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Rural Caregiver Network Project Final Summative Internal Evaluation Report

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**Rural Caregiver Network Project
Final Summative Internal Evaluation Report
September 2012**



**Prepared for Eastern Area Agency on Aging
By:
University of Maine Center on Aging**

Project funding provided by the Harry and Jeanette Weinberg Foundation, grant# 10200

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Internal Evaluation Report Summary

The following report summarizes information collected from caregivers served through the Rural Caregiver Network project in addition to project partners and others who have been involved in project activities. The sources of information for this report include the following: 88 intake surveys gathered from caregivers, 69 follow-up surveys from caregivers; 84 caregiver and professional training surveys, and 26 project partner process survey responses. Findings that were found to be statistically significant are noted in the report.

SERVICE TOTALS NOTE: It is important to note that service recipient counts have been revised from previous internal evaluation reports through the use of more robust estimation techniques in order to avoid duplicate counting of service recipients when possible.

Overall Summary of Evaluation Findings:

- The project is serving a critical population of rural caregivers who are lower-to-middle income, and are providing a high level of care to their care recipients. Their care recipients are declining in health and demonstrating an increased and on-going need over time.
- Despite high levels of need among caregivers and their care recipients, caregivers served through the project have increased their health ratings, self-efficacy, and life satisfaction levels over time. Risk has decreased slightly over time while burden remained unchanged among caregivers. This finding may be considered positive as one would expect to see risk and burden increase (and efficacy ratings decrease) in the face of substantial, on-going caregiver demand over time.
- Caregivers are experiencing an increase in service access, a decrease in service barriers, and they are receiving support from a wider variety of agencies over time which points to the expected advantages of a network-based approach.
- Education and training components of the project have been very successful based on information gathered from caregivers, professionals, and students trained through this project.
- Successes and areas for improvement have been identified by project stakeholders through the data collection process. This feedback can be used as a roadmap for additional efforts that may be undertaken in the future.

- Overall, evaluation data indicate that the project has met many of its original goals and objectives. The project has also been successful in identifying potential areas for impact in the future based on perceived community needs and service gaps.
- Future directions for caregiver programming and supports post-grant include undertaking efforts to fill key gaps around flexible and affordable respite, offering case management services that are low-cost or free, investigating strategies for dovetailing with recent Affordable Care Act efforts, and maintaining on-going collaboration among partnering agencies.

Project Overview

The Rural Caregiver Network Project, funded by the Weinberg Foundation, is a caregiver support initiative that has integrated both formal and informal resources and agencies to build a network of support for caregivers of older adults in rural Washington and Hancock Counties in Maine. The network infrastructure of social service providers, a school of social work, and a research center on aging was built and then mobilized through this project in order to reduce the use of institutional care and maximize residents' ability to access home and community-based services which can be provided at a lower cost to caregivers and families. Every partnering organization involved has their own unique configuration of services and expertise which has enhanced significantly the caregiver resources in the region.

This project, at its core, utilizes a network approach where services and functions are parceled out to partnering agencies based on track record and expertise rather than one agency providing the bulk of caregiver services. The intent of this approach is to encourage partnerships that will strengthen service linkages for caregivers over the long term by building relationships among rural providers. This model is a response to the frequent scarcity and fragmentation of services found in rural underserved areas.

The integration and customization of services to the region was based on the findings from two extensive community needs and resources assessments. Providing the tools rural caregivers must have in order to navigate successfully the disparate service and resource systems in any community is the urgent need that has been addressed through project services. Affordable respite options have been provided through partnerships with local adult day service programs and the Senior Companion Program. Care coordination and navigation services were developed along with caregiver trainings that addressed identified caregiver needs for basic hands-on care techniques including transferring, toileting, and bathing, among others. Project services were marketed and promoted through the use of both word-of-mouth local outreach as well as multimedia regional approaches. All services were monitored and assessed by a Caregiver Steering Committee to further support participant-driven service strategies.

See below for a chart of project partners and their respective roles in the project. Replication information is provided in this report for key project components. In addition, a one-page information sheet about the project is included in the appendix.

| <i>PARTNER AGENCIES</i> | <i>PROJECT ROLE</i> | <i>PARTNERSHIP ACTIVITIES AND PRODUCTS</i> |
|--------------------------------|----------------------------|---|
| Eastern Area Agency on Aging | Lead Agency | Coordinate project, administer contracts, facilitate provider network |

| | | |
|--------------------------------------|--|---|
| | | and Steering Committee, conduct outreach/media campaign, develop Care Navigator position, develop web-based resources for caregivers, and oversee agency caregiver training mini-grants |
| UMaine Center on Aging | Project Evaluation | Needs and resources assessment work in years one and two, assisting project sites with cross-site and internal evaluation protocols, reporting for the grant |
| Friendship Cottage | Adult Day Service Provider | Develop a Caregiver Advocate position, administer respite fund, provide respite options |
| Rosscare | Caregiver Training and Staff Development | Co-develop Care Navigator position with EAAA, develop a web-based caregiver training module |
| Regional Medical Center of Lubec | Service Provider/Host site for Caregiver Advocate position | Develop a caregiver advocate position in year two of the grant |
| Senior Companion Program | Respite Provider | Provide respite services to fill gaps in Hancock County. |
| UMaine School of Social Work | Integration of Student Learning | Develop field rotation opportunities for students to increase interest in working with older adults and caregivers |
| Friends in Action | Caregiver Training | Plan and host 2 caregiver training sessions |
| Hancock County Homecare and Hospice | Service Provider | Provide massage therapy to caregivers who are caring for a hospice patient (mini-grant project) |
| Hospice Volunteers of Hancock County | Service Provider | Develop supports specific to those caregivers who are caring for a veteran. This includes support groups, staff trainings, and a coordinator who will assist with the special needs of this population (mini-grant project) |

| | | |
|----------------|--------------------|--|
| | | |
| UMaine Machias | Caregiver Training | Developing and delivering a caregiver resource day on campus in spring (mini-grant, partial) |

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Evaluation Methodology

The University of Maine Center on Aging served as the evaluator for this grant project. The evaluation employed a mixed methods approach which engaged stakeholders at all levels of service provision including caregivers, services providers, and community members. The Center on Aging utilized the following methods to conduct the 3-year program evaluation:

Needs and Resources Assessments

Two needs and resources assessments were carried out in Washington and Hancock Counties to create a baseline reading on the needs that could be addressed in this region and the resources that could be tapped for this project. These assessments entailed administering community focus groups and surveys with a large variety of stakeholders.

Assessment surveys were designed to elicit information from community members, caregivers, and professionals regarding their knowledge of services available to caregivers of older individuals, as well as their perceptions of the strengths and deficiencies of these services. There were a total of 98 survey respondents in Washington County and 50 respondents in Hancock County. Respondents were a mix of retirees, as well as individuals that are currently employed in diverse professions ranging from local government to healthcare, as well as full-time caregiving among others. From April-July 2010, five focus groups were convened in Hancock County. A total of twenty-eight (28) individuals participated in these focus groups. Four of the focus groups solely involved caregivers, while the fifth group was a mixture of caregivers, providers, and community members. The caregiver focus groups consisted of individuals recruited from the community, adult day centers and caregiver support groups, while the mixed group was recruited with the help of the Healthy Island Project (a community partner). During the spring of 2011, three focus groups were held in Washington County. A total of 18 individuals participated in these focus groups. Two of these focus groups solely involved caregivers, while the other was a mixture of caregivers, providers, and community members. The caregiver focus groups consisted of individuals recruited from the community, one being the Passamaquoddy Nation.

Needs and resources assessment information provided both a roadmap for providing effective and helpful services to caregivers but also provided feedback on potential directions for caregiver supports into the future beyond the scope of this current grant project. Detailed reports from both of these assessments are available online at:
<http://mainecenteronaging.umaine.edu/publications>

Caregiver Evaluation Surveys

An evaluation survey was devised for caregivers who received direct services from the project. This survey included both Weinberg cross-site measures encompassing demographics, care provision, caregiver risk, and burden among others. This survey also included additional elements specific to the internal evaluation including utilization of partnering agencies, nursing home placement of care recipient, satisfaction with services, suggested improvements to services, and caregiver efficacy. Surveys were given to caregivers who demonstrated a relationship with partnering agencies over the course of time (multiple service contacts). Surveys were administered to caregivers served through the following agencies: Eastern Area Agency on Aging, Senior Companions, Hancock Homecare and Hospice, Friendship Cottage, and Robert & Mary's Place Adult Day Program.

Caregiver surveys were administered in a timed series format at intake (or after several service contacts depending on the agency) and again at four months. This 4-month follow-up schedule proved to be challenging for hospice caregivers as many care recipients passed away during this time period. The follow-up schedule was then modified to a 2-month follow-up time frame for Hancock County Homecare and Hospice clients. Initial surveys were administered by site staff and/or graduate students who were trained in the survey protocol. All follow-up surveys were conducted by phone or mail and administered by Center on Aging staff.

Eighty-eight (88) intake caregiver surveys have been received over the course of the project and 69 follow-up surveys have been completed. The completion rate for follow-up surveys was 81% when accounting for those who were not eligible for follow-up due to the grant close-out date.

Service and Outreach Data Collection

The evaluation team worked closely with each service provider partner to devise a method for collecting and tallying service provision data. For some partners this meant crafting service data forms that staff would complete as they had interaction with clients and for others it meant creating their own internal databases that could easily track project-related activities including direct client contact hours and outreach and capacity building activities. Data were collected every two months to coincide with the Weinberg cross-site evaluation reporting schedule.

Training Evaluations

Training evaluation templates were developed to measure the impact of training on three key groups served through this project: caregivers, professionals/volunteers, and interns. Each training survey included Weinberg cross-site evaluation items (demographics, background, knowledge of resources, caregiver risk and burden, etc.) along with internal evaluation items that

measured the impact of the training on the individual. Key measures included in this section of the survey were: rating and description of new skills obtained, rating and description of new resources that the participant learned about during the training, rating of how helpful the training was, and suggestions for future trainings and improvements. In the instance of caregiver and professional/volunteer trainings, individuals were invited to take a brief 1-month follow-up survey. This survey measured the specific skills and resources utilized by the participant after the training. Eighty-four (84) training surveys have been collected over the course of the 3-year project.

Annual Process Evaluation Survey

An annual process evaluation survey protocol was developed in order to measure the impact of the project on partnering agencies, community members, and caregivers. In addition, the process evaluation survey included qualitative questions around implementation of the project at each partner site, service gaps not yet addressed by the project, suggestions for improvements, along with information on unanticipated outcomes; and new partnerships, policies and protocols that have arisen out of project activities. Two versions of the process evaluation survey were devised. One version was distributed electronically to provider partners and the other was tailored to the activities of the Caregiver Steering Committee which was distributed to members via mail or in-person. A total of 26 process evaluation surveys have been collected from project partners over the course of the 3-year project.

Profile of Caregivers Served Through the Project

Overall, the project has served primarily caregivers who are female, white, and come from households with an aggregate income of less than \$60,000 per year. Most are caring for spouses or their parents and have been doing so for several years. Caregivers are providing a high level of care on a daily basis with the intensity of caregiving remaining stable over time. In this respect, the project is serving a critical population of caregivers who are experiencing a high level of personal demand based on their caregiving responsibilities.

Demographics

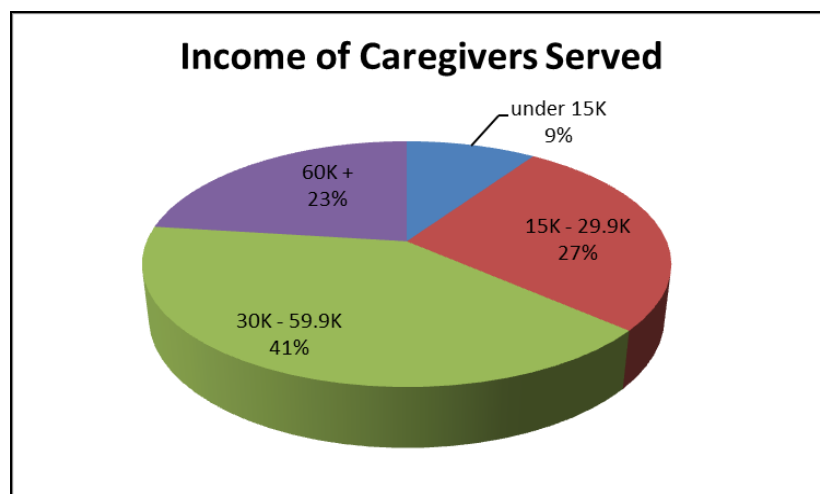
Average age: 64 years

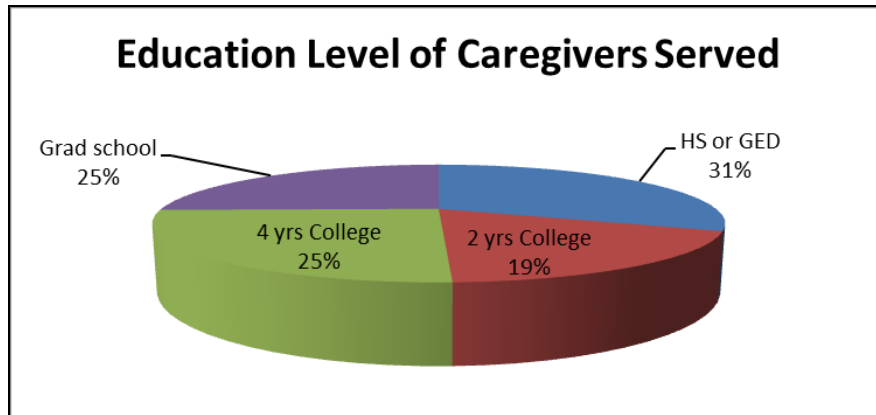
Gender: 80% female, 20% male

Race: 98% white, 2% American Indian

Income: 36% of caregivers report an aggregate household income of under \$30,000 per year, 77% of households served through the project report an aggregate income under \$60,000 per year.

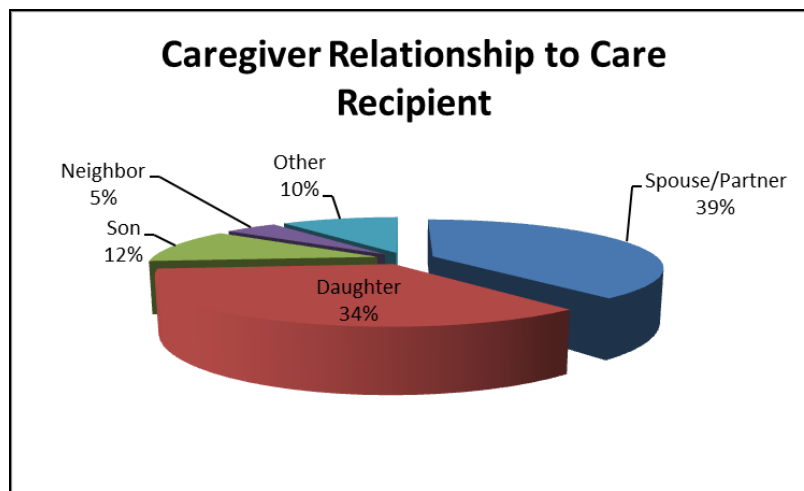
Education: 50% of caregivers have a high school diploma or some college.

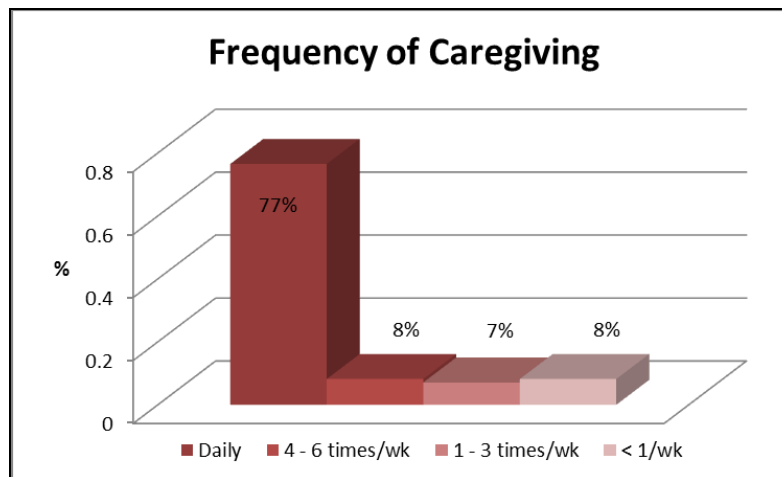
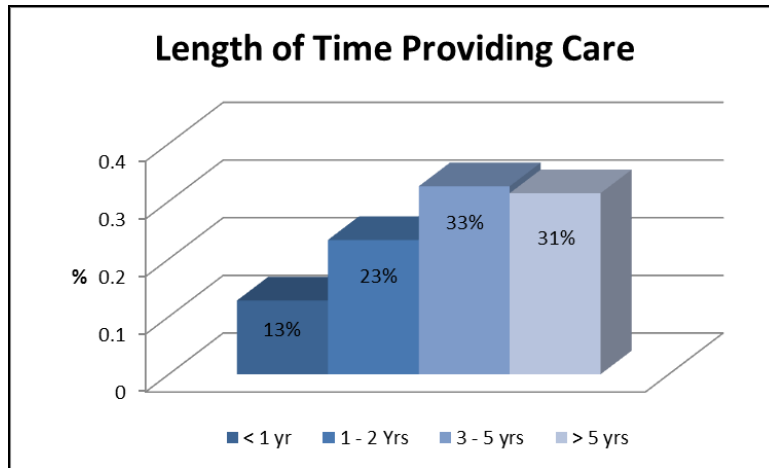




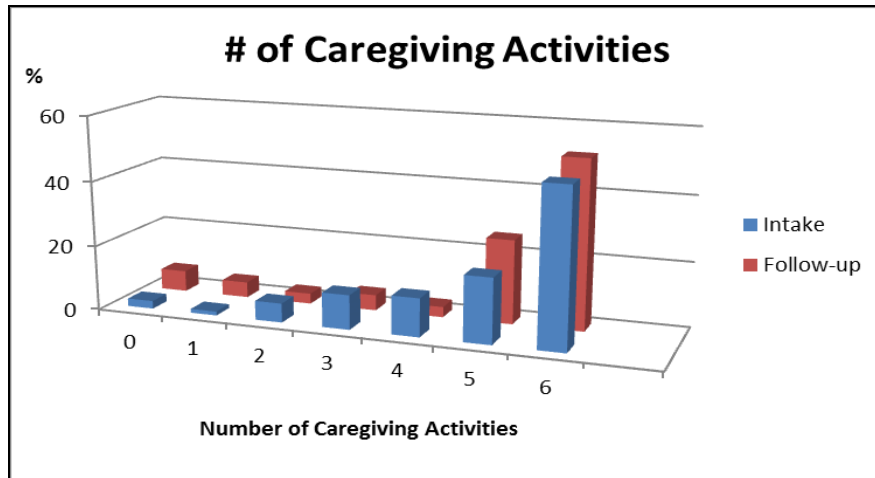
Caregiving Experience and Intensity

There is a high level of caregiving provided by those served through the project. A majority of caregivers are providing care on a daily basis and have been providing care for at least one year or longer. The intensity of caregiving has remained high but stable over time.

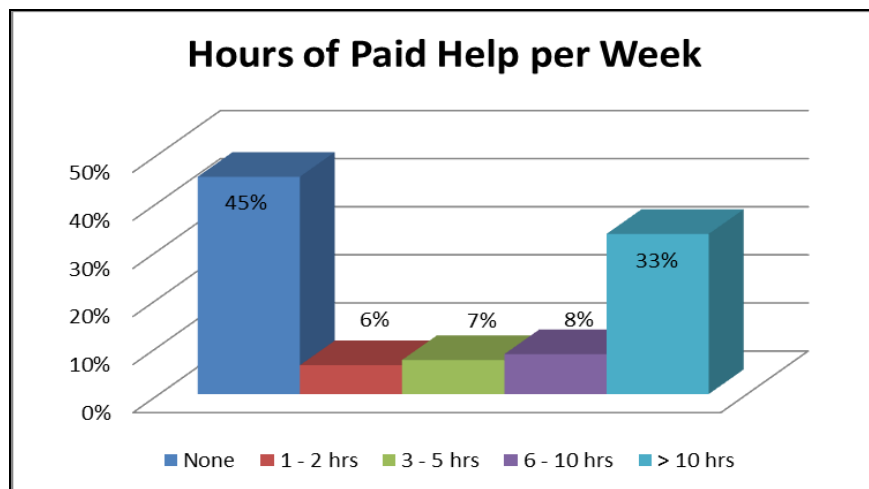




- The types of care provided to care recipients remained steady over time. The average number of care activities provided was 4.81 at intake and 4.77 at follow-up. Activities most commonly include personal care, housekeeping, transportation, shopping/errands, supervision, and money management.



- On average, caregivers are providing 80 hours per week of care to their care recipients. Fifty-eight percent (58%) of caregivers served through the project utilize five hours or less of outside paid help. The remaining 42% use six or more hours per week of paid help.



- The numbers of challenging behaviors and presenting issues exhibited by care recipients did increase slightly over time with an average score of 2.85 at intake and an average of 3.15 at follow-up. This difference was found to be statistically significant ($p < .05$). Issues exhibited by care recipients include: incontinence, wandering, abusive behavior, sadness, falls, and memory loss.

Caregiver Survey Findings

The following section outlines the changes seen among caregivers served through the project over time. Intake surveys are administered to caregivers at initial onset of services and again at four months post-intake (or 2 months post-intake for hospice caregivers). Overall, caregivers have experienced increases in health ratings, life satisfaction and their sense of efficacy. Caregiver burden and depression scores have remained stable over time. Caregivers also experienced an increase in their ability to access needed services over time.

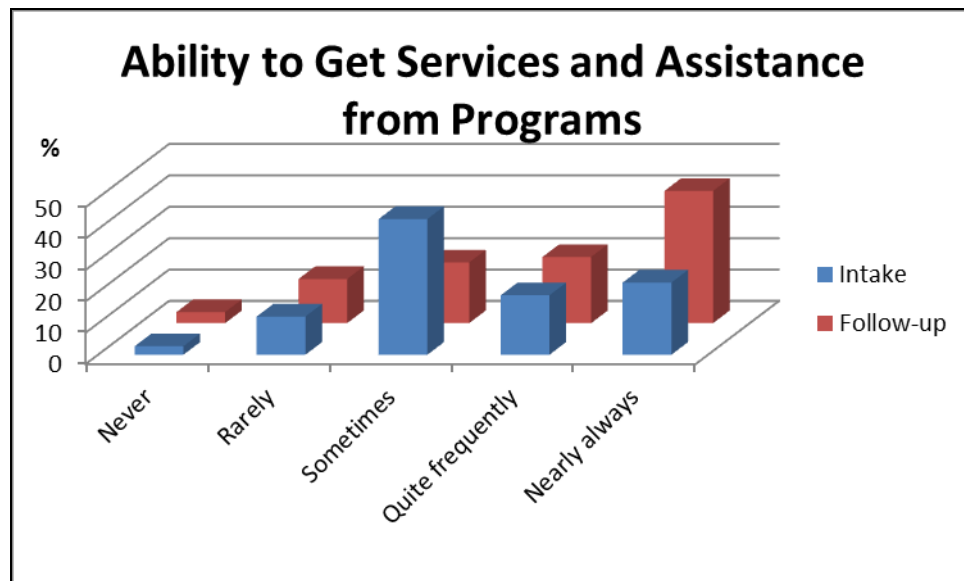
- Caregiver health ratings increased slightly over time with an average score of 3.27 at intake (good health rating) to 3.40 at follow-up (approaching a health rating of “very good”).
- Life satisfaction did increase slightly over time and remained positive overall with an average of 3.03 (satisfied) at intake increasing to 3.26 at follow-up (satisfied). Life satisfaction increase was found to be statistically significant ($p < .05$).
- Both the loss of interest in doing things and depression scores among caregivers remained stable over time.
- Caregiver efficacy has increased significantly over time while risk decreased over time and burden scores remained stable. The caregiver efficacy findings were found to be statistically significant ($p < .05$).

Service Utilization

Snapshot: The project is primarily serving caregivers who have interacted with partner agencies in the past. The project has been successful in increasing the number of different types of community supports accessed by caregivers. In addition, the project aimed to have 10% of caregivers self-identify as a result of project outreach efforts. One indicator we have of this caregiver self-identification process is the proportion of caregivers who are newly seeking services through the grant. At this point, preliminary findings tell us that 29% of caregivers who reach the project have not been served by partnering agencies within the past month and the majority of caregivers have been receiving services from partnering agencies for less than a year. Slightly more than half of the caregivers served through the project found their way to services through marketing/outreach and word-of-mouth.

- 70% of caregivers served have been receiving services via a project partner for 12 months or less. The remaining caregivers have been receiving services for a year or more at intake into the project.

- 29% of clients served have not received services in the past month from network partner sites indicating that they are either new clients or newly reconnecting with services.
- 68% of caregivers have self-referred into project services indicating that outreach through various channels (including word-of-mouth) has been successful. Fifty-three percent (53%) of caregivers served through the project learned about services through word-of-mouth, radio, newspaper, mail, print, or web outreach.
- Survey findings indicate that caregivers served through the project experienced a slight increase from intake to the 4-month follow-up in service utilization.
- At intake, 8% of caregivers served through the project are caring for an individual who is currently placed in a nursing home. At follow-up this figure jumps to 16% of caregivers.
- Caregivers served by the project have experienced an increase in their ability to access services and assistance over time as illustrated below. This increase in service access was noted to be statistically significant ($p < .05$)



Training Components-Results from Training Evaluations

Based on evaluation findings, the student and caregiver training components of the project have been successful in increasing skill levels and awareness among caregivers. In addition, students who completed rotations through the project experienced an increased interest in working with caregivers and older adults as a result of their involvement in the project.

- 85% of caregivers reported feeling more confident in their caregiving abilities after attending trainings. In addition, 90% of caregivers better understood the importance of respite and self-care after attending trainings. All caregivers (100%) reported that the trainings were helpful to them overall.
- 95% of caregivers reported using skills they learned at caregiver trainings one month after attending. Most common skills used after training include:
 - Transfer techniques
 - Assisting loved one with walking/mobility
 - Communication skills
 - Understanding behaviors
 - Patience
 - Using respite/making time for self-care
- 81% of caregivers reported using new resources that they learned about at caregiver trainings one month after training. New resources that were used include:
 - Hospice
 - Eastern Area Agency on Aging/Partners in Caring
 - Elder attorney
 - Support groups
 - Elder Independence of Maine
 - Caregiver guides and other resource materials

Student Feedback: Nine surveys were received from rotation students who interned at various locations throughout the project.

- The majority of students surveyed (89%) reported that the rotations were helpful to their professional development. All students reported learning new skills and increasing their knowledge of available resources as a result of their rotations. New skills and knowledge gained included:
 - Learned how rewarding it can be to work with this population
 - Best Friends approach to Alzheimer's care

- How to facilitate a caregiver support group
 - Learned about working with people who have dementia
 - Gained greater appreciation for how important and beneficial this program can be for clients and caregivers
 - Resources for caregivers
 - Learned about nursing homes and how to make that experience more comfortable for the caregiver and care recipient.
- The majority of students (89%) reported feeling better prepared to work with older adults and caregivers. All students experienced an increase in their interest in working with caregivers. The majority of students reported an increased interest in working directly with older adults as a result of their rotations.
 - Improvements for future rotations did include more time to interact with caregivers, regularly integrating student feedback into the rotation/internship design, and opening up more rotation opportunities in the future so that more students can benefit from a variety of learning opportunities in the community.

Progress on Identified Goals and Objectives from Original Grant Proposal

Based on evaluation data collected over the course of the project, the project activities have satisfied, and in some cases exceeded, many of its original goals as outlined in the grant proposal.

1. Gain an understanding of the desires of caregivers in the region with the objective of designing services that truly respond to the wants and needs expressed by caregivers.

Identified Outcome: Decreasing the number of residents needing to be placed in institutional care

Findings to-date: While project partners have been able to obtain an understanding of the desires of caregivers in the region and use that information to respond to identified needs, survey data indicate that nursing home placement has actually risen over time. One explanation for this could be the continued need for caregivers to self-identify earlier on in the caregiving process as opposed to seeking services later on in the caregiver trajectory when nursing home placement is imminent. Additional information from caregiver surveys demonstrates that project services are successful in meeting the needs of caregivers. Based on satisfaction data collected, we know that 95% of caregivers who used project services found them to be helpful and 93% were satisfied or highly satisfied with the services they received.

2. Increase the availability and affordability of adult day services across the region.

Identified Outcome: Making adult day services a realistic option for at least 50 caregivers by the end of the second year

Findings to-date: Over the course of the project, 43,716 adult day service hours have been provided by project partners to 66 caregivers. Of those caregivers, 40 received assistance from the newly established respite funds to support 2,034 hours of adult day services. Based on needs and resources assessment findings, adult day programming that is affordable and flexible is an on-going need in the project region and may be an area to examine for sustainability purposes. Our experience also indicates the willingness of rural older adults and their caregivers to utilize adult day services when such services are thoughtfully conceived and marketed (a service which some older adults and caregivers in rural communities have been known to resist taking advantage of because of pride and a strong independent spirit). The recent success of expanded hours at Friendship Cottage underscores that flexible service delivery is attractive to caregivers.

3. Provide alternative respite services for caregivers.

Identified Outcome: Providing a beneficial break for at least 100 caregivers in Hancock County by the end of the second year

Findings to-date: Based on program service records, an estimated 112 caregivers across the Hancock County region have received a beneficial break from their caregiving duties through attendance at support groups, caregiver retreats, or through respite offered by Senior Companions.

4. Provide access to personalized help through care management services for caregivers.

Identified Outcome: Providing at least 1,500 hours of navigation services to at least 150 caregivers in both counties by the end of the second year and 200 caregivers by the end of the third year.

Findings to-date: A total of 1,124 hours of care management and navigation services have been provided over the course of the 3-year project. Staff have served an estimated total of 564 caregivers to-date. These service statistics indicate that the project has served more caregivers than projected but that the total number of hours anticipated is lower than expected. This may be due to caregivers having immediate needs met through short-term interventions from staff members as compared to longer on-going relationships with staff. These data also speak to not only the potential adequacy of more brief interactions with project staff but also the preference by rural caregivers for time-limited, brief intervention assistance.

5. Use various media to make caregiving a household term.

Identified Outcome: Helping 10% of the caregivers in both counties of Downeast Maine to self-identify and seek information, respite and support group services and other options

Findings to-date: Based on survey evaluation findings, 70% of caregivers served have been receiving services via a project partner for 12 months or less. The remaining caregivers have been receiving services for a year or more at intake into the project. Almost 30% of clients served have not received services in the past month from network partner sites, indicating that they are either new clients or newly reconnecting with services. Fifty-three percent (53%) of caregivers served through the project learned about services through word-of-mouth, radio, newspaper, mail, print, or web outreach. Word-of-mouth continues to be the strongest marketing tool for the project with 39% of caregivers finding out about services through family and friends (informal supports).

Additional Findings of Interest

- Given the network-based nature of services provided through the grant, evaluators considered the continued use of partnering agencies by caregivers over time as a measure of the value and personal satisfaction derived from such connections by caregivers. Preliminary findings indicate that use of partnering agencies has increased slightly over time with an average usage of 1.08 partner agencies increasing to an average of 1.25 at follow-up. Fifty percent of caregivers served through the project experienced an increase in partner agency usage over time indicating that the project has had some success in helping caregivers connect with a variety of agencies for support.

| Caregiver Network Project Service Data Summary | | | | |
|--|-----------------------------------|---------------------------------|--|---|
| Type of Service | How many? (total # of clients) | How much? (total # of hours) | Goal | Meet or exceed? |
| Adult day services | 66 | 43,716 | 50 ADS clients | Exceeded goal |
| Support groups | 84 | 255 | 100 clients between support groups, Senior Companions, and caregiver retreats | Exceeded goal |
| Senior Companion Services | 17 | 2,729 | | |
| Caregiver retreats | 11 | 18 | | |
| Caregiver Resource Center Support | 21 | 94 | 1500 hours/200 caregivers for Caregiver Resource Center, Care Management/ Care Navigation through EAAA | Exceeded caregiver count goal/did not meet hours goal |
| Care management-including Lubec Care Coordinator | 500 | 898 | | |
| Care navigation | 43 | 132 | | |

| | | | | |
|---|----|-------|------------------------------|---------------|
| Volunteer trainings (graduate interns) | 15 | 5,700 | 12 student interns | Exceeded goal |
| | | | | |
| Volunteer and community trainees | 25 | 50 | no specific goal in grant | N/A |
| Caregiver trainings | 54 | 262 | no specific goal in grant | N/A |
| Caregiver trainings- SAVVY | 12 | 144 | no specific goal in grant | N/A |
| | | | | |
| Caregiver massage services | 44 | 104 | no specific goal in grant | N/A |

| | Count | Hours of Training/ Service |
|---|------------|----------------------------------|
| OVERALL | | |
| Trainees | 106 | 6,156 |
| Caregiver Service Recipients | 786 | 47,946 |
| Outreach Activities | 266 | N/A |

Financial Impact Assessment

At the request of the Weinberg Foundation, the following financial impact assessment provides a snapshot of the cost savings realized through project activities. The basic premise of this analysis is that by supporting caregivers, and enhancing their ability to care for their loved one in their home, that institutional care can effectively be avoided. Informal family care provides a significant cost savings over the fees associated with private pay and nursing home care.

If you define nursing home level of care as providing daily care to a loved one, 78% of caregivers served through the project are providing nursing home level of care. We have served an estimated 286 caregivers in the following categories: ADS, respite, retreats, caregiver hospice massage services, caregiver resource center, support groups, and care navigation. Based on that information the following calculations provide an estimate of cost savings for the project:

- Per Maine Office of Elder Services, the current cost of nursing home care in Maine:
\$192.59/day
- 78% of caregivers providing nursing home level care x 286 caregivers = 223 providing daily care
- Of those, 87% were able to keep their loved one at home instead of nursing home care:

$223 \times .87 = 194$ caregivers keeping loved one at home instead of nursing home care

Of those, the average amount of time they kept their loved one at home based on our follow-up surveys at 4 months (or at 2 months for hospice): 2.68 months

- $194 \text{ caregivers} \times 2.68 \text{ months} \times 30 \text{ days per month} \times \$192.59 \text{ per day nursing home costs} = \$3,003,942^{**}$

****Caregivers likely kept their loved ones home longer than that, but our follow-up only covers 2-4 months of time so this is a conservative estimate of cost savings.**

Return on investment: Every \$1 the Weinberg Foundation invested in this project resulted in approximately \$4.62 in nursing home cost savings.

Project Successes as Identified by Caregivers, Project Partners, and Steering Committee Members

There were many successes identified by caregivers, project partners, and Steering Committee members. Successes include raising awareness of caregiving issues, increased collaboration and resource sharing, as well as needed agency-based changes that will improve services to caregivers into the future.

Specific Successes of the Project from Process Evaluation Feedback:

- Raising awareness of needs and resources
- Development of a Caregiver Steering Committee
- Data collection efforts
- Men's support group
- Activities moving into Washington County
- Service development at Friendship Cottage
- Family Caregiver Navigator
- Education/training-both online and in-person
- Increased collaboration amongst community providers and the maximizing of resources
- Increased outreach and connections to the medical providers via various partners
- The use of advanced degree social work students to enhance caregiver services throughout the region helping to foster a greater interest in the field of geriatrics
- Database/service tracking mechanisms have been modified to better track services provided
- Helping caregivers self-identify and obtain services and supports needed to continue to provide care

New Partnerships and Collaborations

- Family Caregiver Navigator has networked with a local health system to provide caregiver wellness programming via employee health
- Through the development of the Hancock Resource Exchange, a wide group of providers connect quarterly and share resources
- Senior Companion volunteer opportunities created for providing caregiver respite
- Friends in Action as caregiver training partners now continue to provide the venue for future training sessions
- Care Coordinator hiring in Regional Medical Center in Lubec creates new links, including the Regional Medical Center in Eastport
- New Hospice and Home Care providers added through allocation of mini-grant funds to impact caregivers of veterans and to provide alternative therapies to caregivers

- Through the use of grant funds obtained through United Way, the extension of educational/training opportunities with other providers such as Faith in Action and their affiliations has expanded caregiver and organization networking
- MSW field internships creating new partnerships among community and higher education provider networks

New Infrastructure and Policies Resulting from the Project

- Agencies have revisited and revised employee policies related to "time away" or flexible work schedules for caregiver duties
- Revisions have been made in the development of new assessment/service plans and fee-for-service billing procedures relative to the Navigator position
- A Weinberg Graduate Social Work Student Practicum Unit was developed
- All aspects of the Caregiver Advocate have been created to support the goals of this grant and the needs of caregivers within a given community
- New methods of tracking how services are delivered have been put into place at partnering agencies
- The capacity to carry out outreach and media campaigns specific to caregiving has been greatly expanded and will continue into the future

Unanticipated Outcomes

- An enhanced awareness among clinical providers (hospitals and physician practices) of the specialized needs of caregivers for aging adults with chronic illness/disease
- An expansion of potential adult day medical models to other communities not directly involved in the grant activities (Piscataquis County)
- The reestablishment of the Adult Day Association lends itself to providing a more unified resource to other potential adult day providers
- Personal impact: "One community volunteer in particular was reluctant to spend time with a care recipient with dementia. Once the volunteer realized the journey with the care recipient was joyful and exciting, the volunteer has a greater understanding of the journey of dementia and enjoys the visits"

| <i>Project Impacts as Identified by Project Partners and Steering Committee members</i> | | |
|--|--|---|
| <i>Impact on Caregivers</i> | <i>Impact on Care Recipients</i> | <i>Impact on Community Members</i> |
| <ul style="list-style-type: none"> ○ Through the use of increased media, caregivers are learning more ways to access services ○ Improved knowledge and self-care, more assistance and support, improved respite options ○ Caregivers that use services seem less stressed, they have developed friendships with each other, and at times socialize with each other ○ Wider variety of support options are now available ○ More caregivers willing to try services ○ Increased self-identification as a caregiver rather than a son/daughter/spouse, etc. ○ Caregivers are benefiting from support groups ○ Flexible weekend respite hours help to meet caregiver needs | <ul style="list-style-type: none"> ○ With increased options for respite, care recipients can remain home longer and avoid institutional care - i.e. medical model of adult day ○ Care recipients are increasing the number of hours in adult day services ○ Improved care provided by caregivers ○ Improved relationship with caregiver ○ Accessing quality services and supports ○ Care recipients appear to be happier and more engaged in services/higher functioning | <ul style="list-style-type: none"> ○ Increased opportunities for volunteer work and student learning in the field of gerontology ○ Through increased media, community members can start to self-identify earlier on and better prepare and plan for caregiver role ○ Improved knowledge about the role of both caregiver and receiver - more willingness to help ○ The community is more involved and interested in our program ○ Increased awareness of caregiving in general and available resources ○ Agencies and organizations are sharing resources and maximizing their efforts ○ Increased linkages with health care providers around caregiver issues ○ Along with increased collaboration comes territorial challenges among those who serve caregivers |

Areas for Improvement and Sustainability as Identified by Caregivers, Project Partners, and Steering Committee Members

Suggestions for improving project services were offered by project partners and include continued outreach, more hands-on support, more public information, and increasing opportunities for program linkages and collaboration. In addition, service gaps were identified by project partners including more overnight respite options, transportation, and group home options. Service gap information can be used to spearhead additional programming.

Suggested Improvements

- More clarity around adult day service financial obligations for clients/better understanding of payment structure
- Having an all-wheel drive van at Friendship Cottage for accessing steep or icy drive ways and eliminating the need to reschedule due to weather
- More direct hands-on guidance rather than printed materials when possible
- More frequent workshops and trainings
- More public information in general
- Services are carved out by individual agencies that can't really be controlled - Efforts to coordinate should be increased
- Partners could encourage the use of Navigator services to caregivers they work with
- Regular networking opportunities for agencies and caregivers
- More education on what constitutes 'respite care'

Service Gaps Identified

- Overnight respite options
- Drop-in or more flexible respite programs without set hours
- Group home or residential setting for those with Alzheimer's disease
- Transportation and easily accessible resources
- Affordable home care, including adequately paid home care providers to assist with caregiving needs
- More care management needed
- Grant writing support for individual organizations
- There continue to be respite gaps in Washington County particularly given that adult day program development in this region has been put on hold
- Care navigation continues to be a challenge for those without financial resources to pay for the service
- There is an on-going need for respite during caregiver trainings so that caregivers can take the time to attend trainings without worrying about their loved one

Strategies That Partners are Using to Address Gaps

-
- Continuing to apply for grants that fill caregiver needs, such as training and respite
- Expanding into a fee-for-service case management component - With federal grant funds, no caregiver would go without support/services regardless of ability to pay
- One agency will continue to offer free case management to clients including assisting them with locating resources they qualify for
- Offering a scholarship fund for case management services when possible

Strategies for Sustainability

- Continue to have student placement affiliation agreements with Friendship Cottage, the Center on Aging, Eastern Area on Aging, and the Regional Health Center at Lubec
- Continue to identify and apply for grants
- Continue to coordinate enrichment activities for students in the field including workshops and guest lectures
- The Caregiver Curriculum is available to consumers online and is highlighted in ongoing community education seminars
- The Caregiver Navigator position will continue to add a case management component as part of a fee-for-service program as she also works with caregivers through Older American Act funds in Penobscot County
- Caregiver respite opportunities and expanded support groups will continue through state and federal grant funds
- Provider partnerships will continue via quarterly established resources exchanges in each county
- Steering committee members have agreed to serve as advisors in future caregiver resource development
- Outreach and marketing materials developed through this project have expanded outreach capacity and agencies will continue to use these materials into the future

Replication Information

The following information was gathered from project partners regarding the project components they felt were most readily replicable. The replication information in this section provides an overview of key project components as well as practical information about lessons learned over the last three years. This section does not represent an exhaustive list of project activities but focuses in on several central components of our efforts.

FRIENDSHIP COTTAGE

Friendship Cottage Adult Day Center in Blue Hill has been a resource to caregivers in Hancock County since July 2008. This location offers a medical model adult day service program to care for the dependent adults of Hancock County while assisting and supporting their informal caregivers. Prior to the development of the Weinberg project, the day center offered information to caregivers across the lifespan, but there were limits to the information and resources that could be provided as their library was still under development and staffing was limited.

Caregiver Resource Center



Presentation at the Caregiver Resource Center

As a result of the Weinberg grant, Friendship Cottage was able to expand their Caregiver Resource Center and Community Advocacy efforts to provide advocacy, resources, and support to caregivers. In addition to funding received through the Weinberg grant, Friendship Cottage received a mini-grant totaling \$500.00 and donations of books to support the lending library.

Community Advocate

The grant project allowed for the development of a Community Caregiver Advocate position. The Community Advocate position was setup to provide assistance to caregivers by offering information, support, and making referrals to other community-based organizations as needed. In addition, the Community Advocate facilitated monthly support group meetings for the caregivers where there is open enrollment and topics of interest identified by caregivers (See appendix for a copy of the Caregiver Advocate job description). Those eligible to receive caregiver advocacy and support only needed to identify as a caregiver. There are no other costs or eligibility requirements.

The second goal of the Community Advocate position was to leverage community resources to address caregiver needs. For example, during career days and job fairs, the Community Advocate made efforts to recruit high school students for volunteer work within Hancock County. This outreach was facilitated by the requirement that Hancock County high school students complete 400 hours of volunteer work. The volunteer opportunities with caregivers highlighted by the Community Advocate provided an opportunity to address community needs and the educational needs of local students.

In terms of recruitment, it was found that the person filling the Community Advocate role needed to be flexible as this position is not always full-time. To recruit the Advocate, ads were placed in the local newspapers with a job description that included a preference for an undergraduate degree within the Human Services field. The essential component to successful development of this role involved the reliance on the School of Social Work's internship support which allowed Friendship Cottage to expand the position and fill service gaps as needed when the advocate was unavailable.

When considering developing a Community Advocate position, it is important to take funding sources into consideration, as well as the large amount of upfront work that needs to be done. During the initial part of the grant period, systems and relationships needed to be developed which required collaboration and outreach efforts. Once relations were established within the community, the position moved from a 40 hour per week position to 20-30 hours per week as necessary to support advocacy needs. In terms of funding, at Friendship Cottage, there is no fee for community advocacy service. Therefore, the revenue has to come from alternative resources that include the adult day center. Funding needs to be secured for this advocacy position and is an on-going challenge.

Men's Support Group

Early needs assessment work and community focus groups that came out of the project supported the need for a male caregiver support group. It was noted that men often have different needs than female caregivers and were not interested in attending a coed support group. Therefore, a unique support group was developed to fill what was perceived as service gaps for this particular population of caregivers. One of the perceived differences between men and women that led to the creation of a second support group was that men often do not desire to receive support regarding their feelings, but they have different issues that need support. For example, as one male caregiver shared with the Steering Committee, learning to help your wife put on pantyhose was a new and unanticipated challenge he faced as a caregiver. The initial concerns that often drive a male caregiver to support groups involves their desire to "fix" a problem, such as mastering basic cooking skills or addressing the difficulties associated with the hands-on personal care needs of their dependent adult and discomfort regarding this required care. While these utilitarian issues will initially bring them to a support group, men often stay for the emotional support they receive from other members once they begin to feel comfortable in the group.

A male graduate student intern was recruited to facilitate this specialized support group. Initially, Friendship Cottage provided respite for the caregivers' dependent adult, but this form of support couldn't continue due to lack of reimbursement. Despite the change in respite support, there was no impact to the male caregiver attendance.

The initial development of the group entailed contacting male caregivers already known to Friendship Cottage. There were press releases, advertisements, and flyers placed in men's bathroom facilities, churches, and other community centers. Two-thirds of the response came from the publicity efforts made at the initial stage of support group development.

Respite Fund



Friendship Cottage Adult Day
Program

A respite fund was developed through project efforts to ensure that caregivers had access to affordable respite care options and that no one would be turned away from adult day services due to their inability to afford respite care. It was noted that caregivers in the region needed more respite than what was allotted for through their existing benefits such as Medicaid or VA benefits. In addition, families were experiencing considerable lag time between applying for and ultimately receiving VA respite benefits.

The respite fund was designed to fill funding gaps for caregivers and their families. At one point in the project,

Section 61 funding, which provides state funds in Maine for respite, ran out while services needed to continue to be provided for an additional month in the region. The respite funds allowed for adult day programs in the region to continue to provide services for the additional month needed for caregivers and their Medicaid eligible care recipients. In addition, respite funds allowed caregivers to access respite services on Saturday in order to run errands, work extra hours, or meet other needs.

Development of the Respite Fund

- Friendship Cottage communicated with other day programs in Hancock County for input on development of the fund
- Friendship Cottage worked with Caregiver Steering Committee and Friendship Cottage Advisory Board members- Information was presented to the Caregiver Steering Committee and the respite fund was approved
- To support access to the fund, emails and application attachments were sent to all adult day center providers with instructions on how their caregivers could utilize the respite fund

Respite Fund Criteria

The following criteria were developed for the Respite Fund by program staff, providers, and Steering Committee members. An application form is provided in the appendix of this report.

1. The care recipient must be a participant enrolled in a licensed Adult Day Service Program (ADSP) in Hancock County.
2. Participants may apply for an additional 5 hours of respite per month, not to exceed 20 hours in a calendar year.
3. Participant may receive respite care at the ADSP they are enrolled in or in home by an informal caregiver who has been approved to be on the Caregiver List at Friendship Cottage.
4. Reimbursement will be at the rate of \$10.00 per hour. Additional charges by the ADSP or informal caregiver will be the responsibility of the participant.
5. Additional respite hours may be approved at the discretion of the Program Site Manager at Friendship Cottage.
6. All applications will be reviewed by the Program Site Manager and Community Caregiver Advocate at Friendship Cottage to determine all funding sources have been utilized.

Tip for Those Undertaking Similar Efforts

- Try and develop a partnership with all adult day programs in your area to pool funds together for respite. Establish a funding protocol/application process for respite needs.
- The fund can be a means of supporting both formal adult day programs as well as informal private care to supplement adult day programming. In this instance, caregivers have found it helpful to have access to a list of private care providers in the community who have completed a background check and could be called upon to provide supplemental private care as needed. Such a list was maintained at Friendship Cottage and was a critical resource to caregivers.

To learn more about the Resource Center, Community Advocate, Men's Support Group, or the Respite Fund: Contact Anne Ossanna, Program Site Manager, Friendship Cottage, aossanna@whcacap.org, 207-374-5612.

EASTERN AREA AGENCY ON AGING

Eastern Area Agency on Aging (EAAA) has been serving Penobscot, Piscataquis, Hancock, and Washington counties since 1973. Related caregiver efforts undertaken by Eastern Area Agency on Aging include a pilot project in 2001 where the EAAA partnered with local physicians and the University of Maine Center on Aging in support of screening patients and family members within the primary care setting in order to identify caregivers and their support needs. EAAA has served caregivers since 1999 and offers caregiver support services for both Hancock and Washington counties.

Family Caregiver Navigator

Through review of the needs assessment data gathered in the first year of the project, there was an identified need for case management services for caregivers that resulted in the hiring of a Caregiver Navigator through EAAA. Caregivers need support to alleviate stress and provide care to their care recipient. Relying on a Caregiver Navigator would save the caregiver time and frustration with searching for resources and information.

The Caregiver Navigator position was designed to provide consultation, assess support needs, and assist the caregiver in developing and carrying out a support plan that best fits their needs. Elements of the plan may include, but are not limited to: self-care, check-ins, long-term or assisted living searches, caregiver stress-relief, respite, shoveling yards, etc. The needs are endless but the key is that they're identified by the caregiver and brokered by the Caregiver Navigator.

The initial plan was to provide a comprehensive assessment but due to the barrier related to the cost/payment for this service it was offered but not requested by caregivers. Instead, the Family Caregiver Navigator provided a complimentary initial consultation and recommendations. Once the caregiver identifies the support need(s), family meetings are arranged where needs can be formally addressed. The Navigator facilitates this meeting if deemed necessary, a plan is developed with the family, and then action steps are taken to meet the identified needs. The Caregiver Navigator provides recommendations and estimates the time needed to complete each task, for example, a facility search may require 300 minutes of service time. The estimation of required time is an estimation only and, prior to signing the contract, the caregiver is made aware of this. If it is anticipated that the Navigator will go over the estimated time, then the Navigator makes efforts to inform the caregiver of this change.

Service closure is based on when tasks (identified needs) are completed or when the caregiver opts to terminate the agreement. Most caregivers will opt to keep their agreement open for the year contract just in case another need arises.

Eligibility for Caregiver Navigator Services

- Caregivers receive the service through a referral process from EAAA or they can self-refer.

- This project component was specific to Hancock County. The caregiver is not required to reside within the state of Maine but the care recipient needs to reside within Hancock County.
- There is a fee for service; however, if assistance is needed, the caregiver can complete a financial aid form to gain scholarship funding.
- The fee for services was set at \$60.00 per hour which is billed in 15 minute increments.
- There is a signed agreement with each caregiver for a year but it can end at the caregiver's discretion. If deemed necessary, the caregiver can request ongoing services which would result in the caregiver signing another year contract.
- There is no set standard for contact between the Caregiver Navigator and the caregiver. The time spent supporting the caregiver depends on the caregiver's needs. In some instances there is monthly or quarterly contact but most often there is bimonthly contact.

Outreach/Marketing

In order to access caregivers, the Caregiver Navigator went to hospitals, talked with hospital staff in charge of discharge planning and healthcare providers and made outreach visits to other community organizations in Hancock County. A diverse array of professionals have been educated about these services including social workers, clergy, nurses, doctors, and primary care office staff. Outreach for navigation services should be an on-going activity to ensure that caregivers who are interested and need such services can benefit from them.

Food for Thought/Tips for Those Undertaking Similar Efforts

- Referrals were at times low in Hancock County. The belief among professionals is that people are getting by on their own and hospital staff are providing adequate information and resources to the patients served and their caregivers. Based on informal feedback from caregivers served through this project, this view is not often shared by caregivers, many of whom report receiving fragmented services and information as they navigate the service system.
- Another concern is that providers (potential referral sources) have a preconceived notion that the caregivers are unable to afford the fee for Caregiver Navigator service and therefore they do not offer the information as a resource. This mentality can create service access barriers.
- Alternative funding models for the Caregiver Navigator are possible. When building a budget, programs can examine how this service can be offered at no cost to the

consumer/caregiver or the Navigator fee could be based on income. The cost for services need not be a barrier.

- The value of caregiver navigation services is often misunderstood. Saving caregivers time and knowing how to navigate the system for long-term care support or other needs is of great value and benefit to caregivers. This value is often difficult to communicate to caregivers and explaining the purpose and value of Navigator services is an essential part of doing outreach

Caregiver Steering Committee

A Steering Committee was developed to keep the grant project on track and ensure client input into the project. This steering committee was an integral, pre-planned part of the grant project developed to serve as a guiding body over the three-year course of the grant. Steering committee members included caregivers from Hancock and Washington County. The project partners submitted names/nominations of caregivers whom they felt would be interested and motivated to serve in this component of the project. The caregivers were then contacted individually and invited to join the Steering Committee.



Caregiver Steering Committee

During the first year of the project, the committee was comprised of 12 caregivers who were currently or had recently actively cared for a dependent adult. The committee leadership included a chair and co-chair. The EAAA Project Director served as secretary to the committee and kept the committee engaged and informed. The members were pulled from Hancock County in the first year as intensive project efforts were rolled out in this area of the state first and then subsequently Washington County. Committee members were provided with background, summary, and timeline information that included the three year timeline of the project plan. The committee held monthly meetings, every 2nd Friday of the month, with lunch included. The committee received reminder emails of the upcoming committee meetings, and minutes of the meetings were disseminated.

During the initial six months of the project, several caregivers disengaged from the steering committee. Part of this change was the result of some caregivers' inability to commit to monthly meetings. Additionally, travel from Washington County was a barrier for some caregivers. Travel to the steering committee meeting site located in Hancock County required one hour of travel time which impacted Washington County caregiver availability. Conference calls were attempted but barriers were encountered to utilizing this technology to expand access to meetings. This is a continual challenge in engaging rural caregivers in an advisory capacity.

Steering Committee Oversight

- During the initial six months of the project, Steering Committee members spent time becoming acquainted with the project, learning about service systems and about partnering agencies. As requested by the steering committee members, during each monthly meeting, one community partner presented information about their agency and project component.
- Steering Committee members were provided with information about commonly used assessment tools, approaches, and acronyms used within service delivery so that they could make informed decisions about project activities.
- Any actions taken during the course of the grant were presented to the Steering Committee for review and approval. The Steering Committee provided guidance on both day-to-day logistics of the grant work as well as broader, more strategic activities that revolved around the long-term implications of the project.

The Steering Committee added richness to the project by generating new ideas for supports and activities that could be carried out via the project. The committee created the idea for a “toolkit” project which entailed the development of packets of caregiver information that were distributed to private practices, health centers, and other community-based agencies that come into contact with caregivers and older adults. Within these tool kits, the Steering Committee members provided a list of resources for caregivers to utilize and one of the committee members drafted a letter that was included in the packet “welcoming” the reader to their caregiving journey (See appendix for a copy of this letter and an FAQ booklet developed for this toolkit).

Mini-Grants

Funds were put into the project in the form of mini-grant opportunities in order to attract providers who were not initially a part of the core project partner network. The proposals were presented to the Steering Committee for input. The Steering Committee advised on the mini-grants and asked for a report of the use and outcome of the funds for the grantees.

Through the provider network, a Request for Proposals (RFP) was developed, and the information was sent out via email about mini-grants being offered that would support the development of new strategies or services to enhance caregiver services and wellbeing. The value of the mini-grant process was to develop innovative ways to address caregivers needs (See appendix for a copy of the mini-grant RFP).

Mini-grant awards varied but were generally around \$1,500. Funds were used by hospice and Alzheimer programs and a curriculum was developed titled: *Bereaving on the Installment Plan* at Friendship Cottage and this was part of the seven week directed support group.

Mini-grants were also utilized to support volunteer hospice agencies in Hancock County. Hancock County Homecare and Hospice was provided a mini-grant for the provision of massage therapy for caregivers. Other funds were utilized to educate staff and volunteers about needs of caregivers caring for veterans.

Caregiver Training

Caregiver trainings was an area that was not originally part of the project plan, but rather arose from community conversations that took place during the needs and resources assessments that were carried out in the first year of the project. The specific training areas of need identified by caregivers and community members included basic skills and dementia specific trainings. This area of need was also identified in steering committee meetings.

The trainings were developed to address topics that included: communicating with loved ones diagnosed with dementia; caregiver self-care (medication, diet, exercise, etc.); basic care needs of the care recipient; and resource information for caregivers. In addition to trainings developed under this grant, the SAVVY Caregiver training was offered to caregivers. This training is an evidence-based model which takes place over six weeks and is focused on dementia care. After successful completion of trainings in Hancock County, the training was replicated in the Washington County area. The SAVVY Caregiver Training became more accessible to Washington and Hancock County caregivers after two staff were trained as master trainers and EAAA entered into a contract with the State of Maine to fund this service. As a result, there are four SAVVY Caregiver trainings being offered in Washington and Hancock County.

Eligibility for Training

- The SAVVY Caregiver training is an evidence-based curriculum focused on dementia care. The curriculum is designed to be delivered over the course of six weeks and that curriculum is adhered to closely by master trainers. In addition, there are specific eligibility criteria for participating in this training including that the caregiver has to be someone providing in-home care to a dependent person diagnosed with dementia or a dementia-related condition.
- Basic skills trainings developed specifically under this grant require that the person identify as a caregiver of a dependent adult.

Marketing

- There was extensive marketing with brochures, flyers, and news stints to advertise the trainings available to caregivers (See appendix for sample training brochure).
- In addition, the caregivers attending the trainings were provided satisfaction surveys that included questions about what caregivers would like for future trainings. MSW students were often tapped to assist with surveying caregivers.

- United Way grant funds were relied on to assist with subcontracting with an RN nurse trainer who specialized in training CNAs and the trainer adapted the training to address informal caregiver basic skills training needs. The funds also supported a follow-up training that doubled in participant size as a result of “word by mouth” advertisement.
- The key to increasing participation is to support the caregivers having a positive experience with initial trainings and for this positive experience to be shared with other community member who are caregivers.

To learn more about the Family Caregiver Navigator, Caregiver Steering Committee, mini-grants, and caregiver training: Contact Deb Poulton, Deputy Director, Eastern Area Agency on Aging, dpoulton@eaaa.org, (207) 941-2865.

UNIVERSITY OF MAINE SCHOOL OF SOCIAL WORK

The mission of the University of Maine School of Social Work is to improve the quality of life for all people by promoting excellence in social work practice with systems of all sizes. The school has a long tradition of professional social work education which began in the 1950’s and the Baccalaureate and Master’s programs have been fully accredited by the Council on Social Work Education since 1979 and 1991, respectively. The establishment of a Center on Aging reflects the school’s commitment to adapt to the changing needs of our increasingly aging society.

Weinberg Student Unit



Kara Janes (far left), Weinberg Student Unit intern, participates in a discussion during a caregiver retreat.

A unique student learning unit was developed specifically for this project which was designed to increase long term service capacity within the Washington and Hancock county region. This unit was comprised of undergraduate and graduate social work students with an interest in gerontological practice. The intent of incorporating social work students into this caregiver project was to: 1) Increase the knowledge and skill level of future providers who are likely to work with older adults and their caregivers; 2) Support students interest in pursuing gerontological social work practice in the future; and 3) To support the capacity of small non-profits to engage students in service learning opportunities with older adults and their caregivers.

Gerontological social work is not often an area of high interest among social work students when compared to other fields such as child welfare, substance abuse, and mental health, among others. To address this, stipends were provided to students to create an incentive for them to explore this area as a future career path. In addition to stipend support, additional clinical-level supervision was provided to MSW students as a resource to encourage participation, education, leadership, and professional development. All students involved in the project rotations were provided with additional learning opportunities to strengthen their connection and commitment to the social work field. These opportunities included specialized seminars and workshops as well as networking sessions where students could connect with other social workers in the field. Students were also invited to all project meetings and were provided with the opportunity to share their field work experience with project partners during project meetings.

Sample Student Activities

- Assist with direct service provision at adult day service sites
- Lead support groups
- Co-lead community focus groups for project needs and resources assessments
- Provide administrative support to partnering sites
- Locate resources for caregivers
- Develop outreach materials for caregivers
- Direct service and one-on-one consultation with caregivers
- Plan and assist with delivery of caregiver training and subsequent surveys of caregivers

A total of 15 MSW and undergraduate student interns participated in supporting project activities. Internship placements were developed at Friendship Cottage, Center on Aging, and the Regional Medical Center Lubec (RMCL). These new internship sites will now continue on into the future. Furthermore, the development of student internship opportunities has solidified the School of Social Work's commitment to incorporating caregiver support and service learning opportunities into their field unit for the foreseeable future.

To learn more about the student learning component: Contact Nancy Kelly, Field Director, UMaine School of Social Work, nancy.kelly@umit.maine.edu, 207-581-2378.



Kara Janes, one of the first students to complete a Weinberg Student Unit internship, went on to participate in the Learning by Living program where she voluntarily lived in a nursing home for 10 days and has now gone on to share her experience with professionals and students alike through local and national presentations. Kara has received national and local recognition for involvement in this program as the first social work student to undertake such a field experience.

Photo courtesy of the Bangor Daily News / Gabor Degre.

SUGGESTIONS FOR OVERALL PROJECT IMPLEMENTATION

The following suggestions have been provided by project stakeholders (providers and Caregiver Steering Committee members) to those who wish to undertake a project model similar to the Rural Caregiver Network Project:

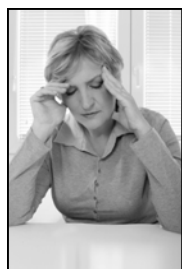
Building Relationships

- “Have regular meetings with partners to keep them in on the activities of one another and of the interactions with the grantor. Have a steering committee and get as many caregivers on that committee as possible. Provide respite during meetings for caregivers to participate.”
- “To use a collaborative process with many different agencies and people, maybe groups who you do not think are natural partners.
- “In rural areas, you need more funding for transportation for collaboration and visits.”
- “Take the time to build community support.”

- “Get health providers on board and with a buy-in early on as partners. Assure that partners have very clear and detailed MOU's in place and that reports capture progress prior to distribution of funds.”
- “During this grant year, we have experienced a significant growth in health providers hiring their own geriatric care managers as a response to the Affordable Healthcare Act. In some ways, this has seemingly hindered the sharing of referrals as they are all trying to build their own niche within.” This is an area for future collaboration and outreach.

Project Implementation and Sustainability

- When you have diverse partners at the table you run the risk of creating “silos” which can inhibit your project implementation/a sense of cohesion.
- “Over-recruit for Steering Committee advisory members, as caregivers are very stretched and it is difficult to sustain their involvement throughout a long period”
- Look closely at the availability of broadband internet in rural areas before incorporating new technology. This was a challenge for the Rural Caregiver Network Project
- Investigate alternative sources of project funding early on in the process. There is an expectation among the public that services will be free and on-going
- The role of the social model of adult day service, particularly with limited availability, does not attract consumers and does not appear to meet the needs of the community



PARTNERSHIPS...



... make for happy caregivers



Project Showcase: Developing a Rural Based Caregiver Network and Support Systems

Caring for and keeping a loved at home takes great strength and stamina. The demands are high while the resources in a rural setting can be difficult to locate and to access. Through the generous funding of the Harry and Jeanette Weinberg Foundation, a committed group of partner agencies are tackling the many aspects of these rural challenges by:

Gaining an understanding of the desires of caregivers in the region with the objective of designing services that truly respond to the wants and needs expressed by caregivers.

Increasing the availability and affordability of adult day services across the region.

Providing alternative respite services for caregivers.

Provide access to personalized help through care management services for caregivers.

Using various media to make caregiving a household term and help caregivers self-identify earlier in the journey.

Expanding on the educational, training and support program opportunities.

What we are doing for caregivers:

Caregiver supports available by telephone, in person, with families or in support groups.

Affordable respite opportunities in the home and in a medical adult day program.

Services of a caregiver navigator offers comprehensive assessment and service planning for caregivers and families.

Training opportunities for caregivers to learn new skills in both caregiving and in caring for themselves.

Ongoing caregiver surveys to further assess caregivers needs and the burden they are feeling.

PARTNERS

Eastern Area Agency on Aging: lead, facilitate, coordinate and management steering and advisory committees, finances, Navigator position and coordinate media efforts to increase awareness of caregiving role. Manage “mini-grants” to other partners to expand on caregiver resources.

University of Maine Center on Aging: conducts needs assessment and project evaluation

University of Maine Cooperative Extension Senior Companion Program: provides volunteer in-home respite services.

University of Maine School of Social Work: provides learning support of graduate level students in various caregiver experiences to further enhance interest in the field.

Regional Medical Center at Lubec: provides health center location for the development of a Caregiver Navigator for Washington County.

Rosscare: develops curriculum for caregivers including health risk assessments, wellness strategies and provides clinical oversight of Caregiver Navigator.

Washington Hancock Comm. Agency (Friendship Cottage): provides advocate position to extend caregiver services and resources in Friendship Cottage and community and manage respite subsidy fund.

Eastern Area Agency on Aging, 450 Essex St, Bangor, ME 04401

Community Caregiver Advocate Job Description

**Washington Hancock Community Agency
Job Description**

Job Title: Community Caregiver Advocate
Division: Friendship Cottage
FSLA Status: Non-exempt
Supervisor: Program Site Manager
Position Supervises: None
Mandated Reporter: Yes
VDT Operator: No
Worksite: Blue Hill
Hours Per Week: Part Time
Work Hours: As scheduled
Days Per Week: As scheduled

Summary: Position will advocate for caregivers, assessing their needs and helping them identify and obtain access to local resources.

Essential Duties and Responsibilities include the following. Other duties may be assigned.

- Advocates for caregivers
- Connects caregivers with local resources
- Facilitates support groups when necessary
- Coordinates education programs
- Organizes caregiver retreats
- Helps organize medical and other transportation
- Arrange for private or volunteer in-home respite
- Assists in publication of Friendship Cottage newsletter
- Updates website content as required

Qualifications

- LSW preferred
- Valid Maine driver's license

Required education/training:

Preferred education/training:

Required skills/abilities:

- Computer skills
- Written and verbal communication skills
- Organizational skills
- Marketing skills
- Excellent interpersonal skills are required

Work Environment: Work environment is an Adult Day service facility. Travel throughout Hancock County.

Respite Fund Application Form

Weinberg Respite Fund Application

Date of Application: _____

Name of Adult Day Service Program: _____

Program Site Manager: _____

Participant ID# _____ Payment Source: _____

Date of Respite: _____ Requested Hours: _____

Location of Respite: _____ ADSP _____ In Home

Name of In Home Caregiver: _____

Explanation of why respite hours are needed: _____

TO BE COMPLETED BY FRIENDSHIP COTTAGE STAFF

_____ APPROVED _____ DENIED - Reason Denied _____

Total Monthly Respite Hours: _____ Total Yearly Respite Hours: _____

Signature of Friendship Cottage Staff

Date

Caregiver Outreach Materials



Are you a Caregiver?

Caring for an aging loved one can be stressful, regardless of the fact that it is done out of love and respect. After all, they cared for you now you are caring for them. Or maybe you are caring for an aging spouse, elderly friend or neighbor.

Just what is a caregiver? Look at the following questions. If you answer YES to any of them, you are a caregiver.

- Do you take care of a loved one at home?
- Do you grocery shop for a friend/loved one?
- Do you take others to their doctor's appointments?
- Do you help an older person manage finances?
- Are you overwhelmed by all your responsibilities?
- Do you manage someone else's medications?

Caregiving is not easy but the most important thing to remember is that you don't have to do alone.



Call Karen Quirk,
Family Care Coordinator at EAAA
733-1090 ext. 2181

Caregiver Self Assessment

Caregivers are often so concerned with caring for the needs of those they are helping that they lose sight of their own well-being. If you are assisting someone on a regular basis with a chronic health condition, please take just a moment to answer the following:

Have you often...

Felt that you couldn't leave the person you care for alone..... Yes ☐ No ☐

Felt completely overwhelmed with the responsibilities you have .. Yes ☐ No ☐

Felt a loss of privacy and/or personal time due to your caregiving responsibilities..... Yes ☐ No ☐

Been edgy or irritable..... Yes ☐ No ☐

Had sleep disturbed because of your caregiving responsibilities.. Yes ☐ No ☐

Had crying spells..... Yes ☐ No ☐

Felt strained between work and family responsibilities..... Yes ☐ No ☐

Had health problems that are taking a toll on you mentally or physically..... Yes ☐ No ☐

If you checked YES to any of the above, you may be at risk for health problems. Here are some next steps you should consider:

- Consider seeing a doctor for a check-up for yourself
- Consider joining a support group for caregivers*
- Consider having some relief from caregiving*



***For more information on help for Caregivers,
please contact:
Eastern Area Agency on Aging
at 1-800-432-7812**



The Harry and Jeanette Weinberg Foundation, Inc

Caregiver Packet Materials

Greetings,

The information in this packet is an attempt to support you on your caregiver journey.

There are many agencies, organizations, programs, support groups, and individuals who may be able to help support you in the care of your loved one. In this packet you will find information that will connect you to the Family Caregiver Program at Eastern Area Agency on Aging, resource lists, manuals, support groups, and a brief overview of information you may need in the future.

I, like you, walked away from a doctor's appointment years ago and wondered, "Now what?" Taking care of someone is a daunting task. I tried my best to research the diagnosis, the medications, the financial implications, and the long term prognosis. Everyday I had a different question or a new worry.

I encourage you to begin seeking assistance as soon as possible. Letting others into your life is a challenge, but the world starts to reveal interesting and supportive connections.

This journey is about YOU and your loved one. You will be told many times to take care of yourself. If you don't, who else will run the show?

I wish you well.

Sincerely,

Claire EB Cullinane

Surry, Maine

Steering Committee of the Eastern Area on Aging Caregiver Project sponsored by The Weinburg Foundation

Eastern Area Agency on Aging

Mission

Eastern Area Agency on Aging is the best source of information, options and services for seniors, adults with disabilities and caregivers, serving Hancock, Piscataquis Penobscot and Washington counties.



Frequently Asked Questions by New Caregivers

EASTERN AREA AGENCY ON AGING

450 ESSEX ST.,

BANGOR, ME 04401

941-2865

1-800-432-7812

TTY: 992-0115



*This booklet is meant as an overview only.
Please contact specific agencies for up-to-date
details and availability of services, income
guidelines, etc.*

Getting Started/Contacts:

Q: Where do I begin to gather information?

A: For all types of caregiver support, contact: **Eastern Area Agency on Aging by phone: 1-800-432-7812 or www.eaaa.org**

They will help you prioritize and organize your concerns as well as educate you on specific information regarding your individual situation.

You can also call 2-1-1 or search the web for 2-1-1 Maine for more resources.

- For health care specific information, talk candidly with physicians.
- For questions about MaineCare, or Long Term Care MaineCare, contact:
- **Department of Health and Human Services directly: 800-432-7823**
- Legal questions? Contact:
An Elder law Attorney, or
Legal Services for the Elderly at: 1-800-750-5353.

This would include information on Advanced Directives, Living Wills, and Power of Attorney

- Medicare/prescription drug questions: Eastern Area Agency on Aging.
- Concerned about abuse, neglect or exploitation of an elder or an adult with a disability?
Call Adult Protective Services intake at: 1-800-624-8404
- For information about applying for Social Security Disability call:
- **The Social Security Administration: 1-877-405-1448**
- Resources for Adults with Disabilities:
Alpha One 941-6553

Q: How do I find a list of local Residential Care and Adult Family Care Homes?

A: Go to the **Office of Elder Services website at <http://www.maine.gov/dhhs/oes/>** On the left, go to OES online services and click on Assisted Living Facilities. You will find all sorts of interesting information on this website in regard to eldercare services.

- **Hospice:** The care is Palliative in nature, focusing not on treatment of a terminal illness, but on comfort. Hospice offers a team oriented approach that addresses the medical, physical, social, emotional and spiritual needs of the patient. Services can be offered in-home, in a hospital or in a Nursing Facility.

You can also contact:

Hospice Volunteers of Hancock County: 667-2531 for free non-medical support and comfort and bereavement care.

Caregiver Support Services:

Q: Why would I want to go to a support or education group?

A: Support and education groups provide caregivers the opportunity to meet people who are experiencing the same types of questions that you may be.

Support groups give the members time to share ideas, experiences, and thoughts with others who truly understand. They are generally free of charge, confidential, and available throughout Hancock County.

Veterans Services:

Contact Community Liaison Mike Perkins:

255-3306 for information on what services may be available and for help with applications.

Housing Services/Options:

Q: What is the difference between Assisted Living and Nursing Home Care?

A: An assisted living community provides communal living, housekeeping, laundry, meals, exercise and wellness programs, opportunities to socialize with other residents, and assistance with activities of daily living (ADLs) like bathing and dressing.

Adult Family Care Homes are smaller types of Assisted Living Facilities that are in home-like settings and have fewer residents.

In a nursing home residents are under the 24-hour care of licensed or registered nursing staff (in a skilled nursing facility) or certified nursing assistants (in an intermediate care facility).

Q: How do I research the credibility of local Nursing Facilities?

A: Go to www.medicare.gov on the Resource Locator Button, choose, Nursing Home, and follow the directions there to compare facilities and get reports from current state conducted surveys.

Services / Options:

Q: Who is responsible for setting up services for the person that I care for?

A: If the person is in a hospital, or other facility, there are staff members, often social workers and/or nurses who help coordinate in-home care if it is necessary.

It is important to connect with that staff to get specific questions answered, share any concerns and advocate for the person that you care for.

If the person in the home requires some practical care assistance, share your concerns with the physician. Skilled services may be possible or a Goold assessment may be in order.

Homecare Services:

Q: What is a MED (Goold) Assessment?

A: Goold Health Systems does a MED assessment (often referred to as a Goold assessment) for the elderly and other consumers who are seeking home care services, including disabled adults who want to live independently.

The assessment is done free of charge for people who are in immediate need of services. When possible Goold will also assess people who just want to know what services are available and affordable. **There is no charge, and the assessment is confidential. Call them, toll free, at 1-800-609-7893.**

After the assessment a referral will be made to Elder Independence of Maine (EIM). EIM is a statewide agency that coordinates home care services for clients. They will contact you and your providers to coordinate your care.

Q: How is homecare secured and paid for?

A: There are four (4) ways to access in-home care in Maine.

1. Skilled care: Doctor ordered, Medicare paid, short term rehabilitative services (physical therapy, home health, oxygen therapy)

2. MaineCare Waiver: (under \$10,000 in liquid assets)
A Goold Assessment is required for both:

A. Nursing Home Level of care - needing assistance with bathing, dressing, grooming, transferring out of a chair/bed, cognitive impairment is also considered.

B. Long Term Care - financial eligibility: the person being assessed must have less than \$10,000 in assets listed in their name. Must talk with DHHS about all of the particulars, and file a Long Term Care MaineCare application.

3. MED Assessment for Home Based Care Services:
for those who have assets between \$10,000-\$50,000 (\$75,000 for couple). Needs include assistance with bathing and grooming.

4. Private pay or with Private Long Term Care Insurance: State Guidelines - Liquid Assets in excess of \$50,000 for a single person and \$75,000 for a married couple require private payment of in-home care if the care is not "skilled".

Transportation Services:

- **Washington Hancock Community Agency (1-877-374-8396)** - For MaineCare recipients who need rides to medical appointments.
- **Faith in Action Community Connections (664-60165)** - Volunteer driving program that covers Hancock County. Rides can be medical or social in nature, FIA can also offer some visiting, light housework, and errand services as well.

Downeast Transportation (667-5796) - Offers accessible bus services on an established route throughout Hancock County for a minimal fee.

Alzheimer's/Dementia Services:

- Alzheimer's 24 hour support:
Maine Alzheimer's Association 1-800-660-2871
- Local Alzheimer's education, support and respite services: **Eastern Area Agency on Aging 1-800-432-7812**
- **Respite:** Defined as a break for caregivers of people with a dementia diagnosis. EAAA offers a respite program called *Partners in Caring* that may provide some funding to help to pay for respite time for eligible families, including those who are receiving services from Medicare Hospice and Veteran's Services.

Other Services:

- **Private Case Managers** are available at a cost. You can access by calling EAAA.
- **Homemaking** (housekeeping, laundry, etc)

Call Catholic Charities at: 1-888-477-2263 for more information. If a person receives skilled care, some homemaking may be part of the care plan. Homemaking can also be purchased privately and there are several Homecare Agencies listed in the local phone book.

Meals on Wheels - Available for a person who is homebound, unable to cook for themselves, or does not have a person to cook for them. An assessment will be completed and services coordinated by Eastern Area Agency on Aging.

The Senior Companion Program: Offers free visiting services and help to homebound elders to maximize, maintain, and regain their independence.

Call 1-800-287-0274 for more information.

Mini-Grant RFP



The Harry and Jeanette Weinberg Foundation, Inc.

SEEKING PROPOSALS

On behalf of the Weinberg steering committee, the Eastern Area Agency on Aging is pleased to make grant funds available to qualified organizations/groups that care about Caregivers.

Through our Weinberg initiative, \$15,000 is being made available to fund up to five Hancock and Washington County community providers interested in enhancing the lives of Family Caregivers, especially in the areas of education, training or resource expansion.

Funds may be used in collaboration with other agencies to develop and deliver workshops and/or special presentations for caregivers in the Hancock and Washington county regions.

A brief description (one page) summary of the proposed plan, timeframe, partners and requested amount of funds and budget should be submitted to Deb Poulton, Facilitator, Weinberg Steering Committee by July 1, 2011 for Committee review.

Preference in selection will be given to collaborative proposals. Additional questions or proposals should be directed to:

Weinberg Steering Committee
C/O Deborah Poulton

Eastern Area Agency on Aging
450 Essex Street
Bangor, Maine 04401

Tel. 992-0129 or dpoulton@eaaa.org



Sample Training Brochure

You want to be the best caregiver you can be. We want to help. This seminar can provide the "best of the best" in resources.

Register today!

Participants will gain skills and confidence in providing at-home care to a loved one

Caregivers will feel more confident about leaving a loved one with a volunteer in order to take a needed break.



Call us!

We can help you
with your caregiving experience
664-6016

Reserve your spot by March 30,
by calling:
Friends in Action
664-6016
OR
fia@gwi.net

Caregiver participants can be reimbursed a stipend for the care of their loved one, as well as mileage reimbursement.

For more information on this,
please call
Janet Lewis,
Eastern Area Agency on Aging
1-800-432-7812

Project is funded by grants through United Way, Weinberg Foundation and the collaborative efforts of EAAA and Friends in Action.



Basic Training for **PRACTICAL CAREGIVING** Spring Session

Don't miss this
FREE workshop!

WHEN

Saturday, April 9, 2011
8:30 - 3:00

WHERE

Friends in Action
SENIOR CENTER
125 State St.
Ellsworth

This **FREE** training is designed and continued for the fall session for caregivers in Hancock County *and* for volunteers who provide support and respite to caregivers.

Resource materials, massage and more...

Respite and mileage reimbursement available for caregiver trainees

Welcome

8:00 a.m. - 8:30 a.m.

*Registration & Coffee
Adaptive Equipment & Resource
Materials Exhibit*

9:00 a.m. - noon

Practical Caregiver Skills

This session is limited

Building upon the skills taught in the session I, this 3 hour session will give you an overview of the most common medications used by those with chronic diseases and those with Alzheimer's/ Dementia and how to manage these on their behalf. Time will also be allowed to share best practices and to answer questions specific to your individual needs.

Presented by Kim Sewall, RN and certified Personal Support Services (PSS) trainer who will present skills training and demonstrations on basic care, as well as how to help with medication management.

12:00 -12:30: *Enjoy a delicious buffet lunch, which is provided*

12:30 -1:30: *Join a panel discussion
Hear from a panel of experts and ask questions on topics of long term care, advance directives, personal care, communication and working with challenging behaviors.*

Afternoon Sessions: 1:00 - 3 p.m.
Choose (2) two

Creative Communication Skills

Effective communication is the key to connecting in a positive way with others to make them feel understood, valued and loved. We communicate with persons with dementia throughout the disease process, even after the ability to understand and express oneself verbally ends.

Presented by Kristie Miner , who is the dementia program director at Westgate Manor, is a volunteer with the Alzheimer's Association.

Long Term Care Planning & Resources

Information, discussion and handouts provided in this session will help you to plan for the long-term care of your loved one, give you the real story on what benefits and options exist, and how to navigate the system successfully.

Presented by Janet Lewis, LSW, Caregiver Specialist at Easter Area Agency on Aging.

Legal and financial issues related to Caregiving

Learn the differences between guardianship, Power of Attorney and how make plans for the future needs of your loved one

Presented by Julie Mallett, who is an attorney with Legal Services for the Elderly. LSE represents elderly clients in MaineCare appeals, nursing home discharge cases, exploitation litigation, and assists clients with powers of attorney/advance directives.

Hands-on skills (repeat from fall session)

Are you taking care of a loved one at home? Do you have little or no medical training and wish you could have your questions answered?

In this session Kim Sewall will delve into the many hands on skills you need to know to help you care for your loved one. This is a must do for those who missed the fall session!

Just for You THE VOLUNTEER

Volunteers and friends wanting to learn more about how to help out caregivers are encouraged to attend this afternoon session.

Jo Cooper, Executive Director of Friends in Action will be available to share opportunity and skills especially for you.



Reserve your spot by
March 30!
CALL
Friends in Action
664-6016
OR e-mail
fia@gwi.net