

# **Aging Futures**

. . . older adults living well  
as they define it.

## **Caregiver Workgroup Report**

**2003**

**A Community Partnership for Older Adults Project**

A National Program of The Robert Wood Johnson Foundation

Aging Futures Partnership  
Broome County, New York

# Our Mission

*Creating and strengthening community systems,  
thus enabling persons age 60 and over to maintain  
the highest quality of life.*

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# About the Partnership

*“The beauty of collaboration is the acknowledgement that each organization has a special function, a power that it brings to the joint effort. At the same time, each organization provides valuable services or products critical to the health of its community.”* (Winer Collaboration Handbook: Creating, Sustaining, and Enjoying the Journey, 1994)

Since 1989 Broome County has benefited from a dedicated Partnership of consumers, educational institutions, public and private and not-for-profit agencies and faith communities dedicated to enhancing the quality of life for seniors in Broome County. Aging Futures demonstrates their commitment to strengthening Broome County’s long term care system by:

- Engaging seniors, listening to their needs and including them in planning processes
- Promoting the independence of seniors
- Building and supporting a responsive long term care system

Broome County was one of 13 communities nationwide to receive a planning grant from The Robert Wood Johnson Foundation, as part of their Community Partnership for Older Adults initiative. The grant, awarded in August 2002, supported our local Partnership in coordinating a planning process to meet the needs of vulnerable elders and their caregivers in Broome County.

Aging Futures Partnership goals:

- Strengthen a long standing and diverse Partnership focused on long term care services and supports
- Understand local needs, prioritize action steps and act collectively to address them
- Develop strategies that will bring about change in both practice and policy
- Secure funding and evaluate our efforts
- Support and coordinate community education about senior issues

# **Aging Futures**

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# Caregiver Workgroup Report

## I. INTRODUCTION

- A. **Overall Goal of Aging Futures:** The Aging Futures Partnership is dedicated to enhancing the quality of life for all people over the age of 60 in Broome County. The Aging Futures planning initiative began in 1989 and continues today to support the work of agencies in Broome County that serve seniors. The Aging Futures Partnership offers seniors the opportunity to be involved in problem solving and recognizes that to foster change in our community and our long term care system, we need to collaborate. Aging Futures builds on the strengths of our community and works towards innovative approaches that address unmet needs.
- B. **Desired Outcomes:** To assure that community supports that promote well being, maximize independence and minimize functional decline and its effects are in place.
- C. **The Charge of the Workgroup:** The Caregiver Workgroup met 5 times in the spring of 2003 to identify one or more strategies that would support vulnerable seniors in remaining independent and capable of living in their preferred environment.
- D. **Rationale for Selection of Caregiver Support and Education:** A breakdown in informal caregiving contributes to the increased chance of future hospitalization and/or institutionalization, and greater expenditure of healthcare dollars, especially Medicaid and Medicare dollars. (Naylor, 1994) "The consequences of a high caregiver burden include an increased risk of the need to place the family member in a long term care facility as well as increased use of formal in-home services." (Brown, et al., 1990) For vulnerable elder patients, it is the existence of a committed and capable family caregiver that helps to ensure a transfer to home rather than to a nursing home, and a reduction in the number of re-encounters with the acute care facility. Obviously, without intervention and support, caregivers and their families are placed at even greater risk.

Interventions aimed at caregivers have been shown to be effective. Education and useful practical information geared toward caregivers at the point of their transition into new caregiver duties is recommended by the research focused on caregiver needs. "To facilitate the adoption of caregiver roles, we suggest the development of brief education programs to improve caregiver abilities to assess care recipient needs and access community services." (Piercy & Chapman, 2001) "Short-term educational groups that focus on information-sharing or personalized

problem solving (rather than emotional support) would differ from traditional caregiver support groups because they are time limited in duration.” (Piercy & Chapman, 2001) The need for education and information is supported by Conger and Marshall who found that skill acquisition was identified as “the first step toward gaining confidence in caregiving ability and competence in caregiving.” (Conger & Marshall, 1998) In one study, “institutionalization of dementia patients was delayed by 329 days in the intervention group of caregivers, compared with the group of caregivers who did not receive counseling and other forms of support.” (Mittelman, M.S., et al., 1996)

A recent national survey by the National Family Caregivers Association (NFCA) found that more than one quarter (27%) of the adult population has provided care for a chronically ill, disabled or aged family member or friend during the past year.

“The term caregiver refers to anyone who provides assistance to someone else who experiences limitations in activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends, neighbors and volunteers who provide help or arrange for help. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. They provide help with household chores, finances, or with personal or medical needs. This definition does not include formal caregivers who are paid care providers associated with a service system.” (A Compendium of HHS Caregiver Support Activities, Administration on Aging, 2003)

Of caregivers providing help after a recent hospital stay, 74% report caring for a family member while 12% are caring for a friend or companion. The majority of caregivers who are caring for a family member are caring for a parent or in-law (45%). Even under the best of circumstances, caregivers are at risk of mental and/or physical illness. Over 30% of caregivers suffer from depression, 40% report high levels of caregiver strain, and 30% are in poor health (Navaie-Waliser et al., 2000). A 1997 survey of family caregivers conducted by the National Alliance of Caregiving and the AARP indicated that 46% of caregivers suffer from clinical depression – 49% of the females and 31% of the males. (Family Caregiver Alliance Fact Sheet) “Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.” (George, 1991) Perhaps even more significant is the impact caregiver strain can have on care recipients.

Interventions that conceptualize professional or formal caregivers and family caregivers as partners, each with unique and vital skills and resources, are particularly advantageous. A cooperative relationship between informal caregivers and formal services has been shown to be both preferable and

empirically sound. (Bould et al., 1989; Litwak, 1985). By meshing the strengths inherent in both the formal and informal systems, continuity across transitions is ensured. “The formal system has unique and vital resources – particularly expertise and power – and the informal network has equally vital and unique resources – particularly proximity, affection, long-term commitment, and intense knowledge of the elder.” (Walker, 1995) As one caregiver said during the planning phase of Mt. Sinai’s successful Caregivers and Professionals Partnership Program (CAPP), “Treat us like partners, not pests!” (Levene, 1998) Such interventions lead to better care and morale for both professional and lay caregivers. (Archbold et al., in press; Harvath et al., 1994)

Broome County’s caregivers have expressed a general lack of confidence in their ability to perform their duties. Caregivers often feel unprepared for their role and do not know where to turn for help. Broome County residents can benefit from several programs that support caregivers. However, specific interventions for caregivers in transition are limited. Discharge planning processes traditionally focus on the patient and are not specifically designed to assist caregivers.

Members of the Caregiver Workgroup were interested in complimenting existing services with a more “high touch” service that broadens the continuum of available services.

#### **E. Rational for Selection of Caregiver Support at Transition:**

The Caregiver Workgroup identified the transition point when caregivers are faced with discharge of their care receivers from an acute care hospital setting to home as a priority. Transitions are defined as “the rights of passage of people who are ill and frail, when families must then help them navigate in a fractured long-term care system.” (Levene, 1998) A study of rural older adults confirmed that health care transitions were characterized as crises “compounded by surprise, limited knowledge of local resources exacerbated the crisis, inconsistent discharge planning disrupted transitions, changing family support necessitated admission to nursing homes...”(Magilvy, et al., 2000)

Families in transition often find themselves overwhelmed and without an understanding of helpful community services. It is at this transition from hospital to home, or nursing home to home after rehabilitation, where the “high touch” support of the Caregiver Guides could be very beneficial.

The transition into new health care related caregiver responsibilities is often prompted by an acute medical episode involving a hospital stay. The level of involvement adult children have in their parents’ care has been shown to progress through delineated stages from a recognition of responsibility to the active provision of help, often prompted by a health crisis requiring hospitalization. “Practitioners may assist adult children in moving...to the next state of effectively dealing with their chronic illnesses and symptoms.” (Circirelli, 2000) Whether

the hospital stay stems from a new diagnosis or an acute flair-up of an existing chronic illness, hospitalization of the care recipient upsets the balance of daily life. The care recipient may be transitioning into another level of care, at least temporarily, that the caregiver also must adjust to.

Many caregivers do not fully anticipate the extent of their duties after discharge and therefore have a difficult time preparing. “A sudden crisis in a parent’s health may orce an adult child into a caregiving role prematurely.” (Cicirelli, 2000) Although the caregiver may have been given a wealth of information on services available, if they are not already familiar with the aging services system, it can be a daunting task to navigate through the myriad of information without some assistance. Caregivers and patients alike have a difficult time absorbing information and training prior to discharge due to the strain and stress of the circumstances. The caregiver is off-balance, forced into an unfamiliar environment while attempting to cope with a crisis situation that may have a significant impact on their life for weeks or months to come.

What practical measures can be taken to help bridge the gap for the caregiver between institutional care and home care to ensure a seamless and successful transition?

Providing information, support and follow-up at this point will better prepare the caregiver for new responsibilities and tasks at home. Hospital discharge planners and management personnel confirmed this need and join in this collaborative pilot model.

- F. **Population to be Served:** The population to be served would be one hundred caregivers identified by hospital staff, who could potentially benefit from support in a hospital-to-home transition.

**G. Rational for Selection of Returning Home Program:**

Broome County has a rich and proven history of successfully implementing information-based volunteer programs that provide both information and assistance on a variety of topics, and as such believes that the Returning Home Program can be successful and sustainable for years to come.

The intervention will consist of trained Caregiver Guides who will provide hospital-referred caregivers with information, support and at-home follow-up. In year one, a paid Caregiver Guide will establish procedures, select resources and evaluate progress. Volunteer Caregiver Guides will be integrated in year two.

The program’s two-year model will provide an opportunity to analyze the caregiver/patient intervention and to ascertain its impact and potential to change the hospital-to-home protocol as well as delay institutionalization.

“Formal interventions may be especially important to families at transition points, when decisions or new skills are needed in order to continue to provide care” to mesh the informal and formal care systems. (Walker, 1995) “Because a lack of understanding about the family member’s disease process may worsen caregiver stress, the caregiver’s knowledge about...the illness and available resources should be explored and additional information provided when needed.” (Parks, 2000)

“Changing health care policies, which have shortened hospital stays...have resulted in the discharge of increasingly frail older people who are in greater need of intensive home health care than ever before.” (Hooyman & Kiyak, 1996) The trend over the past 20 years towards community-based care has led “...health care facilities increasingly to shift ADL caregiving responsibilities to the community or family members. In contrast to IADL assistance, which involves predominantly household tasks, ADL help is an aspect of health care.” (Walker, 1995) These family members add to their other household responsibilities the provision of health care once thought to be too specialized or too complicated for minimally trained lay persons to carry out.” (Walker, 1995). Fifty percent of caregivers report helping with ambulating. Forty-five percent report help with medication management, and 38% with the use of medical equipment. (DesRoches, 2002)

Comprehensive discharge planning protocols that include a caregiver assessment, caregiver involvement in the care plan, and telephone outreach to both the patient and caregiver after discharge have shown significant results. In one particular randomized clinical trial, the introduction of such a comprehensive discharge planning protocol implemented by geriatric nurse specialists resulted in “fewer readmissions, fewer total days rehospitalized, lower readmission charges, and lower charges for health care services after discharge.” (Naylor, et al., 1994) “The findings reinforce the need for strong collaboration among physicians, nurses, patients, and caregivers regarding both the patients’ readiness for discharge and the plans and services necessary to prevent negative outcomes.” (Naylor, et al., 1994) The findings also confirm that follow-up after discharge with patients and their caregivers is an important component of highly successful discharge plans. At 6 months, the intervention “generated estimated savings in Medicare reimbursements for all post index hospital discharge services of almost \$600,000 for the survey participants, a mean per patient savings of \$3000.” (Naylor, et al., 1994)

**Best Practices and Literature Review:** Two Philadelphia hospitals, supported by the National Institute of Nursing Research (NIH) have implemented caregiver support programs with positive outcomes. Through a multidisciplinary team of hospital staff, a program of comprehensive discharge planning and follow-up focused on family caregivers has been able to boast of significant outcomes. The readmission rate for patients whose caregivers benefited from the program was only 20%, as compared to 37% for others. The estimated savings for post-

discharge healthcare is over \$600,000. (Naylor, 1994) Refer to the section on “Interventions” above for additional information on this successful program model.

Mt. Sinai Hospital is also one of the seven hospital models funded by the United Hospital Fund’s \$2 million Family Caregiving Grant Initiative that has coordinated new activity to support caregivers. The focus of the initiative was to respond more effectively to the needs of family caregivers during and after hospitalization of their relatives/friends/companions. (Levene, 1998) “There is a clear need for hospital-based family caregiver programs in today’s health system,” said Carol Levene, director of the Fund’s Families and Health Care Project and author of the report, “Making Room for Family Caregivers.” “This initiative demonstrates that hospitals can be an important source of support for caregivers. Not only did caregivers benefit from these important projects, but hospital staff gained as well.” David A. Gould, the Fund’s senior vice president said, “Our grant funded projects are beacons for others who understand how important it is to reshape our health system with family caregivers as partners.” The Caregivers and Professionals Partnership Program (CAPP) at Mt. Sinai Hospital in NYC is a multifaceted, interdisciplinary program comprised of a resource center for caregivers staffed by social workers who offer support and referral to community services. In addition, Mt. Sinai adopted a Performance Improvement Initiative to increase institutional responsiveness to caregivers and a Caregiver Institute providing education on caregiver issues for both staff and caregivers. Helene Ebenstein, Coordinator of the CAPP Program, provided valuable information about the CAPP Program and comments on plans for the Returning Home: Caregiver Support Program model.

## II. PROPOSED SPECIFIC IMPLEMENTATION STRATEGY

A. **Outcomes:** By providing caregivers with supports that bridge the transition from hospitalization to home, caregivers will be more aware of what will be expected of them and where to turn for help if they experience difficulty after discharge. Expected measurable outcomes include caregivers who express:

- A greater degree of preparation for their caregiver duties.
- Increased confidence in their ability to locate community-based services.
- Reduced caregiver burden.

The proposed strategies will:

:

- Bridge the transition from acute hospital to home.
- Enable caregivers to be better prepared for duties.
- Enable caregivers to understand and access services.

In the long term, it is expected that through this intervention:

- Patient outcomes will improve.
- Re-encounters with the hospitals will decrease.
- There will be increased efficiency within the hospital and in community service utilization.

Ultimately, as shown through outcomes from similar caregiver focused programs, the program strives to demonstrate a reduction in the rate of re-encounters through emergency room and inpatient visits for care recipients, and ultimately a delay or prevention of institutionalization.

- B. **Activities:** The Returning Home Caregiver Program Support Model will provide caregivers assistance at the transition of vulnerable elder patients from an acute care hospital setting to home. The two local hospital systems, Our Lady of Lourdes Hospital and United Health Services, are partnering with the Aging Futures Program to pilot this project. Implementing the Returning Home Model will require collaboration and business agreements with both hospitals. Directors of Care and Discharge Planning were active members of the Caregiver Workgroup and have been involved in this model's development process. They expressed an enthusiastic response to the ideas presented.

To ensure a successful and mutually effective business agreement, the following activities have been identified as essential:

- Define indicators for identifying vulnerable elderly patients for referrals.
- Identify one or two hospital units targeted for caregiver contact.
- Assure respect for and compliance with HIPAA Regulations.
- Develop a collaborative working agreement with hospital care management/social work staff.
- Establish location and hours for a resource area.
- Establish hours for "Caregiver Guide" contact with caregivers.
- Plan for ensuring hospital staff are aware of program.
- Provide on-going meeting to discuss program impact.

Hospital staff will identify high-risk patients and ask for patient approval to include a Caregiver Guide in the care plan. Hospital staff will provide referrals. A paid Caregiver Guide Coordinator will provide the service during the year one development phase. Trained volunteer Caregiver Guides will be introduced in year two. Caregiver Guides will initiate contact with the identified caregivers of vulnerable elder patients prior to discharge, and offer personalized telephone follow-up and assistance after discharge.

The service will:

- Target one or two hospital units with high percentages of vulnerable, elderly patients with a goal of supporting 100 caregivers per year.
- Make Caregiver Guides (paid staff and volunteers) available during evenings and weekends when caregivers are most likely visiting patients.
- Ensure that guide contacts with authorized caregivers will be established by proactively visiting referred patient rooms during appropriate hours. Through the power of personal contact, caregivers will be made aware of the potential of turning to the Guide after discharge should problems/questions arise.
- Offer caregivers, through the Guides, non-clinical support throughout the stay, and be a supportive resource for hospital staff.

It is expected that Guides' contacts with caregivers prior to discharge will be comprised of a brief introduction and distribution of follow-up contact information. It may result in an extended question and answer session and ongoing support during hospitalization to ensure that caregivers:

- Know what to ask of the facility staff.
- Understand the information provided to them.
- Are adequately trained for anticipated caregiver duties related to medical care.
- Can anticipate and be prepared for challenges likely to occur after discharge.
- Are aware of community services.
- Use of the tools and the hospital-based resource area.

Caregiver Guides will make follow-up phone calls to caregivers after the care recipient is home to see how things are going. They will be trained to provide appropriate referrals for needed services and to assist with access to services if requested by the caregiver. The frequency, intensity, and focus of the contacts will be driven by the needs of the caregiver.

Caregiver resources will be located in each hospital as a satellite of the Caregiver Resource Center located at the Broome County Office for Aging. The Office for Aging Resource Center is staffed by a caseworker and provides an extensive variety of caregiver resources that are continually updated. Hospital based satellite centers will provide caregivers with resources when they are likely to be needed most.

Materials may include:

- Video tapes and/or DVDs (also available for loan) that address caregiver challenges and community resources (to be developed).
- Tools such as medication trackers, medical notebooks and checklists to centralize the information that health care providers need (to be developed and/or existing tools to be investigated) to promote continuity across the

multiple providers that are characteristic of the medical care of vulnerable elders with chronic illness, and to build caregiver confidence.

- Information on caregiver supports and elder services in the community, including the *Broome County Elder Services Guide*, a comprehensive directory of services for mid-life and older adults.
- When stationed in certain locations, live Internet access to the online Guide, or an offline demonstration of the Guide, and a list of caregiver-related websites (list available on a refrigerator magnet - to be developed).

A Caregiver Advisory Committee, comprised of health care professionals, facility representatives, aging services representatives and caregivers will support the continued development of this program.

### **C. Outputs:**

- Business agreements with two hospitals
- Protocol
- Returning Home referrals
- Returning Home clients
- Follow-up telephone contacts
- Educational tools such as medical services notebooks and medication trackers space
- Volunteer training curriculum
- Volunteers recruited and trained

### **D. Assumptions for Outcomes, Outputs and Activities:**

- Home health needs frequently change and increase following hospitalization and significantly increase the responsibilities and tasks of the caregiver.
- Caregivers utilizing the program will make a knowledgeable, confident transition to home and there will be a reduction in re-encounters with acute care facilities.

Although the Returning Home: Caregiver Support Program model shares some important conceptual themes and implementation strategies with the similar Best Practice models cited above, it is decidedly unique in the following ways:

- Use of trained program volunteers. The use of a trained volunteer base reduces overall program costs and eases the challenges of sustainability.
- The addition of educational tools that would significantly enhance the usefulness of the program for family caregivers.
- Because of the documented common perception that caregivers do not recognize themselves as such, the Returning Home: Caregiver Support Model stresses the importance of proactively reaching out to family caregivers rather than relying on their initiative to seek out supportive services. Proactive engagement through personal contact in an opportune setting is a unique feature of the proposed implementation strategy.

E. **Resources:** This model program has been planned based on a budget allocation of \$25,000 - \$30,000 annually and efforts may be piloted with funding from The Robert Wood Johnson Foundation's Community Partnership for Older Adults. It is assumed that after a two-year startup period, activities will be integrated into other agency or community efforts. The following resources are needed.

**Program Staffing:**

- Paid full-time Program Coordinator in year one, gradually shifting to fewer hours over time.
- Trained volunteer Guides

**Caregiver Tools and Materials:**

- Educational tools and resources that increase caregiver awareness
- Video tapes and DVDs showing typical caregiver scenarios with information on local resources
- Medication Tracking Tool
- Medical Tracking Notebook
- Caregiver checklists
- Caregiver Guide contact business card

F. **Lead Agency for Implementation of Initiative or Components of Initiative:** Criteria for selection will include experience and success in implementing similar initiatives, capacity, commitment, credibility in community, knowledge, and experience in management of volunteer programs.

G. **Evaluation / Conclusion:** An evaluation will be undertaken to determine the impact of the enhanced contact with caregivers during periods of transition and the cost effectiveness of the intervention.

The impact on caregivers: A survey to assess the overall helpfulness of the Caregiver Guide service will be conducted several months after discharge. The survey will measure the impact the strategy had on the caregiver's level of

preparedness and ability to access services. Surveys will be administered by mail and via telephone.

Program staff will also record the number of in-coming calls to the Caregiver Guides as an indicator of support that is valued. Simultaneously, the Broome County Office for Aging Senior Resource Line will track the number of incoming calls to determine if caregivers are accessing the services more frequently.

Cost Impacts and Health Status Indicators: Longer-term outcomes, namely a reduction in the number of re-encounters and a delay in institutionalization based on caregiver self-reporting, will also be implemented. Hospital workgroup members indicated that a means is in place to track re-admissions and agreed to track patients whose caregivers received assistance from a Guide and the impact on hospital re-admissions.

### **Conclusion:**

The active and enthusiastic participation of the many Caregiver Workgroup members over the summer of 2003 is much appreciated. The members of the committee were energized by the idea that our community could work together to assist caregivers at one of the most stressful junctions of their caregiver “careers”, the hospitalization of a loved one. Often hospitalization is a turning point for caregivers, where many may be thinking that they just can’t care for a loved one any longer and are considering nursing home placement. Therefore caregivers at this critical transition point need to be provided with the best and most up-to-date information on services available in the community, if they are to continue caring for a loved one at home. It is the hope of the Caregiver Workgroup that the support necessary for the caregiver to continue can come from the Returning Home Program. Both hospital systems in our community participated in this workgroup and have pledged their support to partner with the community in implementing this program. The presence of volunteers in the hospitals to work with caregivers could influence the manner in which hospitals conduct discharge planning, from being patient centered to family centered, thus instituting true systems change for our community and a model for others.

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Action for Older Persons, Inc. has received certification from the National Family Caregivers Association to offer seminars entitled "Communicating Effectively with Health Care Professionals: A seminar for Family Caregivers" over the course of the next year. These seminars will be presented in partnership with the Broome County Office for Aging Caregiver Services Program.