

Key findings

- *Sixty percent of family caregivers are helping a close family member, such as a spouse, parent, or child, and one-third live with their care recipient.*
- *Getting information on available services is the most prevalent need among New Jersey family caregivers. Seventy-percent need some level of help, with one-quarter expressing need for a lot of help with this aspect of caregiving.*
- *Help learning about their care recipient's disease (60%), coping with the stress of caregiving (49%), and communicating with professionals (46%) are the next three most prevalent needs among New Jersey's family caregivers.*
- *When caregivers are helping more than one person or living with their care recipient, need for help is generally greater. Need for help is also consistently greater among those caring for a close family member such as a partner, parent, or child than among those caring for some other relative or friend.*

In New Jersey as in the nation, family caregivers play a vital role in helping older adults and individuals with disabilities live comfortably in their own homes and communities. Currently, the State's Medicaid program is undergoing a transformative shift, re-balancing long-term care from institutional settings to a more patient-centered home and community-based service model. Additionally, various healthcare quality improvement efforts emphasizing the prevention of hospital readmissions have increased awareness of family caregivers' value in patient care. For example, the Agency for Healthcare Research & Quality funded the development of the Re-Engineered Discharge (RED) Toolkit which targets family caregivers as a critical element in the success of the discharge plan.¹ The Caregiver Advice, Record, Enable (CARE) Act, passed in New Jersey in 2014 and being promoted across the country by AARP, requires specific caregiver engagement activities as part of a patient's transition from hospital to home.²

Given the importance of family caregivers in the health care system, support for their needs becomes integral to successful patient care. In 2008, interviews conducted with four focus groups of 40 family caregivers in New Jersey and California investigated how they describe their needs for professional help.³ Caregivers reported a wide spectrum of needs that fell into thirteen categories such as assistance in finding available services, learning direct care tasks, understanding disease processes, and addressing end-of-life issues. The 2009 New Jersey Family Health Survey (NJFHS) followed up on these findings by inquiring of a statewide sample of unpaid family caregivers how much help they needed in eight of the identified categories.¹ Table 1 shows the questions asked of caregivers in the NJFHS, ordered from the highest priority need to the lowest (as ranked by the focus group participants). This Facts and Findings uses the data collected from these and other questions in the NJFHS to describe caregivers in the State, the prevalence of their needs, and characteristics associated with expressing need for help in their role as caregivers.

¹ See the Methods section at the end of this report for details on the NJFHS and the identification of family caregivers.

Table 1 | **NJFHS Questions on Caregiver Needs**

| |
|--|
| How much help have you needed getting information about available services ? |
| How much help have you needed coping with the stress of caregiving? |
| How much help have you needed communicating with professionals? |
| How much help have you needed learning about your care recipient's disease ? |
| How much help have you needed finding competent hired help ? |
| How much help have you needed learning care tasks , such as knowing how to use medical equipment or how to move the care recipient? |
| How much help have you needed getting information about medicine ? |
| How much help have you needed addressing end-of-life issues? |

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Table 2 | **Characteristics of Caregiver – Care Recipient Dyads**

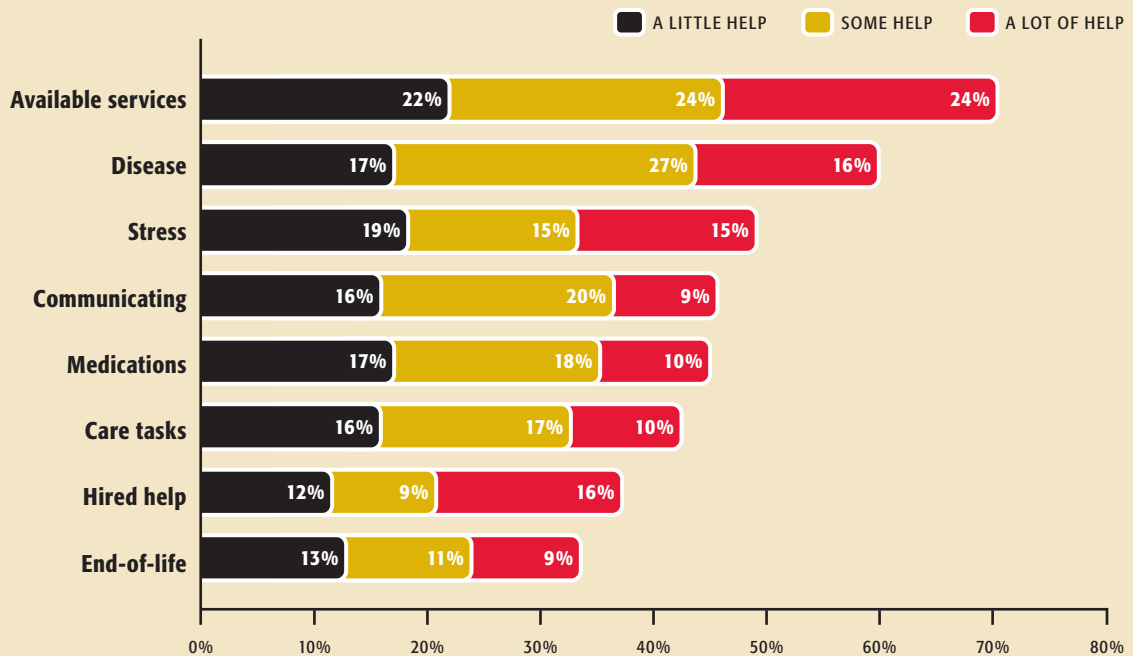
| Characteristics of Caregiver – Care Recipient Dyads | % |
|---|------|
| Caregiver helping more than one person | 34.2 |
| Care recipient & caregiver co-habiting | 33.8 |
| Relationship of care recipient to caregiver | |
| Spouse/ partner | 9.9 |
| Parent/ Parent-in-law | 39.6 |
| Own child | 9.2 |
| Other | 41.2 |

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As illustrated in Table 2, close to one-third of caregivers help more than one person.ⁱⁱ Approximately one-third also responded that they live with their care recipient. Forty percent of caregivers care for a parent or parent-in-law and another 41% care for someone who is not a parent, spouse, or child.

ⁱⁱ These caregivers were asked to respond to the remaining questions with respect to the person they helped the most.

Figure 1 | **Prevalence of Expressed Need for Help in Caregiving Role**



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Figure 1 illustrates the prevalence of expressed needs for help as reported by family caregivers. The highest priority need—help getting information on available services—was expressed by 70% of caregivers in the statewide sample, with 24% reporting they needed *a lot* of help in this area. Approximately 60% of respondents reported they need some degree of help (a little/some/a lot) learning about the disease of their care recipient, making that the second most prevalent need. Forty-nine percent of caregivers reported they need some degree of help (a little/some/a lot) coping with stress. In the remaining categories, between 30–45% of caregivers expressed a need for some degree of help. Dealing with end-of-life issues was the least prevalent need at 33%. Across categories, the distribution of responses among the three need levels (a little/some/a lot) did not reveal any notable variation.

Help getting information about available services, help getting information on their loved one’s disease, help coping with the stress of caregiving, and help communicating with professionals are the four most prevalent needs of New Jersey’s family caregivers. They were also the four needs with the highest prioritization in the 2008 pilot study. In order to identify whether the prevalence of these top needs varied by characteristics of the caregiver and care recipient relationship, we examined the percentage of caregivers saying they needed any help (either a lot, some, or a little) by the characteristics listed in Table 2.

Table 3 | **Prevalence of Need for Help by Characteristics of Caregivers and their Care Recipients**

| | % Expressing Any Need for Help (a little/some/a lot) | | | |
|--|--|---------|--------|---------------|
| | Available Services | Disease | Stress | Communicating |
| Caregiver helping more than one person | | | | |
| Yes | 81.0** | 61.9 | 59.0* | 47.4 |
| No | 65.6 | 58.8 | 44.4 | 45.2 |
| Care recipient & caregiver co-habiting | | | | |
| Yes | 72.7 | 65.1 | 61.7** | 50.8 |
| No | 69.4 | 56.8 | 42.2 | 43.1 |
| Relationship of care recipient to caregiver | | | | |
| Spouse / Partner | 74.6* | 68.4** | 57.4** | 41.9** |
| Parent/ Parent-in-law | 73.9 | 64.9 | 57.4 | 56.1 |
| Own child | 87.5 | 82.2 | 74.1 | 61.9 |
| Other | 60.7 | 44.9 | 31.9 | 30.2 |

* p < .10 , **p<0.05 in tests of differences in the prevalence of need for help by characteristics of caregivers and their care recipient

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When a caregiver is helping more than one person they are more likely to report needing help. Over 80% need help getting information on available services, significantly higher than the 66% of caregivers assisting only one person (Table 3) needing help with this task. The caregivers helping more than one person are also significantly more likely to report needing help coping with stress (59% vs. 44%). Differences in need for help are also seen when comparing caregivers who live with a care recipient and those who do not. The most prominent difference is in help coping with stress, with 62% of co-habiting caregivers reporting a need for help compared to 42% of caregivers who live

separately from their care recipient. Finally, the relationship between caregivers and their care recipient is significantly associated with several needs. In general, need for help getting information on available services, coping with stress, communicating with professionals, and learning about their care recipient’s disease is greater among those caring for a close family member such as a partner, parent, or child than among those caring for some other relative or friend. Information on age and the severity of their physical or mental health problem was not available for all care recipients in the NJFHS, though these factors would likely contribute to caregivers’ expressed need for help.

Family caregivers are at the intersection of two health system reforms unfolding in New Jersey – delivering effective care in home and community-based settings instead of more expensive care in hospitals and nursing homes, and engaging patients and their families as partners in that care.⁴ Our data show that family caregivers in New Jersey commonly report needing some degree of help in their role as caregivers, especially in obtaining information on available services (70%) and learning about their care recipient’s disease (60%). These needs are often greater among caregivers who live with their care recipient and who are helping more than one person. When the care recipient is a close family member, such as a spouse, parent/parent-in-law, or especially a caregiver’s own child, need for help is greater.

Hospital and nursing home discharge planning would benefit from consideration of the support needed by family

caregivers.⁵ Nurses, social workers, and care managers can use this information to align resources and training with family caregivers’ needs. For example, being prepared to educate family caregivers on their family member’s disease and pointing them to appropriate services for their loved one and for help managing their own stress, should be a standing part of discharge planning toolkits. Help with needs having a lower prevalence might be targeted to caregivers who live with their care recipient or are closely related. Discharge planners might consider a formal caregiver assessment to help identify exactly which caregivers need assistance with responsibilities like finding competent hired help and dealing with end-of-life issues. Overall, responding to the evidence that many caregivers need proactive help from professionals in a variety of non-medical tasks is an important extension of the direct patient care required to improve health outcomes in New Jersey.

References

- ¹ Levine C, J Rutberg, B Jack, and R Cancino. [Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-engineered Discharge](#). New York: United Hospital Fund, 2014.
- ² Abramo J. [“Governor Christie Signs the CARE Act: AARP Celebrates Victory for NJ Caregivers.”](#) AARP. Last modified November 13, 2014.
- ³ Yedidia MJ, and A Tiedemann. “How Do Family Caregivers Describe Their Needs for Professional Help?” *American Journal of Nursing* 108, no. 9 Suppl (2008): 35–7.
- ⁴ Agency for Healthcare Research and Quality. [2013 Annual Progress Report to Congress: National Strategy for Quality Improvement in Health Care](#). Washington, DC: U.S. Department of Health & Human Services, 2013.
- ⁵ NAHQ (National Association for Healthcare Quality). [Empowering Family Caregivers Assures Successful Acute Care Transitions](#). Chicago: NAHQ, 2015.

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- Susan Brownlee, Joel C. Cantor, Kristen Lloyd. [Covering the Uninsured: Which New Jersey Adults Will Decide to Enroll in 2014?: Facts & Findings](#), July 2013.
- Kristen Lloyd, Dorothy Gaboda, Joel C. Cantor. [New Jersey’s Long-Term Uninsured Adults Eligible for Coverage under the ACA: Facts & Findings](#), May 2013.
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Methods

The 2009 New Jersey Family Health Survey (NJFHS) was designed to provide population-based estimates of health care coverage, access, use, and other health topics important for New Jersey policy formulation and evaluation. It was funded by the Robert Wood Johnson Foundation and designed and analyzed by Rutgers Center for State Health Policy (CSHP). The survey, conducted between November 2008 and November 2009, was a random-digit-dialed telephone survey of 2,100 families with landlines and 400 families with cell phones residing in New Jersey. It collected information about a total of 7,336 individuals and had an overall response rate of 45.4% (52.6% for landlines and 26.0% for cell phones). The adult who was most knowledgeable about the health and health care needs of the family was interviewed. All estimates presented are weighted to accurately reflect the New Jersey household population.

Further information on the 2009 NJFHS, including a comprehensive methods report and the full text of the survey questionnaire, can be found on the Center's website:

[The 2009 New Jersey Family Health Survey Methods Report](#)
[The 2009 New Jersey Family Health Survey Questionnaire](#)

To identify those who were caregivers, NJFHS respondents (ages 18+) were asked if they regularly provided someone with help dressing, bathing, running errands, managing medicines, or other personal care tasks because of a physical or mental health problem. Respondents were instructed not to include help provided for pay. Those who answered in the affirmative were classified as family caregivers. Because not all adults in the household were queried as to their caregiver status, and only adults most familiar with the health and health care needs of their family were eligible to respond to questions related to caregiving, our sample may not be representative of all caregivers in New Jersey. In this Facts & Findings, we focused solely on caregivers who cared for a loved one who did not reside in an institutionalized health care facility such as a nursing home. A total of 364 respondents qualified as family caregivers of an individual in a home or community-based setting. Table A1 compares characteristics of respondents who identified as caregivers with those who did not.

Table A1 | **Characteristics of Caregivers versus Non-Caregivers in the 2009 NJFHS**

| | Caregivers % | Non-Caregivers % |
|--------------------------|--------------|------------------|
| Gender** | | |
| Male | 27.1 | 39.4 |
| Female | 72.9 | 60.6 |
| Age** | | |
| 18-49 | 45.8 | 52.4 |
| 50-64 | 36.9 | 28.2 |
| 65+ | 17.3 | 19.4 |
| Poverty | | |
| 0-200% FPL | 27.0 | 21.4 |
| 201-400% FPL | 24.6 | 27.9 |
| >400% FPL | 48.4 | 50.7 |
| Education | | |
| High School or less | 37.6 | 37.7 |
| Some college | 26.6 | 20.7 |
| Bachelors degree | 19.4 | 24.2 |
| Advanced degree | 16.4 | 17.4 |
| Race/Ethnicity* | | |
| Non-Hispanic white | 64.9 | 70.2 |
| Non-Hispanic black | 18.4 | 11.6 |
| Hispanic | 11.6 | 13.3 |
| Other | 5.1 | 4.9 |
| Language | | |
| English | 90.2 | 87.6 |
| Other | 9.8 | 12.4 |
| Employment Status | | |
| Working full-time | 49.8 | 48.9 |
| Working part-time | 14.1 | 12.4 |
| Not working | 5.4 | 7.4 |
| Not in labor force | 30.6 | 31.3 |
| Family Structure | | |
| Married with children | 19.0 | 25.9 |
| Married- no children | 27.0 | 25.1 |
| Unmarried with children | 9.8 | 8.9 |
| Unmarried- no children | 44.2 | 40.1 |

Note: FPL=Federal Poverty Level
 * p < .10, **p<0.05 in tests of differences in the distribution of characteristics between caregivers and non-caregivers.

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In this Facts & Findings, observations were excluded using "pairwise deletion", meaning that a person's record was not deleted entirely from the sample if it had any missing data, but was only dropped when it had a missing value for the specific variable under analysis. Prevalence of needs by caregiver/care-recipient characteristics (Table 3) and differences between caregivers and non-caregivers (Table A1) were assessed using Chi-square tests for complex survey data and found to be significant at the 10% and 5% levels where noted.

CSHP's Facts & Findings

Facts & Findings from Rutgers Center for State Health Policy highlight findings from major research initiatives at the Center, including the New Jersey Family Health Survey. Previous Facts & Findings, along with other publications, are available at www.cshp.rutgers.edu.

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