

**THE SURVEY OF INCOME AND
PROGRAM PARTICIPATION**

**PRELIMINARY ESTIMATES ON
CAREGIVING FROM WAVE 7 OF
THE 1996 SURVEY OF INCOME
AND PROGRAM PARTICIPATION**

No. 231

**John M. McNeil
Census Bureau**

PRELIMINARY ESTIMATES ON CAREGIVING FROM WAVE 7 OF THE
1996 SURVEY OF INCOME AND PROGRAM PARTICIPATION

By

John M. McNeil
Housing and Household Economic Statistics Division
Bureau of the Census

December 10, 1999

This paper reports the results of research and analysis undertaken by Census Bureau staff. It has undergone a more limited review than official Census Bureau publications. This report is released to inform interested parties of research and to encourage discussion.

PRELIMINARY ESTIMATES ON CAREGIVING FROM WAVE 7 OF THE 1996 SURVEY OF
INCOME AND PROGRAM PARTICIPATION

John M. McNeil
Housing and Household Economic Statistics Division
U. S. Bureau of the Census

Questions on caregiving were included in wave 7 of the 1996 panel of the Survey of Income and Program Participation (SIPP). Wave 7 interviews took place during the period April 1998 - July 1998. The purpose of the caregiving questions was to identify individuals who gave regular unpaid care to a family member or friend who had a long-term illness or disability. When a caregiver was identified, additional questions were asked about the relationship between the caregiver and the recipient, about the time spent on caregiving activities, and about the type of care provided.

The questions about caregiving that were asked in wave 7 of individuals age 15 years old and over and are shown in Appendix A of this paper.

Background

Caregiving is widely recognized as an important social issue and questions about the need for care, and whether an individual is a care provider, have been asked several times since the inception of SIPP. Questions have generally focused on the need for care. Questions about the need for personal assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) [*a list of ADLs and IADLs is shown in a note at the end of this paper*] were asked in the 1984, 1985, 1986, 1987, 1988, 1990, 1991, 1992, and 1993 panels, and again in the 1996 panel. Questions that asked if individuals were care providers have been asked less frequently. Such questions were asked in the 1985, 1986, 1987, and 1988 panels, and again in the 1996 panel.

The SIPP data have generally showed that approximately 4 percent to 5 percent of the noninstitutional population 15 years old and over need personal assistance with an ADL or IADL. A report based on data collected in the 1984 panel showed that 7.7 million individuals (4.3 percent) needed personal assistance, a report based on data from the 1985 and 1986 panels showed that 8.2 million (4.4 percent) needed personal assistance, and a report based on data from the 1992 and 1993 panels showed that 9.5 million (4.7 percent) needed personal assistance. The only report that presented data on the number of individuals who provided care was based on data collected in the 1985 and 1986 panels. The report showed that 5.8 million individuals gave some form of care to a household member and 15.1 million individuals gave some form of care to someone outside their household (the report does not show an unduplicated count of the number who provided some form of care regardless of whether the care was for someone inside or outside the household).

There are major differences between the earlier panels and the 1996 panel in the wording of the questions about whether an individual provided care to someone else. The wording of the earlier panels identified individuals who provided some personal assistance regardless of whether that assistance was given on a regular basis. The 1996 panel questions identified individuals who provided care on a regular basis to someone with a long-term illness or disability. In the earlier panels, individuals who provided care were identified in two ways. Those individuals who provided help to a household member were identified indirectly. When an individual was identified as someone who needed personal assistance, information about helpers was obtained by asking questions about the relationship and residence of those who helped. This information made it possible to identify the individuals in the household who provided help. Those individuals who provided help to someone outside their household were identified by a direct question. The wording of the question was as follows: "These next few questions concern helping others with personal care, housework, meal preparation, shopping, or getting around outside the home. During the

past month, did ... give this kind of help to anyone outside of ...'s household?" The wording of the question leaves open the possibility that some help was provided for economic or social reasons rather than the reason of illness or disability.

1996 Panel Caregiver Questions

The inclusion of caregiver questions in wave 7 of the 1996 panel was in direct response to statements of data needs provided by caregiver associations and by the offices of Congressman Charles T. Canady and Congresswoman Constance A. Morella. Following a preliminary meeting to identify major goals, the Census Bureau prepared a draft of questions intended for inclusion in wave 7 of the 1996 SIPP panel. The questionnaire draft was distributed for review to a number of interested parties, including the National Family Caregivers Association, a representative of the National Well Spouse Foundation, the World Institute on Disability, and the Interagency Subcommittee on Disability Statistics. The final set of questions was adopted after a consideration of the comments that were received.

Preliminary Nature of the Analysis

The only data now available to us from wave 7 are the unedited responses that were reported during the household interview. This means that the data have not yet gone through the procedure that will result in a data set that has no missing items, that will be internally consistent, and that will have weights attached that will make it possible to produce unbiased national estimates.

Because it will be some time before we have an edited and weighted data file containing information on caregiving, we have prepared preliminary tabulations for research and review purposes. The tabulations are based on two files created from the data that are now available and are presented in the attached

tables 1 through 5. Table 1 shows unedited and unweighted data on the prevalence of caregiving. The file used to create these data is not edited in the way that it will be at some future date. However, an examination of relationships among variables has been used to replace missing values with values that seem reasonable according to the observed relationships. Tables 2 through 5 are based on a modified version of the file that was used for Table 1. This second file was created in two steps. First, the wave 7 file used to create Table 1 was matched to a file from wave 2 of the 1996 panel (wave 2 interviews were conducted during the period August 1996 - November 1996). The match produced a file which contained the caregiver data from wave 7 and person weights from wave 2. Some individuals were not matched, so another step was taken to insure that the sum of the weights in the new file would add up to an independent estimate of the total number of individuals age 15 and over. The weights were adjusted so that the sum of the weights would equal the sum of the weights from the March 1998 Current Population Survey.

Highlights From Tables 2 Through 5

[Note: The estimates shown below and in the attached tables are preliminary and should not be expected to match the estimates that will be produced from a final edited and weighted file.]

- ! The number of individuals who provided regular unpaid care to a family member or friend was 9.3 million. These caregivers provided care at a rate of 14 billion hours a year, or about 29 hours per week per caregiver. (Table 2)

- ! Approximately two-thirds of caregivers were women, and these 6.1 million women provided care at a rate of 9.9 billion hours per year. The 3.2 million men who were caregivers provided care at an annual rate of 4.2 billion hours. (Table 2)

- ! The number of individuals who provided care to someone in their own household was 4.5 million, and the number who provided care to someone outside their household was 5.0 million (a few individuals provided care to both type of recipients). (Table 3)

- ! Individuals who provided care to someone inside their household tended to provide more hours of care than individuals who provided care to someone outside the household. The first group averaged 42 hours of care per week, while the second group averaged 16 hours of care per week. (Table 3)

- ! Individuals who provided care to someone within the household also had a longer history of providing care. Caregivers in this group had spent an average of 8.1 years providing care to the household recipient. Caregivers who provided care to someone outside the household had spent an average of 4.1 years providing care to the nonhousehold recipient. (Table 3)

- ! Among 4.5 million individuals who provided care to someone in the household, 2.5 million helped a recipient with activities of daily living (dress, eat, bathe, or get to the bathroom), 3.1 million helped with medical needs, 3.0 million helped with money management (the last two figures are not statistically different), and 3.9 million helped with trips outside the home. (Table 4)

- ! Among the 5.0 million who provided care to someone outside the household, 1.6 million helped with activities of daily living, 2.0 million helped with medical needs, 2.5 million helped with money management, 2.8 million helped with household chores, and 3.6 million helped with trips outside the home. (Table 5)

Conclusion

The caregiver questions used in the wave 7 SIPP interviews appear to have produced a reasonable estimate of the number of individuals who provide regular unpaid care to a family member or friend who has a long-term illness or a disability. The preliminary estimate of 9.3 million caregivers can be compared to earlier SIPP data (collected during the period October 1994 - January 1995) that showed that 9.5 million individuals needed personal assistance with an ADL or IADL.

Notes

The following Census Bureau reports contained data on the need for personal assistance: (1) Disability, Functional Limitation, and Health Insurance Coverage: 1984/85, Series P70-8, (2) The Need for Personal Assistance with Everyday Activities: Recipients and Caregivers, Series P70-19, (3) Americans With Disabilities: 1991-92, Series P70-33, and (4) Americans With Disabilities: 1994-95, Series P70-61. Only the second report listed contained data on the number and characteristics of caregivers.

The list of activities of daily living generally covered in SIPP includes (1) getting around inside the home, (2) getting in or out of bed or a chair, (3) bathing, (4) dressing, (5) eating, and (6) toileting. The list of instrumental activities of daily living generally covered in SIPP includes (1) going outside the home, (2) keeping track of money and bills, (3) preparing meals, (4) doing light housework, and (5) using the telephone. In the past few years the activity of taking prescription medicines has been included in the list of instrumental activities of daily living.

TABLE 1. UNEDITED AND UNWEIGHTED ESTIMATES OF THE PREVALENCE OF CAREGIVING: 1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION

	Total	Provided regular unpaid care to a family member or friend with a long-term illness or a disability		
		Number	Percent	Average hours of caregiving per week
Age 15 years and over	54,113	2,469	4.6	30
SEX				
Male	24,866	813	3.3	25
Female	29,227	1,656	5.7	32
RACE AND ETHNICITY				
White	45,115	2,028	4.5	29
Black	6,626	333	5.0	29
Hispanic origin (any race)	5,344	200	3.7	32
AGE				
15 to 24 years	9,159	161	1.8	21
25 to 44 years	20,892	704	3.4	25
45 to 54 years	9,021	610	6.8	29
55 to 64 years	5,809	448	7.7	29
65 to 74 years	5,041	326	6.5	38
75 years and over	4,191	220	5.3	43

TABLE 1. UNEDITED AND UNWEIGHTED ESTIMATES OF THE
PREVALENCE OF CAREGIVING: 1998 DATA FROM THE SURVEY OF
INCOME AND PROGRAM PARTICIPATION

	Total	Provided regular unpaid care to a family member or friend with a long-term illness or a disability		
		Number	Percent	Average hours of caregiving per week
MARITAL STATUS				
Married, spouse present	28,792	1,434	5.0	31
Married, spouse absent	455	43	9.5	23
Never married	14,063	434	3.1	25
Other	10,803	558	5.2	31
RELATIONSHIP TO REFERENCE PERSON				
Reference person with relatives	19,919	1,090	5.5	32
Reference person with no relatives	7,591	283	3.7	20
Spouse of reference person	13,690	705	5.2	29
Child of reference person	8,195	226	2.8	29
Other relative of reference person	2,198	96	4.4	35
Nonrelative of reference person	2,520	69	2.7	26
EMPLOYMENT STATUS				
Age 21 to 64 years	38,947	1,821	4.7	27
Employed	30,667	1,224	4.0	22
Full-time	25,374	961	3.8	21
Not employed	8,280	597	7.2	38

TABLE 2. AN EXPERIMENTAL ESTIMATE OF THE ANNUALIZED NUMBER OF CAREGIVING HOURS SPENT BY CAREGIVERS: 1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION

	Total in thousands (estimated using experimental weights)	Provided regular unpaid care to a family member or friend with a long-term illness or a disability		
		Number in thousands (estimated using experimental weights)	Percent	Annualized number of caregiving hours (In millions)
Age 15 years and over	209,291	9,323	4.5	14,066
SEX				
Male	98,719	3,208	3.3	4,182
Female	110,572	6,116	5.5	9,883
RACE AND ETHNICITY				
White	177,043	7,891	4.5	11,802
Black	23,419	1,075	4.6	1,624
Hispanic origin (any race)	19,495	755	3.9	1,290
AGE				
15 to 24 years	33,572	556	1.7	612
25 to 44 years	81,576	2,652	3.3	3,313
45 to 54 years	35,021	2,318	6.6	3,307
55 to 64 years	23,285	1,742	7.5	2,584
65 to 74 years	19,613	1,212	6.2	2,403
75 years and over	16,224	844	5.2	1,848

TABLE 2. AN EXPERIMENTAL ESTIMATE OF THE ANNUALIZED NUMBER OF CAREGIVING HOURS SPENT BY CAREGIVERS: 1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION

	Total in thousands (estimated using experimental weights)	Provided regular unpaid care to a family member or friend with a long-term illness or a disability		
		Number in thousands (estimated using experimental weights)	Percent	Annualized number of caregiving hours
MARITAL STATUS				
Married, spouse present	114,505	5,626	4.9	8,801
Married, spouse absent	1,639	147	9.0	169
Never married	53,666	1,607	3.0	1,963
Other	39,481	1,943	4.9	3,132
RELATIONSHIP TO REFERENCE PERSON				
Reference person with relatives	78,343	4,098	5.2	6,727
Reference person with no relatives	30,117	1,142	3.8	1,170
Spouse of reference person	54,337	2,782	5.1	4,132
Child of reference person	32,526	800	2.5	1,172
Other relative of reference person	6,906	278	4.0	575
Nonrelative of reference person	7,063	224	3.2	290
EMPLOYMENT STATUS				
Age 21 to 64 years	151,679	6,896	4.6	9,456
Employed	120,439	4,667	3.9	5,110
Full-time	99,677	3,684	3.7	4,003
Not employed	31,240	2,229	7.1	4,345

TABLE 3. MEAN NUMBER OF YEARS CARE HAS BEEN PROVIDED AND MEAN NUMBER OF 13
HOURS PER WEEK CARE IS PROVIDED TO PERSONS INSIDE AND OUTSIDE THE HOUSEHOLD:
1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION
(WEIGHTED DATA. NUMBERS IN THOUSANDS. WEIGHTS BASED ON EXPERIMENTAL METHODS)

	Total	Provided care to one or more persons inside the household			Provided care to one or more persons outside the household		
		Total	Mean hours of inside care per week	Mean years care provided to first inside recipient	Total	Mean hours of outside care per week	Mean years care provided to first outside recipient
EMPLOYMENT STATUS							
Age 21 to 64 years	151,679	3,002	39	7.6	4,026	16	4.1
Employed	120,439	1,785	32	7.5	2,966	14	4.2
Full-time	99,677	1,430	30	7.4	2,321	14	4.1
Not employed	31,240	1,218	50	7.6	1,060	18	3.8

U.S. Bureau of the Census

TABLE 4. TYPES OF CARE PROVIDED BY PERSONS WHO PROVIDED CARE TO ONE OR MORE PERSONS INSIDE THEIR HOUSEHOLD: 1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION
(WEIGHTED DATA. NUMBERS IN THOUSANDS. WEIGHTS BASED ON EXPERIMENTAL METHODS) 16

	Total	Types of care provided to first inside-the-household recipient									
		Helped with activities of daily living		Helped with medical needs		Helped with money management		Helped with household chores		Helped with trips outside the home	
		Num.	Per.	Num.	Per.	Num.	Per.	Num.	Per.	Num.	Per.
EMPLOYMENT STATUS											
Age 21 to 64 years	3,002	1,375	45.8	2,129	70.9	2,042	68.0	NA	NA	2,655	88.4
Employed	1,785	872	48.9	1,230	68.9	1,222	68.5	NA	NA	1,574	88.2
Full-time	1,430	709	49.6	942	65.9	965	67.5	NA	NA	1,246	87.2
Not employed	1,218	503	41.3	899	73.8	820	67.3	NA	NA	1,081	88.8

U. S. Bureau of the Census

TABLE 5. TYPES OF CARE PROVIDED BY PERSONS WHO PROVIDED CARE TO ONE OR MORE PERSONS OUTSIDE THEIR HOUSEHOLD: 1998 DATA FROM THE SURVEY OF INCOME AND PROGRAM PARTICIPATION
(WEIGHTED DATA. NUMBERS IN THOUSANDS. WEIGHTS BASED ON EXPERIMENTAL METHODS)

	Total	Types of care provided to first outside-the-household recipient										
		Helped with activities of daily living		Helped with medical needs		Helped with money management		Helped with household chores		Helped with trips outside the home		
		Num.	Per.	Num.	Per.	Num.	Per.	Num.	Per.	Num.	Per.	
EMPLOYMENT STATUS												
Age 21 to 64 years	4,026	1,329	33.0	1,757	43.6	2,116	52.6	2,348	58.3	2,977	73.9	
Employed	2,966	948	32.0	1,243	41.9	1,505	50.8	1,675	56.5	2,145	72.3	
Full-time	2,321	716	30.8	947	40.8	1,182	50.9	1,265	54.5	1,613	69.5	
Not employed	1,060	382	36.0	514	48.5	610	57.6	673	63.5	832	78.5	

U. S. Bureau of the Census

APPENDIX A:
SIPP 1996 PANEL
WAVE 7 TOPICAL MODULE
HOME HEALTH CARE

Universe: AGE ge 15

>HH01A<

There are situations in which people provide regular unpaid care or assistance to a family member or friend who has a long-term illness or a disability.

During the past month, did you provide any such care or assistance to a family member or friend living here or living elsewhere?

INCLUDE ONLY UNPAID CARE ACTIVITIES. INCLUDE ONLY THOSE CARE ACTIVITIES MADE NECESSARY BY THE ILLNESS OR DISABILITY OF THE RECIPIENT.

- (1) Yes
- (2) No

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH02<

Did you provide such care or assistance to someone living here?

- (1) Yes
 - (2) No
-

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH03<

For how many persons living here did you provide care or assistance?

___ Number

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH04<

For which person(s) in this household did you provide care or assistance? (Please list only the two persons for whom you provided the most assistance.)

IF THERE IS ONLY ONE ENTRY, ENTER "N" AFTER THAT ENTRY.

___ ___

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH05<

What is your relationship to [FAMILY MEMBER'S NAME]?

- (1) Spouse
 - (2) Partner
 - (3) Child
 - (4) Grandchild
 - (5) Parent
 - (6) Brother/sister
 - (7) Other relative
 - (8) Nonrelative
-

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH06<

For how many years have you provided care or assistance to [FAMILY MEMBER'S NAME]?

ENTER "0" IF LESS THAN 1 YEAR.

___ Years

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH07<

What kind of assistance did you give to [FAMILY MEMBER'S NAME]? Did [HESHE]:

ENTER (1) YES OR (2) NO FOR EACH.

- | | | |
|----|--|-----|
| a. | Help him/her dress, eat, bathe, or get to the bathroom? | ___ |
| b. | Help with medical needs such as taking medicines or changing bandages? | ___ |
| c. | Help him/her keep track of bills, checks, or other financial matters? | ___ |
| d. | Help by taking him/her shopping or to the doctor's office? | ___ |

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH08<

How many hours a week did you usually spend providing care or assistance for [FAMILY MEMBER'S NAME]?

___ Hours

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH09<

Did [FAMILY MEMBER'S NAME] receive similar unpaid care or assistance from any other persons?

- (1) Yes
- (2) No

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2 and HH09 eq 1

>HH11<

In terms of providing unpaid care and assistance to [FAMILY MEMBER'S NAME], were you the person who provided the most care or were there others who provided just as much or more?

- (1) Provided the most care
- (2) Others provided as much or more care

Universe: AGE ge 15 and HH01 eq 1 and PCNT ge 2

>HH12<

Sometimes people receive home health care services such as visits by nurses or therapists or home health aides. Did [FAMILY MEMBER'S NAME] receive these types of home health care visits?

- (1) Yes
 - (2) No
-

Universe: AGE ge 15 and HH01 eq 1

>HH13<

Did you provide care or assistance to any persons who lived outside of your home?

- (1) Yes
- (2) No

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH14<

For how many persons living outside of your home did you provide care or assistance?

___ Number

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH15<

What was the name(s) of the person(s) outside your home for whom you provided care or assistance? (Please list only the two persons for which you provided the most assistance.)

IF THERE IS ONLY ONE ENTRY, ENTER "N" AFTER THAT ENTRY.

	No.	Name
___	01	Person
___	02	Person

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH16<

What is your relationship to [PERSON'S NAME]?

- (1) Spouse
- (2) Partner
- (3) Child
- (4) Grandchild
- (5) Parent
- (6) Brother/sister
- (7) Other relative
- (8) Nonrelative

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH17<

For how many years have you provided care or assistance to [PERSON'S NAME]?

ENTER "0" IF LESS THAN 1 YEAR.

___ Years

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH18<

In what type of residence did [PERSON'S NAME] live? Was it a house or apartment or was it some type of care facility?

- (1) House or apartment
- (2) Care facility

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH19<

What kind of assistance did you give to [PERSON'S NAME]? Did you:

ENTER (1) YES OR (2) NO FOR EACH.

- | | | |
|----|---|---|
| a. | Help him/her dress, eat, bathe, or get to the bathroom? | — |
| b. | Help with medical needs such as taking medicines
or changing bandages? | — |
| c. | Help him/her keep track of bills, checks, or other
financial matters? | — |
| d. | Help by preparing meals, doing laundry, or cleaning
the house? | — |
| e. | Help by taking him/her shopping or to the doctor's
office? | — |

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH20<

How many hours a week did you usually spend providing care or assistance for
[PERSON'S NAME]?

— Hours

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH21<

Did [PERSON'S NAME] receive similar unpaid care or assistance from any other
persons?

- (1) Yes
(2) No
-

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH22<

Did you regularly spend time with [PERSON'S NAME] in order to provide companionship and emotional support because of this illness or disability?

- (1) Yes
- (2) No

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1 and HH21 eq 1

>HH23<

In terms of providing unpaid care and assistance to [PERSON'S NAME], were you the person who provided the most care or were there others who provided just as much or more?

- (1) Provided the most care
- (2) Others provided as much or more care

Universe: AGE ge 15 and HH01 eq 1 and HH13 eq 1

>HH24<

Sometimes people receive home health care services such as visits by nurses or therapists or home health aides. Did [PERSON'S NAME] receive these types of home health care visits?

- (1) Yes
 - (2) No
-