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Maine Primary Partners in Caregiving

Eastern Agency on Aging

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MAINE PRIMARY PARTNERS IN CAREGIVING

A Project Manual

A joint project of the Eastern Agency on Aging
and the University of Maine Center on Aging,
in partnership with the Aroostook Area Agency on Aging, Horizons Health Services,
Norumbega Medical, Rosscare, and Senior Spectrum.

U.S. Administration on Aging NFSCSP Grant # 90CG2533

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The UMaine Center on Aging, representing the Project's research, evaluation, and education arm, was composed of Lenard Kaye (Co-Principal Investigator), Sandy Butler (Senior Researcher), Winston Turner (Research Analyst), Leah Ruffin (Project Coordinator), and Nancy Webster (Education Specialist). Earlier contributors to the project at the Center included Elizabeth Johns, Daryne Sandford, and Carol Solinger. Carol took responsibility for preparing the initial draft version of this manual. Megan Bromley also provided supplemental editing services. Others at the Center contributing to the Project included Kristin Nadeau, Judy Anderson, Christine Martel, Deb Turner, and Jennifer Crittenden.

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Aroostook Valley Health Center	Madawaska Regional Health Center
Dr. Bergin's Practice	Milo Family Practice
Family Practice Center of EMH	Norumbega Evergreen Woods
Horizon's Fort Fairfield Health Center	Norumbega Internal Medicine
Horizon's Limestone Health Center	Norumbega Medical (Dr. Hallbert)
Horizon's Mars Hill Health Center	Penobscot Community Health Center
Horizon's Mental Health Services	Washburn Health Clinic
Horizon's OBGYN Service	Horizon's Occupation Health Service
Husson Family Practice	Horizon's Presque Isle Health Center
Horizon's Surgical Practice Services	Horizon's Pulmonary Health Service

PART 1 INTRODUCTION

MAINE PRIMARY PARTNERS IN CAREGIVING: Our Role and Our Development

American households are changing. Many are expanding their already substantial workloads to include caregiving of relatives, friends, or neighbors who would be forced to live in residential or medical facilities without this critical support. With **80% of all elder caregiving occurring within the home setting**, it is clear that families play a fundamental role in the provision of long-term care to older adults. This trend will only increase in size and importance as the U.S. aging population continues its steady growth. Current medical service delivery trends and a developing emphasis on home-based health services also serve to underscore the role of domestic caregivers.

While caring for loved ones is an important function of many American households, providing care to those with chronic illnesses or disabilities often proves overwhelming. Stress may result from the constant and evolving challenges of caregiving, with feelings of anger, hopelessness, and frustration frequently experienced by the caregivers themselves. Given that caregivers often neglect their own needs in favor of the needs of others, it is unlikely that they will address the tolls these mounting difficulties take on their own well-being. When these problems are neither addressed nor resolved, **both the physical and mental health of the caregiver suffer**, simultaneously jeopardizing the health of the care recipient.

Fortunately, current research finds that early intervention is effective in lessening caregiver burden and avoiding the cited caregiving risks. By identifying caregivers and providing appropriate support, health service providers can offer proactive assistance to this key group. **Maine Primary Partners in Caregiving (MPPC)** was created with exactly that goal in mind. A public forum was first convened in which health service providers and caregivers themselves could address caregiving issues, allowing caregivers to consider their roles objectively and learn more about their own needs and how best to serve them. Input from the forum revealed that the most efficient way to identify caregivers was to ask people directly about any caregiving responsibilities they had, with primary care practices (PCPs) serving as locations where this inquiry could be made. Not only would PCPs be able to reach many caregivers, but their endorsement of service referrals would be meaningful to their caregiver-clients and thus make them more likely to take advantage of these referrals.

In order to make this concept of early intervention and support a reality, a partner-

**More than one in five
U.S. households
currently provide care
to a family member
over the age of 18**

**Estimated annual cost
of family caregiving
in the U.S. in 2004:
\$257 billion**

ship was formed between the Eastern Agency on Aging and the University of Maine Center on Aging, both located in rural central Maine. Several PCPs within a three-county region were also enlisted for their help. Its structure and objectives outlined, this innovative program was proposed to the U.S. Administration on Aging (AoA) in October 2001 with a resulting three-year grant. Other Area Agencies on Aging (AAAs) were recruited as the partnerships grew in number and more direct services were provided to caregivers in various regions throughout Maine.

Evaluation of the program's effectiveness was a critical and necessary component in pioneering this multidisciplinary approach to early caregiver identification and intervention. Accordingly, the UMaine Center on Aging, along with a team of social work professors and graduate students, developed and conducted the program's research element. Longitudinal findings are currently being compiled while preliminary results are being presented and published.

What We Will Achieve

Goals and objectives for the MPPC project were developed by the UMaine Center on Aging and the Eastern Agency on Aging, with input garnered from service providers and caregivers. These goals are reviewed annually to ensure their continued relevance.

The **four major goals** and related **objectives** of the MPPC project are:

GOAL 1: *To demonstrate that rural primary health care practices are an effective point of early intervention for individuals undertaking caregiver responsibilities*

OBJECTIVES:

- 1a. To increase significantly the rate of PCP referrals of adult patients to participating AAAs during the course of the MPPC project
- 1b. To identify primary care patients involved in family caregiving at a rate equivalent to the estimated proportion of adult caregivers in the general population
- 1c. To document that at least 90% of eligible patient caregivers wishing information, support, and education interventions are served according to MPPC protocol

GOAL 2: *To show that caregivers will accept and utilize information, support, and training when the need for such is identified and/or validated by their personal physicians or other health care staff*

VOCABULARY ROUND-UP

PRIMARY SERVICE AGENCY:

Effectively, the project leader, coordinating partnerships with PCPs and serving as liaison between project members; also in charge of funding issues

PRIMARY CARE PRACTICES:

Referred to as PCPs, these individual medical practices are the sites at which patient screening/caregiver identification occurs

OBJECTIVE:

- 2a. To document that the majority of patients who report feeling stress related to caregiving and/or wish to change the nature of the caregiving arrangement (as indicated on the brief screen) will accept a referral

GOAL 3: *To demonstrate that the multiple risks of rural caregiving will be ameliorated by a combination of information, support, and training by MPPC Caregiver Specialists, and the field coordination/liaison efforts of health care providers*

OBJECTIVES:

- 3a. To record high levels of satisfaction from individuals receiving single-contact service with rendered interventions
- 3b. To document that caregiver well-being is buoyed by receiving multiple-contact service as reflected in positive changes over time in stress/burden levels, depression levels, life satisfaction/morale levels, satisfaction with caregiving arrangements, confidence/competence levels, isolation/loneliness levels, and quality of family relations

GOAL 4: *To show that a productive community service partnership among primary care practitioners, a health care provider, AAAs, and a university center on aging can be established and sustained in service to family caregivers*

OBJECTIVES:

- 4a. To document compliance with protocol among all partners throughout the course of the project
- 4b. To document a low rate of withdrawal from the project by primary care practitioners
- 4c. To document an increase in the number of participating primary care practitioners
- 4d. To secure the necessary funds to sustain the project subsequent to the three-year AoA funding period
- 4e. To have the MPPC model replicated in one or more parts of the country within four years of project implementation

HOW THE MPPC PROJECT WORKS:

An Overview

A **brief screen** is administered to all individuals over 18 years of age during routine PCP visits, identifying persons currently undertaking caregiver responsibilities.

**VOCABULARY
ROUND-UP**

CAREGIVER SPECIALIST:
Individual responsible for collection of screens, caregiver contact, and training/education efforts; essentially the backbone of the project

- If s/he is not a caregiver, the “no” answer would be checked on the screening tool. These negative response screens are then collected by the PCPs and gathered by the Caregiver Specialist during routine monthly office visits.
- If s/he is a caregiver, the “yes” answer would be checked on the screening tool. These positive response screens are **faxed immediately to the appropriate AAA**, which then activates the referral pathway.

“Yes” responses prompt a local AAA-based Caregiver Specialist to contact the newly identified caregiver by phone to ascertain appropriate support services for that individual.

- If the Caregiver Specialist contacts the caregiver and a **one-time only-interaction** is desired, two actions occur:
 - 1) A **services evaluation postcard** is sent to the caregiver, providing feedback regarding the helpfulness of the Caregiver Specialist’s outreach.
 - 2) A **follow-up phone call** is made by the Caregiver Specialist in one month, letting the caregiver a) know someone is still concerned about his/her well-being and b) discuss his/her caregiving experiences with an informed and interested professional. The phone call also provides insight into any changes in the caregiving situation and the opportunity to find out if services are now needed.
- If the Caregiver Specialist contacts the caregiver and **ongoing assistance** is requested, the specialist will then assess the caregiver’s needs and respond to them with customized services including information, referral, counseling, and education/training resources. These caregivers are now referred to as **multi-contact clients**. Services may continue as long as needed. *There is no cost to the caregiver for any of these services.*

Multi-contact clients are invited to participate in the research portion of the MPPC project, though there is no obligation for them to do so.

- 1) If a multi-contact client agrees to participate in the research, a UMaine Center on Aging researcher responsible for a series of three telephone interviews over 12 months will contact him/her. Results from the interviews will document the caregiver’s experiences longitudinally while also determining the success of early intervention and services in alleviating caregiver stress.
- 2) Research will **evaluate outcomes** of the MPPC project and gauge caregiver well-being. Other areas of evaluation include service utilization patterns, quality of community partnerships, and caregiver profiling.

- Research **findings** will be presented at conferences and published in professional journals.

What We've Discovered

- Over 8,000 caregiver screens were completed in the course of the project. Of those screened, 436 (5%) were identified as caregivers to older adults. Analysis of Time 1 interview data confirms that large proportions of caregivers who have not previously initiated efforts to access the service network evidence noteworthy levels of depression and burden. **Higher depression scores are associated with lower levels of expressed caregiver competency and confidence**, increased perceptions of caregiver burden, a greater sense of social isolation, and smaller social networks.
- Initial caregiver contacts tend to result in the **provision of information** rather than more intensive, involved interventions. Such dissemination of information is proving to be an **effective early intervention strategy**, forestalling the need for premature and/or more expensive modes of intervention.
- The implementation of HIPAA (Health Insurance Portability and Accountability Act) during the project curtailed screening at several practices, while other practices raised HIPAA compliance issues as a possible barrier to screening continuation. Remodeling of reception space caused a moratorium on screening in some practices. Such unanticipated obstacles underline the importance of **maintaining dialogue between PCPs and Caregiver Specialists** in order to avoid potential impediments to the provision of caregiver screening.

Additional MPPC Project Benefits

- Medical professionals are viewing firsthand **the importance of proactive** patient care.
- Time-constrained medical practices are provided with an effective method of connecting caregiver patients to invaluable resources through the MPPC referral system.
- Regardless of whether or not they accept offered services, caregivers are made aware of the **wealth of support** available to them and of the **potential for future assistance** should the need arise.

PART 2

LAYING THE GROUNDWORK

Successful replication of the MPPC project relies upon thoughtful planning, careful consideration, and steadfast determination. The following section provides insight into the planning stage of the project, examining the areas of:

- **Project staff:** *Introducing the Caregiver Specialist and other members of the MPPC project team*
- **Partnerships:** *Learning how to select and recruit the best potential program partners and maintain their on-going support and enthusiasm*
- **Funding:** *Addressing the topics of subcontracting, available funding sources, and how to procure and sustain necessary project funding*

KEY PLAYERS IN THE MPPC PROJECT

The appointment of qualified, committed individuals to the following positions is vital to the success of MPPC-based programs.

Caregiver Specialist

Serving as a **liaison between project partners** and **link to caregiver services**, the pivotal position of Caregiver Specialist requires great dedication. Depending on the agency's activity level and the extent of PCP compliance, the position is either part- or full-time. Client contact usually occurs on weekends and evenings, given caregivers' busy schedules and limited availability.

Specific PCP-related activities of the Caregiver Specialist include:

- Maintaining partnerships with each project site
- Visiting PCP sites on a monthly basis
- Educating and training front office workers
- Motivating protocol adherence by PCP office staff and recognizing/rewarding their efforts
- Tracking numbers of screening tool responses from PCPs

Services/information the Caregiver Specialist offers to the caregiver include::

- Case management
- Home visits
- Continued client contact
- Referrals to other agencies and/or professionals
- Tip sheets for caregivers, caregiving booklets, disease-specific information, and a lending library of caregiving-related information

- Lists of area support groups focusing on generalized caregiver issues such as grieving, stress, and depression
- Website with information and links
- Coordination of limited emergency respite
- Caregiver advocacy

The following qualities are critical to the Caregiver Specialist's performance:

- Established strength in the areas of **communication, facilitation, and motivation**
- **Accessibility** and **responsiveness** to caregivers, as well as PCPs, bolsters confidence in the program
- **Knowledgeable** and **efficient** Caregiver Specialists support the credibility of the program
- **Strong communication skills** enable the Caregiver Specialist to **listen perceptively** as well as to **effectively convey information**
- **Flexibility** allows the Caregiver Specialist to handle unforeseen challenges creatively and successfully

"This job requires a person with high energy and commitment."

**Deb Chapman,
Caregiver Specialist
Administrator**

Caregiver Specialist Administrator

The Caregiver Specialist Administrator provides **regular supervision and support** to the Caregiver Specialist, helping to identify appropriate approaches for dealing with challenging cases. By **coordinating the multiple services** received by caregivers, the Administrator also ensures that services are provided efficiently and not duplicated.

Tasks of this position include:

- Maintaining direct contact with the primary administrator of each PCP
- Resolving difficulties that arise within program protocols and between partnering agencies
- Providing assessment and communication expertise in support of the Caregiver Specialist

Project Liaison

A Project Liaison provides bureaucratic expertise and a respected voice with which to communicate the project's philosophy and objectives. This dynamic, enthusiastic individual should command the respect of the medical community and possess a strong commitment to and understanding of the project's goals. The Project Liaison's extensive knowledge of the PCP culture and system will enable him/her to be an effective project marketer as well as troubleshooter should difficult negotiations or complications arise.

FORMING PARTNERSHIPS

Once a community's caregiver needs have been assessed, strong working partnerships must be forged between the **primary service agency** and the **primary care practices** (PCPs), as well as the **research agency**, if the program contains a research component. *Careful selection of partners is critical to a program's success.*

Systematic consideration of PCPs' values and service delivery systems will help identify practices whose own objectives closely mirror those of the program. Furthermore, practices should share the philosophy that **providing social services to caregivers is a natural and valuable extension of health care services.**

When deciding which PCPs to engage as partners, be aware that each practice entails particular drawbacks and benefits.

HERE'S WHAT THE CAREGIVER SPECIALISTS SAY:

"The Caregiver Specialist should be someone who has compassion. It is helpful to have been a caregiver him- or herself."

**Ruth Pierson,
Caregiver Specialist**

- **Small PCPs** promote the development of a **highly personalized relationship** among the Caregiver Specialist, the Project Liaison, the research partner, the practitioner, and office personnel. Culture within a small practice generally reflects the values of the practitioner; hence, a practitioner's endorsement of the project **implies staff endorsement** as well. Establishing the value of caregiver assistance is therefore a readily attainable goal in the small practice environment.

However, a small office provides the program with **fewer caregiver contacts** than would a large office. Multiple small office partnerships also demand cooperation among different office systems and administrations, adding **bureaucratic complications.**

- **Large PCPs** bring multiple physicians into the project, generating **many caregiver contacts.** Coordinating duties of the Caregiver Specialist and Project Liaison are also simplified since a single program administrator is often the point of contact for numerous practices, **reducing opportunities for inter-office confusion.**

However, each office within a large practice has its own values and culture, meaning that **uniform support of the project may be difficult to achieve.** More time and energy therefore must be put into informing each office's staff of the program's goals and the means by which they are met.

Large PCPs may be governed by **rigorous Institutional Review Board (IRB) standards.** In such cases, meeting all compliance standards may prove very time-consuming.

Having selected partnering PCPs, each partner should be presented with the MPPC's fundamental hypothesis:

When PCPs consistently work towards identifying caregivers and offer early, prompt interventions, better health care will be extended to caregivers and their communities.

Caregivers' psycho-social health needs must be addressed in a time-efficient manner, helping to ease their stress and related detriments to their own health. Raising community awareness of the inherent difficulties of caregiving while helping caregivers improve their own health is a goal whose importance should be readily apparent to participating PCPs.

MARKETING, PART 1: Bringing PCPs into the Partnership

In order to bring selected PCPs into the program partnership, **recruitment techniques and principles** must be used with skill and forethought. Essentially, PCPs must appreciate that both they and the community they serve will benefit from project participation and that **the value of these benefits will offset the fact that no monetary reimbursement accompanies their involvement.**

The task of marketing can be broken down into several steps:

Step 1: *Identify key PCP contact*

Find out which individual at the selected PCP holds **decision-making authority** within the practice through a brief analysis of the practice's system and hierarchy. Bear in mind that this individual is not necessarily the practitioner.

Step 2: *Meet the key PCP contact*

Contact ideally should be made by a program member with a **pre-established professional relationship** with the PCP. An initial meeting should be arranged during which the program member will 1) provide a project overview and 2) gauge the PCP's motivational values. The project overview should cover the following topics:

- Program purpose, partners, roles, and goals
- Explanation of caregiver risks and responsibilities
- MPPC project genesis and early identification model
- Program challenges

A slide show presentation is an excellent method by which to provide a clear and consistent program overview.

**HERE'S WHAT THE
CAREGIVER SPECIALISTS
SAY:**

**"Choose someone who
does not have the urge to
fix everything."**

**Lynn Leighton,
Caregiver Specialist**

“Marketing is the process of planning and executing the conception, pricing, promotion, and distribution of ideas, goods, services, organizations, and events to create exchanges that satisfy individual and organizational goals.”

The American Marketing Association

Step 3: *Gauge PCP’s motivational values*

Determining the PCP’s motivational values through inquiring about its strengths and focus provides insight into what would **satisfactorily compensate the PCP for its unpaid role in the program**. The program can then be pitched to the PCP in terms reflecting its own central goals and values, increasing the likelihood that the PCP will agree to become a project partner.

As reflected in the steps detailed above, effective program marketing relies upon a personalized approach to each potential PCP partner. Presenting the program in terms that parallel the PCP’s own priorities and objectives provides compelling reasons for partnership and encourages enthusiasm within the PCP, an important element of future program success.

Establishing Partnerships

Keep the following tips in mind when building relationships with partners selected for program participation:

- Consider formulating a brief **inter-agency contract** to clarify roles and responsibilities. This formal commitment among partners will help prevent future misunderstandings and enhance fulfillment of service obligations.
- **Confidentiality** is crucial in a multi-agency partnership. Caregivers are entitled to confidentiality, and every effort must be made to preserve their anonymity while facilitating access to appropriate services. In addition, HIPAA privacy guidelines must be observed.
- Be realistic in goals and scope at the onset of a new program. Starting out with only a few partners will help establish protocol and resolve any initial problems. Other partners may then enter into the program with relative ease.
- Allow adequate time for **orientation to the medical system**, as it operates under a different set of rules than the social services system.

MARKETING, PART 2:

Strengthening Partnerships

Having recruited PCPs to become program partners, the on-going task of marketing remains critical to a successful partnership. Maintaining the positive attitudes generated during the recruitment process becomes the Caregiver Specialist’s responsibility. Regular communication, reiteration of program goals, and enumeration of program successes are all part of this effort. Original methods of commending PCPs and their staff also create and sustain enthusiasm toward the program. Examples of

such methods include:

- *Submitting press releases to newsletters, local newspapers, or other publications to which the sponsoring agency has access.* This public acknowledgement underlines each PCP's commitment to caregivers and their families while also serving as an **effective, no-cost marketing device** to the broader community. A copy of any such publication should also be sent to each PCP.
- *Providing the PCP with a frameable letter of acknowledgement for "quality community work" from the sponsoring agency's Board of Trustees.* Since board members are typically prestigious members of the community, such a commendation would be meaningful to the PCP and would enhance its reputation.
- *Creating a certificate of recognition, award, or plaque to honor service to caregivers.* Intended for display in waiting rooms, these awards should be dated to indicate up-to-date compliance with program protocols.

When presenting honors to partnering PCPs, establish a **standardized awards process** with a clear set of guidelines and procedures in order to maintain quality standards. Also be aware that when a PCP accepts a public award and acknowledgement for service, the primary service agency has the right to send a **letter of reminder** to that PCP should it later become noncompliant in the project.

Additional Marketing Tools

Marketing efforts also should be directed towards **caregivers** and the **general public** in order to increase their awareness of challenges facing caregivers and their families. Marketing tools in this area include:

- **Posters**

Posters, brochures, and/or flyers placed in every exam room are a useful means of marketing within the PCP environment. Detachable business cards and/or phone number tabs of the Caregiver Specialist should be included with the posters for clients' future reference. Such materials must be striking in design to attract caregivers' attention.

- **Press Releases**

Weekly articles on various topics pertinent to caregivers can become part of the local newspaper. These regular publications will produce reader demand for such information and enhance community awareness of the issues caregivers face and the resources available for their assistance.

"In a sense we are breaking the rules. Social services are integrated collaboratively within the medical network; we're working with physicians and we're working with services that confront life and death issues regularly."

**Dr. Lenard Kaye,
Co-principal Investigator**

Funding

A three-year federal grant from the U.S. Administration on Aging (AoA) funded the MPPC project. The Eastern Agency on Aging, based in Bangor, Maine, is the **primary service agency** and takes charge of reapplications, report submission, direct communications with the AoA, and allocation of all monies. All other participating partners are considered subcontractors, consisting of the UMaine Center on Aging, under the umbrella of the University of Maine, Orono, as well as two other AAAs, Senior Spectrum and Aroostook AAA. Project expenses consist primarily of personnel-related costs, including the salaries of three Caregiver Specialists and several part-time researchers.

Federal Grant Special Issues

When applying for and working with federal, state, local, or philanthropic funding sources, keep the following points in mind:

- When managing a multiyear grant, the primary agency often must reapply for each year's grant portion. Additionally, an annual budget usually must be formulated and submitted.
- A quarterly or semi-annual report may be required by the funder, detailing how much money has been spent and tracking progress toward project goals and objectives.
- With the advent of the Internet, all budget aspects may be handled electronically.

Subcontractors

Working with subcontractors demands a thorough understanding of the intricacies of each entity. Whether organizations are federal, state, local, academic, or private, each has its own unique set of rules and policies. A state university, for example, is a particularly complex subcontractor in that it already has both state and federal regulations to which it must adhere. Inclusion of such multi-faceted subcontractors requires a very carefully crafted contract; the greater the awareness of subcontractor-specific regulations, the less opportunity there will be for conflict.

Sustainability

Since little capital may be available to sustain the program, the dedication and vested interest of its partners are critical to its successful continuation. For their part, AAAs should include funding for Caregiver Specialists as a part of their directive; Specialists will then endeavor to incorporate identified caregivers into their ongo-

ing caseload. PCPs already play their role in the project without monetary compensation, meaning that they contribute to program sustainability through sound relationships with their partners and dedication to program objectives. Overall, a committed level of responsibility and involvement among partners provides the optimum assurance of program sustainability.

Areas of Further Funding Needs

While the Caregiver Specialist is able to make service referrals to caregivers, many of these recommended services are unavailable due to lack of resources and long waiting lists, especially in rural areas. Rural provision of care services for caregivers is a threefold problem in that 1) services often are not available, 2) lack of transportation renders available services unavailable, and 3) available personnel are perpetually overburdened. Identifying additional funding sources for these much-needed services is therefore a perennial issue in MPPC-related programming.

Potential Sources for Funding

Multiple potential funding sources may be accessed readily via the Internet, ranging in scope from local to national. A good place to start is by visiting **Grants.gov**, the single online access point for over 900 grant programs offered by the 26 Federal grant-making agencies and organizations. The website is a great way to find and apply for competitive grant opportunities from all Federal grant-making agencies.

Participants can search databases of funding sources by subject, topic, or agency. You may also register for a daily e-mail service that will deliver customized funding searches to your in-box.

PART 3

PROGRAM ADMINISTRATION

Administering an MPPC-based program requires a thorough understanding of the screening, referral, and educational processes around which the program functions. The following section discusses:

- **The Screening Process:** *The development of the screening tool, how to prepare for its successful distribution, and how to encourage its proper use within PCPs*
- **The Referral Process:** *How to make initial contact with caregivers, continue with appropriate follow-up contact, and provide relevant feedback to PCPs*
- **Program Curriculum:** *How to provide caregiver-related educational opportunities to caregivers, health care professionals, business professionals, and students of related disciplines; nationwide resources for curriculum development*

THE SCREENING PROCESS

In order to achieve program success, the screening tool must be distributed properly at PCPs; **as the link between caregivers and the referral process, its importance cannot be overestimated.** Since front office staff are directly responsible for screening tool distribution, they must possess a thorough understanding of the program's goals and believe them to be worthwhile. To facilitate this understanding and support, **the Caregiver Specialist conducts initial and ongoing training among staff,** consistently clarifying his/her role and services while also introducing new staff to the program's workings. A clear line of communication between the project agency and partnering PCPs also must be maintained to resolve any misunderstandings or questions regarding program protocol. Staff efforts should be rewarded as well, celebrating their contribution to the caregiver community.

The following guidelines and suggestions address how best to achieve the tasks outlined above to ensure **screening tool distribution** success.

Preparing for Screening Tool Distribution

When partnerships are formed at the beginning of the project, the **practitioner and administrator** of each PCP agree to participate in the project. While the office manager oversees and organizes the work done by office staff, the staff itself—**receptionists**, usually—actually distribute the screening tool to the practice's clients. Given the sizeable workload already managed by these hard-working individuals, **it is imperative that they understand and place value upon the project's goals,** see-

ing screening tool distribution as part of an important effort rather than one more task to accomplish.

Staff understanding and appreciation of project objectives is achieved through training and education delivered by the Caregiver Specialist, explaining how the burdens and risks faced by an increasing number of caregivers **take a toll on their general health and well-being**. During the initial meeting of the Caregiver Specialist, PCP office manager, and staff, program services will be outlined to provide realistic expectations and avoid any confusion as to what exactly will be offered to clients through the referral process. Any preconceived notions regarding caregivers (e.g., age or sex) also must be addressed so that screening tool distribution will not be a selective process. Supplying each PCP with a **program manual** and a **script for use in screening tool distribution** will help ensure consistent and accurate presentation of the screening tool; having these references at hand will also make staff more confident and comfortable with the screening process.

Take the following considerations into account when preparing a PCP for screening tool distribution:

- Front office staff may have **limited experience with the caregiver role**. Therefore, take ample time to explain to them the challenges encountered by caregivers, using analogies involving parents, grandparents, etc., where appropriate to illustrate the importance of caring for caregivers.
- PCPs often experience a high rate of staff turnover, meaning that **training and education must be an on-going task** of the Caregiver Specialist in order to maintain uniform understanding of and adherence to program goals and protocol.
- **The term “caregiver” may not resonate with office staff or the general public**, as it could indicate a paid health care worker as easily as an unpaid family care provider. Using the terms “help” or “helper” clarifies the role and avoids misunderstandings.
- Since some caregivers see a practitioner more than once a year, they may receive multiple offerings of the screening tool and become resistant to filling out the same paperwork. Regardless of this possibility, make sure that staff **distribute the screening tool to all clients 18 years of age or over**, rather than “self-select” to avoid provoking client frustration. A **positive attitude towards the screening tool and its distribution** is the correct means by which to avoid negative client reactions while properly complying with program protocol.

- Make sure that clients are offered the screening tool each time they come in for a check-up. Since **a person may take on the caregiver role at any point in his/her life**, their caregiver status must be assessed during each PCP visit.

The Screening Tool

The screening tool now used at PCPs has evolved over the course of the project in response to feedback from the office personnel and caregivers, resulting in **simplified formatting and language**. “Easy Screen,” the current screening tool, is included in this manual, while two previous versions, each with the same screening questions but uniquely different looks, are available upon request. Also included are step-by-step instructions for screening tool distribution and a short script to aid staff in screening tool presentation [see **Appendix B**].

The following lessons were learned during screening tool development:

- Keep it short and simple.
- Leave **ample blank space** on the form.
- Present only the “yes” and “no” questions on the front of the screening tool to **distinguish it from other forms**. Clients answering “yes” then fill out further questions on the screen’s opposite side.
- Type should be set with a **large font** for those with vision problems; 16-point Arial is recommended.
- Include a space for the caregiver to fill in his/her **mailing address**. Due to their busy lives, caregivers can be very difficult to reach by phone.
- Avoid the word “caregiver” in the screening tool text, as it is more commonly used by service professionals. Many individuals do not identify themselves as caregivers.

Screening Tool Distribution

According to screening protocol, PCP clients age 18 and over are asked to fill out the screening tool when they visit for a routine check-up. There are two possible responses to the screening tool:

- **YES**, s/he is helping to take care of someone. An individual with a “yes” response is instructed to fill out a set of related questions on the reverse side of the form. **“Yes” responses are faxed to the Caregiver Specialist that same day.**
- **NO**, s/he is not helping to take care of someone at present. “No” responses are

The tone in which the screening tool is presented greatly impacts how it is received. Remind staff not to be apologetic during screening tool distribution; they are offering a lifeline to critical services far more valuable than the few moments it takes to complete the screening tool.

collected and stored at the front desk for collection by the Caregiver Specialist during his/her monthly visit to the PCP.

While protocol dictates the screening tool be distributed when clients come in for check-ups, **consider screening all patients**. Since caregivers' hectic schedules may not allow time for check-ups, their only visits to PCPs probably occur when unanticipated illness or injury demands an office visit.

Each PCP is unique; therefore, different methods of screening tool distribution are appropriate for different offices. Development of an effective, efficient, and customized method of integrating screening tool distribution into standard office procedures is accomplished through collaboration between the Caregiver Specialist and office staff. Some offices, for example, distribute the screening tool by attaching one to every billing sheet. Taking time to devise a compatible distribution process is critical: **the better the distribution process, the better the program results**.

Having established a suitable method for screening tool distribution, be sure to make **periodic evaluations** of the method's success. Meetings between office staff and the Caregiver Specialist will highlight any areas for improvement and ensure that the best practice model is found. Informal exchanges should also occur during the Caregiver Specialist's monthly pick-ups of "no" responses; any problems that have arisen can be addressed at this time, **reinforcing protocol compliance and maintaining clear lines of communication**.

Follow-up

After the initial meeting of the Caregiver Specialist and PCP office staff, a meeting should be held the **following month** to review how the screening tool distribution process is working. This provides an opportunity for the Caregiver Specialist to answer any questions or address any difficulties that have emerged during the early phases of the program, as well as to reinforce the importance of the program's objectives and the benefits caregivers can expect to receive. If the process is running smoothly, then the Caregiver Specialist's monthly pick-up should provide sufficient contact with the PCP.

Aside from offering a chance for problem solving, these monthly visits also offer the Caregiver Specialist the opportunity to provide positive reinforcement to office staff. Presenting **case studies** of caregivers whose lives have been improved by the program (with confidentiality strictly maintained) will provide staff with **concrete evidence of the value of their own efforts** and the value of those efforts to the caregiver community. Realizing the difference they make will **foster staff enthusiasm**

Bring food to PCPs during monthly pick-ups. A warm box of doughnuts gives staff a morning boost and reminds them that their dedication is appreciated.

towards the program, generating greater support and renewed efforts on the all-important front lines of screening tool distribution.

Formal Recognition

Semiannual **luncheon meetings** for the Caregiver Specialist and office staff involved in the program provide a meaningful opportunity to recognize staff efforts and celebrate program successes. At this time, individuals have the chance to share their own “stories from the field” and direct the Caregiver Specialist’s attention to any questions or concerns. **Plaques or other awards** should be presented at the luncheon meetings to honor the outstanding efforts of particular individuals, while **certificates of appreciation** from community leaders recognizing the entire practice’s dedication would also provide a significant form of acknowledgement and inspiration.

THE REFERRAL PROCESS

Once a client responds “yes” on the screening tool, the **referral system is engaged**. These affirmative responses are faxed that very day to the Caregiver Specialist, whose job is then to initiate contact.

The referral process is the means by which **resources and services are offered to caregivers**, providing them with an opportunity to focus on their own needs and well-being. Before contacting clients brought to the service agency’s attention through the use of the screening tool, the Caregiver Specialist should give careful consideration to the plight of the caregiver and the inherent difficulties of his/her situation.

The following caregiver characteristics should be kept in mind when contacting clients:

- Caregivers experience many **losses**, ranging from loss of independence to loss of income. Added to the losses experienced by the care recipient, the caregiver may feel an all-encompassing sense of loss.
- Caregivers may be **very reluctant to ask for help**, feeling that asking for help would be a sign to others that they were not living up to their responsibilities.
- Caregivers, like most other people, are generally **very private** and disinclined to allow strangers to pry into their lives or come into their homes.
- Caregivers may have **trouble identifying their own needs** as they are much more focused on the needs of others, particularly those of the care recipient.
- Caregivers can experience **very high levels of stress** and are also extremely **vulnerable to depression**; they can also **feel isolated**.

Don’t assume that service providers already know the exact nature of caregiver wants and needs.

An initial roundtable discussion among caregivers, conducted by the primary service agency, provides real insight into what services caregivers require.

“Service providers must be really willing to listen to what caregivers have to say and believe it. We have a tendency to discount caregivers.”

**Roberta Downey,
Co-principal Investigator**

- Caregivers often care for their **children and parents simultaneously**, with extended family caregiving duties straining relationships within their immediate family. In addition, caregivers may feel **abandoned** by other family members.
- Many individuals have been caregivers for long periods of time; it is not uncommon for caregivers to have been caregiving for **many years**.
- Caregivers often experience **increased financial burden** due to caregiving activities.
- Caregivers often find that **their own health has been compromised** while caring for someone else.
- Caregivers sometimes feel they simply **need a break**. Respite services often prove hard to obtain, however, so the need for personal time goes unmet.
- Caregivers may find that their workplace **jobs are in jeopardy** due to time spent away from work completing caregiver tasks.
- Caregivers do not always utilize offered services, such as support groups; they are **often too busy to take time to do something for themselves**.
- Caregivers can receive **great satisfaction** from their caregiving roles even while feeling stressed.

Don't assume that service providers already know the exact nature of caregiver wants and needs. An initial roundtable discussion among caregivers, conducted by the primary service agency, provides real insight into what services caregivers require.

Initial Contact

Once a client responds “yes” on the screening tool, and it is faxed to the Caregiver Specialist, telephone contact ideally should occur **within two business days of receiving the response**, providing a high level of continuity between the PCP and Caregiver Specialist.

A standardized introduction and intake questionnaire are recommended as a point of reference when initiating client contact. As part of the introduction, great emphasis should be placed on the fact that the **ultimate goal of the referral process and the program itself is to make the caregiver's life easier**. Using the intake questionnaire as an outline for the conversation ensures that all pertinent information is gathered during the interview; this information is then used in the assessment of the

client's needs and the assignment of relevant services.

While the task of gathering information is important, the Caregiver Specialist also should be certain to **engage the caregiver** and provide him/her with the opportunity to share his/her unique experiences of caregiving. Having a concerned professional listen to and appreciate their personal accounts is highly rewarding for these hard-working individuals and may be regarded as a service in and of itself.

- Once the first contact has been made and **further contact requested**, a customized caregiver packet is organized and sent to each client. Included in the packet are a follow-up letter explaining available services and a caregiver questionnaire intended for client use. This questionnaire provides the caregiver with the opportunity to assess his/her own needs prior to the follow-up appointment with the Caregiver Specialist.
- **If, however, further contact is not requested**, a postcard is mailed to the caregiver regarding his/her satisfaction with the Caregiver Specialist service. Should the caregiver wish to contact the Caregiver Specialist in the future, the Specialist's address and phone number are included. Additionally, another phone call will be made by the caregiver in a month's time to check in on the caregiver's situation.

Follow-up Contact

Depending on the service agency's philosophy and available resources, the next contact with caregivers requesting further contact is either by way of another **phone call** or a **home visit**.

Phone Call Follow-up

If the follow-up will be a phone call, that call should take place **within two weeks** of the initial contact, with the primary goal of offering appropriate referrals and services. Thereafter, follow-up is continued on an **as-needed basis**.

Home Visit Follow-up

Home visits may be difficult to arrange due to their time-consuming nature and the reluctance some caregivers may feel about letting strangers into their homes. Should a client and agency elect to use a home visit as follow-up, however, the Caregiver Specialist will receive access to a **rich source for data collection** from which the needs assessment will benefit.

If a home visit is agreed upon, the agency should mail the caregiver a letter outlining the program and providing a brief introduction to the Caregiver Specialist with

whom s/he will meet, along with a picture of that individual. This mailing **clarifies the purpose of the home visit and lays the foundation for a comfortable familiarity** between the Caregiver Specialist and the caregiver.

Usually lasting from one to two hours, the initial home visit gives the caregiver the **chance to speak at length with a sympathetic listener**, establishing a comfortable working relationship between the two individuals. During the visit the Caregiver Specialist can gather data, make a needs assessment, and discuss possible interventions with the caregiver. **Other family members are also welcome** to join in the discussion and help form a plan of services.

Once the home visit is over, the Caregiver Specialist should leave behind a **business card, list of area support groups, and tips for caregiver self-care**. Maintaining contact beyond the initial home visit is important; by letting the caregiver know that a follow-up phone call will be made, the Caregiver Specialist offers a **lifeline** and the promise of future communication. At the Caregiver Specialist's discretion, an additional home visit may occur after the follow-up phone call. Since each caregiver's scenario is unique, the Caregiver Specialist will make such decisions selectively.

Whether a phone call or home visit is employed as follow-up, the Caregiver Specialist should keep the following considerations in mind:

- It is important to find out exactly which services are and are not available for their clients.
- Continue follow-up contact with caregivers. While their questions may be answered fully and correctly, it is unlikely they will absorb all new information. Therefore, **repetition of information** is often the best way to communicate with a preoccupied, overburdened caregiver.
- Sometimes information supplied is not relevant to the caregiver's situation at that exact moment; later, when it is relevant, the information has been lost or forgotten. Again, frequent repetition of information will help resolve this problem.
- Admit not knowing the answer to a caregiver's question when that is the case. Rather than supply an incorrect or incomplete answer, **take time to research the question** and promptly report back to the caregiver with the new information.
- Make contacts and follow-ups in a timely fashion to **build a caregiver's trust**. Since the Caregiver Specialist may be the caregiver's only lifeline, s/he must be

able to rely upon the Specialist as a reliable and competent point of contact.

- Support of other knowledgeable professionals will help the Caregiver Specialist address difficult caregiver situations. **Partnership-wide collaboration** is key to the successful resolution of these complicated cases.

Feedback to the Primary Practitioner

Due to the significant risks involved in caregiving, it is important to **notify the primary practitioner** about any patients who are caregivers. Once a client has identified him/herself as a caregiver through the screening tool, a **program sticker** is attached to that individual's chart, alerting the practitioner to three important facts:

- 1) the patient is at risk for **multiple stress-related illnesses** due to his/her caregiving role;
- 2) **intervention** by the Caregiver Specialist is occurring; and
- 3) the program of caregiver identification and referral is **functioning correctly**.

Once the Caregiver Specialist has successfully contacted the self-identified caregiver, a letter is sent to the primary practitioner to let him/her know that services have been initiated.

PROGRAM CURRICULUM

Education is a critical component of any MPPC project. Caregivers, health professionals, students, and employers of caregivers are important audiences for **workshops, web-based seminars, and educational printed material**. As the number of caregivers nationwide grows, an understanding and appreciation of caregiver efforts and the challenges they face must be fostered among professionals and the public alike.

Caregiver Education

Caregivers are on the front lines of caregiving, assuming roles for which they have received **no formal training**. Disseminating information via newsletters, newspaper series, fact sheets, pamphlets, workshops, and support groups is an effective means by which to reach this highly active group of individuals. Caregivers will benefit from a **wide range of curriculum topics**, ranging from hands-on physical care skills to legal issues; this multi-topic approach to education reflects the diverse tasks caregiving entails.

Workshops

Self-care is a critical topic for caregiver education; as such, it should be a topic of

caregiver workshops. One possible self-care seminar is “Recomposing a life: Dealing with life changes when assuming the role of caregiver.”

Printed Material

Fact sheets targeted to the caregiver and distributed by the Caregiver Specialist and PCP are a convenient and effective means of circulating specific information while providing contact information for further assistance. The MPPC project has generated fact sheets addressing various aspects of caregiving, customized to the needs of actual caregivers or professionals caring for caregivers [see **Appendix A**]. Topics addressed include:

- 1) **Family Caregiving.** This fact sheet helps define the role and characteristics of caregivers.
- 2) **Caregiver Depression.** This fact sheet describes depression and lists its symptoms, providing tips on how to deal with depressive feelings.
- 3) **The Health Care Team Includes the Caregiver.** This fact sheet highlights the importance of the caregiver when considering health care for the care recipient.
- 4) **Intimacy.** This fact sheet addresses changing relationship issues.
- 5) **Elder Abuse, Neglect, and Exploitation.** This fact sheet alerts readers to the risks of elder mistreatment.
- 6) **Men Provide Care to Relatives Also.** This fact sheet highlights special issues facing male caregivers.
- 7) **Caregiving Resources.** This fact sheet lists state (Maine) and national resources available to caregivers.

HEALTH CARE PROFESSIONAL EDUCATION

Research is revealing the extent of the physical and emotional health risks facing caregivers. With **over 22 million caregivers in the U.S.**, awareness of their roles and needs is critical to health care professionals. Educating these professionals on the subject of caregiver health enables them to participate successfully in MPPC-based programs that seek to identify caregivers and offer them assistance before they suffer from stress levels that threaten their entire well-being.

Seminars

Suggested topics for Health Care Professional seminars include:

- “Family Elder Caregiving: The Case of Men Who Help”

- “Rural Caregiving: Preventing Isolation and Burnout”
- “Depression and Caregiving: Incidence and Risk”
- “Lessons Learned from the National Family Caregiver Support Programs”
- “Providing Care for Developmentally Disabled Older Adults”
- “The Special Challenges of Caregivers of Alzheimer’s Patients”
- “Locating Essential Caregiving Resources”
- “The Case of the Long Distance Caregiver”
- “Ethics and the Questionably Competent Caregiver”
- “Dealing with End-of-Life Issues for Caregivers and Elders”

STUDENT EDUCATION

The rising population of older adults has consequences that will affect health and social service professionals on many levels. Infusing the undergraduate and graduate curricula of students in these professions with gerontological and caregiver content is an important goal. Resources like the *Sage-SW Teaching Resource Kit*, produced by the Council on Social Work Education (CSWE) and the John A. Hartford Foundation, and the *Best Nursing Practices in Care for Older Adults*, produced by the Hartford Institute for Geriatric Nursing at New York University, help to support this objective by providing instructors with curricular materials to assist in the integration of aging in course content.

BUSINESS PROFESSIONAL EDUCATION

Many business professionals number caregivers among their employees and therefore need to deal with issues surrounding this group of individuals. Caregiving duties may impact the workplace in the forms of **absenteeism, exhaustion, or early retirement**, all of which result in **net financial losses** for business. Educating business professionals on the nature and risks of caregiving focuses on how these negative trends can be minimized to benefit both employers and the caregivers they employ.

Workshops

Suggested workshop topics for business professionals include:

- “Family Caregiving Employees: Who Are They and How Are They Managing?”
- “Designing an Elder Care Program in Your Business”
- “The Latest Federal/State Statutes on Family Leave and Health Care”
- “Tax Breaks and the Caregiving Employee”

- “Developing a Caregiving Toolkit: Essential Information to Provide Your Employees”
- “Recognizing the Signs of Depression and Stress in Caregiving Employees”

NATIONAL RESOURCES FOR CURRICULUM DEVELOPMENT AND EDUCATION

There are many resources available nationwide for professional and caregiver education. Some of these opportunities are extended through the Internet as web-based seminars, while other opportunities are offered by a variety of organizations through multiple venues.

- **NATIONAL ALLIANCE FOR CAREGIVING (NAC)**

www.caregiving.org

The National Alliance for Caregiving is a non-profit coalition created in 1996 by the American Society on Aging, the Department of Veterans Affairs, and the National Association of Area Agencies on Aging to support family caregivers and the professionals who serve them. Within the NAC, the **AXA Foundation Family Care Resource Connection** collects, reviews, and expertly rates educational resources for caregivers and related professionals.

- **AARP**

www.aarp.org

AARP is a nonprofit, nonpartisan membership organization for people age 50 and over. AARP’s mission is dedicated to enhancing quality of life for all as we age. At the time of press, AARP’s website offers free online caregiving seminars, as well as articles about caregiving, tip sheets, and links to helping agencies.

- **CHILDREN OF AGING PARENTS (CAPS)**

www.caps4caregivers.org

Children of Aging Parents is a non-profit, charitable organization and a member of the Independent Charities of America. Its mission is to assist the nation’s caregivers of the elderly or chronically ill with **reliable information, referrals and support**, as well to **heighten public awareness** that the health of family caregivers is essential to the quality care of the nation’s growing elderly population. CAPS offers educational outreach, support groups, a speakers’ bureau, and sponsorship of caregiver research.

PART 4 BEYOND THE BASICS

Beyond the basic concerns of planning and administering an MPPC-based program lie the potential for program validation, advanced problem solving, and capitalizing on the potential uses of technology. This section considers these areas in terms of:

- **Research:** *How to incorporate a research component into an MPPC replication to provide validation and establish the best practice model*
- **Special Issues:** *How to cope with and overcome unexpected difficulties, taking lessons learned by the MPPC team*
- **Technology and the Future:** *What gains the promise of technology holds for caregiver care and screening in the 21st century*

RESEARCH

The research component of the MPPC project was designed to demonstrate that information, training, and supportive services provided to caregivers on a **preemptive basis** would **improve quality of life** for these individuals and their families. Formulated and implemented within a university setting, research was conducted by a team of researchers along with graduate social work students who carried out the important task of **validating** the MPPC project. This validation lends important **credibility** to the project and also **encourages replication** efforts throughout the state and country.

As with any research effort, **record keeping** is of great importance. Ample filing space is required to keep records organized, stored, and **confidential**. Thus, be sure to maintain ample storage and devise a system of organization before commencing research.

OBJECTIVES

In order to measure the achievement of program goals accurately, research should adhere to a **strict protocol** and should be administered within a **structured time frame**. The MPPC study was designed to analyze quantifiable data using multiple measures, with recognized scales and indices covering several domains. These domains included:

- depression
- burden intensity
- types of tasks
- social support networks
- isolation
- competency

The above measures were then compared with caregiver demographic information

to better explain and interpret the intervention's impact.

GETTING STARTED

In order to verify that research-related questions are appropriate for each participating community, the research instrument should be **pilot tested** at each new site. To do so, randomly selected caregiver volunteers who *would not be part of the final study* should be interviewed using the pilot research tool, then asked for feedback about the tool and the interview process. **Service providers** should also review the instrument and critique it for further refinement.

Remember, while academic researchers may be experts on questionnaire construction, the input of caregivers and service providers is critical to making sure that questions are pertinent and clear. **A user-friendly, community-specific research instrument will provide the best research results.**

INSTITUTIONAL REVIEW BOARD

Once the research tool has been finalized, the research team must submit the design to the Institutional Review Board (IRB). Universities and many health care centers have their own IRBs and requirements; **approval by all appropriate boards is essential** in allowing the project to run legally and efficiently. A designated member of the research team should take responsibility for securing relevant board approvals.

It is important to note that different PCPs have different IRB requirements. As mentioned earlier, the PCP's IRB process should be considered when choosing partners.

DESIGN

The MPPC project was designed with two levels of caregiver participation: **single contacts** and **multiple contacts**. Project research only involved caregivers having multiple contacts with the sponsoring agency and who agreed to participate in the program's research component. When a caregiver agreed to participate in research, the Caregiver Specialist initiated contact with the mailing of:

- a cover letter explaining the research project
- a set of questions for initial interview
- a release form with a stamped/self-addressed envelope to be signed and returned to the research team

Following the return of the release form, the interviewing process proceeded. The interviewer, a member of the research team, contacted the caregiver to clarify procedures, answer any questions, and set up a time for the first interview. A total of three, approximately 30-minute phone interviews were administered over a 12-month

period, with a copy of the questionnaire sent to the caregiver prior to each interview [see Appendix C]. A letter was sent to the interviewee prior to each interview appointment with the following text:

Thank you for your help in the research part of the Maine Primary Partners in Caregiving Project. As per our conversation today, I am enclosing a copy of the questionnaire that you will have in front of you for your phone interview. We have you scheduled for _____. Someone from the UMaine Center on Aging will be contacting you at that time. We anticipate the interview lasting about a half hour. If you have any questions or concerns, please feel free to call me at _____ or email at _____.

Interview scheduling and coding was conducted as follows:

Time I: immediately after receipt of signed release

Time II: 6 months after first interview

Time III: 12 months after first interview

Quantitative data collected from the interviews were entered into an **Excel spreadsheet**; once enough data was collected, it was collated, processed, and transported into a **statistical package** for analysis.

Additionally, permission was sought from participating caregivers for the research team to speak to the Caregiver Specialist following each interview. If permission was granted, post-interview updates were given to the Caregiver Specialist to 1) maintain open communication between the research team and Caregiver Specialist and 2) provide important feedback regarding the caregiver's condition.

Following the third and final interview with the caregiver, a thank you note was sent in recognition of that individual's donated time, help, and participation in research. The following is an example of appropriate text for the thank you note:

Thank you very much for participating in this important project. Your input has been very helpful to us and has provided valuable information about caregivers that will be used to make recommendations to service providers in the future. At the conclusion of our research, we will send you a report on our findings.

INTERVIEWERS

A small, reliable team of dedicated interviewers is recommended in order to achieve the best data collection. Since caregivers are generally very busy during regular working hours, interviewers must be **available during evenings and weekends** to conduct interviews at the caregivers' convenience. Even then, caregivers may miss appoint-

ments, necessitating patience and friendly persistence on the part of the interviewer.

Training of Interviewers

A training session should be required of each interviewer. Topics to be covered in this session include:

- Program overview
- Rationale for interviews
- Program participants
- Review of questionnaires
- How to properly negotiate the research tool

The following points and considerations should be conveyed during interviewer training:

- **Confidentiality is of the utmost importance.** Conduct interviews in private, with no one else in the room; don't leave personal information or interview forms out in the open. ~ Put the interviewee's ID number, not name, on the questionnaire. ~ Return questionnaires for data entry in an envelope. ~ If you know the person to be interviewed, pass the name to another interviewer.
- **Conduct interviews in a quiet space.** Since interviews are scheduled at the caregiver's convenience, the interviewers should select a location available at all hours.
- **Write legibly.** Any notes made during the interview should be clear and legible, written in full sentences.
- **Be prepared for caregivers to forget appointments.** Realize that some caregivers will not be at home when you call. ~ Be patient; call again and politely request a new appointment. ~ Be understanding and sympathetic towards the caregiver, remembering that s/he is **doing the project a favor** through voluntary research participation.
- **Become familiar with the questionnaire.** The interviewer must be comfortable with the questionnaire in order to guide the interviewee through it smoothly. ~ Review potential stumbling points, such as the need to reword certain questions for gender appropriateness, well ahead of time.
- **Don't allow "intermediate" answers.** Since the questionnaire results will be analyzed by a computer, fractions are not acceptable responses. Gently suggest that the interviewee select one of the responses offered, without actually choosing an answer for him/her. Explaining that a computer and not a

person will read the interview results may be helpful.

- **Interviews last an average of 30 minutes but some people need much longer.** Interviewees may not be comfortable with the regimented nature of the questionnaire, finding it useful to talk their way towards answers. Interviewers should therefore allow at least 60 minutes for each interview.
- **Understand the definition of a caregiver.** Individuals only stop being caregivers when 1) the care recipient dies, 2) the care recipient improves to the point that care is no longer required, or 3) another individual assumes all the responsibility of caregiving. If the care recipient enters a nursing home or other residential facility, however, it may be assumed that the caregiver is still **actively providing care** in the form of visits, running of errands, monitoring of care, etc.
- **The interview process changes if the individual is no longer a caregiver at the time of the call.** If the interviewee is no longer a caregiver when the Time I interview occurs, the interview is cancelled. However, if the first interview has been completed, several portions of the Time II and Time III questionnaire still require completion, even if the person is no longer actively caregiving. Usual procedures are followed to schedule Time II and Time III interviews; however the modified research tool is used.
- **The care recipient may die during the 12-month interviewing period.** A waiting period of three months is recommended before proceeding with the next interview. When contact is made following the care recipient's death, the modified research tool reflecting on the individual's past caregiving experiences should be used.
- **Careful record keeping is important.** The interviewer should note times and dates of attempted/unsuccessful calls as well as times and dates of successful calls/completed interviews. Having completed an interview, the interviewer also should note the appropriate date for the next interview and make sure it occurs within two to three weeks of that time period.

Additional Counselors

Occasionally, an interviewer will encounter a caregiver in a distressing situation. To deal with these potential scenarios, a referral procedure should be established by which caregivers are referred to and receive guidance from an appropriate professional. Always make sure the referral procedure is clearly documented and that all interviewers are familiar with and trained in its use. Although rare, some caregivers may

identify situations where the caregiver and/or the care recipient are at risk of abuse, neglect, exploitation, or even suicide. Be sure to know your community's mandated reporting laws and resources. Situating the research element of the project within a university setting allows for the inclusion of trained counselors, making them readily accessible in the event of caregiver crises.

RESULTS

MPPC data are being analyzed continually. Results thus far indicate that caregiving is **exceptionally difficult work** that becomes more and more difficult as the health of the care recipient deteriorates. Current findings also suggest that **stress levels can be controlled, if not reduced**, by utilization of services offered by Caregiver Specialists; early intervention appears to **stave off caregiver crises**. Furthermore, reduction of depression, stress, strain, and sense of isolation has occurred between Time I and Time II interviews.

Suggested Research

To provide a more thorough evaluation of research findings, the inclusion of a comparison **control group** is suggested. Such inclusion could be accomplished by involving screened caregivers who do not want ongoing services. These individuals would be invited to participate in the research aspect of the program as the control group; their reported experiences would help clarify the effectiveness of providing early services to caregivers.

CONCLUSION

The MPPC program can stand alone without a research component. However, given the growing number of caregivers nationwide, gathering more data about their common experiences is critical to any effort to provide for and/or improve their collective well-being. Through a **clearer understanding of caregiver needs**, the goal of a **more refined and effective system of early identification and intervention** can and will be achieved.

SPECIAL ISSUES

Even the best program planning cannot prevent the occurrence of unanticipated events that necessitate program alterations or adaptations. **Flexibility** and **open communication** between program partners will encourage a united response to these unforeseen challenges, resulting in solutions appropriate for each partner and benefiting the entire program.

Consistently open communication is key to dealing with any and all problems that may arise in the course of the program.

Health Insurance Portability and Accountability Act

One such challenge for the MPPC project was the passage of the Health Insurance Portability and Accountability Act (HIPAA) on April 15, 2003. PCPs were required to comply with this federal legislation mandating that each PCP client sign a “release and understanding of rights regarding protected health information.” With this added regulation and attendant paperwork, already-burdened office staff found their **workloads significantly increased**.

Since distribution of the MPPC screening tool was not a mandatory procedure for office staff, its **importance was diminished** in favor of the mandatory HIPAA paperwork. As a result, the number of caregiver referrals from PCPs decreased.

Careful monitoring of the number of distributed screens is a useful indicator of the influence issues such as HIPAA have on program protocol. Even more importantly, **regular conferencing with partners** provides an opportunity to address these potential problems and propose solutions before they have a negative impact on the program.

Inclusion of Diverse Communities

Another special issue confronted by the MPPC project was that of including **diverse cultures** in the project. Reaching out to diverse communities can be a complex and challenging task. Identifying a **key community contact** who commands the community’s respect and is interested in the program is essential to successful involvement of that group. These community contacts can also provide insight into how best to implement the program and **adapt it to suit the target population’s needs**. While these efforts may demand extra time, they are of paramount importance when extending the program to diverse populations.

DEPRESSION SCALE

Given the fact that **depression is a common outcome of caregiving**, the research instrument includes a valid and reliable measure of depression. Its intent is to measure the level of self-perceived depression by caregivers and it is not, therefore, a professionally diagnosed measure of clinical depression.

As the MPPC project evolved and more PCPs joined the partnership, a review by a medical Institutional Review Board (IRB) became necessary. This review generated a productive discussion concerning what actions to take when a caregiver scored 16 or more on the depression scale. While such a score suggested a degree of depressive symptomatology, it did not indicate clinical depression. It therefore was concluded that scoring 16 or higher on the scale **warranted attention, but not clinical intervention**.

“There was a sense of heightened anxiety in the office as the date of [HIPAA] initiation drew near.”

**Amy Cotton,
Project Liaison**

Since depression is a serious potential consequence of caregiving, it is recommended that all partners agree upon the best way to measure and manage symptoms of depression in the early stages of program design. Doing so will help minimize the need for later debates and discussions.

Other issues that arose in the course of the discussion were:

- Confidentiality. Caregivers only gave permission for research questionnaire results to be included in an anonymous research database and to be shared with the Caregiver Specialist (if specified), not to their physician.
- Skewed responses. There was concern that caregivers would give inaccurate responses if they thought that information would be shared with their primary care practitioners.
- Too many referrals. Since almost 40 percent of caregivers scored 16 or higher on the depression scale, it would be impractical to make that many referrals back to the primary care practitioners.

The decision reached by the MPPC team was that researchers would **report back to the Caregiver Specialist if a caregiver scored 16 or more** on the depression scale. Weighing this score in conjunction with his/her own clinical assessment, the Caregiver Specialist would then determine if action should be taken. If action was indicated, the Caregiver Specialist would **recommend to the caregiver** that s/he contact the practitioner him/herself. By handling the issue in this way, confidentiality would be maintained, the caregiver's privacy would not be violated, and only individuals with strong indications of significant depression would be referred back to their practitioners.

TECHNOLOGY AND THE FUTURE

Foremost among the goals of the MPPC project is to make the identification and referral of caregivers a **routine, standardized procedure** within PCPs. To make this goal a reality, **a)** practitioners need to include caregiver-identifying measures in their psycho-social/medical patient evaluations and **b)** a system must be developed for the intake of this information.

Including caregiver identification in medical evaluations would entail requiring patients to complete **in-depth personal health histories** that would be updated periodically to take into account any changes in health or lifestyle. This inclusion also would represent the medical community's implicit acknowledgement of the impact of caregiving upon the caregiver's health, validating concerns surrounding the risks of caregiving.

Developing a system for the intake of caregiver-related information gleaned from patient evaluations calls for the wealth of potential offered by technology. Adapting technology to serve program needs demands forethought and careful consideration, particularly where **privacy and security issues** are involved.

Technology's capabilities and shortcomings are currently under exploration by the Bangor, Maine practice of Drs. Frank Bragg and Charles Burger. Their reflections and insights help illuminate the technological possibilities available to the MPPC project and its replications.

Email

The rural practice of Drs. Bragg and Burger has tracked **67 percent of its patients** as having email access. Given this sizeable percentage and the increasing accessibility of the Internet, the potential for a cyber connection between patients and PCPs is readily apparent.

Drs. Bragg and Burger have capitalized on this potential by allowing patients to **email the practitioners directly**. A patient's e-correspondence is linked to his/her electronic medical record; the email also appears on the practitioner's desktop as a tab attached to the patient's chart. Once that email has been responded to, the response is converted to a note in the patient's medical record.

Since email is likely to be part of caregivers' personal and/or professional lives, it provides an excellent method by which they can **notify practitioners about health issues** and **receive medical advice in a timely fashion**. Thus, even time-strapped caregivers who feel they lack the spare time for a check-up will have a **convenient connection to their practitioners**. Practitioners then can evaluate the issues detailed and address any concerns related to the patient's caregiving activities before full-scale health problems develop.

Problem Knowledge Couplers

The practice of Drs. Bragg and Burger utilizes decision-making tools called Problem Knowledge Couplers (produced by PKC Corporation of Burlington, Vermont) as their database software as well as an electronic medical record (EMR) tool (Logician, produced by GE Medical Systems). For a fee, the software can be **tailored to each practice**, factoring in the PCP's particular focus and values. Large quantities of data taken from patients' psycho-social/medical histories and health events over a period of time can then be **organized and analyzed** according to the PCP's specifications. Sorting by caregiver status, for example, would provide insight into demographic and epidemiological trends concerning that group.

Using this customized software, Dr. Burger envisions the sorting of caregiver information into two paths:

- The first path would **note the patient's caregiver status** and **make a referral to an AAA for services** should the patient so desire; a variety of resources

"Technology is somewhat of a Faustian bargain: you get something and you give something up. [...] For us, it is a process to try to keep from getting so caught up in our toys that we forget about who is sitting in front of us."

Dr. Charles Burger

could be referenced automatically for this caregiver.

- The second path would **highlight the patient’s caregiver status as a potential health risk on the medical flow sheet** and incorporate it into the patient’s health assessment and treatment plan.

Couplers would thereby **integrate a patient’s caregiver status into his/her health-care** while providing **immediate access to resources and services** that could work towards alleviating caregiver burden. This integration would make great strides in reaching the MPPC project’s goal of making caregiver identification and referral a standardized, routine procedure within PCPs.

Technology holds great promise for the future of caregiver identification and intervention. Incorporating new technology within PCPs has its difficulties, however; in the words of Dr. Burger, its implementation “is like trying to paint the boat while you are sailing it.” Additionally, the possibilities offered by technological advances must be reconciled with the **imperatives of privacy and security**, particularly under HIPAA regulations. Successful integration of technology therefore must meet the above challenges through strong collaborative efforts and determination, striving towards the goal of improving caregiver care and services in the 21st century.

“Technology has enormous potential and is coming into its own for clinical physician support systems.”

Dr. Charles Burger

Using databases to pinpoint caregiver patients, PCPs can notify caregivers of educational events, community services, or health bulletins relevant to their particular needs and concerns.

Who Cares for the Caregiver

Family Caregiving

Depression in the Elderly

Depression



APPENDIX A

**Caregiving
Fact Sheets**



WHO CARES FOR THE CAREGIVER? PRIMARY CARE PRACTICE FACT SHEET #1

Family Caregivers Profiled

America's stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And to tell you the truth, sometimes she doesn't feel that great herself.

An estimated 15 to 25 million adults in the United States currently provide informal care (i.e., unpaid care) to relatives and friends.

Recognition of informal caregivers' contributions was heightened recently by estimates that project the economic value of their services to be \$196 billion, a figure that far exceeds national spending for home health care and nursing home care.

With ongoing public and private-sector efforts to limit post-acute and long-term care payments, the health care system's reliance on family caregivers will inevitably intensify.

Vulnerable caregivers not only have the responsibility and challenges of providing care to family members; they are also trusted companions, surrogate decision makers, and patient advocates.

Although informal care can positively affect the physical and psychological well-being of care recipients, its provision often comes at a personal cost to the caregiver. Studies have shown that caregiving can adversely influence the caregiver's physical and psychological health.

Factors that predispose family caregivers to poor outcomes and increased vulnerability include advanced age, the demands of employment, and inadequate social supports. Many vulnerable caretakers meet the demands of caregiving while coping with their own deteriorating health.

Caregivers are often the "invisible patients." Their own health care and other needs are often overlooked.

PRIMARY CARE PRACTICE TIPS

- **Ask about the "invisible patient." At every visit, check with both the patient and the "invisible patient."**
- **Be an advocate for respite and well care, and for swift attention to any health problems caregivers have.**
- **Make sure the caregiver knows how to do what is necessary to care for the patient, and that the caregiver is able to do it.**

**For more info call your Area Agency on Aging
1-877-353-3771**

A Joint Project of the Eastern Agency on Aging and the University of Maine Center on Aging in partnership with Aroostook Area Agency on Aging, Senior Spectrum, Rosscare, Norumbega Medical, Horizons Health Services, Indian Township Tribal Health Center, and Bucksport Regional Health Center

U.S. Administration on Aging NFCSP Grant #90CG2533
July 2002



FAMILY CAREGIVING FAMILY FACT SHEET #1

Family Caregiving Defined

Family caregivers are the immediate family, relatives and life partners who provide care directly or manage the care of older individuals who are ill or disabled. They may also be older individuals caring for ill or disabled children or grandchildren.

Who are family caregivers?

We are a diverse group of individuals who are traveling a complex journey. Some caregivers thrive, some simply survive and others suffer severe consequences.

For whom do we care?

48% care for spouses or life partners, 24% care for a parent and 19% care for a child or grandchild.

Most caregivers are female and the average age is 46. In one in four American households one individual is caring for a family member 50 and older.

Close to two in three caregivers are working, 52% full time and 12% part time. Nearly half of family caregivers spend in excess of 40 hours a week caregiving tasks.

The caregiver journey has demanded that individuals shift roles. Caregivers have moved from spouse/life partner to caregiver, from son and daughter to caregiver, and perhaps dramatically altering their life style along the way.

Caregivers are daughters and sons, who have stretched from the child of their parents to the caretakers of their parents. Most often they have extensive other family and life responsibilities.

Caregivers are parents and grandparents who thought they had long relinquished the responsibility of parenting and suddenly, due to life alterations, they find themselves, once again, in the parenting role.

FAMILY CAREGIVING TIP:

The caregiving journey is often mediated by a sense of humor, laughter, tears and support. Support includes family members, friends, community professionals and moments of respite. Caregiving is a journey not to be traveled alone. We are here to help.

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July 2002

DEPRESSION IN THE ELDERLY **PRIMARY CARE PRACTICE FACT SHEET #2**

Depression is the most common psychiatric disorder seen in individuals over the age of 65. It is estimated that at least one million of the nation's 31 million people age 65 and older suffer from major depression, and an additional five million have depressive symptoms severe enough to necessitate treatment.

- The incidence of depression among community-dwelling individuals over the age of 65 is anywhere from 10 to 15% and rises sharply among institutionalized individuals, to 25-30%.
- The National Institute of Health (NIH) Consensus Statement indicates only about 10% of the older adults needing psychiatric treatment ever receive such service.
- Depression is a major source of both morbidity and mortality, resulting in impaired functional status, impaired cognition, and suicide.
- Another obstacle to diagnosing depression in the older population is the fact that both patient and physician may incorrectly attribute depressive symptoms to the aging process.
- Expectations of functional ability may be low for this age group, and impairment in functional capacity caused by depression may be overlooked.
- Cognitive impairment frequently accompanies depression and is manifested by poor concentration, impaired short-term memory, and apathy.
- An individual may have difficulty with the Mini-Mental Status Exam, particularly in the areas of object recall, attention, and calculation.
- Suicide risk is higher for elderly white men than for any other age, gender, or racial group.
- Older adults are more successful at committing suicide than younger individuals. Older individuals are alone more, have time to plan their suicide, and when confronted with concurrent medical conditions tend to have more pessimistic views of the future.
- Most older adults who successfully suicide have seen their physician within the previous 48 hours.
- When recognized and treated, clinical depression may be successfully managed in over 80% of cases.

PRIMARY CARE PRACTICE TIPS

The primary care practitioner's best ally in the diagnosis of depression in older adults can be the family caregiver. Family caregivers see and speak to their older relatives on a regular basis. They may be best equipped to observe changes in a loved one's mental health and wellbeing. Husbands, wives, sons, daughters, and other family members who care for older relatives can be the eyes and ears of health care professionals. Together they can partner effectively in identifying and responding to evidence of depression in older relatives.

For more info call your Area Agency on Aging
1-877-353-3771



DEPRESSION FAMILY FACT SHEET #2

Could the sadness, loneliness or anger that some of us feel today be a sign of depression? It is not unusual for caregivers of relatives and friends to develop mild or moderate depression as a result of the constant demands they face in providing care.

Caregiving does not cause depression nor will every caregiver experience negative feelings that go with depression. However, caregivers often sacrifice their own physical and emotional needs and when this happens providing care can strain even the most capable person.

Early attention to symptoms of depression through exercise, a healthy diet, the positive support of family and friends, or consultation with a trained mental health professional may prevent the development of a more serious depression over time.

What are the symptoms of depression?

- A change in eating habits – eating more or eating less
- A change in sleep patterns – too much sleep or not enough
- Feeling tired, exhausted or overwhelmed all the time
- A loss of interest in things that once brought you pleasure
- Feeling nothing you do is good enough
- Irritability, easily agitated or easily angered
- Thoughts of death or suicide
- Any of these symptoms lasting more than two weeks

Lack of sleep is a major cause of depression in caregivers. Try to maintain a regular sleep schedule.

“Pulling yourself up by your bootstraps” and “getting a grip” will not alleviate depression.

Depression deserves to be treated with the same attention and consideration afforded any other illness. The important thing is to seek help.

For your health and the health of those around you, take some time to care for yourself.

Depression is a highly curable illness with appropriate medical care. Again, please do not hesitate to seek help from your physician or a qualified mental health provider.

**For more information, talk to your primary care physician
or contact your Area Agency on Aging: 1-877-353-3771**

A Joint Project of the Eastern Agency on Aging and the University of Maine Center on Aging in partnership with Aroostook Area Agency on Aging, Senior Spectrum, Rosscare, Norumbega Medical, Horizons Health Services, Indian Township Tribal Health Center, and Bucksport Regional Health Center

MAINE PRIMARY PARTNERS IN CAREGIVING (MPPC) PROJECT

Do you help someone 60 years of age or older who is not in good health or is not managing as well as he or she used to?

YES _____ If yes, please see back of form.

NO _____ If no, please return form to front desk.

APPENDIX B

Screening

THANK YOU

MPPC

- (circle one)
- Is it ever hard to help this person in any way? YES NO
- Do you ever worry about the health or well-being of this person? YES NO
- Do you ever feel stressed when you are helping this person? YES NO
- Have you had a major weight change within the past year? YES NO

We would like to have a Caregiver Specialist call you about support services for people who help care for others. There is no obligation or fee for this program.

When is the best time and day for someone to call you? _____

Telephone number _____ E-mail address _____

Name (Please print) _____

Mailing Address _____

PROTOCOL FOR MPPC SCREENS

1. The brief patient screen and attached flyer should be given to **each and every person** over the age of 18 who comes into the office for a **routine office visit (i.e., who will be seeing a primary care provider)**. The screen should **not be given to persons who are acutely ill, or who are seeing only the medical assistant/office nurse for blood pressure checks, finger sticks, blood draws or injections. This should reduce the burden that some offices have felt in giving out the screens.** Do not prescreen patients to determine if they are providing assistance to someone aged 60 or older. **Please use the following script when giving out the screens:**

“OUR PHYSICIANS ARE PARTNERS IN A HEALTH PROJECT AND WOULD LIKE YOU TO COMPLETE THIS SCREEN.”

2. Please **hold** all of the screens that are filled out for patients **who are not providing assistance** to someone aged 60 or older and they will be picked up by the Caregiver Resource Specialist at a later date.

3. Please **fax** to the Caregiver Resource Specialist all the completed screens for patients **who are providing assistance** for someone aged 60 or older **within 1 business day**.

4. If a patient prefers to **take the screen home**, a self-addressed envelope from Eastern Agency on Aging should be given for mailing the screen back to the Caregiver Resource Specialist.

5. If a patient comes in with a caregiver and that caregiver requests information about the program, he/she may fill out a patient screen. Please have someone from the front staff indicate on the screen that the person is **not a patient of your facility**. That screen should also be **faxed** to the Agency **within 48 hrs.** and will be forwarded to the appropriate Caregiver Specialist within the Agency. (They will receive assistance through their local Agency on Aging.)

6. When running low on screens or self-addressed stamped envelopes, please contact the Caregiver Resource Specialist for more **supplies**.

7. Please remember, there is no charge or obligation and no income and financial eligibility requirements. These services are free to anyone.

APPENDIX B

Screening

Informed Consent

You are being asked to take part in a study of people who provide care to elderly loved ones. We are interested in learning about the social and service needs of people who provide care to older adults. We are inviting you to the project because you told the Area Agency on Aging you provide care to an older loved one or family member.

The Maine Primary Partners in Caregiving is a joint project of the Eastern Agency on Aging, the University of Maine Center on Aging, Aroostook Area Agency on Aging, Eastern Maine Medical Center, Horizons Health Service, Indian Township Tribal Health Center, Norumbega Medical, Rosscare, and Senior Spectrum.

APPENDIX C

Research Tools

What you will be asked to do

If you agree to take part in this study, we will ask you to complete three surveys, one now, one in 6 months, and again in 12 months. The surveys will ask you about the type of help you provide to the elderly person and your feelings about providing that help (for example, “How often do you feel stressed between caring for your relative and trying to meet other responsibilities?”). You will be asked how much help you get from other family members or friends, and how you are feeling (for instance, “How would you rate your overall health at the present time?”).

The surveys will be given by telephone. You will receive a copy of the questions ahead of time so you can follow along. Each interview will take one half hour to finish.

Voluntary participation

Your participation in the research effort is voluntary. You do not have to join the project to continue getting any services you do now. You do not have to finish the three interviews. You do not have to answer any questions that you do not wish to answer. You will not be paid for your time.

Confidentiality

The things you say during the interview will be kept confidential. We will not tell anyone your name or any other personal information about you. Any publications that come from this research will report only summarized information about all the people in the project. We will never link your name or identity to any of your answers. We will keep the original surveys for at least 5 years for research purposes, but will destroy information linking your name with your answers as soon as we finish the research (within one year).

Risks for you

There are no expected risks to you. If you feel upset or worried about your feelings during the interview process, or if we feel you are in need based on your answers to the questions, we will give you referral information for services that may help.

Benefits to you

While there are no benefits to you, you may feel good knowing that you have helped the project understand caregiver burden.

Questions

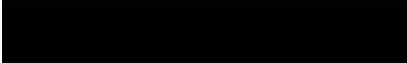
If you have questions about joining this study, please call Dr. Len Kaye at the UMaine Center on Aging at XXX-XXX. If you have questions about your rights as a research subject, please call Ms. Gayle Anderson from the University of Maine Office of Research and Sponsored Programs, XXX-XXXX or the Office of the EMMC Institutional Review Board, XXX-XXXX.

Signature

By signing this form, you are agreeing to take part in the Maine Primary Partners in Caregiving Project for the next year. You will be given a copy of this form for your records.

Signature

Date

**APPENDIX C****Research
Tools**

Caregiver I.D. _____
Date of Interview _____
Provider Office I.D. _____
Name of Interviewer _____

Maine Primary Partners in Caregiving Project

A Joint Project of the Eastern Agency on Aging and the University of Maine Center on Aging in partnership with Aroostook Area Agency on Aging, Bucksport Regional Health Center, Horizons Health Services, Indian Township Tribal Health Center, Norumbega Medical, Rosscare, and Senior Spectrum

(U.S. Administration on Aging NFCSP Award # 90CG2533)

RESEARCH TOOL Time I

I. Demographics

We are interested in knowing a few things about you and your living situation. The following questions will allow us to compare your situation (without identifying you by name) with other caregivers in Maine.

APPENDIX C

Research Tools

1. What is your relationship to the person for whom you provide care?

1. spouse _____
2. son/daughter _____
3. sibling _____
4. friend _____
5. other _____ (please specify) _____

1.a. Do you provide care for more than one person? yes _____ no _____

*** If yes, please choose the person for whom you provide the most care to answer the following questions.

2. Do you live with the person for whom you provide care? yes ___ no__

2.a. If no, how many miles away does this person live from you? ___ miles

2.b. Does this person live in a nursing facility, adult foster care, or assisted living? yes ___ no ___

3. Do other adults (people 18 and over) live in your home? yes ___ no ___

3.a. If so, how many? _____

4. Are there children under 18 living in your home for whom you are responsible? yes ___ no ___

4. a. If so, how many? ___

5. Do you receive help from other family members in your caregiving? yes ___ no ___

5.a. Does the person to whom you provide care receive any in-home care (e.g., chore worker, nurse's aide, personal care attendant)? yes ___no___

6. What is your marital status? (choose the one that best describes your current status)
1. married _____
 2. widowed _____
 3. divorced _____
 4. never married _____
 5. partnered but not married _____
7. Are you employed outside the home? yes _____ no _____
8. Where do you live? Town _____ County _____
9. With what racial or ethnic group do you most identify?
1. European American/white _____
 2. African American _____
 3. Native American _____
 4. Latino or Hispanic _____
 5. Asian American _____
 6. Franco American _____
 7. Other _____ (please describe) _____
10. How far did you go in school?
1. Eighth grade or less _____
 2. Some high school _____
 3. High school graduate _____
 4. Some college _____
 5. Associate's or vocational degree _____
 6. Four year college degree _____
 7. Some graduate education _____
 8. Graduate degree _____
11. Do you have a religious affiliation? yes _____ no _____
11. a. If yes, what is your religious affiliation?
1. Catholic _____
 2. Protestant _____
 3. Jewish _____
 4. Buddhist _____
 5. Muslim _____
 6. Hindu _____
 7. Other _____
12. What is your household income?
1. less than \$10,000 _____
 2. \$10,001 to \$20,000 _____
 3. \$20,001 to \$30,000 _____
 4. \$30,001 to \$40,000 _____
 5. \$40,001 to \$50,000 _____
 6. greater than \$50,000 _____

APPENDIX C

Research Tools

13. How old is the person for whom you provide care? _____

14. How old are you? _____

15. What is the gender of the person for whom you provide care?
(1) Male ____ (2)Female ____

16. What is your gender? (1) Male ____ (2)Female ____

II. Caregiver Burden

Providing care to a loved one is hard work. We are interested in knowing how your caregiving work affects your life. Using the following scale, please indicate how often you feel the following way.

0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite frequently, 4 = Nearly always

1. that because of the time you spend with your relative that you don't have enough time for yourself? 0 1 2 3 4
2. stressed between caring for your relative and trying to meet other responsibilities (work/family)? 0 1 2 3 4
3. angry when you are around your relative? 0 1 2 3 4
4. that your relative currently affects your relationship with family members or friends in a negative way? 0 1 2 3 4
5. strained when you are around your relative? 0 1 2 3 4
6. that your health has suffered because of your involvement with your relative? 0 1 2 3 4
7. that you don't have as much privacy as you would like because of your relative? 0 1 2 3 4
8. that your social life has suffered because you are caring for your relative? 0 1 2 3 4
9. that you have lost control of your life since your relative's illness? 0 1 2 3 4
10. uncertain about what to do about your relative? 0 1 2 3 4
11. that you should be doing more for your relative? 0 1 2 3 4
12. that you could do a better job caring for your relative? 0 1 2 3 4

APPENDIX C

Research Tools

III. Family Support and Social Involvement

Caregiving is at times an isolating experience. People receive different amounts of help from their family and friends. We would like to know about the support you receive in your caregiving work and about how caregiving might affect your social life. Using the following scale please answer the following four questions.

0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always

1. During the past week or so, have you been satisfied with the support your family has given you? 0 1 2 3 4
2. Do you feel you do more than your share of the caregiving compared to other family members or other members of your support network? 0 1 2 3 4
3. In general, how often do one or more persons help you to provide care to your relative? 0 1 2 3 4
4. Do you feel more cut off from your regular social activities than before? 0 1 2 3 4

IV. Social Network

We are interested in the number of friends and relatives (including spouse, children, etc.) on whom you can count when you need assistance or someone to talk to. Using the categories below, please answer the following six questions about your social network.

0 = none 1 = one 2 = two 3 = three or four 4 = five to eight 5 = nine or more

1. How many relatives do you see or hear from at least once a month? 0 1 2 3 4 5
2. How many relatives do you feel close enough to that you can call on them for help? 0 1 2 3 4 5
3. How many relatives do you feel sufficiently at ease with that you can talk about private matters? 0 1 2 3 4 5
4. How many friends/neighbors do you see or hear from at least once a month? 0 1 2 3 4 5
5. How many friends/neighbors do you feel close enough to that you can call on them for help? 0 1 2 3 4 5
6. How many friends/neighbors do you feel sufficiently at ease with that you can talk about private matters? 0 1 2 3 4 5

APPENDIX C

Research Tools

V. Knowledge

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. Using the following response categories, please indicate how much each statement describes your thoughts and feelings.

0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always

1. I believe that I know a great deal about my relative's condition. 0 1 2 3 4
2. I know where and how to request help from others when I need it. 0 1 2 3 4
3. I feel confident that I know how to manage a difficult situation. 0 1 2 3 4
4. I believe that, all in all, I am a capable caregiver. 0 1 2 3 4
5. I have been able to develop ways to manage the stresses of caregiving. 0 1 2 3 4
6. I feel I get the emotional support I need. 0 1 2 3 4

APPENDIX C

Research Tools

VI. Health and Well-Being

We are interested in how you would describe your health and well-being. Using the categories below, please answer the following three questions.

1 = Excellent 2 = Good 3 = Fair 4 = Poor

1. How would you rate your overall health at the present time? 1 2 3 4
2. Taking everything into consideration, how would you describe your satisfaction with life in general at the present time? 1 2 3 4
3. How would you rate your mental and emotional health at the present time? 1 2 3 4

In order to answer the final question regarding your health, please use the following three categories:

1 = not at all 2 = to some extent 3 = very much so

4. Does your health limit the kind or amount of care you can give to the elderly person to whom you provide assistance 1 2 3

VII. Task List

Caregivers provide many different kinds of assistance. We are interested in the types of tasks you perform in your caring work, and how difficult these tasks are for you. Using the response categories in column B, please let us know how often you do each of the six task categories listed in column A. For each type of assistance you do provide, please use the categories in column C to let us know how difficult these tasks are for you.

Column B: How often do you provide each task?
 0 = never 1 = rarely 2 = occasionally 3 = most of the time

Column C: How difficult is each task for you to provide?
 0 = not at all 1 = mildly 2 = somewhat 3 = very

A	B	C
1. Personal Care (e.g., bathing, dressing, toileting, feeding)		
2. Physical Assistance (e.g., transferring in and out of bed, getting around inside and outside)		
3. Light Housework (e.g., cooking, cleaning, shopping, laundry)		
4. Home Maintenance (e.g., repairs, shoveling)		
5. Managing Affairs (e.g., medications, finances, using the telephone)		
6. Ongoing emotional and social support (e.g., checking in routinely)		

APPENDIX C

Research Tools

VIII. Depression

Below is a list of the ways you may have felt or behaved recently. For each statement, using the scale below, please indicate the category that best describes how often you have felt this way **during the past week**.

0 = Rarely or none of the time (less than 1 day) 1 = Some of the time (1 or 2 days) 2 = Occasionally (3 or 4 days) 3 = Most days (5 to 7 days)

DURING THE PAST WEEK:

- a. I was bothered by things that don't usually bother me. 0 1 2 3
- b. I did not feel like eating; my appetite was poor. 0 1 2 3
- c. I felt that I could not shake the blues even with help

from my family and friends.	0	1	2	3
d. I felt that I was just as good as other people.	0	1	2	3
e. I had trouble keeping my mind on what I was doing.	0	1	2	3
f. I felt depressed.	0	1	2	3
g. I felt that everything I did was an effort.	0	1	2	3
h. I felt hopeful about the future.	0	1	2	3
i. I thought my life had been a failure.	0	1	2	3
j. I felt fearful.	0	1	2	3
k. My sleep was restless.	0	1	2	3
l. I was happy.	0	1	2	3
m. I talked less than usual.	0	1	2	3
n. I felt lonely.	0	1	2	3
o. People were unfriendly.	0	1	2	3
p. I enjoyed life.	0	1	2	3
q. I had crying spells.	0	1	2	3
r. I felt sad.	0	1	2	3
s. I felt that people disliked me.	0	1	2	3
t. I could not get “going.”	0	1	2	3

APPENDIX C

Research Tools

Closing: Is it OK for me to let your Caregiver Specialist know that we have spoken? yes _____ no _____

If so, may I communicate your service needs to her? yes _____ no _____

Thank you very much for your participation in this research project. We will call you again in about six months to see how things are going for you then.

Further comments:

Caregiver I.D. _____
Date of Interview _____
Provider Office I.D. _____
Name of Interviewer _____

Maine Primary Partners in Caregiving Project

A Joint Project of the Eastern Agency on Aging and the University of Maine Center on Aging in partnership with Aroostook Area Agency on Aging, Bucksport Regional Health Center, Horizons Health Services, Indian Township Tribal Health Center, Norumbega Medical, Rosscare, and Senior Spectrum

(U.S. Administration on Aging NFCSP Award # 90CG2533)

RESEARCH TOOL Six/Twelve Month Follow-Up (Times II & III)

I. Demographics

Six/twelve months ago we asked you a lot of questions about your living and caregiving situation. Today we would like to check to see if anything has changed since we last spoke. We expect many of your responses to these first questions will be just the same, so we will go through this section quickly.

Time III: (For a small number of you, we know you reported no longer providing care at the time of the second interview, but we are asking these questions again in case you have resumed your caregiving since that time.)

1. Six/twelve months ago you reported that you were providing care to _____ . Is that still true? yes _____ (go to 1.e.)
no _____ (go to 1.a.)

1.a. Are you caring for anyone? yes _____ (go to 1.b.) no _____ (go to question 6 and complete demographic section and the rest of questionnaire but skip caregiving questions, i.e., sections II, III, V, and VII)

1.b. What is your relationship to the person for whom you provide care?

1. spouse _____
2. son/daughter _____
3. sibling _____
4. friend _____
5. other _____ (please specify) _____

1.c. How old is the person for whom you provide care? _____

1.d. What is the sex of the person for whom you provide care?
male ___ female ___

1.e. Do you provide care for more than one person? yes _____ no _____

***If yes, please choose the person for whom you provide the most care to answer the following questions.

2. How long have you been providing care for this person? _____ months.

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3. Do you live with the person for whom you provide care? yes ___ no ___
- 3.a. If no, how many miles away does this person live from you? ___ miles
- 3.b. Does this person live in a nursing facility, adult foster care, or assisted living? yes ___ no ___
4. Are other people in your family system affected by your caregiving duties? yes ___ no ___ If so, how? _____

5. Do you receive help from other family members in your caregiving? yes ___ no ___
- 5.a. Has this changed since we last spoke? yes ___ no ___
If so, can you tell us how it has changed? _____

- 5.b. Does the person to whom you provide care receive any in-home care (e.g., chore worker, nurse's aide, personal care attendant)? yes ___ no ___
6. Do other adults (people 18 and over) live in your home? yes ___ no ___
- 6.a. If so, how many? _____
7. Are there children under 18 living in your home for whom you are responsible? yes ___ no ___
7. a. If so, how many? _____
8. What is your current marital status? (choose the one that best describes your current status)
1. married ___
 2. widowed ___
 3. divorced ___
 4. never married ___
 5. partnered but not married ___
9. Are you employed outside the home? yes ___ no ___
- 9.a. Has your employment status changed in the last six months? yes ___ no ___ (go to 9.c.)
- 9.b. If so, how has it changed? _____

- 9.c. Has caregiving affected your employment status in any way? yes ___ no ___ (go to 10) 9.d. If yes, please explain how.

10. What is your household income?

- 1. less than \$10,000 _____
- 2. \$10,001 to \$20,000 _____
- 3. \$20,001 to \$30,000 _____
- 4. \$30,001 to \$40,000 _____
- 5. \$40,001 to \$50,000 _____
- 6. greater than \$50,000 _____

10.a. Has this changed in the past six months? yes _____ no _____ If yes, how? _____

II. Quality of Caregiving Experience (Complete only if still caregiving)

Providing care to a loved one is hard work. We are interested in knowing how your caregiving work affects your life. Using the following scale, please indicate how often you feel the following way.

0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always

- 1. that because of the time you spend with your relative that you don't have enough time for yourself? 0 1 2 3 4
- 2. stressed between caring for your relative and trying to meet other responsibilities (work/family)? 0 1 2 3 4
- 3. angry when you are around your relative? 0 1 2 3 4
- 4. that your relative currently affects your relationship with family members or friends in a negative way? 0 1 2 3 4
- 5. strained when you are around your relative? 0 1 2 3 4
- 6. that your health has suffered because of your involvement with your relative? 0 1 2 3 4
- 7. that you don't have as much privacy as you would like because of your relative? 0 1 2 3 4
- 8. that your social life has suffered because you are caring for your relative? 0 1 2 3 4
- 9. that you have lost control of your life since your relative's illness? 0 1 2 3 4
- 10. uncertain about what to do about your relative? 0 1 2 3 4
- 11. that you should be doing more for your relative? 0 1 2 3 4



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12. that you could do a better job caring for your relative? 0 1 2 3 4

13. While caregiving can be stressful, it can also be satisfying. How would you describe your caregiving experience overall? _____

13.a. What three things have been most satisfying in your caregiving experience?

1. _____

2. _____

3. _____

13.b. What three things have been most difficult?

1. _____

2. _____

3. _____

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III. Family Support and Social Involvement *(Complete only if still caregiving)*

Caregiving is at times an isolating experience. People receive different amounts of help from their family and friends. We would like to know about the support you receive in your caregiving work and about how caregiving might affect your social life. Using the following scale please answer the following four questions.

0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always

1. During the past week or so, have you been satisfied with the support your family has given you? 0 1 2 3 4

2. Do you feel you do more than your share of the caregiving compared to other family members or other members of my support network 0 1 2 3 4

3. In general, how often do one or more persons help you to provide care to your relative? 0 1 2 3 4

4. Do you feel more cut off from your regular social activities than before? 0 1 2 3 4

IV. Social Network *(Everyone complete this section)*

We are interested in the number of friends and relatives (including spouse, children, etc.) on whom you can count when you need assistance or someone to talk to. Using the categories below, please answer the following six questions about your social network.

0 = none 1 = one 2 = two 3 = three or four 4 = five to eight 5 = nine or more

1. How many relatives do you see or hear from at least once a month? 0 1 2 3 4 5
2. How many relatives do you feel close enough to that you can call on them for help? 0 1 2 3 4 5
3. How many relatives do you feel sufficiently at ease with that you can talk about private matters? 0 1 2 3 4 5
4. How many friends/neighbors do you see or hear from at least once a month? 0 1 2 3 4 5
5. How many friends/neighbors do you feel close enough to that you can call on them for help? 0 1 2 3 4 5
6. How many friends/neighbors do you feel sufficiently at ease with that you can talk about private matters? 0 1 2 3 4 5

V. Knowledge *(Complete only if still caregiving)*

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. Using the following response categories, please indicate how much each statement describes your thoughts and feelings.

0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite frequently, 4 = Nearly always

1. I believe that I know a great deal about my relative's condition. 0 1 2 3 4
2. I know where and how to request help from others when I need it. 0 1 2 3 4
3. I feel confident that I know how to manage a difficult situation. 0 1 2 3 4
4. I believe that, all in all, I am a capable caregiver. 0 1 2 3 4
5. I have been able to develop ways to manage the stresses of caregiving. 0 1 2 3 4
6. I feel I get the emotional support I need. 0 1 2 3 4

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7. Is there any additional information or training that would be particularly helpful to you in your caregiving work? Yes _____ no _____ If yes, what would that be? _____

VI. Health and Well-Being (Everyone complete this section)

We are interested in how you would describe your health and well-being. Using the categories below, please answer the following three questions.

1 = Excellent 2 = Good 3 = Fair 4 = Poor

1. How would you rate your overall health at the present time? 1 2 3 4
2. Taking everything into consideration, how would you describe your satisfaction with life in general at the present time? 1 2 3 4
3. How would you rate your mental and emotional health at the present time? 1 2 3 4

In order to answer the final question regarding your health, please use the following three categories:

1 = not at all 2 = to some extent 3 = very much so

4. Does your health limit the kind or amount of care you can give to the elderly person to whom you provide assistance? 1 2 3

VII. Task List (Complete only if still caregiving)

Caregivers provide many different kinds of assistance. We are interested in the types of tasks you perform in your caring work, and how difficult these tasks are for you. Using the response categories in column B, please let us know how often you do each of the six task categories listed in column A. For each type of assistance you do provide, please use the categories in column C to let us know how difficult these tasks are for you.

Column B: How often do you provide each task?

0 = never, 1 = rarely, 2 = occasionally, 3 = most of the time

Column C: How difficult is each task for you to provide?

0 = not at all 1 = mildly 2 = somewhat 3 = very

A	B	C
1. Personal Care (e.g., bathing, dressing, toileting, feeding)		
2. Physical Assistance (e.g., transferring in and out of bed, getting around inside and outside)		

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A	B	C
3. Light Housework (e.g., cooking, cleaning, shopping, laundry)		
4. Home Maintenance (e.g., repairs, shoveling)		
5. Managing Affairs (e.g., medications, finances, using the telephone)		
6. Ongoing emotional and social support (e.g., checking in routinely)		

7. All in all, in the past week, about how many hours did you devote to care giving? (Include all your caregiving for adults combined, even if for more than one person.) _____ hours

VIII. Depression *(Everyone complete this section)*

Below is a list of the ways you may have felt or behaved recently. For each statement, using the scale below, please indicate the category that best describes how often you have felt this way during the past week.

0 = Rarely or none of the time (less than 1 day) 1 = Some of the time (1 or 2 days) 2 = Occasionally (3 or 4 days) 3 = Most of the time (5 to 7 days)

DURING THE PAST WEEK:

- | | | | | |
|---|---|---|---|---|
| a. I was bothered by things that don't usually bother me. | 0 | 1 | 2 | 3 |
| b. I did not feel like eating; my appetite was poor. | 0 | 1 | 2 | 3 |
| c. I felt that I could not shake the blues even with help from my family and friends. | 0 | 1 | 2 | 3 |
| d. I felt that I was just as good as other people. | 0 | 1 | 2 | 3 |
| e. I had trouble keeping my mind on what I was doing. | 0 | 1 | 2 | 3 |
| f. I felt depressed. | 0 | 1 | 2 | 3 |
| g. I felt that everything I did was an effort. | 0 | 1 | 2 | 3 |
| h. I felt hopeful about the future. | 0 | 1 | 2 | 3 |
| i. I thought my life had been a failure. | 0 | 1 | 2 | 3 |
| j. I felt fearful. | 0 | 1 | 2 | 3 |
| k. My sleep was restless. | 0 | 1 | 2 | 3 |
| l. I was happy. | 0 | 1 | 2 | 3 |
| m. I talked less than usual. | 0 | 1 | 2 | 3 |
| n. I felt lonely. | 0 | 1 | 2 | 3 |
| o. People were unfriendly. | 0 | 1 | 2 | 3 |
| p. I enjoyed life. | 0 | 1 | 2 | 3 |
| q. I had crying spells. | 0 | 1 | 2 | 3 |
| r. I felt sad. | 0 | 1 | 2 | 3 |
| s. I felt that people disliked me. | 0 | 1 | 2 | 3 |
| t. I could not get "going." | 0 | 1 | 2 | 3 |

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IX. Satisfaction with Services (*Everyone complete this section*)

We are interested in learning about how useful the services you've received from _____ (Caregiver Specialist) and _____ (AAA) have been for you.

1. Have you had contact with your Caregiver Specialist, _____, since last we spoke? yes _____ no _____

2. How would you rate the quality of service you've received from _____ (Caregiver Specialist and AAA)?
 1. excellent _____ 2. good _____ 3. fair _____ 4. poor _____

3. Did you get the kind of services you wanted? yes _____ no _____

4. To what extent has the services met your needs?
 1. almost all my needs have been met _____
 2. most of my needs have been met _____
 3. only a few of my needs have been met _____
 4. none of my needs have been met _____

5. Have the services you've received helped you deal more effectively with your caregiving?
 1. yes, they helped a great deal _____
 2. yes, they helped somewhat _____
 3. no, they really didn't help _____
 4. no, they seemed to make things worse _____

6. If you could have just what you wanted and needed, what would be most helpful to you in your caregiving work?

Closing: Is it OK for me to let your Caregiver Specialist know that we have spoken? yes _____ no _____

If so, may I communicate your service needs to her? yes _____ no _____

Thank you very much for your participation in this research project. We appreciate your taking the time to contribute to our research on Maine caregivers, and we look forward to sharing our findings with you.

Further comments:

ARE YOU ASSISTING AN OLDER RELATIVE
OR FRIEND BY...

- Driving
- Preparing meals and/or grocery shopping
- Helping with household chores
- Bathing and dressing
- Handling finances and paying bills
- Helping them take medications
- Running errands
- Providing emotional support or companionship
and are beginning to feel stressed?

Do you have questions about financial, legal, homecare and healthcare
services for older persons and their families?

We've got answers.

THE MAINE PRIMARY PARTNERS
IN CAREGIVING PROJECT

*For more information, talk to your primary care physician or contact your local
Agency on Aging at 1-877-353-3771.*

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