2%	1.1%	0.8%		
70+	0.6%	4.5%	2.5%	0.6%		

Step 3: Sum the results of Step 2 to generate a total estimate of potential caregivers.

CAREGIVER CHARACTERISTICS

This section reviews caregiver characteristics for the broad group of those caring for individuals with a long-term illness or disability and then focuses on the best available estimates of the characteristics of the target populations for the NFCSP.

Caregivers of Individuals with a Long-Term Illness or Disability

The SIPP provides the most recent estimates of caregivers of a chronically impaired population.⁴ These data confirm previous research regarding caregiver characteristics, including that:

- People at all stages of life gave and received informal care.
- Adults of all ages assumed caregiving responsibilities, but those in middle-to-late middle age (age 45–64) had the greatest likelihood of being a caregiver.
- Men and women provided informal care; however, women found themselves in this role more often and for longer, more intense periods.
- Caregivers included individuals with competing demands—about one-half employed, one-third with minor children in their home, and one in five both employed and with children.

Additional details on caregiver characteristics, the average hours per week and average number of years spent caregiving, can be found in the issue brief *Characteristics of Caregivers Based on the Survey of Income and Program Participation* by Lisa Maria Alexih, Sharon Zeruld, and BrieAnne Olearczyk, The Lewin Group at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

NFCSP Target Populations

Caregivers of Older Care Recipients

The National Long-Term Care Survey (NLTCS) Caregiver Supplement provides the most comprehensive information about caregivers of older care recipients. The care recipient population for whom the caregiver data were gathered is a little more restrictive than that of the NFCSP because it includes individuals with disabilities age 65 and older, rather than 60 and older. In addition, the data include only primary caregivers. Nevertheless, the NLTCS Caregiver Supplement contains the most information about primary caregivers focused on older Americans. **Exhibit III.6** suggests that caregivers of older Americans are a vulnerable group with almost one-half over age 65 themselves and nearly one-third in fair-to-poor health status. As with general caregivers, women provided care in the majority of cases. However, for older care recipients, husbands played a notable role, constituting 16 percent of primary caregivers, the oldest subgroup of caregivers, and often the lone caregiver (no additional informal or paid assistance). Just like the general

⁴ Alexih, L., Zeruld, S., and Olearczyk, B. (2001). *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/IssueBriefs.html>.

caregivers, the subgroup caring for older care recipients must contend with competing familial and employment demands.

**Exhibit III.6
Characteristics of Primary Caregivers
of Older Americans, 1999**

Caregiver Characteristic	All Caregivers	Relationship of Caregiver to Disabled Person				
		Wife	Daughter	Husband	Son	Other
Population (1,000s)	2,767	639	837	463	284	543
Row Percentage	100.0	23.1	30.3	16.7	10.3	19.6
Column Percentage Distribution						
Type of Caregiver						
Primary caregiver only	34.4	48.3	29.1	41.8	25.8	24.4
Primary caregiver with unpaid help only	52.4	39.4	57.4	49.0	58.4	59.7
Primary caregiver with paid help only	4.5	5.9	4.7	3.6	4.2	3.6
Primary caregiver with paid and unpaid help	6.0	2.8	6.8	3.7	8.9	8.8
Missing	2.7	3.6	2.1	2.0	2.6	3.5
Race/Ethnicity						
Age in Years						
14-44	11.4	1.0	16.5	0.5	23.2	18.7
45-64	38.0	15.1	65.6	2.2	57.7	42.7
65-74	21.2	35.8	12.3	34.3	10.0	12.6
75+	22.4	37.7	2.3	58.0	1.8	16.0
Missing	7.0	10.4	3.4	4.9	7.3	9.9
Mean age	62.7	71.6	54.8	76.9	53.6	57.4
White	64.9	74.6	78.4	88.1	80.9	0.0
Black	6.2	7.3	11.5	4.2	3.5	0.0
Hispanic	6.4	11.2	7.6	7.1	12.0	0.0
Other	1.8	2.9	2.1	0.7	3.6	0.0
Unknown	20.7	3.9	0.4	0.0	0.0	100.0
Living Arrangements						
Lives with disabled person	68.9	98.4	49.3	97.8	53.3	48.0
Lives separately from disabled person	31.1	1.6	50.7	2.2	46.7	52.0
Marital Status						
Married	71.3	99.5	57.3	99.5	46.1	49.1
Widowed	6.0	0.0	9.7	0.0	1.4	14.7
Divorced/separated	11.5	0.5	19.9	0.0	23.9	14.8
Never married	10.0	0.0	12.0	0.5	27.8	17.4
Missing	1.2	0.0	1.1	0.0	0.9	3.9
Household Members Under 18 Years of Age						
None	89.7	95.1	83.9	98.0	86.8	86.9
1	5.6	3.5	8.5	0.3	4.4	8.5
2	3.4	0.8	5.8	1.1	6.7	3.1
3 or more	1.3	0.7	1.9	0.6	2.1	1.5
Employment Status						
Working	31.7	5.5	50.1	8.5	60.2	38.7
Not working	67.2	93.2	48.7	91.5	37.8	59.7
Missing	1.2	1.3	1.2	0.0	2.1	1.6

Exhibit III.6
Characteristics of Primary Caregivers
of Older Americans, 1999, continued

Caregiver Characteristic	All Caregivers	Relationship of Caregiver to Disabled Person				
		Wife	Daughter	Husband	Son	Other
Unemployed Caregivers						
Had to care for care recipient	9.5	9.5	13.4	3.9	11.8	12.1
Not working for other reasons	90.5	90.5	86.6	96.1	88.2	87.9
Health Status						
Excellent	23.6	13.1	27.6	16.1	31.8	31.8
Good	43.2	44.5	45.9	48.5	35.8	36.7
Fair/poor	30.6	39.5	25.4	31.8	29.0	27.8
Missing	2.7	2.9	1.1	3.6	3.4	3.7

Note: Data are based on caregivers for individuals age 65 and older. Race/ethnicity based on the race/ethnicity of the care recipient and, therefore, unavailable for non-relatives.

Source: The Lewin Group tabulation of the 1999 National Long-Term Care Survey.

Older Grandparents Caring for Minor Grandchildren

Tabulations of the March 2001 CPS provide a clearer picture of the characteristics of older grandparents caring for minor grandchildren, as *Exhibit III.7* shows. To facilitate an understanding of the characteristics of those grandparents in the NFCSP target population relative to grandparents caring for grandchildren who fall outside the age requirements, the exhibit includes the two groups, plus a comparison to general households with an age 60 and older householder. Based on the characteristics of the householder, all of the comparisons reside at the household level. The NFCSP grandparent population compared to non-NFCSP grandparents tended to:

- Care for more grandchildren,
- Be a male head of household,
- Be Black and live in a city center,
- Have a lower level of education,
- Be no longer in the labor force,
- Have lower income, and
- Have poorer health status.

Within the NFCSP grandparents, grandfather-headed households were much more likely to have both grandparents present (93.8 percent were married) compared with grandmother-headed households (27.7 percent married). These patterns held true relative to the general householder age 60 and older, with the following exceptions: NFCSP grandparents were more likely to have female-headed households, and among those employed, the NFCSP grandparents were more likely to hold a part-time job, while employed householders age 60 and over tended to have a full-time job.

Exhibit III.7
Characteristics of Grandparent Households Caring
for Minor Grandchildren, 2001

Characteristics	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	Total Grandparent Households	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	House- holders Age 60+
Total	933,595	326,621	1,260,216	100.0%	100.0%	100.0%
Number of Grandchildren						
1	715,745	210,735	926,480	76.7%	64.5%	NA
2	154,512	74,568	229,080	16.6%	22.8%	NA
3+	63,339	41,317	104,656	6.8%	12.6% *	NA
Sex						
Male	306,815	138,491	445,307	32.9%	42.4%	49.9%
Married	234,933	129,898	364,832	76.6%	93.8%	72.2%
Female	626,780	188,129	814,910	67.1%	57.6%	50.1%
Married	167,789	52,131	219,920	26.8%	27.7% *	20.7%
Race/Ethnicity						
White non-Hispanic	464,202	150,640	614,842	49.7%	46.1%	80.1%
Black non-Hispanic	282,815	126,335	409,150	30.3%	38.7%	9.2%
Hispanic	128,279	39,429	167,708	13.7%	12.1% *	5.4%
Other	58,300	10,216	68,516	6.2% *	3.1% *	5.3%
Metropolitan Area Status						
Central city	226,037	114,356	340,393	24.2%	35.0%	22.6%
Suburbs	321,353	103,951	425,304	34.4%	31.8%	39.4%
Non-metropolitan area	386,205	108,314	494,519	41.4%	33.2%	38.0%
Education						
Less than high school	325,525	152,201	477,726	34.9%	46.6%	28.1%
High school graduate	357,423	99,521	456,944	38.3%	30.5%	33.7%
Some college	178,619	44,325	222,944	19.1%	13.6% *	20.0%
College graduate+	72,029	30,574	102,603	7.7%	9.4% *	18.2%
Employment Status						
Not in labor force	497,758	232,148	729,906	53.3%	71.1%	77.7%
Part-time	287,944	52,790	128,876	30.8%	16.2%	7.7%
Fulltime	93,731	35,145	340,735	10.0%	10.8% *	13.8%
Unemployed	54,162	6,537	60,699	5.8% *	2.0% *	0.8%
Family Income/Poverty Level (2000)						
Under 100%	931,595	324,620	1,258,216	19.2%	24.9%	12.4%
100 – 149%	114,761	62,633	177,394	12.3%	19.2%	14.8%
150 – 199%	94,689	43,280	137,968	10.1%	13.3%	12.3%
200+%	544,805	139,308	684,113	58.4%	42.7%	60.5%
Health Status						
Poor	89,543	31,762	121,305	9.6%	9.7% *	11.4%
Fair	202,176	87,643	289,818	21.7%	26.8%	22.0%
Good	314,784	99,264	414,048	33.7%	30.4%	32.6%
Very good	220,985	74,781	295,766	23.7%	22.9%	22.7%
Excellent	106,107	33,171	139,279	11.4%	10.2% *	11.4%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

Source: The Lewin Group calculations using data from the March 2001 CPS Income Supplement.

Exhibit III.7
Characteristics of Grandparent Households Caring
for Minor Grandchildren, 2001, continued

Characteristics	Grandparent <Age 60 or Child Age 19+	NFCSP Target Population	Total Grandparent Households	Grandparent <Age 60 or Child Age 19+	NFCSP Target Population	House- holders Age 60+
Family Income/Poverty Level (2000)						
Under 100%	931,595	324,620	1,258,216	19.2%	24.9%	12.4%
100 – 149%	114,761	62,633	177,394	12.3%	19.2%	14.8%
150 – 199%	94,689	43,280	137,968	10.1%	13.3%	12.3%
200+%	544,805	139,308	684,113	58.4%	42.7%	60.5%
Health Status						
Poor	89,543	31,762	121,305	9.6%	9.7% *	11.4%
Fair	202,176	87,643	289,818	21.7%	26.8%	22.0%
Good	314,784	99,264	414,048	33.7%	30.4%	32.6%
Very good	220,985	74,781	295,766	23.7%	22.9%	22.7%
Excellent	106,107	33,171	139,279	11.4%	10.2%*	11.4%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

Source: The Lewin Group calculations using data from the March 2001 CPS Income Supplement.

NFCSP Care Recipients

Older Adults

The aging network is intimately familiar with the characteristics of older Americans receiving informal care because it constitutes the traditional service population; but it has less knowledge of grandchildren cared for by grandparents that the NFCSP targets. Based on 1998 data from the SIPP, 5.1 million individuals age 60 and older received care from family and friends. *Exhibit III.8* summarizes the key socio-demographic characteristics as well as functional status for this group by the relationship to the first listed caregiver. *Appendix B* contains data for those age 75 and older and for those with 2 or more activities of daily living (ADLs). Some highlights include the following:

- In general, individuals age 60 and older receiving assistance from family or friends were more likely female, unmarried, living with others, had moderate income, and an instrumental activity of daily living (IADL) impairment relative to ADL impairments.
- Care recipients age 60 and older more often had adult children as primary caregivers (38 percent), followed by spouses (33 percent) and others (28 percent).
- For the age 60 and older care recipient population, females made up the majority of spouses providing care (58 percent wives) and children providing care (70 percent daughters).
- Adult children care for parents who were older on average than those cared for by spouses; however, spouses cared for individuals with more ADL impairments on average than children.

- Recipients of care from their spouse were better off financially than those receiving care from a child or others, primarily because the former enjoyed two social security benefits, while the majority of the latter were widowed.
- Care recipients with 2 or more ADLs were about one-half as likely to live alone, and their spouse was more likely to be the primary caregiver.
- Older care recipients (those age 75 and older) were more likely to be widowed and, as a result, less likely to be receiving care from a spouse.

**Exhibit III.8
Characteristics of Older Americans Receiving Care
from Family and Friends, 1998**

	All Care Recipients Age 60+	Relationship of Caregiver to Disabled Person				
		Wife	Husband	Daughter	Son	Other
Population (1,000s)	5,154	1,001	731	1,379	578	1,465
Row Percentage	100.0	19.4	14.2	26.7	11.2	28.4
Column Percentage Distribution						
Age in Years						
60–69	25.3	32.6	41.0	18.7	15.2	22.8
70–79	35.2	38.0	38.5	32.9	36.4	33.5
80+	39.4	29.5	20.5	48.5	48.4	43.7
Mean age	75.5	73.6	72.1	77.1	77.4	76.4
Gender						
Male	35.6	100.0	0.0	16.9	25.0	31.3
Female	64.4	0.0	100.0	83.1	75.0	68.7
Marital Status						
Married	45.0	100.0	100.0	17.6	22.5	14.7
Widowed	41.3	0.0	0.0	70.3	66.6	53.1
Divorced/separated	8.0	0.0	0.0	10.1	10.0	14.5
Never married	5.7	0.0	0.0	2.0	0.9	17.8
Living Arrangements						
Lives alone	30.2	0.0	0.0	40.9	37.7	51.7
Lives with spouse only	34.3	81.2	85.3	11.0	10.8	9.0
Lives with children	18.5	12.5	11.1	27.2	30.9	13.2
Other arrangements	17.1	6.3	3.6	20.9	20.7	26.1
Family Income/Poverty Level (1998)						
Below 100% poverty	18.4	7.5	4.7	22.1	18.5	29.0
100%–150% poverty	21.0	17.8	16.1	22.9	22.8	23.0
150%–300% poverty	37.7	41.7	48.9	34.3	37.6	32.4
Above 300% poverty	23.0	33.0	30.3	20.7	21.2	15.6
ADL Score						
No ADLs	52.1	43.9	40.1	55.1	57.6	58.6
1–2 ADLs	26.0	26.5	31.8	25.7	24.7	23.8
3–4 ADLs	9.4	13.3	12.5	7.9	10.9	6.0
5–6 ADLs	12.5	16.3	15.7	11.3	6.8	11.5
Mean ADL Score	1.35	1.73	1.71	1.25	1.04	1.14

Exhibit III.8
Characteristics of Older Americans Receiving Care
from Family and Friends, 1998, continued

	All Care Recipients Age 60+	Relationship of Caregiver to Disabled Person				
		Wife	Husband	Daughter	Son	Other
IADL Score						
No IADL	4.2	7.8	8.2	2.3	1.9	2.4
1–2 IADLs	53.4	43.2	45.2	53.2	56.7	63.5
3–4 IADLs	23.1	22.2	29.7	24.9	23.4	18.6
5–6 IADLs	19.3	26.9	16.9	19.6	18.1	15.6
Mean IADL Score	2.51	2.74	2.46	2.59	2.48	2.31

Source: The Lewin Group tabulations of the 1996 SIPP, Wave 5.

Minor Grandchildren

To understand the characteristics of minor grandchildren receiving care from older grandparents, *Exhibit III.9* presents data from the March 2001 CPS. For grandmother-maintained relative to grandfather-maintained households meeting the NFCSP criteria, grandchildren in grandmother-maintained households more likely:

- Were Black,
- Had public health insurance (Medicare or Medicaid),
- Lived in city centers in households with three or more members under age 18,
- Had lower income, and correspondingly
- Were more likely to receive assistance from a variety of public programs.

Exhibit III.9
Characteristics of Grandchildren
Meeting NFCSP Requirements, 2001

Characteristics	NFCSP Grandfather-Maintained	NFCSP Grandmother-Maintained	NFCSP All Grandparent-Maintained	All Children
Children (number)	226,440	387,502	613,942	72.6M
% distribution	100.0%	100.0%	100.0%	100.0%
Race/Ethnicity				
White non-Hispanic	50.2%	29.9%	37.4%	61.5%
Black non-Hispanic	30.7%	59.8%	49.1%	15.3%
Hispanic	16.0% *	6.3%	9.9%	16.6%
Other non-Hispanic	3.2% *	4.0%	3.7%	6.6%
Age in Years				
Under 6	18.6% *	15.2%	16.4%	32.6%
6–11	41.3%	33.5%	36.4%	34.2%
12–17	40.1%	51.3%	47.2%	33.2%

**Exhibit III.9
 Characteristics of Grandchildren
 Meeting NFCSP Requirements, 2001, continued**

Characteristics	NFCSP Grandfather- Maintained	NFCSP Grandmother- Maintained	NFCSP All Grandparent- Maintained	All Children
Gender				
Male	49.3%	54.1%	52.4%	51.2%
Female	50.7%	45.9%	47.6%	48.8%
Nativity				
U.S. born, U.S. parents	91.7%	95.4%	94.0%	78.1%
U.S. born, 1 foreign parent	2.9% *	2.5%	2.6%	6.0%
U.S. born, 2 foreign parents	4.0% *	1.2%	2.2%	11.0%
Foreign born	1.4% *	0.9%	1.1%	4.9%
Health Status				
Good, fair, or poor	26.3% *	29.0%	27.9%	19.5%
Very good	27.7%	20.8%	23.4%	29.3%
Excellent	46.0%	50.2%	48.7%	51.2%
Insurance Coverage				
Private insurance	44.0%	25.2%	32.2%	70.6%
Public insurance only	20.6% *	50.7%	39.6%	17.9%
No health insurance	35.3%	24.1%	28.2%	11.6%
Metropolitan Area Status				
Central city	31.5%	45.3%	40.2%	23.7%
Suburbs	38.6%	25.9%	30.6%	44.6%
Non-metropolitan area	29.9%	28.9%	29.2%	31.6%
Household Members under 18 Years of Age				
One	43.8%	42.2%	42.8%	22.4%
Two	34.4%	20.3%	25.5%	39.7%
Three or more	21.9% *	37.5%	31.7%	37.9%
Family Income/Poverty Level (2000)				
Under 100% of poverty level	19.9% *	33.9%	28.7%	16.7%
100%–149% of poverty level	17.4% *	25.6%	22.6%	10.7%
150%–199% of poverty level	10.5% *	11.5%	11.1%	10.5%
200% of poverty level	52.2%	29.0%	37.6%	62.1%

Exhibit III.9
Characteristics of Grandchildren
Meeting NFCSP Requirements, 2001, continued

Characteristics	NFCSP Grandfather- Maintained	NFCSP Grandmother- Maintained	NFCSP All Grandparent- Maintained	All Children
Household Public Assistance				
No public assistance	64.6%	36.6%	46.9%	71.0%
Any public assistance program	35.4%	63.4%	53.1%	29.0%
School lunch program	25.4% *	53.3%	43.0%	23.6%
Food stamps	10.8% *	26.8%	20.9%	10.7%
AFDC, ADC, TANF, GA**	6.6% *	23.0%	17.0%	5.5%
SSI	9.8% *	12.2%	11.3%	3.3%
Housing assistance	1.9% *	10.3%	7.2% *	5.7%
Energy assistance	1.0% *	8.0%	5.4% *	3.2%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

** AFDC-Aid to Families with Dependent Children, ADC-Aid to Dependent Children, TANF-Temporary Assistance to Needy Families, GA -General Assistance, and SSI-Supplemental Security Income.

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

Grandchildren in households meeting the NFCSP requirements differed substantially from all children in that they more likely:

- Were non-White,
- Were school age (as a result of the age requirement for the grandparents),
- Were U.S. born (as well as their parents),
- Suffered poorer health and were without health insurance,
- Lived in a city center as opposed to the suburbs,
- Had family income less than the poverty level (28.7 percent versus 16.7 percent), and
- Received public assistance (53.1 percent versus 29.0 percent).

The data indicate a vulnerable group of children, with those in grandmother-maintained households more vulnerable but also more likely tied into the public support system.

EFFECTS OF CAREGIVING ON CAREGIVERS

This section borrows heavily from Rhonda Montgomery and Karl Kosloski's issue brief *Change, Continuity and Diversity Among Caregivers*, found at <http://www.aoa.gov/carenetwork/IssueBriefs.html>. Depending on the caregiver's familial role, the types and intensity of tasks that caregivers perform vary dramatically. The variability in caregiving behaviors indicates that the caregiving experience can differ significantly for caregivers. Montgomery's "marker framework" captures caregiving as a dynamic process and serves

as a tool to gauge shifts in caregiving stages and receptivity to services and supports.⁵ The seven markers of this caregiving trajectory are, 1) performance of initial caregiving task, 2) self-definition as a caregiver, 3) provision of personal care, 4) seeking out or using assistive services, 5) consideration of institutionalization, 6) actual nursing home placement, and 7) termination of the caregiver role. An important consideration is that the order and timing of these markers vary, depending on the individual and type of caregiver (e.g., spouse versus adult children caregivers), and these factors have direct relevance for implementing caregiver support programs. In addition to the type of caregiver, an individual's culture might play a significant role in the spacing of these markers.

The caregiving experience of adult children in contrast to spouses illustrates Montgomery's marker framework and the other factors she emphasizes. The careers of adult children and spouses tend to differ both in terms of the factors that define the onset of the role and the factors that prompt family members to abdicate the role. Adult children have greater choice initially assuming the caregiving role and later leaving it than do spouses.⁶ The types of tasks that adult-children caregivers initially assume, such as assistance with banking or shopping, represent a major role change. Therefore, children tend to identify themselves as caregivers at an earlier point in the caregiving process than do spouses. As a result, children more readily associate strains that they experience in their lives (impacts on their time, energy, and other familial relationships) as a result of added care tasks with the caregiving role. This attribution of strain to the caregiving role, prompts adult children to seek information and assistance earlier in the caregiving process and also contributes to their leaving the role at earlier stages in the disease and dependency process. For children, the lack of legal obligations and limited familial expectations to provide care make it easier for some not to assume the role in the first place. Children who do become caregivers leave the role feeling less guilt than spouses.⁷

Despite the fact that spouses might more likely be the sole caregiver and experience greater stress than children, they are less likely to identify as caregivers and seek and use formal support. Factors other than a greater level of obligation felt contribute to spouses' greater propensity to provide more care at a higher intensity than do adult children. Many tasks that children perform as caregivers (e.g., assistance with transportation, banking, and household chores), spouses perform as part of their marital role. Failing to recognize early care tasks as unique from the marital role, spouses likely experience burden and stress in association with the caregiver role only after their afflicted mate becomes dependent and the caregiving spouse begins to provide personal care. Even then, their greater commitment appears to make them persist and endure in the caregiving role even

⁵ Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/IssueBriefs.html>.

⁶ Montgomery, R.J.V. and Kosloski, K.D. (1999). *Family Caregiving: Change, Continuity and Diversity*. In P. Lawton and R. Rubenstein (Eds.) *Alzheimer's Disease and Related Dementias: Strategies in Care and Research*. New York, NY: Springer Publishing Company.

⁷ Montgomery, R. J. V. (1999). The Family Role in the Context of Long-Term Care. *Journal of Aging and Health*, 11(3), 383–416.

if it involves extensive personal care.⁸ The significant change in the marital relationship associated with providing personal care results in spouses reporting greater emotional stress than adult-children caregivers.⁹

Grandparent and other relative caregivers contend with many of the same issues as those caring for older adults, but most do not have to deal with the disease progression aspects. They do face similar challenges related to their assumed role that place them at significantly increased risk for depression, functional limitations, and financial difficulties.¹⁰ More than one in four grandparent-headed households meeting the NFCSP requirements were poor, and among grandmother caregivers, nearly one-third suffered depression and more than one-half experienced at least one limitation in an ADL.¹¹ Relative caregivers also often face multiple challenges in accessing needed health and other services for the children in their care. In 2000, for example, almost one in three grandchildren living in grandparent-headed households that met the NFCSP requirements had no health insurance. For the majority of caregivers who do not have legal custody or guardianship of the children they are raising, such problems are particularly acute.

MEETING THE NEEDS OF CAREGIVERS

For both caregivers of older Americans and grandparents and other relatives caring for grandchildren, the many often interrelated needs of relative caregivers and their families underscore the importance of developing comprehensive and multilevel interventions flexible enough to meet the full range of needs of the community being served. In addition, remaining cognizant of limited resources, states should create services for the most prevalent types of caregivers in their community. Further, to reach caregivers at the “servable moment” rather than after it is too late, as Montgomery indicates, the network needs to consider effective targeting of services and marketing of services. In offering respite, for example, only when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they become receptive (the servable moment) to respite programs. Strategies to increase receptivity should be based on the understanding that different types of caregivers arrive at the servable moment for different reasons and that caregivers use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service. Lastly, programs should create institutional links between service providers to assist the caregivers in identifying services that best meet their needs at any point in the caregiving trajectory. Service provider referrals will enable a program to contend with the changing

⁸ Doty, P. (1986). Family Care of the Elderly: The Role of Public Policy. *The Milbank Quarterly*, 64, 34–75.

⁹ Stoller, E.P. (1992). Gender Differences in the Experiences of Caregiving Spouses. In J.W. Dwyer and R.T. Coward (Eds.), *Gender and Family Care of the Elderly*, (pp. 49–64). Newbury Park, CA: Sage Publications.

¹⁰ Minkler, M. (2001). Grandparents and Other Relatives Raising Children: Characteristics, Needs, Best Practices, & Implications for the Aging Network, Issue brief prepared for the U.S. Administration on Aging. Available at: <http://www.aoa.gov/carenetwork/IssueBriefs.html>.

¹¹ Fuller-Thomson, E. and Minkler, M. (2000). The Mental and Physical Health of Grandmothers Who Are Raising Their Grandchildren. *The Gerontologist*, 37(3): 406–411.

nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create.

Clearly the social context of the caregiving role has significant impact on the caregiving experience and its consequences. The marker framework reminds us that attention must be given to ensuring the appropriate content of the support service or interventions, the appropriate “dosage” of the intervention, and flexibility of support programs to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create. Factors that must be considered for targeting include the family relationship and cultural background of the caregiver, and the marker at which a caregiver is located in the career process.¹²

For example, educational programs can be designed to deliver the information that best matches a caregiver’s current needs. Because children often self-identify as a caregiver earlier in the caregiving process, they are likely to seek help before to the provision of personal care. Hence, their need for information is going to be different than that of a spouse who seeks services much later in process. Children are more likely to seek information about the disease process, the availability of community services, and legal and financial information. Spouses need help with coping skills and information about behavior management and about in-home support services.

¹² Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/IssueBriefs.html>.