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Hancock County Community and Caregiver Needs Assessment Summary of Findings

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**Hancock County Community and
Caregiver Needs Assessment
Summary of Findings**



August 2010

University of Maine Center on Aging

**Prepared for the Caregiver Network Project Partners in
Hancock County**

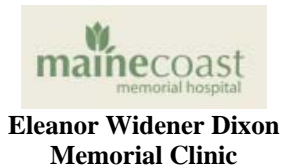
Harry and Jeanette Weinberg Foundation grant# 10200



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We thank as well the following grant project partners who extended assistance through the provider network established by the Weinberg Foundation grant:

- Rosscare-Eastern Maine Healthcare Affiliate
- Washington Hancock Community Agency
- Healthy Peninsula
- Hospice of Hancock County
- Bucksport Bay Healthy Communities Coalition
- Regional Health Center at Lubec

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Overview and Context



The needs assessment work detailed in this report was conducted by the UMaine Center on Aging in the spring and early summer of 2010 as part of the Caregiver Network Project administered by Eastern Area Agency on Aging with funding from the Harry and Jeannette Weinberg Foundation. The University of Maine Center on Aging undertook a needs and resources assessment of the Hancock county region which will serve to inform the services and supports provided through this grant-funded project. The Center surveyed and held focus groups with various stakeholders including caregivers, professionals, and community members in the region to learn about services used and needed by caregivers. The Center created data collection tools that help to shed light on the principles of rural practice that are most appealing to and maximize access for caregivers. The Center has used research findings to identify formal and informal resources that caregivers turn to within the community with the aim of delineating and mapping the natural assets already available in the region that can further enhance the work of the formal provider network (see attachments). In addition, these findings will serve to inform the work completed by the Caregiver Advocate at Friendship Cottage and the newly established Caregiver Navigator position at Eastern Area Agency on Aging. An additional aim of this study was to identify opportunities for future efforts and initiatives that can be undertaken in the region to support caregivers.

Part 1: Hancock County Needs Assessment Survey

Survey Findings Summary

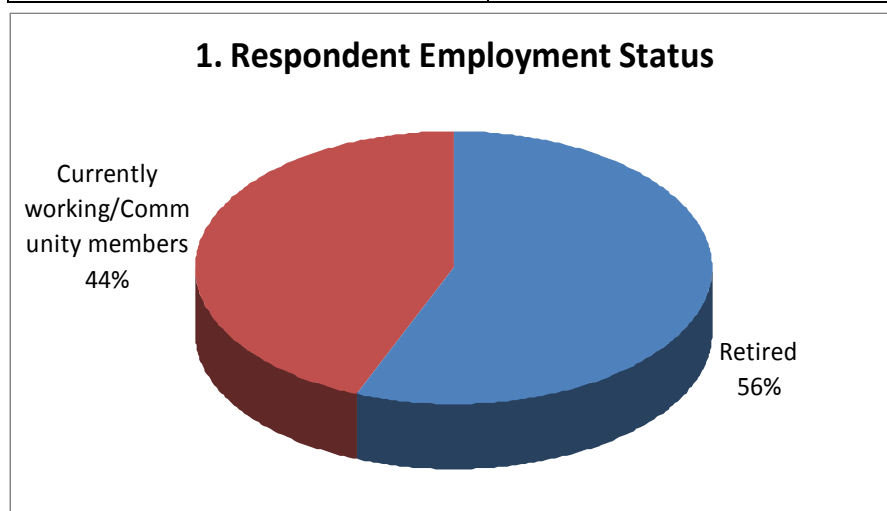
The Hancock County Needs Assessment Survey was designed to elicit information from community members, caregivers, and professionals in Hancock County regarding their knowledge of services and community supports available to caregivers of older individuals, as well as their perceptions of the strengths and deficiencies of these services and supports. There were a total of fifty survey respondents. Respondents were a mix of retirees, as well as individuals that are currently employed in diverse professions ranging from accounting, to nursing, and beyond. Just over three quarters of survey respondents are currently, or have been, care providers for a family member, neighbor, or friend. Individuals surveyed worked and/or lived in 25 communities in Hancock County. Individual perceptions about the availability, strengths, and deficiencies of services for caregivers were diverse, but a number of overarching themes presented themselves:

- Numerous agencies and organizations appear to be well known, including, but not limited to: Friendship Cottage, Bucksport Bay Friends, Eastern Area Agency on Aging, and Bucksport Bay Healthy Communities.
- Respondents felt that missing elements of support for caregivers include a lack of individuals who are willing to listen to caregiver concerns, as well as to provide guidance towards identifying and obtaining useful resources. Compensation for providing care, affordable services, and adequate numbers of professional caregivers were also discussed as service resources that are lacking.
- Obstacles to supporting caregivers locally include doubts about trustworthiness and dependability of care workers, nonexistent or poorly advertised services, a lack of transportation options, and problematic regulations surrounding service eligibility.
- Respondents stated that improved support for caregivers would involve providing more programs and services that are convenient and accessible. Other suggestions included the need to better publicize the existence of programs and services, as well as to foster a culture where acceptance of these services is normal. Finally, respondents noted the importance of advocating for caregivers, as well as raising awareness about the challenges they face.
- Challenges to caregivers viewed as unique to these communities involved a lack of transportation, income inequality and poverty, as well as isolation.
- Potential resources for caregivers viewed as unique to these communities included a culture of volunteerism and support, as well as already existing programs.
- Respondents would like to see more workshops and training related to issues surrounding medications, personal care, dementia and Alzheimer's disease, other medical conditions, diets and nutrition, as well as caregiver self-care.

Please note: The following data present direct quotations from survey respondents, as well as paraphrasing and summaries from researchers.

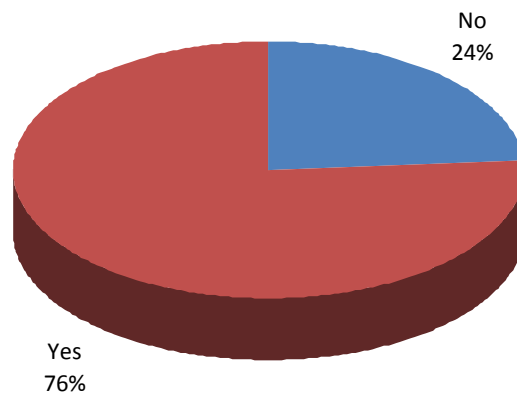
1. What is your position or job title? If you are a community member or retired, please let us know here.

Response	%
Retired	56%
Currently working/Community members Examples in this category include: <ul style="list-style-type: none"> ▪ Paid Caregiver/PCA/Home Health Aid/CNA (6 people) ▪ Activities Director/Coordinator (2 people) ▪ Accountant ▪ Administrative Assistant ▪ Healthcare Provider ▪ Social Worker ▪ Nurse Practitioner ▪ Sales Manager ▪ Translator ▪ Reverend 	44%



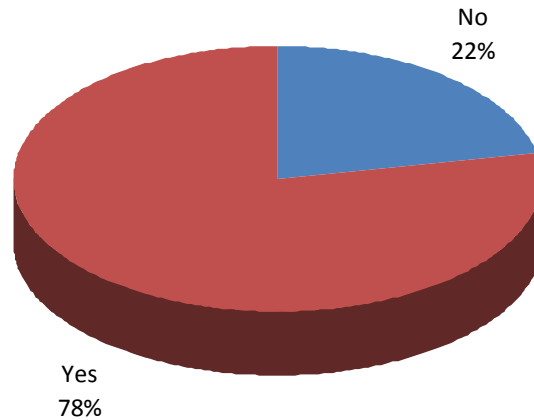
2. Are you currently providing care and support for a family member, friend, or neighbor?

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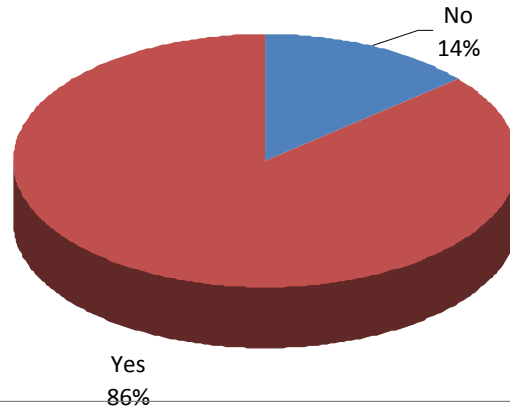
3. Have you provided care and support for a family member, friend, or neighbor in the past?

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4. Do you know of other people in your community who are caregivers for a family member, friend, or neighbor?

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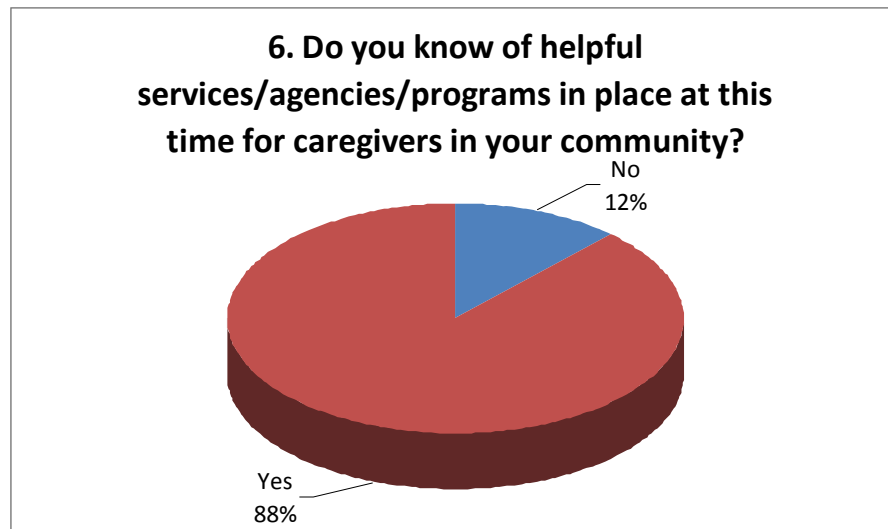


5. In which of these Hancock County communities do you work or live? (Please check all that apply)

Town	# of responses
Bucksport	12
Ellsworth	9
Blue Hill	8
Surry	7
Hancock	6
Brooksville	4
Orland	4
Bar Harbor	3
Penobscot	3
Franklin	2
Lamoine	2
Stonington	2
Verona	2
Brooklin	1
Castine	1
Dedham	1
Deer Isle	1
Eastbrook	1
Sedgwick	1
Sorrento	1
Sullivan	1
Tremont	1
Trenton	1

Waltham	1
Cherryfield	1

6. Do you know of helpful services/agencies/programs in place at this time for caregivers in your community?



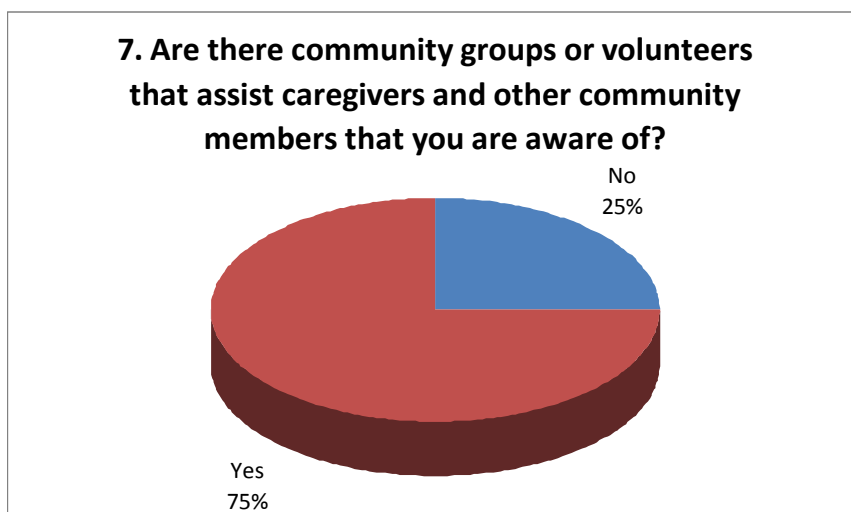
Agencies, organizations, groups, and individuals that were identified specifically as helpful resources:

Sample Responses:

- Brooksville Friends and Neighbors
- Bucksport Bay Friends
- Eastern Area Agency on Aging
- Hospice of Hancock County
- Friendship Cottage
- Robert and Mary's Place
- Bucksport Bay Healthy Communities
- Senior Resource Subcommittee (Bucksport)
- Community Action Resource Exchange
- Faith in Action
- Community Connection
- Partners in Caring (PIC)
- Straus Center
- Meals for ME
- Everybody Eats-St. Dunstan's Episcopal Church
- Sally Smith, MDI Hospital
- Hancock County Homecare and Hospice
- UMaine Center on Aging
- Support groups in the Blue Hill area
- Washington Hancock Community Agency (WHCA)
- BAHHR

- Alzheimer's Association
- CARE
- Home Health
- Terri Lampher
- NeighborCare
- Senior Center
- Caregiver support group at Ellsworth Library
- Janet Lewis
- Terrie Perrine
- Community Health and Counseling Services
- New Hope Hospice
- Hospice of Eastern Maine
- Healthy Island Project
- My Friend's Place

7. Are there community groups or volunteers that assist caregivers and other community members that you are aware of?



Community groups/volunteers mentioned:

Sample Responses:

- Alzheimer's disease group in Southwest Harbor
- Bucksport Community Concerns
- Ellsworth support group
- Faith in Action
- NeighborCare
- Hancock County HomeCare and Hospice
- BAHHR
- Hospice of Hancock County
- Caring Hearts Bereavement
- NeighborCare
- Partners in Caring

- Senior Companions
- CARE
- Bucksport Bay Friends
- Friendship Cottage
- Robert and Mary's Place
- Ellsworth Library (caregivers support group)
- Bucksport Bay Healthy Communities
- Community Connection
- Island Connections
- Healthy Island Project
- Washington Hancock Community Agency (WHCA)
- Meals for ME
- Neighbors Helping Neighbors

8. What do you feel is missing that would be valuable to caregivers in your community?

Themes:

Listening and guidance: Those surveyed highlighted the importance of being listened to by social service providers, as well as the value of having an individual to guide them through the network of agencies that can serve as resources for caregivers.

Financial concerns: A lack of compensation for caregiving, no paid leave time for caregiving duties, and the prohibitively expensive nature of private caregiving services were acknowledged by survey respondents as being problematic.

Staffing shortages: An individual noted that there is a current lack of Personal Care Attendants, PSS services, and certified homecare providers, resulting in staffing shortages and wait lists for those qualified to receive these services.

Other issues raised:

- More emphasis from physicians on providing referrals to social service programs for caregivers.
- Programs that would provide home improvement services, such as carpentry, to caregivers.

Sample Responses:

- "A human being that could "listen" and lead and guide to other agencies."
- "A team of carpenters to come in and build better spaces."
- "Need PCA [Personal Care Attendant] or PSS services. Many people would qualify for this service but are on a waiting list."
- "The biggest hurdle is getting providers to refer patients to available programs."

9. Do you notice any specific obstacles that could get in the way of providing support to caregivers locally?

Themes:

Financial: Financial concerns are a major theme when considering obstacles to providing local support to caregivers. One respondent stated that “low income seniors can’t afford to hire help.” Financing was noted to be a problem in general, and specifically in areas such as providing respite care.

Trust and dependability: Several respondents highlighted trust and dependability as being concerns when utilizing caregivers.

Lacking information/awareness of resources: Several of the respondents stated that they have difficulty identifying caregiver resources. One individual noted: “now that I have the need [for services] I still am not aware of what is available for me.” Another states that there is a “need to find good ways to identify and inform those in need of services of what is available.”

Shortage of resources: Among resources that respondents felt were in short supply were support groups (for males in particular), “education in the real life of caregiving”, weekend workshops, respite care, transportation, and a “clearinghouse or case manager.” One respondent highlighted a lack of help for “errands, simple shopping, meals,” as well as personal care assistance.

Poor transportation options: A third of the individuals responding to this question stated that a lack of transportation and large distances required to get to services are obstacles to getting help.

Regulation: Two respondents had concerns related to program policies and regulations. The first individual stated one problem as being that “Long term care insurance requires certified local homecare providers.” Another individual stated “red tape” as being an issue.

Other issues raised:

- Reluctance by caregivers to utilize resources
- Some caregivers still work, so they cannot attend trainings during the week.
- Indifference
- Stigma attached to Alzheimer’s disease and related disorders

Sample Responses:

- “As many other services...lack of money.”
- “It’s hard to find dependable people to come into the home and help.”
- “Failure to know what’s available.”
- “Transportation!”

10. In your opinion, what can social workers, healthcare providers, politicians, etc. do in helping to provide support for caregivers?

Themes

Accessibility and flexibility: Among suggestions for professionals to help provide support for caregivers, survey respondents stressed the importance of accessibility and flexibility in the

provision of services. One respondent stated the desire for “support groups at convenient times for a working individual.” Another expressed the importance of “resources that are easily accessible.”

Normalizing the use of social services: Several respondents stated that caregivers can be reluctant to utilize available resources for various reasons. One individual highlighted the need to “Encourage caregivers to talk more openly to help remove stigma from conditions that require caregiving, to ease up on the pride of asking for help or support.” Another respondent stated that despite the availability of programs, “many caregivers think they have to do it all themselves.” To address this, the individual suggested ensuring one home visit to discuss available resources with caregivers.

Provide information, and do so in diverse ways: Various respondents stated the importance of being provided with correct information from well-trained professionals. One person surveyed stated that there is a need to “...get physicians more knowledgeable of services and medications.” Another individual stated that health care providers should impart greater information related to medicine side effects. In regard to disseminating information, one respondent stated that professionals should “Get important info to us, where we can go for help. Not everyone including myself have e-mail or computer. I rely on TV, sometimes newspaper, or hear it from a friend, would be nice to have it come in the mail or leave copies at the library or town house.”

Advocate and raise awareness: One theme from question ten deals with the role of politicians, as well as social service professionals, in advocating and raising awareness about the needs of caregivers. Among suggestions of those surveyed, were “pass legislation for better pay for healthcare providers,” having “medical benefits provided as compensation,” and having “politicians campaigning for monetary aid in care for those who need it.”

New programs and services: Survey respondents discussed a wealth of programs and services that they would like to see, including: help with gas money, better services for individuals with dementia such as opportunities for social contact, support groups, workshops, subsidized respite services, “economic relief for those who reduce work hours to be caregivers,” transportation for care recipients, and “in house items that make taking care of elderly easier.” Closely related to these issues was a desire by several respondents to avoid having current programs receive funding cuts.

Other issues raised:

- More support for volunteers.
- Listen to the concerns of caregivers to identify and address challenges and needs.
- Encourage better coordination between service providers.
- Making sure that professional caregivers are dependable.
- Provide support to allow for aging in the home instead of in a nursing home.
- Increase funding for services such as Hancock County Home Care and Friendship Cottage.

Sample Responses:

- “Advocate! Flood the state with requests and let the agencies know how great the need really is.”
- “Be informed and hear their voice.”
- “Provide quality services that are flexible and available.”
- “Finding ways to increase acceptance of using available services. Too often people are reluctant to use support services.”
- “Politicians can recognize the value of caring for elders in their homes or caregivers’ homes and provide financial support similar to what is available to nursing homes.”

11. Are there any special circumstances or conditions that you consider unique to your community that may create particular challenges to caregivers?

Themes:

Distance to services/lack of transportation: One of the most prevalent themes in responses to question eleven dealt with the challenges for caregivers stemming from long distances required to travel to social services, as well as poor or non-existent transportation. Among the transportation challenges highlighted by respondents were: “distance to services,” “transportation in the winter,” “lack of transportation to programs,” and “large distances to be covered for medical appointments.”

Isolation: Several respondents discussed isolation as being a challenge to caregivers. Among examples, individuals surveyed responded that “isolation,” “isolation and rural setting,” and a belief that “neighboring is a thing of the past.”

Poverty and income inequality: Another theme of survey responses for question eleven dealt with issues of poverty and income inequality. One respondent cited the “significant near-poverty of care consumers,” while another mentioned that “Washington County is a poorer county.” In terms of income inequality and perceptions of wealth, one individual stated that “there is also the dichotomy between economic classes as with the comfortable to well-off retirees living next to the struggling fishermen and loggers.”

Other issues raised:

- Caregivers are often reluctant to seek out services.
- The current economy is straining the resources of programs.
- Volunteers are “stretched in too many directions.”
- A lack of available assisted living programs or facilities
- “Our healthcare providers do not refer to local resources.”
- Lack of acknowledgement from communities regarding caregiving challenges.
- “Lack of knowledge of non-professional caregivers.”
- Shortage of trained, competent, professional caregivers.
- “Our community is in my opinion very 'clicky' and would rather see this problem be in another community.”

Sample Responses:

- “Poverty.”

- “The misconception that living in this specific community (Bar Harbor) means you have money.”
- “The rural nature of Downeast Maine – far distances between family & friends and/or services; severe winter conditions; shaky economic security.”
- “Transportation is always difficult.”

12. Are there any special circumstances or conditions in your community that you think may be particularly helpful to caregivers?

Themes:

Culture of volunteerism and support: Various respondents to question twelve highlighted existing volunteers, as well as a pool of untapped volunteers, as being an asset that may be helpful to caregivers. One respondent stated “Great volunteer community” as being one asset; while another individual stated that “many community members are already inclined towards neighbor to neighbor support.” One individual surveyed highlighted “the availability of a healthy older group that might have more volunteer time.”

Existing programs: Many respondents expressed the value of current programs in their communities as being beneficial to caregivers and those receiving care. Among organizations mentioned were: Bucksport Bay Healthy Communities, Friendship Cottage, Bagaduce Area Health Resources, Bucksport Bay Friends, Senior Resource Committee, CARE, BCC, and Senior Companions.

Other helpful factors raised:

- “Prayer”
- Caregivers and care recipients “are welcome and treated well at activities at senior center and church.”
- The availability of some transit options.

Sample Responses:

- “Close knit community.”
- “A small town environment would be good to offer more resources for caregivers including workshops and information.”
- “Growing interest in helping families keep their frail elderly at home.”
- “People are caring and would be more forthcoming if they realized the need.”

13. Do you know of any trainings or workshops offered in your area for caregivers?

- Elm St. Congregational Church – caregiver focus group.
- Hospice of Hancock County – caregiver training sessions.
- Friendship Cottage – caregiver support group, resource center, Savvy Caregivers course.
- Bucksport Bay Friends – Best Friends Training, focus groups, one-on-one meetings with staff, Matter of Balance program, Living Well with Chronic Illness workshops.
- Ellsworth Library – Caregiver’s Support Group.
- Eastern Area Agency on Aging – workshops.

- Robert and Mary's Place.

14. In your opinion, what kinds of workshops or trainings would be particularly helpful to you or others who are caregivers? Please list topics that would be particularly helpful:

Themes:

Medication: Several respondents stated an interest in having workshops or training on drug interactions.

Personal care: A common desire among individuals surveyed was to have training in areas of personal care. There was a particular emphasis on training that was "hands on." Areas of interest by respondents included bathing, bathroom sanitation, feeding, and other personal care skills.

Dementia and Alzheimer's Disease: Individuals surveyed expressed a great interest in workshops or training dealing with Alzheimer's disease or dementia. Potential topics raised included "dementia – mild to severe," "anything Alzheimer's disease-related," and "how to deal with dementia."

Medical conditions: Various responses by those surveyed indicated a desire to have workshops or training on medical conditions such as brain aneurysms, arthritis, stroke, Alzheimer's disease, and dementia.

Diet and nutrition: Diet and nutrition was a focus of some individuals surveyed. Topic suggestions for workshops or training included: "diet and nutrition for those living alone," and "healthy diets, low sodium or low sugar meals."

Psycho-social support and caregiver self-care: Topics for workshops repeatedly raised by numerous respondents dealt with caregiver self-care, including emotional support. Among the responses were a desire for training and workshops that dealt with: "caregiver self help and care," "caring for self," "emotional support," "how to deal with death," and "staying healthy."

Other issues raised:

- "Special considerations for frail elderly."
- Education on available caregiving resources.
- Addressing behavioral issues.
- "How to communicate effectively with the elderly once your role changes due to caregiving."
- How to involve churches.
- "Creative ways to create time for yourself."
- "How to get through the government paperwork to get services."
- How to cover expenses when you are on Social Security or cannot work full time.
- Workshops or trainings "that enhance support between caregivers."
- Having workshops or trainings that provide care for the patient while the caregiver is attending the workshop.
- More local workshops.

Sample Responses:

- “Medications and interactions, special considerations for frail elderly.”
- “Caring for people with dementia.”
- “Caregiver care.”
- “Demonstrations of hands-on caregiving and helpful products.”

15. If you would like, please add any other comments or ideas you may have about this topic. (Direct quotes from surveys noted in “”)

- There is a need to help individuals understand the differences in MaineCare and Federal medical benefits.
- Provide workshops on topics such as: short-term memory, aneurysms, and strokes.
- The need to instill acceptance and compassion, acknowledge changing roles.
- “Breakdown the snob barrier.”
- There is a need to better educate churches about caregiving needs. These churches may have a wealth of resources that could be utilized.
- Improve bus services
- There is a need for better and more accessible information about nursing home placement
- The changing nature of families and caregiving
- Improve services and coordination at the Bucksport Regional Health Center.
- There is a need to provide better education to caregivers on dementia.
- There should be more weekend workshops.
- There is a need for a network of respite caregivers who are partially subsidized to lower costs.
- Utilizing some means of identifying an individual as having dementia (sticker or button to let others know).
- Educate health professionals to be more knowledgeable and active in referring individuals to social services.
- Having an available neurologist in the Bangor area
- “How do we engage health professionals in understanding the importance of social programs?”
- The dichotomy between textbook learning on caregiving and lived experience.

Part 2: Hancock County Community Focus Groups

From April-July 2010, five focus groups were convened as part of the Caregiver Network Project caregiver needs assessment work for 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, held in Stonington, 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. The following section presents a summary of focus groups findings, as well as a more detailed transcription of focus group sessions.

Focus Group Participant Snapshot

- Participants ranged in age from 27 to 84 with an average age of 65.
- 20% have a high school diploma, 44% have some college education, and 36% attended graduate school.
- Half of the participants were currently employed and 42% are retired.
- Participants had a diverse range of work experience/backgrounds including: boat captain, eldercare provider, executive director, homemaker, pastry chef, physician, psychotherapist, school librarian, secretary, social behavior specialist, teacher, farmer, and truck driver.
- Half of the attendees were currently providing care to a friend, neighbor, or family member.
- 92% of the Stonington community focus group had some past experience providing care to a friend, neighbor, or family member and 92% knew of another person in the community who was a caregiver.

Summary of Focus Group Findings

From the focus groups held, it appears that the participants of the groups are lacking some key support that would assist them as caregivers. Financial burdens, insurance issues, and having to assume multiple roles in the lives of their loved ones for whom they feel responsible were noted. The caregivers expressed the challenges of not being an “expert” in the field—having to carry out tasks without the knowledge of where to access resources (or who would be the best one to assist in this capacity). Having to provide care without necessary and sometimes expensive equipment often affects their own livelihood and that of other family members.

Being a caregiver means one is subject to feelings of being overwhelmed, and can lead to depression, as the participants mentioned. Balancing the job of caregiving and fighting against obstacles that block one’s ability to access resources that may be helpful are additional challenges for the caregiver. The physical and emotional challenges that come with providing care can add to their stress level and can hinder the success in providing care for the aging person. Fulfilling dual roles as a loved one and a caregiver is also problematic due to the proximity and history one has with the loved one. Since, as a caregiver, one may have to be more involved with the loved one than they may have in the past (such as providing personal hygiene

care), relationship dynamics can change. Roles are often reversed or at least different for the caregiver (such as mother to daughter or husband to wife).

Caregivers were found to be using “homegrown” solutions to address a lack of resources, such as equipment or additional aids, which could be a hazard to the elderly person in the end. These were seen as temporary solutions to permanent problems for both the caregiver and the elderly person. Some members found they were able to use coping skills to assist them in dealing with their frustrations and lessen the stress of providing care. Though a long list of ways to manage the stress was shared in the focus groups, there were many unresolved needs relating to specific resources in the area the participants lived within. To name a couple: **transportation** and **affordable respite**.

Many of the participants were not aware of, or do not know, how to find resources within their local area(s). An increase in awareness needs to be cultivated among care providers in order to ensure the most appropriate care to the elderly person is provided. Many informal resources, such as family and friends, are limited and cannot be sustained long-term. Formal resources are not always affordable or accessible to the caregiver. Caregivers asked for additional resources to become available to them such as workshops and additional general information to aid them in their part of caregiving, such as ways to afford or access necessary services, development or expansion of additional services, and access to equipment if or when needed to provide care.

Focus Group Questions and Responses

We often hear the word “caregiver” a lot. This word means different things to different people. What does the term caregiver mean to you? Do you consider yourself a “caregiver”?

When asked to define the word “caregiver”, focus group participants associated numerous characteristics with it including: the major time commitment involved, the necessity of assuming multiple roles, and the sense of obligation and duty toward the individual being cared for. Additionally, participants acknowledged the emotional and financial burdens, such as guilt or grief, which can be associated with being a caregiver.

Sample Responses:

- It’s a 24/7 job
- You wear multiple hats/fill multiple roles
- Constant vigilance
- Financial burden/fear of losing life savings
- Grieving all the time
- Play multiple roles-be yourself, doctor, lawyer, caregiver, executive assistant, housekeeper, etc.
- You are a “draftee” into service-thrust into the role suddenly
- No one is prepared to become caregiver.
- Sense of obligation and responsibility (can cause negative feelings)

- Guilt-leaving the house or getting out and spending time for yourself
- Frustration with limited respite
- Challenge of hygiene
- Legalese - having to navigate medical/legal terminology
- Having to be consistent/have a schedule
- Caregiver is an appropriate term-they identify with this term
- Continue to be a caregiver even when person is in a facility
- Raising a child again
- Having to keep it together
- Can be family, friend, paid, volunteer
- If an outside caregiver you work with the care receiver and their partner/spouse
- Strong sense of dependence (“he couldn’t get through the day without me”)

What are some of the biggest challenges you face in relation to being a caregiver? How have you been able to address those challenges?

The biggest challenges faced by caregivers include addressing personal care needs such as incontinence, behavioral issues, hygiene, and transferring the individual under care. Additionally, time management, self-care, transportation, and emotional challenges, as well as understanding the directions and language of medical and legal professionals, were discussed. Caregivers often addressed care needs using “home grown” techniques.

Sample Responses:

- Financial burden*
- Interpret what doctors tell you
- Having to think about keeping them at home or go to a nursing home
- Transportation*
- Caregivers having health issues themselves
- Privacy
- Changing relationships/dynamics
- Incontinence
- Inappropriate behavior in public/constantly watching the person.
- Hygiene
- Insurance/eligibility for services*
- Isolated area especially to receive medical care
- Transferring (esp. when you are the only one who can help).
- Hard to keep your patience*
- Complete dependence
- Caregivers do not identify as caregivers. Think of it as their role as loved one or used to it after years. Thus don’t seek help.
- Volunteer caregivers are unsupported
- Caregiving is disjointed
- Can’t count on paid caregivers, between finding and turnover
- Caregivers do not want help. Loss of control. Pride. Bootstrap mentality.*
- Family support lacking each person comes with different expectations agenda

- Hard to make time for yourself*
 - Traveling/getting out of the house.
 - Guilt for leaving.
- A lot of “home grown” solutions from caregivers for transferring/bathing/hygiene, etc. (baby monitor, transferring with bed sheet, helping people up with chair).

Sample Responses (challenges identified by the community focus group in Stonington):

- Financial burden/poverty*
- Lack of government funding, MaineCare*
- The rural culture of not wanting to ask for help*
- Paid caregivers have to pay for their own transportation
- Volunteer caregivers have to pay for transportation whether to get to care receiver or while transporting*
- Volunteer caregivers sign up to volunteer but don’t follow through
- Caregivers don’t know they need support
- Reluctance: some caregivers don’t want to fill out paperwork or sign their name to something or disclose info about themselves. Many people value privacy in rural areas even if they know they need the service or just want to talk about options.
- Some caregivers may be illiterate-how to do you successfully reach them?
- Seeking help can be overwhelming for caregivers*

* indicates resources identified by professionals, community members, and caregivers across all groups.

Everyone experiences stress from time to time. What do you do to help manage your stress? What has been helpful?

Stress management avenues include engaging in leisure activities, eating, interacting with people, having a personal space to retreat to, and faith.

Sample Responses:

- Baking
- Chocolate
- Walking
- BINGO
- Coffee and talk
- Running business/working (having contact with others)
- Go to your man cave
- Cookouts
- Yard work
- Taking care of animals
- Faith
- Support groups/place to vent and share

- Get up early so you can have “coffee and peace”
- Relatives/Friends/Neighbors
- Online resources
- Going out to the movies

Are there key people in your life that you turn to, to help you manage day to day?

Family and friends were common resources for caregivers in managing daily life.

Sample Responses:

- Family
- Friends

How do you find out benefits that you or your loved one might be eligible for? OR how do other people you know find out about benefits, assistance, and programs that are available (i.e. heating assistance, MaineCare, Medicare coverage, etc.)?

A mixture of formal (programs and agencies) and informal (community members, community groups) were identified as resources. However, it was noted that caregivers were more likely to bring up informal or community-based supports while professionals and other community members were able to identify more formal support resources. Focus group participants learned about services that they are eligible for from various groups, including the Eastern Area Agency on Aging, Friendship Cottage, Faith in Action, Robert and Mary’s Place, as well as TV, newspapers, and workshops. Some participants did not know where to find out about services, or felt that some professionals were not very helpful.

Sample Responses (caregiver groups):

- “I don’t know where to go for information”
- Sometimes you know where to turn but professionals not helpful
- Eastern Area Agency on Aging*
- Workshops
- Dr. Crowley @ Gouldsboro
- Sonogee
- Faith in Action
- Robert and Mary’s Place
- Senior Center
- Partners in Caring
- MS Society
- Newspapers
- TV*
- Word of mouth*
- Alzheimer Spouse website

- Alzheimer's Association
- Friendship Cottage*
- Healthcare providers
- Referral network
- Straus Center
- Bucksport Bay Friends
- Janet Lewis
- Local physicians
- Church ministers
- Anne Ossanna
- Police Department
- Deb Chalmers
- Dr. Kufla
- Dr. Knowles (MDI)
- QMB-Medicare benefit/EAAA
- Sometimes the caregiver needs the services but they don't recognize that they need services or people don't want to pay for it
- Stories were shared about having to divorce spouse to qualify for services

The following resources were identified by the community focus group in Stonington as resources for caregivers:

- Meals on Wheels
- Friendship Cottage*
- Catholic Charities of Maine
- Eastern Area Agency on Aging*
- Island Nursing Home
- Professional caregiver support group (CNA's or anyone else working with residents)
- Parkinson's support group
- Cancer support group Stonington
- Card sharks at ICC
- Word of mouth*
- WERU
- TV features*
- Bone Builders
- Widow/Widower Club at Deer Run
- Healthy Island Project (Community island breakfasts for reps of groups and non-profits to talk about what services are available)
- Hospice of Hancock County
- Hancock County Home Care and Hospice
- Island food pantry
- Burnt Cove market (delivers food and pharmacy items to individuals)
- Pastoral care
- Meant for Each Other
- Neighbor Care-provided 425 rides to community members last year. They not only give rides but they accompany individuals in to their appointments. Medical equipment is available through their exchange initiative.

* indicates resources and information sources identified by professionals, community members, and caregivers across all groups.

What home health agencies have you used in the past? What has been helpful about working with home health agencies? What could be improved about that experience?

When discussing utilization of home health agencies, some focus group participants had not utilized such services, or were unaware of what they are. Others raised concerns about the expensive nature of these services and restrictive eligibility requirements. Another participant discussed the value of home health agencies in reducing care facility placements.

Sample Responses:

- Most participants had not used these services in the past.
- Some asked “what is it?”
- Need to clarify what a home health aid can provide (hands-on care, light housekeeping, etc.)
- There is a perception that it [home health/private in-home care] eats up money fast
- One caregiver noted that it keeps people out of facilities so this option should be supported
- One caregiver noted that if you are self-employed and work from home you may not qualify for home health services due to your 24/7 availability in the home.

What support groups do you go to or are aware of? What is helpful about these groups? In what way could support groups be improved?

In discussing the availability of support groups, as well as their value and possible need for improvements, focus group participants identified various organizations that host support groups including: Friendship Cottage, Ellsworth Library, Straus Center, Robert and Mary’s Place, and Bucksport Bay Friends. Suggested improvements for different programs included a desire for more speakers, nighttime groups, and classes on navigating services. Positive aspects of support groups noted by focus group participants included the fact that they help introduce people who are in similar circumstances.

Sample Responses:

- Ellsworth support group at the library
 - Would be beneficial to have speakers
 - No discussions yet about programs, benefits, navigating paperwork (would be nice to have)
 - Helpful to listen to what others are dealing with and relate to others
- Friendship Cottage group
 - This is a general support group open to all caregivers (not Alzheimer’s disease-specific)

- More discussion on Alzheimer's disease/dementia was desired by some
- EAAA group in Blue Hill area
 - This group is Alzheimer's disease-specific
- Group at Straus Center
 - Helpful to meet others and know you're not alone
 - Caregivers can attend the support group thanks to services that are offered (adult day services)
 - It would be nice to have more people involved in the meetings
 - Maybe different hours would help increase enrollment
 - Support groups hosted on-site at adult day programs-is this a barrier to people using the group?
- A support group in Bucksport would be nice
- Evening groups may be easier for people to attend
 - Maybe for younger caregivers who still work would find evening meetings beneficial

Have you ever used adult day services? What was helpful about the experience and what could be improved?

In discussing the use of adult day services, focus group participants discussed the value of having a greater selection of days and times available for taking advantage of respite services. Other concerns raised included the affordability of adult day services and the need to better tailor the programs to individual caregivers and care recipients.

Sample Responses:

- Have a drop off center for respite
- More days per week of services
- More variety of times
- Transportation is a big help!
 - It is nice for the care recipient to go for a car ride (they enjoy it)
 - Friendship Cottage offers door-to-door service which is crucial
- AD services should meet the needs of unique participants
- Robert and Mary's Place
 - Liked the approach used by staff
- Friendship Cottage
 - Services are helpful
 - Transportation is important
- Bucksport Bay Friends
 - Might be good to add more days
 - More hours would not necessarily help (4 hours is long enough)
- Limited hours can be a barrier for some caregivers
- Affordability is an issue for some caregivers
- Caregiver co-op is a model that is emerging in some parts of Hancock County.
- Weekend/evening respite through adult day programs would be helpful
- Special recommendations that would support male caregivers

- Schedule respite during events men would want to attend (during basketball games, etc.)
- Call it a “pizza date” or “coffee time” instead of “support group” or “respite”
- Share tips and troubleshooting (problem solving)

<p>What type of training or workshops might be helpful to you?</p>

Training and workshop sessions most appealing to caregivers include those dealing with handling the stress associated with caregiving, information on personal care strategies and equipment, improving communication, understanding changing relationships, as well as sessions on medical conditions and disease processes. Additionally, focus group participants were interested in workshops and training on topics such as identifying programs and benefits, and navigating the accompanying administrative tasks.

Sample Responses:

- How to manage feelings of guilt
- How to deal with changes in dynamics between caregiver and care recipients
- How to understand “goobledeegook” (insurance, forms, planning etc.)
- Can my care recipient manipulate me? Are they capable?
- Showering/hygiene/hands on care
- Benefits/programs
- What activities can you do with your loved one? OK to let them zone out? How much stimulation is OK?
- Practical information about Alzheimer’s-not medical or technical
- When is it time to consider a nursing home?
- Ways to de-stress
- TEC center should come in and showcase assistive devices
- Docs or healthcare providers to come in and talk about disease process
- Tools for communication/redirecting
- Best Friends Model
- Dealing with negative feelings from chronic caregiving

<p>Is there any help or assistance you would want that you do not currently have?</p>
--

Caregivers identified numerous types of assistance that they do not have and would like to have available, including counseling, housekeeping assistance, case management or navigator services, respite care, and transportation, among others.

Sample Responses (caregivers):

- Counseling (very important!)
- List of private pay respite providers
- Housekeeping

- Case management
- Transportation
- Wheelchair/medical equipment
- It was noted that some professionals do not return phone calls in a timely manner*
- Person to come in and sit with care recipient (respite)
- The new Caregiver Navigator could help with the following:
 - Help figure out options and benefits (financial/programs/benefits)
 - Find respite care for vacations/sickness
 - Financial planning
 - Coordinate services
 - Help fill out paperwork
 - Someone to check-in once a month
 - Have them on-site at adult day programs

Sample Responses (identified by the community focus group in Stonington as support that would be helpful for caregivers):

- Professionals who work with caregivers should be available to answer questions*
- Make home visits*
- Stronger presence from groups like EAAA to fill in/work with areas that organizations like Healthy Island Project, which are small and strapped for funds, can't reach*
- Educational trainings for caregivers possibly provided by Healthy Island Project, Island Nursing Home, and the Medical Center
- Encourage Bangor specialists to schedule appointments in blocks based on geography 2 days a month for people living in Hancock (assist with transportation issues).

* indicates opportunities identified by professionals, community members, and caregivers across all groups.

Of all the needs we discussed, which are the most important?

Of all the needs raised by caregivers in the focus group, transportation and affordable respite care were viewed as being the most important by participants.

Sample Responses:

- Transportation
- Affordable respite

Is there something that we haven't covered yet that you feel would be important to share with us?

General comments by focus group participants covered numerous topics, such as the need for respite care, as well as the responsiveness of professionals to caregivers.

Sample Responses:

- How to find out about buy-ins for insurance
- Caregivers who attended groups wanted to see more caregivers at groups. It was suggested that caregivers should be more involved with advocacy.
- What is going to happen in the future? Worrying about the future
- Needing more respite time
- Living thrifty can mean you don't qualify for services when you need them
- The concept of "being outside looking in" when loved one is not mentally present/somewhere else mentally
- Issue with responsiveness of professionals-being put on hold, computer is down, etc. etc.
- We need more discussion about things other than Alzheimer's disease
- Perception that local Blue Hill doctors are more engaged in this issue (caregiving) and Bangor doctors aren't-but they are referring people into services.
- No free care available
- Caregivers and loved one can go to senior center together and do activities together
- Others are caregivers but not ready to admit there is an issue

How do you manage traveling/transportation with your loved one?
--

When considering transportation, caregivers mentioned several difficulties, including time and income loss, difficulty with transferring care recipients into a vehicle, as well as the uncertain availability of transportation services. Focus group participants stated the desirability of more formalized transportation options that do not depend on volunteers.

Sample Responses:

- It's a big problem!
- Wheelchair van that could be rented/borrowed
- Transporting loved ones takes time
- If you are self-employed you lose income when you have to transport and take people to appointments
- Caregivers have to cancel outings if transportation is going to be too difficult
- Van at Friendship Cottage is great!
- Transferring can be difficult for older caregivers.
- Need more of a formal system (not dependent on volunteers)
 - Faith in Action is great but it's hard when they cancel
 - Need back-up plan for transportation

How do you manage your other responsibilities besides caregiving?
--

When asked how they manage responsibilities other than caregiving, focus group participants mentioned the role of reliable family and friends, as well as paid staff.

Sample Responses:

- Friends and family you can rely on
- Try to make time for your relationships
- Summer business owner has staff that can spend time with care recipient

Attachments

- I. Two Page Summary of Findings
- II. Powerpoint Presentation on Findings
- III. Asset Map and Hancock County Resources



Challenges Faced by Caregivers in Hancock County and Opportunities for Support: Needs Assessment Findings

Study Background: The Hancock County caregiver needs assessment utilized surveys and focus groups to provide a greater understanding of the experiences of caregivers in Hancock County. Information on the knowledge and use of services, perceptions of the strengths and deficiencies of these services, and recommendations for future improvements was gathered from caregivers, community members, and professionals to inform our assessment. The following are key findings:

Challenges

Transportation: Large distances to services, the need for door-to-door access to these services, reliability issues associated with existing volunteer transportation programs, and the difficulty involved in transferring care recipients makes transportation problematic.

Lack of formal resources/money for expanding services: Available programs and organizations are often far away or spread out within the county and insufficient funding is a barrier to the creation of new services.

Caregiving is complex and demanding: Individuals often do not know they are caregivers or that there is support available through caregiver programs. The job of caregiving means you wear multiple “hats” as you provide care 24 hours a day, 7 days a week. Caregivers often lack the training and support needed when it comes to providing hands-on care. They also face changing relationships with their loved ones.

Respite: Affordable and reliable respite care is needed. Caregivers desire respite options that allow for both in-home and out-of-home support options. Caregivers want these services to be flexible, convenient, and tailored to the individual.

Strengths

Resiliency and strength of caregivers: Caregivers are skilled at creating homegrown solutions to the challenges they face, such as emotional stress and the physical difficulties of caring for another.

Community: There is a culture where neighbors take care of neighbors.

Local resources: Hospice organizations, healthcare and other professionals, adult day programs, government agencies, faith groups, and community members are all resources of value to caregivers. Many caregivers and community members were able to identify local resources they could turn to for help.

Service Needs

Case management and support services: Caregivers raised the need for case-management type services that would provide assistance with arranging respite services, financial planning and applying for benefits, as well as monthly check-ins and other coordination assistance.

Training: Among training topics appealing to caregivers are those that deal with the social and psychological challenges of providing care, such as feelings of guilt, as well as the changing relationship dynamics that many caregivers face with their loved ones. Hands-on personal care techniques, navigating benefits and programs, understanding insurance forms, information on medical conditions, and training about how to locate available services were also topics of interest to caregivers.

Recommendations

Increase awareness of what it means to be a caregiver: In outreach efforts, there is a need to highlight that being a caregiver is a common experience and it is often a demanding and complex one as well. This will help caregivers self-identify and reduce reluctance to ask for help as well as raise the general awareness of the community about caregiving and encourage friends, neighbors, and professionals, to play a role in helping to support caregivers.

Build and strengthen formal and informal service networks: Local communities are already stepping forward to help one another whether through providing transportation or providing respite care. There exists a great opportunity for formal programs and informal community groups and neighbors to connect and coordinate with each other to serve the needs of caregivers and to develop new initiatives to fill the gaps not addressed by current programming.

Develop and advertise affordable and reliable respite options: This includes promoting the private hire caregiver list maintained by Friendship Cottage and replicating this list in other communities so that caregivers have access to individuals who can provide reliable and safe private pay help. In addition, it is important to look for opportunities to support the respite fund that has been developed at Friendship Cottage and is open to all caregivers.

Connect with and engage caregivers in advocacy roles: The existence of local support groups represents a pathway for providing education and outreach to caregivers. Developing opportunities for caregivers to connect with one another and to advocate for and shape the services and supports provided to them is advised as well.



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Challenges Faced by Caregivers in Hancock County and Opportunities for Support

Jennifer Crittenden
Research Associate
UM Center on Aging



Harry and Jeanette Weinberg Foundation Grant # 10200

Overview

- Needs assessment work by Center on Aging will inform activities carried out under Weinberg Grant
- Community needs and resources were assessed with input from a diverse group of community members, caregivers, and professionals
- Asset mapping based on findings

Survey Participants

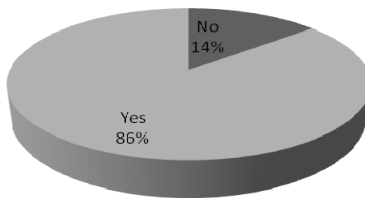
- 50 surveys returned and 28 focus group participants
- 25 towns represented from throughout the county
- Survey respondents:
 - 56% retired
 - 44% currently working:
 - Home health staff
 - Social workers
 - Business/sales
 - Clergy



Survey Participants

- Majority of respondents had some experience with caregiving or knowledge of other caregivers

4. Do you know of other people in your community who are caregivers for a family member, friend, or neighbor?



Focus Group Participants

- Focus Group participants:
 - 76% female; 24% male
 - 20% high school/GED; 44% college; 36% graduate degree
 - Employment background:
 - Boat Captain
 - Executive Director
 - Homemaker
 - Chef
 - Physician
 - Psychotherapist
 - School Librarian
 - Teacher
 - Farmer
 - Truck Driver

Defining Caregiving

- It's paid/unpaid
- Complex relationships
- It's a 24/7 job
- You wear multiple hats/fill multiple roles
- Constant vigilance
- Financial burden/fear of losing life savings
- Grieving all the time
- Play multiple roles-be yourself, doctor, lawyer, caregiver, executive assistant, housekeeper, etc.
- You are a "draftee" into service-thrust into role suddenly
- Sense of obligation and responsibility (can cause negative feelings)
- Continue to be a caregiver even when person is in a facility or at a distance

Challenges

- Transportation
 - Large distances to services
 - Door-to-door transportation needed to access adult day services
 - Transferring into a car challenging
 - Transportation programs relying on volunteers
- Lack of formal resources
 - Resources located far away
 - Insufficient funding to develop programs/services

Challenges

- Caregivers don't often know they are caregivers
 - Need to educate community about this issue in general
- It's all "on-the-job training"
 - Need training and support to help family caregivers with techniques for hands-on care
 - Education on specific medical disorders

Challenges

● Respite

- Need affordable respite options
- Someone who can help with errands/cleaning
- Lack of reliable in-home private pay help
- Adult day programming hours not always convenient
- Need caregiver respite events appealing to male caregivers

Strengths & Facilitating Factors

● Resiliency and strengths of caregivers

- Crafting personal solutions
- Developing personal stress relief techniques

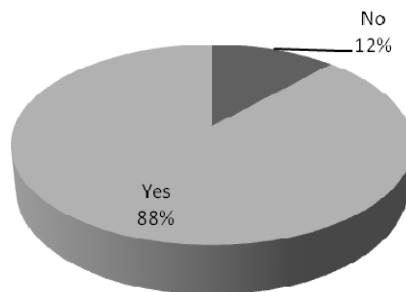
● Community

- Neighbors helping neighbors

● Formal and informal resources available

Formal Resources

6. Do you know of helpful services/agencies/programs in place at this time for caregivers in your community?



Resources (cont'd)

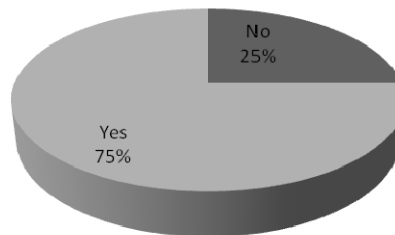
● Formal resources

- Eastern Area Agency on Aging
- Alzheimer's Association
- Adult day programs
- WHCA
- Key professionals
- Healthcare sites
- Hospice agencies



Informal Resources

7. Are there community groups or volunteers that assist caregivers and other community members that you are aware of?



Informal Resources (cont'd)

● Informal Resources

- Churches
- NeighborCare/Neighbors helping one another
- Faith in Action
- Community support groups
- Individual community members



Navigator Position

- Navigator position
 - Help figure out options and benefits (financial/programs/benefits)
 - Find respite care for vacations/sickness
 - Financial planning
 - Coordinate services
 - Help fill out paperwork
 - Someone to check-in once a month
 - Have them on-site at adult day programs

Training Topics

- How to manage feelings of guilt
- How to deal with changes in dynamics between caregiver and care recipients
- How to understand “goobledeegook” (insurance, forms, planning etc.)
- Showering/hygiene/hands-on care
- Benefits/programs
- What activities can you do with your loved one
- Practical information about Alzheimer’s-not medical or technical
- When to consider a nursing home

Other Service Needs

- Counseling
- List of private pay respite providers
- Housekeeping
- Case management
- Transportation
- Wheelchair/medical equipment
- Person to come in and sit with care recipient (respite)

Recommendations

- Use caregiver definitions in outreach campaigns and education efforts
 - Raise community awareness of this as a common experience
 - Help caregivers to seek adult day services sooner in the process
- Continue to build informal networks within the community and strengthen existing networks
 - Communication network
 - Strengthen connections between formal and informal services
 - NeighborCare model replication
 - Use asset map to identify key community partners

Recommendations (cont'd)

- Continue to spread word about Friendship Cottage caregiver list
 - Replicate this in Washington County
- Develop opportunities for private pay caregivers to access training and support
 - Island Nursing Home model
 - Friendship Cottage support group
- Connect with local caregiver support groups to provide presentations and outreach

Recommendations (cont'd)

- Continue to spread the word about the Caregiver Resource Center
 - Open to all caregivers
- Develop initiatives to fill gaps not otherwise addressed by the caregiver network grant
- Continue to increase affordability through respite fund development

Recommendations (cont'd)

- Look for opportunities to engage caregivers in advocacy roles
 - Advisory board roles, consultants, outreach to legislators
- Develop trainings based on caregiver feedback
- Develop forums for caregivers to share their advice and techniques

Questions

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Challenges Faced by Caregivers in Hancock County & Opportunities for Support

Resource Listing & Map

The resources listed below can be used as a guide to the various services in the Hancock County area. These resources were reported by participants of focus groups and surveys conducted by the University of Maine Center on Aging. In follow up data collection more information about each of these organizations was collected. The following resource listing and map can be used to understand what services are already in place and make connections in order to bridge service gaps.

General Resources:

The following resources provide multiple services to caregivers within the areas of awareness/communication, caregiver specific resources, and transportation/mobility.

Eastern Area Agency on Aging (EAAA)

450 Essex Street

Bangor, ME 04401

Phone: (207) 941-2865 or 1-800-432-7812

Contact Person: Janet Lewis-Caregiver Support Specialist for Washington and Hancock
Deb Poulton-Director of the Family Caregiver Program

Services:

- Family Caregiver Program
 - Caregiver support specialist
 - Information, support, education and referral services
 - Consultation around the long term care system
 - Help prioritizing caregiver responsibilities
 - Education about specific diseases, caregiver depression and overall health
- Navigator
- Support groups
- Partners in Caring Program
 - Funding for in-home adult day services, companions, personal care assistance, or a short term stay in a facility
- Medicare prescription drug benefits information and assistance with questions
- State Health Insurance Program (SHIP) information and education for seniors and those with disabilities about medical insurance (including Medicare, MaineCare, long-term, and other insurance needs)
- Lead agency on Weinberg grant
- Media outreach campaign to increase awareness of caregiving issues and support

Faith in Action

125 State Street

Ellsworth, ME 04605-1446

Phone: (207) 664-6016

E-mail: jcooper@faithinactionellsworth.org

Website: www.fianationalnetwork.org/index.cfm

Contact Person: Jo Cooper

Services:

- Transportation
- Senior Center
- Friendly Visitors
- Help with chores
- Resource Center (computer use, research, information about benefits, etc.)
- Collaboration with: EAAA's, Island Connections, CAP agencies, Hospitals, Fire Departments, etc.
- Coming in the Fall/Spring, classes regarding Hands-On Safety such as entering and exiting vehicles or getting in and out of bed—all services are free to the public

Friendship Cottage

P.O. Box 299 or 248 Bucksport Road

Ellsworth, ME 04605

Phone: (207) 664-2424

E-mail: aossanna@whcacap.org

Website: www.whcacap.org/friendship-cottage/

Contact Person: Anne Osanna, Site Coordinator
Sonja Turkanski, Resource Center Coordinator & Community
Caregiver Advocate

Services:

- Adult day program
 - Transportation to and from the site (and occasionally into the community for day trips)
 - Medicine administration
 - Daily activities of living assistance
 - Lunch provided
- Caregiver support group
- Caregiver Resource Center
 - Computer
 - Lending library
- Assistance filling out forms and paperwork for reimbursement for services or insurance coverage)
- Education for caregivers
- Identify resources from within the communities (neighbors, volunteers, etc.)
- Connect caregiver needs with community volunteers
- Community outreach and education
- Private pay caregiver listing

Specific Resources:

The following resources provide specific resources for caregivers. These are divided into three primary themes: awareness/communication, caregiver specific resources, and transportation/mobility.

AWARENESS/COMMUNICATION

EAAA*

Faith in Action*

Friendship Cottage*

*See above for more information.

Healthy Island Project

43 School Street, Suite 2G

P.O. Box 55

Stonington, Maine 04681

Phone: (207) 367-6332

Contact Person: April Coombs – Director

Type of Services:

- Starting “Aging Well” series for older adults in 2011 to learn more about available resources and how to access them. Speakers will include EAAA, local nursing facilities, Friendship Cottage, etc. Consulted with Robert Blake of EAAA and Anne Williams of NeighborCare. Like Living Well and Growing Well
- HIP acts as a bridge for communication support island communities plus some programs open to all of Blue Hill peninsula
- Community breakfasts every other month for representatives to come and share who they are, who they represent, and info in two minutes. At the end everyone gets a chance to ask questions.

Brooksville Friends & Neighbors

Brooksville, ME 04617

Phone: (207) 374-3706

E-mail: dougcowan@gmail.com

Service Area: Brooksville

Contact Person: Doug Cowan

Services:

- Create/facilitate relationships
- Responds to reported needs in community
- The Breeze – goes to all Brooksville residence and sent via email or mail to seasonal residents
- Working on “Aging in Place” initiative

CAREGIVER SPECIFIC RESOURCES

Support Groups

EAAA*

Friendship Cottage*

*See above for more information.

Robert & Mary's Place

50 Meadowview Lane, Ste #35

P.O. box 1533

Ellsworth, ME 04605

(207) 667-5449 OR 667-7034 Cell: (207) 479-0692

Contact Person: Ida Page, Program Director

Service:

- Support group last Friday of the month

St. Savior's Episcopal Church

41 Mt. Desert

Bar Harbor, ME 04605

(207) 288-4215 (Parish)

Service:

- Support group for care providers who support adults with Alzheimer's disease or dementia

Don & Beth Straus Center at the Community Health Center

9 Village Green Way

Southeast Harbor, ME 0479

Phone: (207)244-3267

Contact Person: Debra Chalmers

Service:

- Support group

Parker Ridge

63 Parker Ridge Lane, Unit 290

Blue Hill, ME 04614

Phone: (207) 374-2306

Service:

- Support group once a month on the 4th Tuesday

Adult Day

Friendship Cottage*

*See above for more information.

Bucksport Bay Friends

PO Box 878

Bucksport, ME

(207) 469-1112

Contact Person: Terrie Perrine

Service:

- Adult day program

Robert & Mary's Place

50 Meadowview Lane, Ste #35

P.O. Box 1533

Ellsworth, ME 04605

(207) 667-5449 OR 667-7034 Cell: (207) 479-0692

Contact Person: Ida Page, Program Director

Service:

- Adult day program

Don & Beth Straus Center at the Community Health Center

9 Village Green Way

Southeast Harbor, ME 0479

Phone: (207)244-3267 or (207)288-8652

Contact Person: Debra Chalmers

Service:

- Adult day program

In-Home Respite

Faith in Action*

Friendship Cottage*

*See above for more information.

Neighbor Care

Deer Isle/Stonington Area

Contact Person: Anne Williams

Private Pay Caregivers

Companion and Personal Care Assistance Agencies

Home Health Agencies

TRANSPORTATION/MOBILITY

EAAA*

Faith in Action*

*See above for more information.

Brooksville Friends & Neighbors

Brooksville, ME 04617

Phone: (207) 374-3706

E-mail: dougcowan@gmail.com

Contact Person: Doug Cowan

Service:

- Transportation needs assessment completed
- Provided travel from pick up location or at home with appointment once a week
- Volunteer drivers
- Program not currently running

Downeast Transportation, Inc.

PO Box 914

Ellsworth, ME 04605

Phone: (207) 667-5796

Service:

- Transportation

Island Connections

15 Eagle Lake Road

Bar Harbor, Maine 04609

Service Area: Hancock County

Phone: (207) 288-4457

Contact person: Christopher Keith

Service:

- Transportation

Neighbor Care

Deer Isle/Stonington Area

Contact Person: Anne Williams

Service:

- Transportation from home to various appointments
- Assistive equipment to lend clients

Washington Hancock Community Agency

248 Bucksport Road

Ellsworth, ME

Phone: (207) 667-2424 or 1-877-374-8396

Contact Person: Joe Perkins, Director of Family and Community Services

Services:

- Home modifications called 'Senior Safe' program (bathroom rails, outside access ramps, etc. to make the home more accessible)
- Transportation for non-emergency medical (MaineCare eligible appointments)

Technical Exploration Center (TEC)

34 Summer St., Suite 2A

Bangor, ME 04401

Phone: 207-992-9270 or toll free 866-274-0029 (Voice/TDD) open M-F, 9am-5pm

Fax: 207-992-9273

***Alternative address:**

Maine Coast Community Clinic

190 Beechland Road

Ellsworth, ME 04605

(207) 697-0293

Contact Person: Lynn Gitlow

E-mail: lynn@tecmaine.org

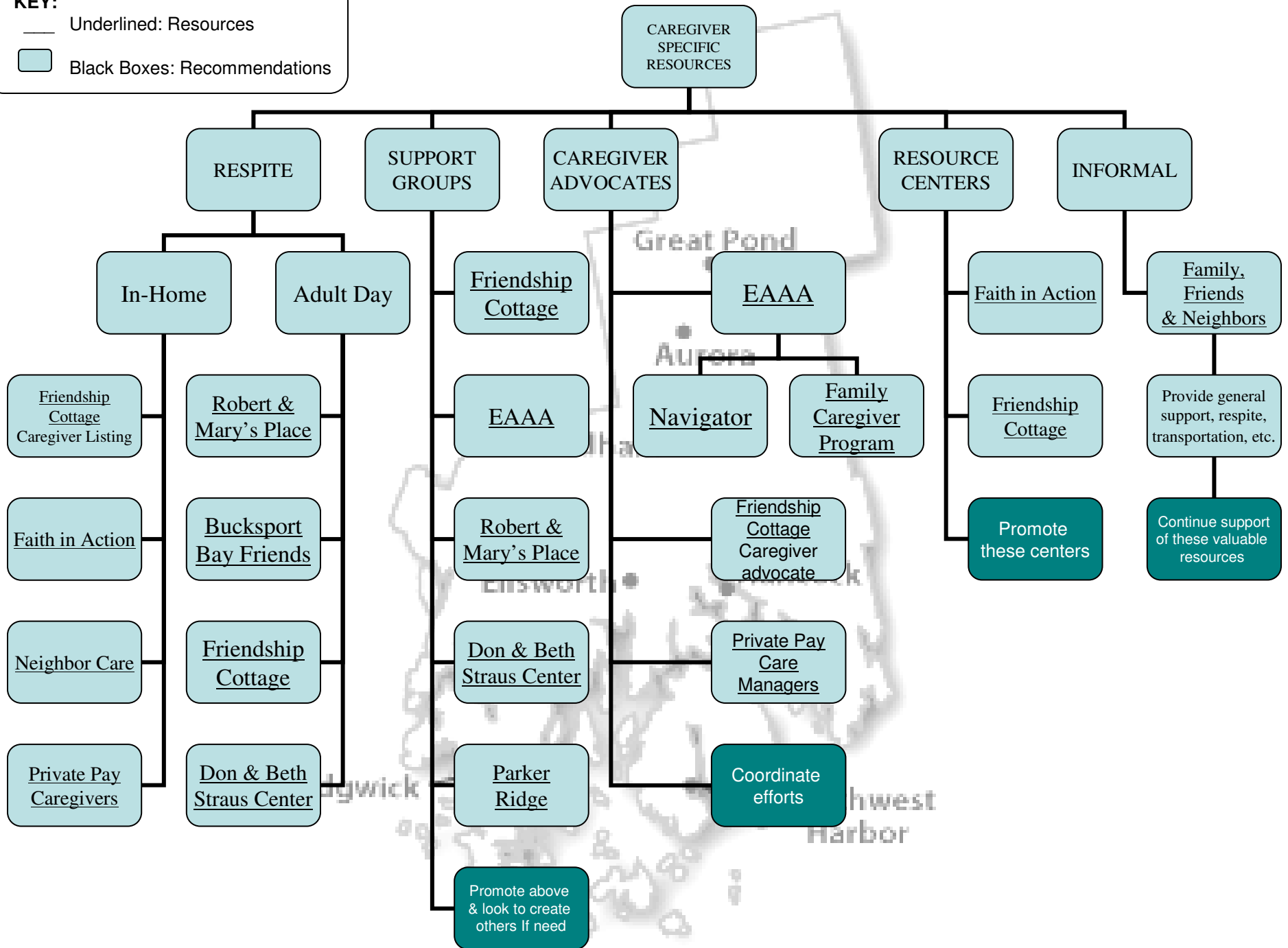
Type of service:

- Education
- Mobility and adaptive equipment
- Lending library (adaptive equipment, books, cassettes, videos, tools, computer software, hardware, and much more)
- Evaluations

KEY:

— Underlined: Resources

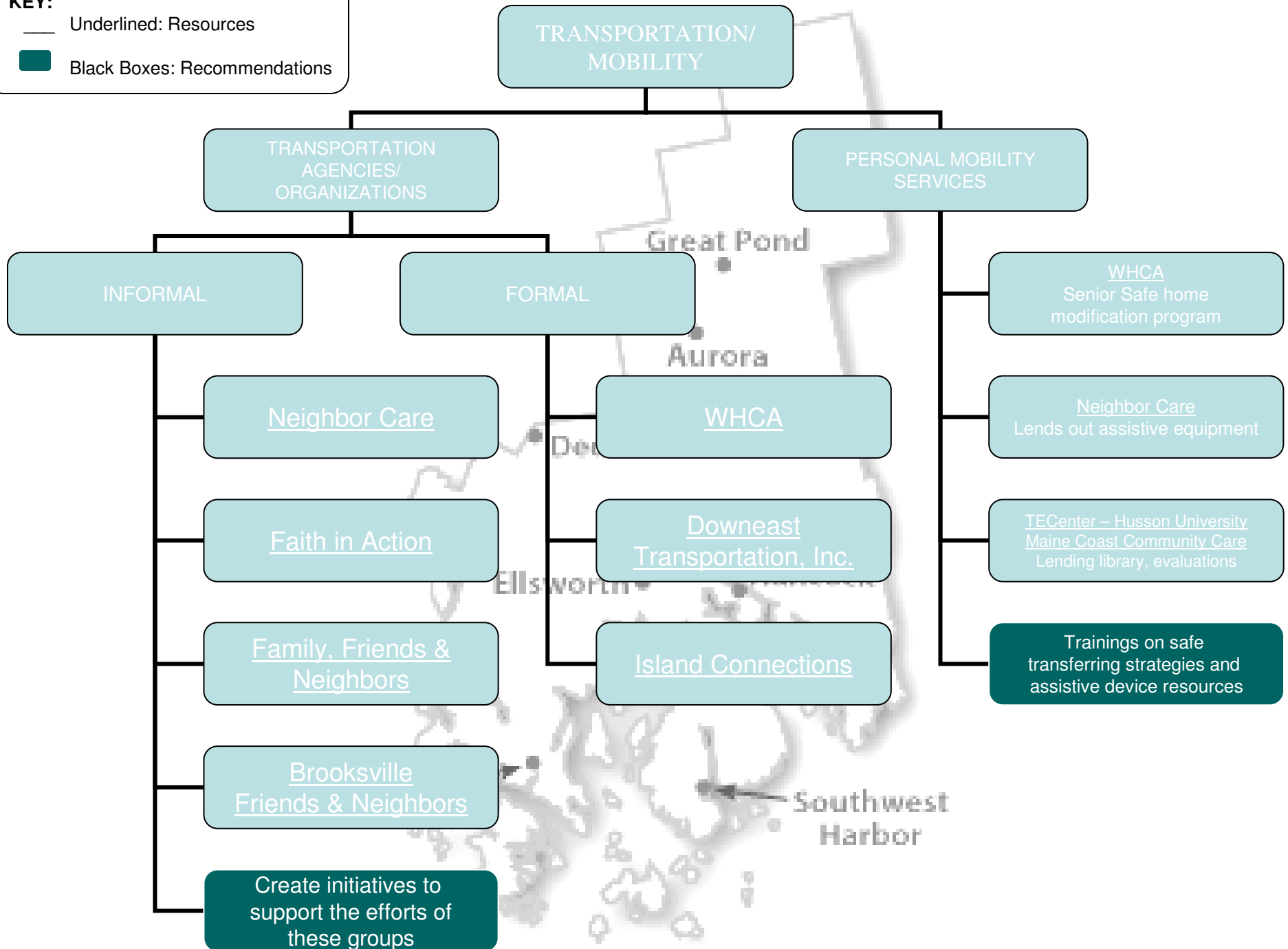
□ Black Boxes: Recommendations



KEY:

 Underlined: Resources

■ Black Boxes: Recommendations



KEY:

— Underlined: Resources

■ Black Boxes: Recommendations

**AWARENESS/
COMMUNICATION**

**CAREGIVER
TRAININGS**

**OUTREACH/
NETWORKS**

EAAA

Offering mini-grants for
educational training

Healthy Island Project
Aging Well Series 2011

Faith in Action
Caregiver trainings in
Fall 10 and Spring 11

Hospice of Hancock County
Grief on the
Installment Plan

Advertise trainings
widely through various
channels

Support the development
of additional trainings

Support general outreach
initiatives and networks

EAAA
Media Outreach Campaign

Utilize findings of how
caregivers define themselves.

Continue campaign over time
to reach new caregivers.

Use local media outlets

Develop initiatives to support
these types of meetings in
other areas to build network

Reach out to other
Friends & Neighbor groups
to work together on initiatives

**Informal/Formal
Networks**

Healthy Island Project
Bi-monthly
networking breakfasts

Brooksville
Friends & Neighbors

Weinberg Network