



Helping Caregivers to Care:

In Search of Public Policy to Support Family Caregivers

**A Report prepared by the
New Jersey Foundation for Aging**

January 2003



**The New Jersey Foundation for Aging
is pleased to present this report on**



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to Support Family Caregivers**

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Helping Caregivers to Care in New Jersey

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Acknowledgements

The mission of the New Jersey Foundation for Aging is to improve and expand new and innovative approaches to the delivery of services that enable older adults to live in the community with independence and dignity. The Foundation seeks to establish a clearer understanding for the public and policy leaders throughout New Jersey of what it means to 'age well' in our state.

In 2002 the Foundation hosted an Annual Statewide Conference that focused on the barriers that family caregivers experience every day as they try to provide care for their loved ones. The Fund for New Jersey graciously provided support to further examine this issue beyond the realm of the conference participants and to underwrite this report. The results rendered in this report offer a summary of the conference results, perspectives gained from several national studies on caregiving and a caregiver survey undertaken for this study.

We appreciate the input from the caregivers who took part in the report survey. Their personal experiences offer snapshots of the diversity of caregiver needs and help to frame suggestions to make their tasks easier.

We were fortunate to have the assistance of Gwenn Karel Levine, Ph.D. on this project. Dr. Levine assisted with survey design, data analysis and preparation of the report.

We offer this data and the recommendations to advance the necessary dialogue to address caregiver issues at the local, statewide and national levels. Caregivers' needs call out for a diverse, multi-disciplinary, culturally inclusive, affordable community based response. We have far to go to accomplish this, however, designing an improved response system for caregivers will serve a common good, for we realize at one time or another we are all involved in caregiving.

Grace Egan, MS, Executive Director
New Jersey Foundation for Aging

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A Policy Paper from the New Jersey Foundation for Aging

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"Life changes totally- relationships with family and friends change. This [caregiving] is not always negative- only the stress of constantly predicting what needs to be done in order to stay ahead of a crisis".¹

A glimpse into the dilemma of family caregiving is articulated in the comment above. Roles change, relationships change, time demands change and yet many families and friends provide the bulk of care to those chronically ill in this country. Cultural competency, complicated bureaucracies, access to appropriate care, etc. all roll into making caregiving a true labyrinth for all those who enter in an effort to provide care for their loved ones. The New Jersey Foundation for Aging set out to explore, illustrate and design a path to improve the system that family caregivers must face each day. The Foundation is partially supported by the Robert Wood Johnson Foundation, which is committed to improving access to health care for all Americans.

The New Jersey Foundation for Aging appreciates the support for this Report that was provided by The Fund for New Jersey whose work supports advocacy and public policy.

Introduction

Informal caregivers are unpaid family and friends who assist people with chronic health conditions. According to *Chronic Care in America: A 21st Century Challenge*,

Chronic care refers to a continuum of care required over a prolonged period of time for people who have lost, or never acquired, functional abilities. A continuum of care ensures that a person receives the care appropriate to his or her condition, when it is needed, in the right amount, and that it is provided efficiently. The concept of a "continuum" assumes that a range of services is available . . .²

¹ Quote from family caregiver survey respondent.

² Source: *Chronic Care in America: A 21st Century Challenge*, Prepared by The Institute for Health & Aging, University of California, San Francisco for The Robert Wood Johnson Foundation, Princeton, NJ, August 1996.

Recognizing the mental health needs of family caregivers

Stigma associated with mental illness and psychiatric treatment creates barriers to seeking and/or receiving needed assistance.

Lack of mental health education/services at accessible locations.

Lack of early identification of mental illness in high-risk families.

Lack of recognition by caregivers (e.g. depression) which result in the under-utilization of mental health programs by caregivers.

Caregivers have too little time to seek help.

Lack of culturally competent, accessible and affordable services.

Fragmentation of the care networks of aging, health, mental health and non-traditional delivery systems perpetuate multiple and distinct care programs and funding as well as differing service limitations.

Looking at the role of faith-based communities serving caregivers

Congregations are generally fragile, volunteer-dependent organizations without a knowledge base of caregiver services, the time or the expertise to negotiate the bureaucracies to access care

Addressing the needs of drug dependent caregivers and/or care recipients

Caregivers and/or care recipients who are drug or alcohol dependent generally have difficulty gauging the depth of their own problems.

These caregivers and/or care recipients tend to lack a mechanism for networking with regard to information on medical diagnoses and medications.

Serving immigrant populations

Language and culture create barriers for immigrant caregivers to seek and/or receive needed assistance.

The population's diverse needs, languages and/or cultural norms that limit communication about such topics as medical diagnoses, money, and dying; conflicts that limit the caregivers' ability to communicate their needs which often results in a degree of isolation.

Lack of supplemental payment for family caregiving limits help.

Lack of transportation results in isolation.

The conference speakers also referenced a model that is often referred to as the 'German Model', cash and counseling, consumer directed care. This is a model that is currently being tested in New Jersey, Florida and Arkansas with support from The Robert Wood Johnson Foundation. The demonstration program in New Jersey is looking at the effectiveness of offering cash and counseling for personal care through the Division of Disabilities Services. The program is in its third year, and results are pending the completion of the pilot. This model offers the care recipient the ability to direct their care providing them the cash support to directly purchase assistance or services. This model is a change in the paradigm for the provision of care. Consideration was given to surveying the Personal Choice clients, however, this study is targeted to the needs of 'caregivers' of care recipients. The participants in the New Jersey Cash and Counseling Project- 'Personal Choice' are the care recipients and for this reason they were not the target group for this study. We await the results of this important pilot.

Background Data

According to *Toward a National Caregiving Agenda: Empowering Family Caregivers in America*,⁴

- Family and friends provide 80% of care to older people.
- Family caregiving occurs inside or outside of the home – before, instead of, or along with paid caregiving.
- Family caregiving keeps the elderly out of nursing homes.
- Family caregivers often perform sophisticated health care tasks that traditionally required skilled nursing staff.
- Caregiving now preoccupies one of every four households.

Chronic Care in America: A 21st Century Challenge, reports:

- In the USA in 1995, 99 million people had chronic conditions characterized by persistent and recurring health consequences lasting for periods of years.

⁴ *Toward a National Caregiving Agenda: Empowering Family Caregivers in America*, proceedings of a Caregiver Empowerment Summit, July 2001, convened by The National Alliance for Caregiving in collaboration with Partnership for Caring, sponsored by MetLife Mature Market Institute and Pfizer Inc.

Coverage

- Private long term care insurance – most people don't yet have this
- Medicare – primarily acute care
- Medicaid – eligibility contingent on spending down almost all assets

3. Caregiving demands often interfere with caregivers' job responsibilities

- Loss of wages, social security benefits, and pensions
- Loss of workplace productivity due to disruptions, absence, leaves of absence, reduction from FT to PT work, early retirement, leaving work entirely

4. There is insufficient training to teach caregivers how to perform difficult personal care tasks or deal with medical equipment and procedures that must be administered at home

- Inadequate preparation for the transition from acute care or rehabilitation to home care – for both the caregiver and care recipient
- Lack of training or support to function as care recipient's health care advocate
- Lack of training or support to increase the care recipient's compliance with recommended health care treatments

The Portrait of Informal Caregivers in America reported that "caregivers are at risk...depressed...their physical and mental health is worse than the general adult population. If they burnout both their loved one and society suffer." The report recognized that caregiving is a long term commitment which consumes a growing degree of personal time while caregivers balance multiple responsibilities. It also noted that support services for caregivers are neither consistent, organized, accessible, nor affordable.

Findings from the NJFA Survey of Informal Caregivers – Family & Friends

Profile of respondents

There were 30 respondents from five agencies located in New Jersey – Old Bridge Senior Center, Family Service of Morris, Day Break in Ocean County, Princeton Senior Resource Center and Parkinson's Center at Robert Wood Johnson University Hospital. A copy of NJFA's Survey of Informal Caregivers – Family and Friends appears in Appendix B.

Years of caregiving. 46.7% of respondents reported that they have been providing caregiving services for 1-5 years, and 46.7% reported that they have been providing caregiving services for 5 years or more. Only 6.7% reported that they had been providing caregiving services for less than one year.

Impact on caregiver. In response to a question about the impact of caregiving on their own health, no respondents cited a purely positive impact. 66.7% felt the impact was negative, 33.3% felt it was neutral, and one respondent (3.3%) felt it was both positive and negative.

Hospitalization. 53.3% of respondents indicated that their care recipient had been hospitalized in the previous 12 months.

Language. 60% of respondents indicated that hospital staff was able to communicate in the respondent's language.

Caregiver instruction. Respondents were asked to select all that applied, 46.7% of respondents indicated that they received instruction about providing Activities of Daily Living (ADL) services, but 50% indicated that they received no instruction. Of those who did receive instruction (14 respondents), 57.1% received instruction from doctors, 35.7% received instruction from nurses, 28.6% received instruction from other hospital personnel, 35.7% received instruction from non-hospital personnel, 35.7% received instruction from friends and/or neighbors, and 28.6% received instruction from others.

Obtaining assistance. When asked whether they have professional help to assist with caregiving services, most respondents indicated that they do not. In this regard, 16.7% receive assistance from nurses, 10% receive assistance from social workers, 3.3% receive services from physical therapists, and 20% receive assistance from any other sources.

When asked whether they have paraprofessional help to assist with caregiving services, 20% of respondents indicated that they receive assistance from home care aides and 20% receive assistance from others.

23.3% of respondents rated professional assistants very good or excellent, 3.3% rate them good, and 16.7% rated them fair or poor. With regard to paraprofessional assistants, 16.7% of respondents rated them very good or excellent and 10% rated them fair or good.

Ability to get help. 46.7% of respondents indicated that they were able to get the help they needed as a caregiver in the previous 12 months, 30% indicated that they were unable to get the help they needed, and one

- I feel as though I have done all possible to still care for husband and hold down a full time job.

Positive comment related to outside help

- Having Day Care to take some of the load off me.

Negative aspects. Respondents were also asked an open-ended question regarding the negative aspects of caregiving.

Comments related to stress, depression, and fatigue

- Depression; don't take care of oneself. Fear of being in this situation again. Pain – heartbreak.
- Very stressful – very frustrating – I have NO life. Constant worry. Get no help – hard to find any affordable help. Society would rather put in nursing home and take all their money instead of letting them stay in homes with family giving care. Depressing – angry with Medicare/Medicaid system. My father worked all his life and gets nothing now. Yet immigrants get Medicaid, etc. Horrible. Should do more for caregivers – would be less burden on State.
- I am old. My daughters (2) died and then I was left to take care of sick husband all alone!
- Every day pressure builds up and caregiver needs a break. He has to go to a nursing home so I can get a break and is very costly. He does not like eating supper home. He likes to go out to Victoria Diner where the owner greets him and makes him feel good and carries on a conversation with him. But this is costly.
- It is stressful taking care of my kids and my father.
- Most of the time it is very demanding because of the patient's change of temperament.
- Time constraints; I am getting tired – have NO life. I can never get away – a meeting, a haircut, lunch with a friend.
- My mother at times does not respect that I have my own life to deal with, as well.

It is clear in the surveys that those caregivers that had a serious health condition seemed the most compromised in obtaining needed services. You will see that 50 % of those with conditions noted they needed help in equipment, with home care with therapy and with transportation. This response far exceeded the other groupings of caregivers. Barriers to these services included "the cost, not covered by insurance, too difficult to arrange or they did not know how to get these services". Caregivers who live in the same home had the highest response to being unable to get counseling for themselves. Caregivers that worked were looking for help with equipment, physical therapy and transportation while those caregivers in a support group had lower responses to unmet needs.

In this regard, please note the group findings in the next section.

Of the caregivers responding to the NJFA survey who are 65 years old or older,

- 57.1% also provide 20 hours or more per week of caregiving services.
- 92.9% also live in the same home as the care recipient.
- 21.4% do NOT participate in a caregiver support group.
- 28.6% reported having a serious health condition.
- 50% reported that the care recipient had been hospitalized in the previous 12 months.
- 50% reported that they did not receive instruction about ADL services and/or medical tasks following the hospitalization of the care recipient.
- 42.9% reported that they do NOT get the help they need.
- 42.9% find caregiving very difficult.
- A number of those caregivers age 65 or older reported that the following types of help were either too costly, not covered by insurance, hard to arrange, or they did not know how to get help:

<u>Service</u>	<u>% of caregivers age 65+</u>
Counseling for themselves	21.4
Counseling for the care recipient	7.1
Help with equipment	14.3
Help with home health care	21.4

- 64.7% also provide 20 hours or more per week of caregiving services.
- 94.1% also live in the same home with the care recipient.
- 11.8% also have a serious health condition.
- 47.1% reported that the care recipient was hospitalized in the previous 12 months.
- 52.9% reported that they did NOT receive instruction about ADL services and/or medical tasks following the care recipient's hospitalization.
- 23.5% reported that they do NOT get the help they need.
- 23.5% find it very difficult to provide caregiving services.
- A number of those caregivers who participate in a caregiver support group reported that the following types of help were either too costly, not covered by insurance, hard to arrange, or they did not know how to get help:

<u>Service</u>	<u>% of caregivers in a caregiver support group</u>
Counseling for themselves	17.6
Counseling for the care recipient	5.9
Help with equipment	5.9
Help with home health care	11.8
Help with meals	5.9
Help with finding a nursing home	11.8
Help with physical therapy	11.8
Help with transportation	5.9

Of the caregivers responding to the NJFA survey who have a serious health condition,

- Most also provide 20 hours or more of caregiving services each week.
- All live in the same home with the care recipient.
- Half do NOT participate in a caregiver support group.
- Half reported that the care recipient was hospitalized in the previous 12 months.
- Only one respondent did NOT receive instruction about ADL services and/or medical tasks following the care recipient's hospitalization.

- A number of those caregivers who live in the same home as the care recipient reported that the following types of help were either too costly, not covered by insurance, too hard to arrange, or they did not know how to get help:

<u>Service</u>	<u>% of caregivers who live in same home</u>
Counseling for themselves	80.0
Counseling for the care recipient	36.0
Help with equipment	16.0
Help with home health care	24.0
Help with meals	4.0
Help with finding a nursing home	12.0
Help with physical therapy	20.0
Help with transportation	16.0

Policy Recommendations

Public Education and Advocacy

Improve the public's understanding of the role family caregivers provide within the health care network

Improve the understanding within the workplace of the role of family caregivers

Improve the public's understanding and recognition of and the need for assistance for grandparents who are raising their grandchildren

Establish statewide and county based task forces focusing on public understanding and education on the needs of caregivers including the professional network but also giving significant weight to participation from family caregivers

Improve the public's understanding of the availability of caregiver services within the community

- Development of marketing materials that address ethnic diversity
- Increased outreach efforts

Advocate for increased financial support for the formalized network of care as well as caregiver options and supportive services

Appendix A

Demographic Description of Age 65+ Population in New Jersey ⁵

Demographic Statistic	1990	2000	Change
Population			
Total population	7,730,188	8,414,350	8.9%
Pop. age 65+	1,032,025	1,113,136	7.9%
Pop. age 65+ as % of total pop.	13.4%	13.2%	--
Pop. age 65+ - Female		666,356 (7.9%)	
Pop. age 65+ - Male		446,780 (5.3%)	
Households			
Total households	2,794,711	3,064,645	9.7%
Householder age 65+ living alone	273,736	300,688	9.8%
Householder age 65+ living alone as % of total households	9.8%	9.8%	
Disability			
Pop. age 65+ non-institutionalized	985,121	1,063,982	+8.0%
Pop. age 65+ non-inst'd w/ disability		411,059	
Pop. age 65+ non-inst'd w/ mobility limitation	145,987		
Pop. age 65+ non-inst'd w/ self-care limitation	117,312		
Veteran status			
Veteran status age 65+	240,620		
Poverty status			
Pop. age 65+ (1989)	985,099		
Pop. age 65+ below poverty	84,200	83,336	-1.0%
Pop. age 65+ below poverty as % of total pop. age 65+	8.5%	7.8%	
Grandparents as caregivers			
Grandparents living in household w/ grandchildren		185,771	
Grandparents living in household and responsible for grandchildren		58,789	
Grandparents living in household and responsible for grandchildren a % of total grandparents in household w/ grandchildren		31.6%	

⁵ 1990 and 2000 US Census. See <http://quickfacts.census.gov/> and <http://factfinder.census.gov/>.

5. Interaction with Formal Systems of Care

Do I have professional help to assist me in providing caregiving services? (Check all that apply)

- (a) Nurse Yes _____ No _____
- (b) Social Worker Yes _____ No _____
- (c) Physical Therapist Yes _____ No _____
- (d) Other Yes _____ No _____

Do I have paraprofessional help to assist me in providing caregiving services? (Check all that apply)

- (e) Home Care Aides Yes _____ No _____
- (f) Other Yes _____ No _____

How do I rate the quality of this help?

- (g) Professional help Excellent _____ Very Good _____ Good _____ Fair _____ Poor _____
- (h) Paraprofessional help Excellent _____ Very Good _____ Good _____ Fair _____ Poor _____

6. Unmet Needs for Caregiving Assistance

(a) In the past 12 months, was I able to get the help that I needed as a caregiver (such as home health care, equipment, meals, etc.)? Yes _____ No _____

If "No", the reasons I was unable to get the help I needed are as follows: (Check all that apply)

Help I Needed	Reasons I Did Not Get the Help I Needed				
	Too costly	Not covered by insurance	I don't know how to get this help	It's too hard to arrange this help	Other reasons (If applicable, write other reasons below OR on the reverse)
(b) Counseling for me					
(c) Counseling for the care recipient					
(d) Equipment					
(e) Home Health Care					
(f) Meals					
(g) Finding a Nursing Home					
(h) Physical Therapy					
(i) Transportation					

7. Caregiver's Perspectives

(a) Am I comfortable about performing caregiving services?
 Very Comfortable _____ Somewhat Comfortable _____ Not Comfortable _____

(b) Is it difficult for me to be a caregiver? Very difficult _____ Somewhat difficult _____ Not difficult _____

(c) What do I think are some positive aspects of being a caregiver? _____

(d) What do I think are some negative aspects of being a caregiver? _____

Survey
Survey of Informal Caregivers - Family and Friends
 New Jersey Foundation for Aging

	8. Caregiving as a Job		9. Caregiver Instruction	10. Hospitalization of Care Recipient
	Which of the following services do I currently provide? (Check all that apply)	How many hours per week do I provide each service? (Indicate hours for all that apply)	If I answered "Yes" to survey question 4(a), which of the following services did I receive instruction for? (Check all that apply)	If I answered "Yes" to survey question 3(a), which of the following activities did I add to my tasks after the hospitalization of the care recipient? (Check all that apply)
Activities of Daily Living (ADL's)				
(a) Bathing or showering				
(b) Getting dressed or getting clothes out of closet				
(c) Feeding				
(d) Managing Incontinence				
(e) Getting in and out of bed or chairs				
(f) Walking across the room				
Incidental Activities of Daily Living (IADL's)				
(g) Shopping or errands				
(h) Housework				
(i) Preparing meals				
(j) Transportation, either driving or helping with public transportation				
(k) Telephone calls for or about the care recipient				
(l) Managing finances, paying bills, or filling out insurance claims				
(m) Arranging for government assistance through programs such as Medicaid, Medicare, and SSDI				
Medical Tasks				
(n) Helping with prescription medications				
(o) Changing dressings or bandages				
(p) Using medical equipment (e.g. oxygen, home dialysis, tubes, catheters)				