

Health and Employment Challenges for Working-Age Caregivers in New Jersey

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The State of New Jersey has recognized for many years the important role of informal caregivers in helping older adults and people with disabilities to live in their own homes and communities. It has been estimated that informal caregivers provide 924 million hours of care annually in New Jersey, at an annual market value of over nine billion dollars. While these individuals willingly provide assistance to their family and friends, increasing evidence shows that caregivers can suffer problems with their own physical and mental health and their paid employment.

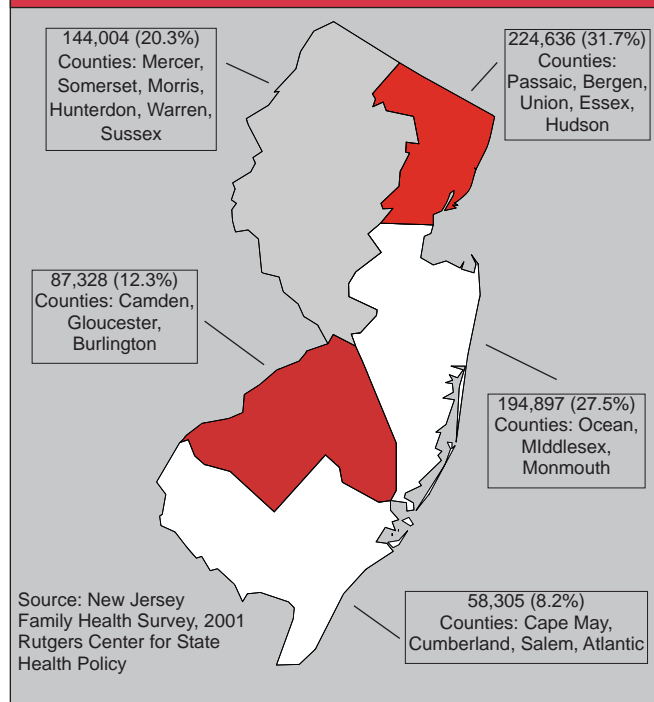
Based on data from the New Jersey Family Health Survey, we estimate that there were approximately 904,280 adult caregivers in New Jersey in 2001, and 78% of these were ages 19 to 64. This issue brief focuses on a description of the characteristics and health issues of working-age caregivers, since they are most likely to balance caregiving responsibilities with full- or part-time employment, increasing their level of

stress and decreasing their ability to attend to their own health.

Who are Working-Age Caregivers?

An estimated 709,710 working-age adults in New Jersey provided care for a family member or friend in 2001. This is 14% of New Jersey residents 19 to 64, compared to one in ten working-age adults in the U.S.² These individuals provide support for family members and friends with both acute and chronic needs for support. Over half of working-age caregivers live in the northern part of the state, while 20% live in the southern counties (Figure 1).

Figure 1: Estimated Number and Percent of Caregivers Ages 19-64 by Area of New Jersey

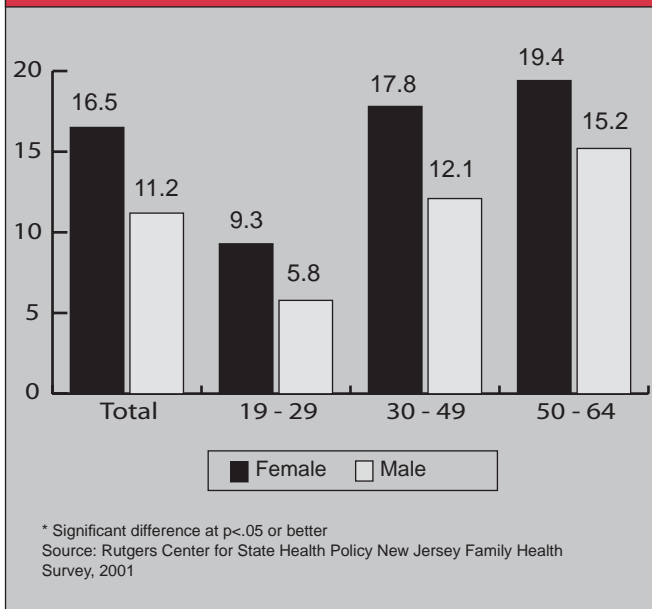


Overall, women were significantly more likely than men to be caregivers, although the gap narrows with increased age (Figure 2). Women 50-64 were most likely to report caring for a sick or disabled family member or friend,

Caregivers in New Jersey

- One in seven adults ages 19-64 reports providing care for a family member or friend, making them an important but often overlooked part of the state health care workforce.
- Most working-age informal caregivers are employed: 60% work full-time, and another 11% work part-time. Many had to quit a job (13%) or cut back on hours (nearly 30%).
- One-sixth of caregivers are uninsured; 40% of these work full-time.
- Caregivers report more health problems, higher health care use, and difficulties in accessing care than non-caregivers. Caregivers were 28% more likely than non-caregivers to report having a physical or mental health problem, twice as likely to report that their health was worse than a year ago, and nearly 40% more likely to report that they had a problem accessing health care.
- New Jersey offers a variety of support services for caregivers, but many report not having looked into these services. New funding would enable the state to promote and maintain existing resources for caregivers and provide more service options.

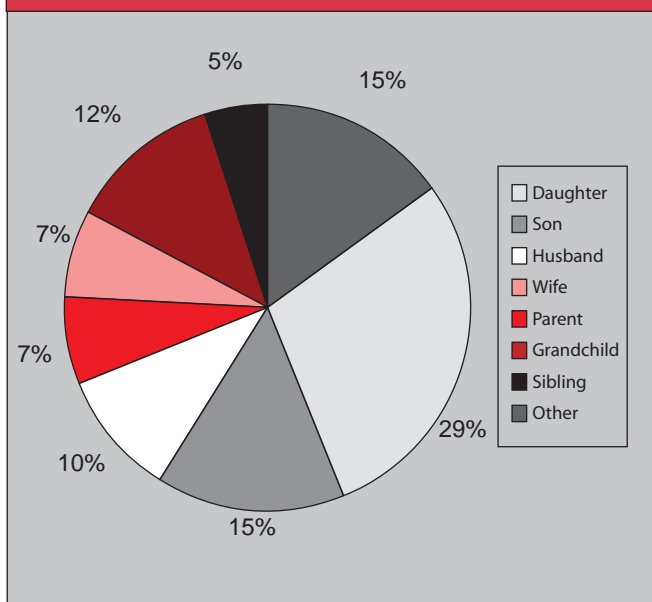
Figure 2: Percent of Caregivers by Age and Gender, Ages 19-64



but the rate of caregiving for both women and men ages 50-64 was more than twice that for ages 19-29.

Adult sons and daughters made up over 40% of caregivers, while working-age husbands and wives accounted for another 17% (Figure 3). Other family members accounted for 28% of caregivers, with grandchildren (12%) and parents (7%) making up most of this group. Friends and other non-family helpers represented 10% of working-age caregivers.

Figure 3: Relationship to Care Recipient of Caregivers Ages 19-64



Caregivers ages 19 to 64 were more likely than non-caregivers to be non-Hispanic white and born in the U.S., and less likely to be non-Hispanic black, Hispanic, or foreign born (Table 1). Caregivers were more likely to be married with no children, although about 44% of working-age caregivers report having children, and some reported that children assisted with caregiving responsibilities.

Caregivers were not significantly different from their peers in education level, poverty status, insurance coverage, or employment status (Table 1). Most caregivers reported at least a high school education, and over half had more. Over 75% of caregivers were from households above twice the federal poverty level, but six percent were living in households below the poverty level. About three-quarters of caregivers reported having private insurance coverage, while 16.4% were uninsured. Over half of the uninsured were employed, with nearly 40% holding full-time jobs.

This survey found that more New Jersey caregivers ages 19-64 were working full-time (60%) than in the U.S. as a whole (51%)¹, while another 11% work part-time. About one-fifth of caregivers reported that they are not in the labor force. Women were more likely to combine full-time employment with caregiving; women represent 52% of caregivers who work full-time and only 40% of non-caregiver full-time workers. Hispanics and people ages 19-29 were less likely to combine full-time work with caregiving activities.

Figure 4: Adults Ages 19-64 with Health Problems by Caregivers Status

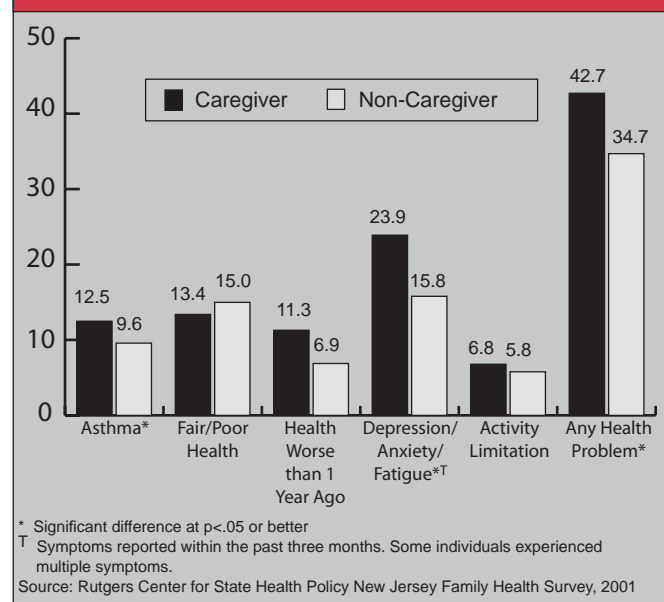
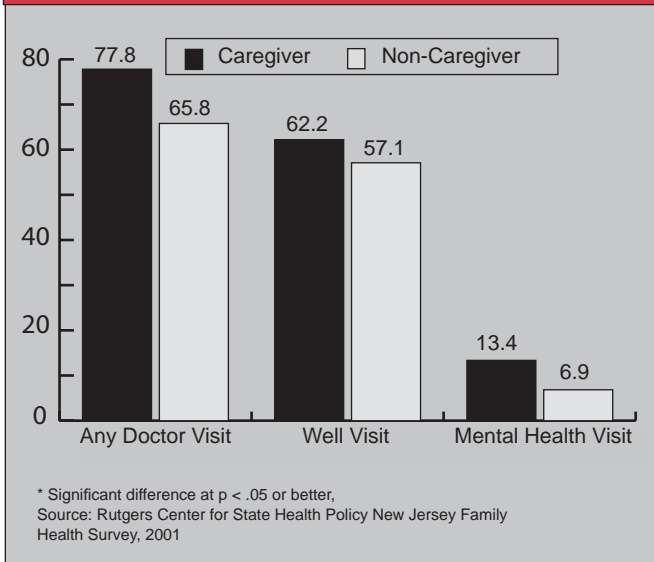


Figure 5: Health Care Service Utilization of Adults Ages 19-64 by Caregiver Status



Caregivers Report More Health Problems and Difficulties Accessing Health Care

Caregivers reported a significantly higher incidence of health problems and higher utilization of health care services, but also more difficulties accessing health care. Caregivers were no more likely than their peers to report that they are in fair or poor health, but they were nearly twice as likely to report that their current health was worse than one year ago (Figure 4). Caregivers were about 50% more likely to report having asthma and having experienced depression, anxiety, and/or fatigue in the past three months. While caregivers used more health care services, they also reported more difficulty accessing health care (Figure 6). Caregivers were nearly 40% more likely to report that access to health care was a problem, even after adjusting for insurance status, poverty, and health status (data not shown). Among caregivers, women were over three times as likely to report difficulty accessing care than men, and the uninsured were twice as likely to report difficulties as those with insurance (data not shown). Significantly more caregivers reported difficulty getting medical care and said that medical costs were a problem. Among caregivers, those who were uninsured and below 200% FPL were three times as likely to say that medical costs were a problem. In addition, a significantly larger percentage of caregivers reported that they delayed getting or didn't fill a prescription. While caregivers were more likely to utilize mental

health care, they did not report more difficulty in obtaining that care.

Combining Employment and Caregiving

Balancing employment and assistance to a loved one can be an ongoing struggle for caregivers. Thirteen percent of caregivers said that they had to quit a job because of their caregiving activities. Of caregivers who were employed at the time of the survey, nearly 30% said that they had to cut back their hours of work in order to provide care, and nearly a quarter reported that they regularly take time off from work to provide care (Figure 7).

Figure 6: Percent of Adults Ages 19-64 Experiencing Access Problems by Caregiver Status

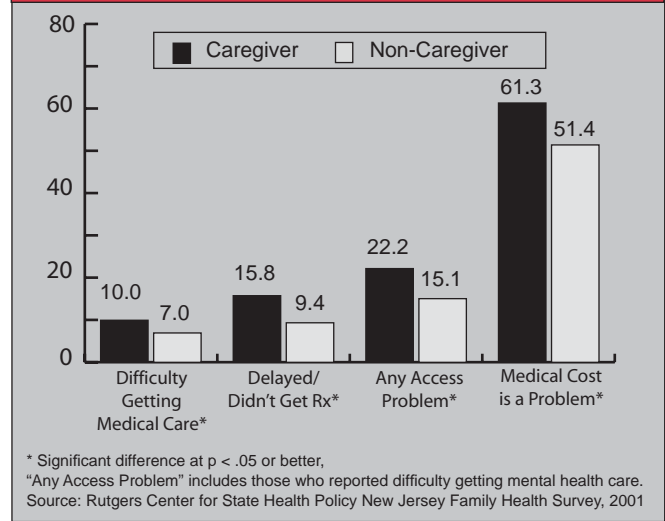


Figure 7: Percent of Working Caregivers Ages 19-64 Experiencing an Impact on Work

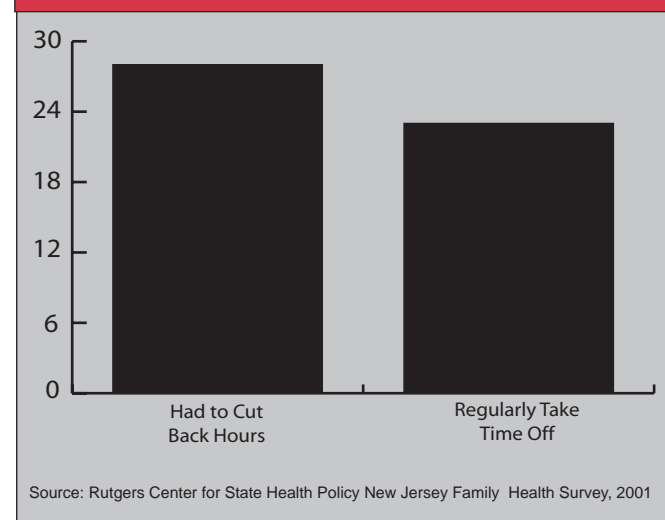


Table 1: Demographics of Caregivers vs. Non-Caregivers (Ages 19 to 64)

	Total		Caregiver		Non-Caregiver	
	n	%	n	%	n	%
Age**						
19 to 29	1,160,143	22.9	86,351	12.2	1,073,792	24.7
30 to 49	2,602,273	51.4	395,249	55.7	2,207,024	50.7
50 to 64	1,300,471	25.7	227,570	30.1	1,072,902	24.6
Gender**						
Male	2,373,415	46.9	266,347	37.6	2,107,069	48.4
Female	2,689,472	53.1	442,823	62.4	2,246,649	51.6
Race/Ethnicity**						
White (Non-Hispanic)	3,309,887	65.4	536,923	75.7	2,772,964	63.7
Black (Non-Hispanic)	646,264	12.8	78,833	11.1	567,431	13.0
Hispanic	737,490	14.6	62,993	8.9	674,496	15.5
Other (non-Hispanic)	369,246	7.3	30,420	4.3	338,826	7.8
Immigration Status**						
Born in U.S.	4,202,342	83.1	639,601	90.2	3,562,741	81.9
Not Born in U.S.	857,506	16.9	69,569	9.8	787,937	18.1
Education						
Less than High School	418,689	8.5	48,242	6.9	370,447	8.7
High School / GED	1,837,247	37.2	276,825	39.5	1,560,422	36.8
More than High School	1,147,343	23.2	143,563	20.5	1,003,780	23.7
College Degree	1,533,788	31.1	231,402	33.1	1,302,386	30.7
Poverty Level						
0% to 100% FPL ¹	354,558	7.1	41,560	5.9	312,997	7.3
101% to 200% FPL	916,206	18.3	130,315	18.4	785,891	18.3
201% to 350% FPL	1,504,498	30.0	212,671	30.0	1,291,827	30.0
> 350% FPL	2,236,597	44.6	323,396	45.7	1,913,202	44.5
Family Structure*						
Married, no children	1,007,623	19.9	169,340	23.9	838,283	19.3
Married, with children	1,888,890	37.3	223,407	31.5	1,665,483	38.3
Single, no children	1,413,281	32.5	230,102	32.5	1,413,281	32.5
Single, with children	436,670	10.3	86,321	12.2	436,670	10.0
Insurance Coverage						
Uninsured	854,877	17.2	116,357	16.4	738,520	17.3
Public	428,120	8.6	55,797	7.9	372,323	8.7
Private	3,685,074	74.2	536,187	75.7	3,148,887	73.9
Employment Status						
Full-time	2,921,170	61.8	408,955	60.1	2,512,215	62.1
Part-time	481,574	10.2	77,315	11.4	404,259	10.0
Unemployed	292,385	6.2	39,701	5.8	252,684	6.3
Not in Labor Force	1,029,993	21.8	154,461	22.7	875,532	21.7

Differences in caregiver status statistically significant at *p<.01, **p<.001

1. Federal Poverty Level

Source: Rutgers Center for State Health Policy New Jersey Family Health Survey. 2001

Flexibility by an employer can help to ease the stresses of trying to juggle job responsibilities and caregiving. About a third of caregivers working at small firms and 40% of caregivers working at large firms reported that their employer allowed them to use flextime or work from home in order to provide care, and about 60% said that their employer was flexible about the hours they worked when they needed to provide care (Figure 8). Half of caregivers working at large firms reported that they can take paid time off to take the care recipient to the doctor, while those working at small firms were more likely to use unpaid time off for doctor visits (Figure 9). Only 10% of employers allowed paid time off to run errands for the care recipient, although between 15 and 20% allowed unpaid time off.

Figure 8: Percent of Working Caregivers Ages 19-64 Able to be Flexible About Work

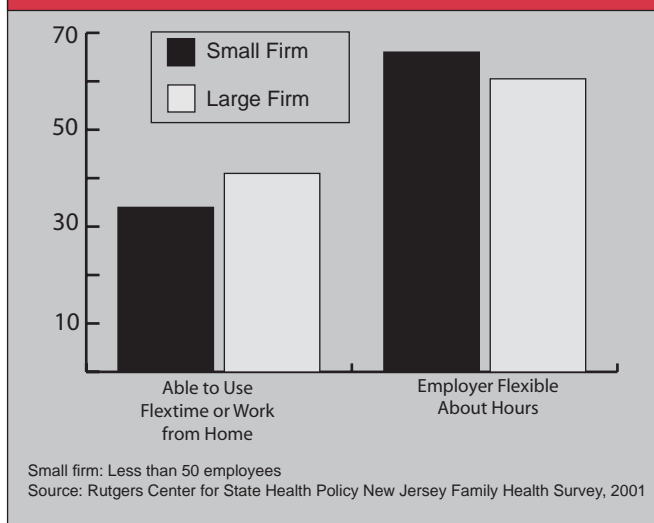


Figure 9: Percent of Working Caregivers Ages 19 to 64 Who Can Take Time from Work for Caregiving

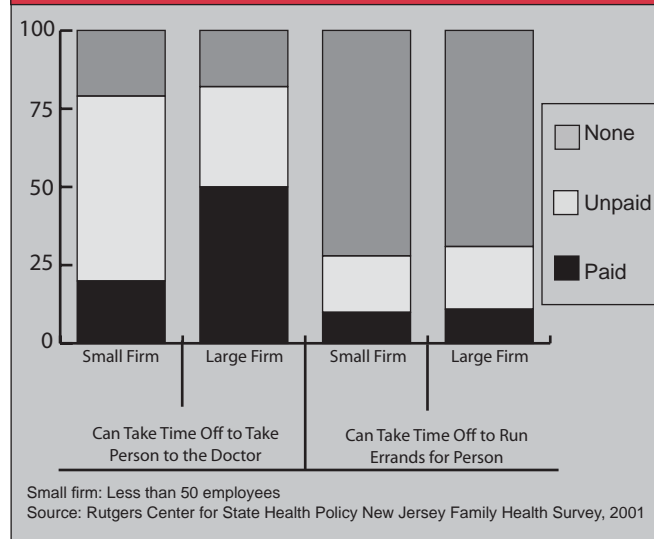
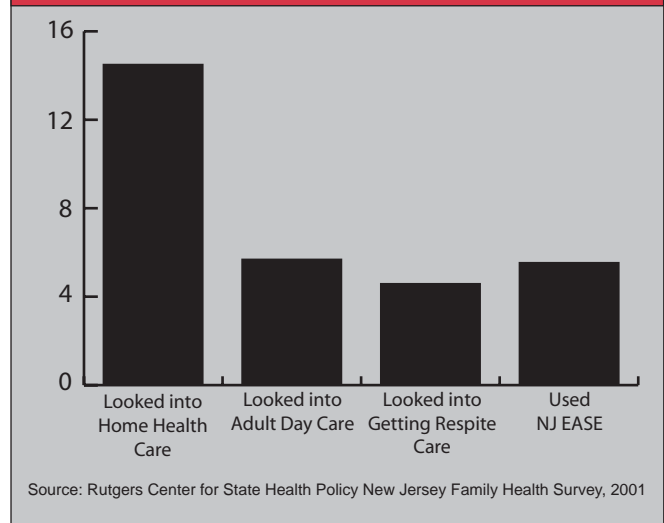


Figure 10: Percent of Caregivers Ages 19-64 Who Looked into Services



Caregiver Support Services

New Jersey has for many years provided a variety of services to support caregivers providing care to older adults and children with special health care needs through the Department of Health & Senior Services and the Department of Human Services. The Caregiver NJ website (www.caregivernj.nj.gov) provides resources to support the role of informal caregivers in the state, including *A Pocket Guide to Caregiver Resources in New Jersey*, and information about services is also available by calling New Jersey Easy Access Single Entry (NJEASE) toll-free at 1-877-222-3737.

The survey asked respondents whether they looked into support services and found that the largest number (15%) had looked into home care (Figure 10). Very few had looked into adult day care or respite services, and only 5% had used NJEASE. Since home care and caregiver issues have been more prominent in public discussion in the past few years, it is possible that a higher proportion would have looked into these services at the current time.

Conclusions and Policy Implications

Working-age caregivers in New Jersey are a valuable part of the healthcare workforce, although most receive no compensation for the services they provide. Over 70% of working-age caregivers are employed, increasing their income but also increasing the stress of caregiving. The New Jersey Family Leave Act provides time off for

the serious illness of a spouse, parent, or child, but this does not help those caregivers who provide daily or weekly support on an on-going basis to someone whose health situation is not 'serious'. Flexibility at work to deal with emergencies is a critical concern for many employed caregivers, and the need to develop policies to address these situations in a way that is perceived as fair to all employees poses a challenge to employers.

Caregivers report more health problems, more healthcare utilization, and more difficulty accessing health care. Fortunately, the majority of working-age caregivers have health insurance, but those who are uninsured are at increased risk for going without needed care. Respite services to allow caregivers time to attend to their own health and personal needs are an important aspect of home and community based supports, and have been provided to New Jersey caregivers through Medicaid Waiver programs, as well as state funded programs, including Jersey Assistance for Community Caregivers, Alzheimer's Adult Day Health Services, and the Statewide Respite Care Program (SRCP). Executive Order No. 100 established the New Jersey Caring for Caregivers Initiative (CGI), and enabled pilot testing of a Caregiver Direction Option, offering support to caregivers by reimbursing them up to \$250 per month (\$3,000 per year) to help purchase services. Expansion of this Option could allow more caregiver flexibility in using respite care and purchasing goods and supplies to maintain their loved ones in the community. With increased funding, the SRCP could offer additional service options that would provide direct relief and support to caregivers.

Our research shows that the majority of working caregivers are not poor, but middle income caregivers who are financially eligible to receive very few of the available home and community based services in New Jersey. Increasing the financial eligibility cap for the

Methods

About the Survey

The New Jersey Family Health Survey (NJFHS) was a random-digit –dialed telephone survey conducted in late 2001 and early 2002 by the Rutgers Center for State Health Policy with funding from the Robert Wood Johnson Foundation. The survey was a statistically representative sample of 2,265 families residing in New Jersey, comprising of 6,466 individuals of all ages who do not reside in an institution. The adult most knowledgeable about the health and health care needs of the family was interviewed. The survey had a response rate of 59.3%.

Defining Caregivers

Caregivers in survey households were identified in two ways. First, if any family members living in the household were limited in certain daily activities because of a health or physical problem, we asked if they received help with these activities and who provided that help, i.e., family members, friends, or professional help. Second, the respondent was asked if any family members living in the household "provide any help such as personal care, running errands, or managing money matters to someone not living there because of a physical or mental health problem?" Therefore, this research includes caregivers who help people with both acute and chronic needs for assistance. Only caregivers living in survey households were included in this study.

Statewide Respite Care Program would provide support for more caregivers throughout the state.

This issue brief has provided a picture of working-age caregivers in New Jersey, who are more likely to combine caregiving and paid employment than caregivers in the nation as a whole. Further state surveys could provide a more complete picture of the support needs of New Jersey's caregivers, so that the state's resources could be better used to sustain and strengthen this important part of the healthcare workforce.

Endnotes

1. National Family Caregivers Association & Family Caregiver Alliance (2006). Prevalence, Hours, and Economic Value of Family Caregiving, Updated State-by-State Analysis of 2004 National Estimates by Peter S. Arno, Ph.D. Kensington, MD: NFCA & San Francisco, CA: FCA. Available at <http://www.caregiver.org/>.
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3. Cannuscio, C.C., Jones, C., Kawachi, I., Colditz, G.A., & Berkman, L. (2002). Reversals of family illness: A longitudinal assessment of informal caregiving and mental health status in the nurse's health study. *American Journal of Public Health*, 92, 1305-1311.



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