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Research and Training Center on Community Living • Institute on Community Integration (UCEDD)

Characteristics of Aging Caregivers in the NHIS-D

Introduction

In 1994/1995, an estimated 84% of all individuals with intellectual and/or developmental disabilities (ID/DD) in the United States lived either with a spouse or with other relatives (Larson, Doljanac & Lakin, 2005). The U.S. Census Bureau reported that 20.7% of the U.S. population in 1995 was 55 years old or older (U.S. Census Bureau, 2004). However, the percent of the U.S. population ages 55

In 1995, an estimated 2.9 million people with ID/DD or with significant FL shared a household with caregivers who were age 55 or older.

and older is expected to grow from 22.7% in 2005 to 30% on 2025. Given this projected aging of the population, this brief focuses on aging caregivers, and describes the characteristics of individuals who are 55 years and older who share a home with a family member with disabilities.

Methodology

In 1994 and 1995 the National Health Interview Survey (NHIS) included a supplement to gather nationally representative information on non-institutionalized persons with disabilities. These individuals were part of the two-year NHIS sample of 108,000 persons in 48,000 households. The National Health Interview Survey's Disability Supplement (NHIS-D) was used to gather information specific to the status of individuals with disabilities such as diagnostic, functional, social, and behavioral characteristics; service needs and use; and related information.

About This Data Brief

This *DD Data Brief* summarizes findings from the National Health Interview Survey Disability Supplement conducted by the U.S. Bureau of the Census, National Center on Health Statistics in 1994 and 1995. It examines characteristics and outcomes for family members, ages 55 and older, who shared households with persons with intellectual and/or developmental disabilities (ID/DD) or functional limitations only (FL Only). This brief estimates the population of aging caregivers and presents logistic regressions examining the factors that influence selected outcomes for those caregivers (poor health status and poor mental health status).

This issue is co-authored by Soo-yong Byun, Lynda Anderson, Sheryl A. Larson, and K. Charlie Lakin from the Research and Training Center on Community Living at the University of Minnesota's Institute on Community Integration.

This will be the last print issue of *DD Data Brief*. See page 11 for details.

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The NHIS-D was conducted in two phases. Phase I was conducted during the core NHIS survey in order to identify persons with disabilities. It included all persons in the sample (202,650 in all). Once people with disabilities were identified, they were given a Phase 2 interview. Children and adults were given separate Phase 2 interviews. The interviews included questions about in- and out-of-home services; housing and family structures; and physical, emotional and social functioning of sample members.

The two-year time span of the NHIS-D allows for more reliable sampling of low-incidence disabilities such as intellectual and developmental disabilities. The 1994 and 1995 samples were combined in this analysis to make use of this strength. The final population weights were divided by two before computing the population estimates reported in this brief.

The sample of aging caregivers and their family members was selected by first identifying people age 55 and over living in a primary household with an individual with ID/DD or FL of any age. The potential pool of caregivers was matched by household identifiers to individuals with ID/DD or FL Only.

Individuals with ID/DD were identified based on the operational definitions in Larson, Lakin, Anderson et al. (2000). People were identified as having intellectual disabilities if a) the household respondent identified that person as having intellectual disabilities, b) intellectual disabilities were given as the reason for general activity limitations in specific areas (e.g., communication) or as the reason for receiving specific services, and/or c) the person was identified as having a condition which is highly associated with intellectual disabilities (e.g., Down syndrome, autism) and was concurrently reported to have serious difficulty learning how to do the things that most people of that age were able to do. People with developmental disabilities were identified as such if they were "unable" to perform or had "serious

difficulty" performing in an age-appropriate manner in three or more of seven domains – self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency – and the limitation was expected to endure "longer than a year" and had been present since before age 18. For this brief, people meeting either or both definitions were included in the group labeled ID/DD.

People were identified as having functional limitations (FL Only) if they had three or more substantial functional limitations in the seven areas measured for the definition of developmental disabilities, but did not meet the operational definition of either intellectual disabilities or developmental disabilities. People were also identified as having significant functional limitations if they had one or two substantial functional limitations in any major life activity with onset at any age.

Caregivers and people with ID/DD or FL Only who had a match on household identifier were included in the data set for this study. One person in each household in which a person with ID/DD or FL Only lived was identified as a caregiver. Households in which the caregivers were younger than 55 years, individuals not living in primary households, and individuals with ID/DD not living with a family member were excluded from this analysis. In households with only one eligible caregiver, that person was selected as the caregiver for this analysis. When more than one eligible caregiver lived in an eligible household a screening process was used to select from among the eligible caregivers one person to include in this analysis. In selecting among multiple possible caregivers, three factors were considered, in this order: gender (women were identified as caregivers before men); disability status (persons who did not have disabilities were identified as caregivers before persons who had disabilities); and age (among persons between 55 and 75 years old the oldest person was considered the

caregiver; in households where all eligible persons were older than 75 the youngest person was considered the caregiver).

In all, 3,026 caregivers were included in the sample including 590 who were the only eligible caregiver in the household (19.5%). In 2,145 households (70.9%) the only eligible woman was selected as the caregiver. In 244 households where there were two or more eligible females, the eligible female without a disability was selected (8.1%). In 26 households where there were two or more eligible men, the eligible man without a disability was selected (0.86%). Finally, in 10 households (0.3%), women over 55 without disabilities were selected based on age.

As anticipated given the sampling methodology, 83.7% of the selected caregivers were female (Relative Standard Error [RSE] = 2.6%) including 77.8% of the caregivers living with persons with ID/DD (RSE = 6.6%) and 85.2% of caregivers living with persons with FL Only (RSE = 2.8%). Only 20 of the selected caregivers reported having one or more substantial functional limitations (1.2% of the sample).

This brief includes several types of analyses using the SUDAANTM statistical software to account for the weighting of data and for the complex sampling design of the NHIS-D. Chi-square analyses were used to compare the demographic characteristics of caregivers, demographic characteristics of persons with disabilities living with aging caregivers, and health outcomes for aging caregivers. Logistic regression analyses were used to examine factors associated with health outcomes for aging caregivers. For the logistic regression analyses only, persons who were 55 and older who were selected as aging caregivers were compared against all other persons who were 55 years old and older in the NHIS-D sample controlling for several characteristics and factors.

For all analyses, population estimates are weighted estimates calculated using the weights provided in the NHIS survey divided by two to account for using both 1994 and

1995 surveys. The RSE is provided as a measure of the estimates' reliability. Estimates with smaller relative standard errors are generally considered more reliable. Any estimate with an RSE of greater than 30 is considered unreliable and is not reported. SUDAAN™ statistical software was used in all analyses to correctly handle the complex sample frame.

Results

Characteristics of Aging Caregivers

In 1995, an estimated 2.29 million individuals 55 years or older cared for a family member with significant functional limitations or intellectual or developmental disabilities with whom they shared a household (see Table 1). This number includes one caregiver per household in which a family member with ID/DD or FL Only lived. Most of the identified caregivers were married (77%), were between the ages of 55 and 64 (54%), reported incomes above the Federal Poverty Guidelines (89%), and identified themselves as White (84%).

There were several statistically significant differences between caregivers of persons with ID/DD and caregivers of persons with FL Only. Specifically, caregivers of people with FL Only were older (15% were 75 years or older versus 9% for caregivers of persons with ID/DD). They were also more likely to be White (86% versus 74%), married (80% versus 64%), and to have incomes above the Federal Poverty Guidelines (90% versus 85%). Caregivers of individuals with ID/DD were more likely to be 55-64 years of age (61%).

In all, an estimated 2,874,604 people with ID/DD or FL Only lived in households with aging caregivers. This included 582,647 individuals with ID/DD and 2,291,957 individuals with FL Only. Of the persons with ID/DD living with aging caregivers, an estimated 356,891 lived with caregivers 55 to 64 years old, 179,204 lived with caregivers 65 to 74 years old, and 46,552 lived with

oer .	oer	FL Only
Characteristics of Aging Caregivers by Disability Level of Family Member	Disability of Family Member	QQ/QI
Table 1: Demographic Characteristics of A		Total

							Disak	Disability of Family Member	mily Memb	er			
		Total				ID/DD				FL Only			
Caregiver Characteristic	z	Estimated Population	RSE1	%	Z	Estimated Population	RSE1	%	z	Estimated Population	RSE1	%	×2
Sample Total	2,275	2,275 2,874,604	2.6		456	582,647	5.8		1,819	2,291,957	2.6		
Age 55-64 65-74 75 and older	1,225 735 315	1,563,565 924,238 386,801	8. 4. 6. 5. 5. 6. 6. 6. 6. 6. 6. 6. 6. 6. 6. 6. 6. 6.	54.4 32.2 13.5	283 135 38	356,891 179,204 46,552	7.1	61.3 30.8 8.0	942 600 277	1,206,674 745,034 340,249	8. 4. 6 6. 8. 8.	52.6 32.5 14.8	18.72**
Race White Non-White	1,856	,856 2,402,090 419 472,514	2.9	83.6 16.4	334	431,194	6.3	74.0	1,522	1,970,897	3.0	86.0 14.0	19.05**
Marital Status Married Never married Formerly married	1,692 53 492	2,167,435 59,491 597,878	3.1 7.7 4.8	76.7 2.1 21.2	274 9 160	360,472 9,601 196,825	6.9 36.7 9.7	63.6 1.7 34.7	1,418 44 332	1,806,963 49,890 401,053	3.2 15.5 5.7	80.0 2.2 17.8	32.15**
Economic Status Above FPG ² Below FPG ²	1,788	2,299,705 295,119	3.0	88.6	345	452,271 78,215	6.6	85.3	1,443	1,847,434 216,905	8.1	89.5 10.5	*90.4

RSE 1 = Relative Standard Error *** p < .001; ** p < .01; * p < .05

FPG² = Federal Poverty Guidelines for the household

caregivers 75 years old or older. Of the persons with FL Only living with aging caregivers, an estimated 1.2 million lived with caregivers 55 to 64 years old, 745,034 lived with caregivers 65 to 74 years old and 340,249 lived with caregivers who were 75 years old or older.

Characteristics of People Living with Aging Caregivers

Table 2 depicts the characteristics of persons with ID/DD or FL Only who were living with aging caregivers. It shows the differences between individuals with disabilities living with caregivers in three age groups (55 to 64 years, 65 to 74 years, and 75 years and older.) Caregivers 55 to 64 years were more likely to be caring for people younger than age 18 (14.8%) than caregivers in any other age group. However, 28% of the caregivers between 55 and 64 were caring for a family member over age 64. Older caregivers were living with older persons with disabilities. For example, 60.3% of caregivers between 65 and 74 were caring for family members 64 and older, as were 68.9% of caregivers over age 75. A surprising number of caregivers between 65 and 74 (6.7%) and 75 and up (5.9%) were caring for family members with disabilities under the age of 18. Across all caregiver ages, family members with disabilities were most likely to be male and to have functional limitations. A more detailed description of the characteristics of individuals with ID/DD living with family members can be found in *Data Brief Volume 3*, *Issue 2*: Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or With Family Members: NHIS-D Analysis (Larson, Lakin, Anderson & Kwak, 2001b).

The items regarding supervision needs of adults with disabilities were from the Adult Phase 2 survey. Population estimates and percentages are based on the Phase 2 population weights. Overall, just over half (56%) of adults with disabilities living with aging caregivers could stay at home alone for more than two hours at a time. Caregivers be-

tween 55 and 64 years were more likely to be caring for a person who could stay home alone for more than two hours at a time (62%) than older caregivers (49% and 48%). Finally, 53% of adults with disabilities living with aging caregivers needed supervision to ensure their safety. There were no differences in the proportion that needed supervision to ensure safety across the three caregiver age groups.

Health Outcomes for Caregivers

A key question was whether being a caregiver for a person with a disability was associated with any health or mental health outcomes for caregivers. To answer this question, the brief first examined whether these outcomes varied by age among caregivers. The research revealed that older caregivers were less likely to report "excellent" health (55-64, 18.1%; 65-74, 13.8%; 75 and up, 12.9%). However, they were also less likely to report "poor" health (55-64, 6.5%; 65-74, 5.2%; 75 and up, 3.6%) (see Table 3). There were no statistically significant differences between caregivers of different ages in the proportion that reported mental health needs. Overall, 9.5% of aging caregivers of people with disabilities reported feeling frequently depressed or anxious, 3.8% reported having serious trouble coping with day-to-day stresses, and 3.6% reported taking medication for mental or emotional conditions in the last 12 months.

Finally, factors associated with poor mental and physical health status for aging caregivers were examined (see Table 4). All persons ages 55 years and older in the NHIS-D sample were included in this analysis. Caregivers of persons with ID/DD or persons with FL Only were compared to people age 55 and older who were not caregivers. Other factors examined included age, race, gender, marital status, economic status, and the number of substantial functional limitations the caregiver reported having. Persons who reported their physical health status was "fair" or "poor" were considered to have

,	Ca	Caregiver 55-64 Years	4 Year	ر ا	Car	Caregiver 65-74 Years	.74 Ye	ars	Care	Caregiver 75 and Older	and C	older		Total			
Characteristic of Family Member With Disability	z	Estimated Population	RSE1	%	2	Estimated Population	RSE1	%	2	Estimated Population RSE ¹	ן RSE ר	%	z	Estimated Population	RSE1	%	~
Sample Total	1,225	1,225 1,563,565	3.5		735	924,238	4.2		315	386,801	6.3		2,275	2,874,604			
Age 18 or younger 19-40 41-64	193 299 384	231,271 404,611 490,417	7.8.6.8	14.8 25.9 31.4	54 103 135	62,304 133,017 171,192	14.6	6.7 14.4 18.5		22,640 27,422 70,149	26.7 18.9 7.4	5.9	266 425 577	316,214 565,050 731,757	7. 4. 6. 7. 8. 4. 8	11.0	260.50**
Gender Male Female	763 763 462			20.0 62.8 37.2		537,720 683,168 241,071	. 4 8 . 8 8.	73.9	240 75	301,123	7.2	77.9	1,550	1,966,846		43.7 68.4 31.6	32.49**
Supervision Needs of Adults¹ Ever home alone for more than two hours	290	368,110 6.3 62.1	6.3	62.1	154	194,727		9.0 48.7	09	74,875 14.7 47.6	14.7	47.6	504	637,711	9.4	55.5	16.73**
Needs supervision to ensure safety	114	142,166 11.0 51.3	11.0	51.3	67	205,462	7.8	56.3	28	32,248 19.1 47.4	19.1	47.4	239	379,876	8.4	52.8	1.63

RSE 1 = Relative Standard Error $^{+}$ = These items were from the Adult Phase 2 survey *** p < .001; ** p < .01; * p < .05

	Careg	Caregiver 55-64 Y	rears	Careg	Caregiver 65-74 Years	Years	Caregi	Caregiver 75 and Older	d Older		Total		
Health Outcome	z	Percent Reporting	RSE1	z	Percent Reporting	RSE1	z	Percent Reporting	RSE1	z	Percent Reporting	RSE1	×
status													
Excellent	193	18.1	7.7	88	13.8	11.0	35	12.9	17.2	316	15.9	6.3	17.71**
Good	631	56.8	4.3	404	58.7	5.2	179	60.2	8.4	1,214	57.9	3.0	
Fair	208	18.6	8.0	157	22.4	8.4	74	24.1	18.4	439	20.6	5.5	
Poor	69	6.5	13.1	36	5.2	18.5		3.6	30.9	116	5.6	6.7	
Mental Health Status Frequently depressed													
or anxious .	96	9.8	11.4	61	10.0	15.9	34	11.6	18.0	191	9.5	8.2	1.85
Serious trouble coping with													
day-to-day stresses Takes medication for mental/	38	۵. 4.	18.2	27	4.2	21.5	12	4.2	29.8	77	8.	13.1	0.62
emotional conditions in													
past 12 months	40	4.2	16.5	22	3.3	20.0	∞	2.2	36.1	70	3.6	33.7	0.18

RSE 1 = Relative Standard Error *** p < .001; ** p < .01; * p < .05

poor health status. Persons who reported they were frequently depressed or anxious, had serious trouble coping with day-to-day stresses, and/or were taking medications for mental or emotional conditions in the 12 months prior to the interview were coded as having poor mental health status. A total of 27,615 records of people ages 55 years or

Table 4: Outcomes for Aging Caregivers of People with Disabilities

	Poor Me Health St		Poor Hea Status	
Caregiver Characteristics	Odds Ratio	Sig.	Odds Ratio	Sig.
Intercept				
Age 55-64 65-74 75 and older	1.0 1.14 1.32	* ***	1.0 1.44 2.07	***
Race White Other	1.0 0.66	***	1.0 1.47	***
Gender Male Female	1.0 1.31	***	1.0 0.97	
Marital Status Married Not married	1.0 1.34	***	1.0 1.36	***
Economic Status At or above FPG ¹ Below FPG ¹	1.0 2.09	***	1.0 3.35	***
Number of Limitati None One Two or more	ons 1.0 3.95 15.37	***	1.0 3.08 7.69	***
Caregiver Status Not a caregiver Caregiver for a persor	1.0		1.0	
with ID/DD Caregiver for a persor	1.32	***	1.03	
with FL Only R ²	0.03		0.06	

 FPG^1 = Federal Poverty Guidelines for the household *** p<.001, **p<.01; *p<.05

older from the NHIS-D were included in these logistic regression analyses.

Overall, a statistically significant 3% of the variability in mental health status could be accounted for by age, race, gender, marital status, economic status, number of the caregiver's limitations, and caregiver status. People who were older, White, female, not married, living in households with incomes below Federal Poverty Guidelines, and who had one or more substantial functional limitations were more likely to report one or more indicator of poor mental health. With all of these factors accounted for, individuals 55 years and older who were caring for a person with functional limitations were 74% more likely to report one or more indicators of poor mental health than individuals 55 years old or older who were not caring for a person with functional limitations.

Overall, a statistically significant 6% of the variability in health status could be accounted for by age, race, marital status, economic status, and number of limitations. Older individuals who were non-White, not married, living in households with total incomes of less than the federal poverty guidelines, who themselves had one or more substantial functional limitation were more likely to report having fair or poor health. Taking these other factors into account among those persons who were 55 years and older, being a caregiver of a person with ID/ DD or functional limitations was not associated with increased odds of reporting poor health status.

Discussion

Characteristics of Aging Caregivers

An estimated 2,874,604 people aged 55 and older were caring for a family member with intellectual and/or developmental disabilities or significant functional limitations in the United States in 2005. Most such caregivers were married, White, and were living above the Federal Poverty Guidelines. There were however, striking differences between

caregivers of persons with ID/DD and those with FL Only. Most remarkable was the fact that although family members of persons with ID/DD were younger, they were also much more likely to be formerly married than caregivers of persons with FL Only. This is consistent with research that shows higher divorce rates among parents whose children have intellectual or developmental disabilities (Risdal & Singer, 2004). In addition to being less likely to be married, caregivers of persons with ID/DD were more likely to be living in households with income below the poverty level. Federal and state family support programs should consider the impact of age, poverty and single parenthood on the need for assistance.

Characteristics of People Living with Aging Caregivers

Overall, 11% of aging caregivers were caring for a child with a disability and 20% were caring for an adult 18 to 40 years old. Nearly 41% of caregivers between 55 to 64 years were caring for a family member who was younger than 40 years old. A smaller proportion of the caregivers in the older age groups were caring for a young family member (21% of caregivers ages 65 to 74 years and 13% of caregivers ages 75 years or older). Caregivers of children face the ongoing challenge of advocating for a free appropriate public education for their child. Caregivers of persons with disabilities between 18 and 40 years old face systems challenges such as navigating public supports available to adults (including work or other day supports, transportation, income supports and medical supports) and clarifying roles regarding decision making or substitute decision making. These caregivers also were responsible for providing supervision to ensure the safety of the adult family member with a disability and for many of them this meant the person could not be left home alone for more than two hours at a time.

Overall, 26% of aging caregivers were caring for a person with a disability who was

41 to 64 years old. Amongst the caregivers 55 to 64 years old, 31% were caring for family members with disabilities who were 41 to 64 years old. By contrast, only 19% of caregivers 65 to 74 years old and 18% of caregivers 75 and older were caring for individuals between 41 and 64 years old. Previous NHIS-D research showed that only between 10% (for adults with three or more FLs but not ID/DD) and 26% (for adults with ID/DD) of adults with disabilities were employed (Doljanac & Larson, 2005; Larson, Lakin, Anderson & Kwak, 2001a). In addition to providing supervision to ensure the safety of these adults, caregivers of people 41 to 64 years old face challenges such as increased support needs due to age related illnesses or injuries.

Almost half of all aging caregivers (44%) were caring for persons with disabilities who were 65 or older. Amongst caregivers 75 and older, nearly 70% were caring for persons who were 65 or older. Similarly, 60% of caregivers 65 to 74 years were caring for a family member who was 65 or older. By contrast, 28% of caregivers 55 to 64 were caring for an older person with disabilities. Challenges for persons caring for seniors with disabilities include navigating the Medicare system, providing supports during their own retirement years, and facing increasing likelihoods of dealing with end-of-life issues.

Health Outcomes for Caregivers

Being an aging caregiver of a person with substantial functional limitations was associated with an increased risk of reporting poor mental health outcomes over and above the increased risks associated with age, race, gender, marital status, economic status, and number of one's own functional limitations. This suggests that public policies that provide assistance to family caregivers to help them with coping with day-to-day stresses, depression and anxiety may be helpful to enable those caregivers to continue to succeed in their caregiving roles.

Conclusion

In 1994/1995, an estimated 84% of all individuals with intellectual or developmental disabilities in the United States lived either with a spouse or with other relatives (Larson, Doljanac & Lakin, 2005). An estimated 562,647 of those individuals lived with family members who were 55 years old or older (14.5% of all community dwelling individuals with ID/DD in 1994). As both caregivers and the people they care for continue to age, the need for services for both caregivers and family members with disabilities will likely increase.

Of growing concern in 2006, of course, is access to nationally representative data that is more recent than 1995 on this topic. The NHIS-D provided a wonderful opportunity to examine many important aspects in the lives of community-dwelling individuals with disabilities, but the data are now quite old and more current data are desperately needed. Given the changing demographic of American society in general, we might expect a significant increase in the number and the proportion of caregivers over 55 years old who are living with and caring for persons with disabilities, but without access to adequate national data sources, it will be difficult to update the figures reported in this analysis.

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Other Issues of DD Data Brief

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- Mothers with Disabilities Characteristics and Outcomes: An Analysis from the 1994/ 1995 NHIS-D. (2005)
- Social Activities of Non-Institutionalized Adults in the NHIS-D: Gender, Age, and Disability Differences. (2005)
- Problems in Defining Mental Retardation and Developmental Disability: Using the National Health Interview Survey. (2005)
- Response Patterns Among Adult Respondents with Mental Retardation in the National Health Interview Survey, 1997-2002. (2004)
- Gender, Age, and Disability Differences in Functional Limitations for Non-Institutionalized Adults in the NHIS-D. (2004)

- Service Use by and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Difference by Age, Gender, and Disability. (2003)
- Health Insurance Coverage and Health Care Experiences of Persons with Disabilities in the NHIS-D. (2003)
- Children with Disabilities: Social Roles and Family Impacts. (2002)
- Functional Limitations of Adults in the U.S. Non-Institutionalized Population. (2001)
- Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or with Family Members: NHIS-D Analysis. (2001)
- Characteristics of and Service Use by Persons with MR/DD Living in Their Own Homes or with Family Members. (2001)
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