

Washington County Community and Caregiver Needs Assessment Summary of Findings



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University of Maine Center on Aging**

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Project Partners in Washington County**

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University of Maine Center on Aging

Camden Hall

25 Texas Avenue

Bangor, Maine 04401

Phone: 207-262-7923

E-mail: info@mainecenteronaging.org

Web: www.mainecenteronaging.org

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Passamaquoddy
Program for the
Elderly



Washington County
Food and Fuel Alliance

A special thank you goes out to those organizations that assisted in distributing the caregiving survey in Washington County:

- Sunrise Care
- Davis Estates
- Washington County One Community
- Down East Hospice
- Washington County Commissioner's Office
- Down East Community Hospital
- Maine Veterans' Home
- Washington County Council of Governments
- Community Caring Collaborative
- Catholic Charities of Maine
- Beth C. Wright Cancer Resource Center
- Harrington Family Health Center

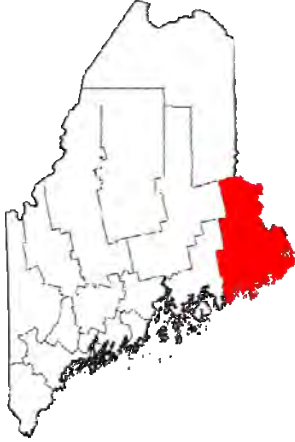
We thank as well the following grant project partners who extended assistance through the provider network established by the Weinberg Foundation grant:

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- Senior Companion Program

Table of Contents

Overview and Context	3
Part 1: Washington County Needs and Resources Assessment Survey	4
Part 2: Washington County Community Focus Groups	19
Attachments	
Two Page Summary of Findings	
Asset Maps and Washington County Resources	

Overview and Context



The needs assessment work detailed in this report was conducted by the UMaine Center on Aging in the spring of 2011 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 Washington 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 newly established Caregiver Coordinator 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: Washington County Needs and Resources Assessment Survey Findings

Survey Findings Summary

The Washington County Caregiver Needs and Resources Assessment Survey was designed to elicit information from community members, caregivers, and professionals in Washington County 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. Respondents were a mix of retirees, as well as individuals that are currently employed in diverse professions ranging from local government to healthcare, full-time caregiving among others. Most survey respondents (81%) are currently, or have been, care providers for a family member, neighbor, or friend. Individuals surveyed worked and/or lived in 39 communities in Washington County. Individual perceptions about the availability, strengths, and deficiencies of services for caregivers were diverse, but a number of overarching themes arose from the responses:

- Caregiving remains a prevalent experience in this region with the majority of respondents having either been a caregiver themselves or currently know of a caregiver in their community.
- Most people turn to family or friends or agencies in the community when they need information about caregiving. Most respondents were able to identify agencies, services, and programs that are available to caregivers. However, only 40% of respondents were able to identify community groups and volunteers who could help caregivers locally.
- Nearly 80% of respondents would make use of adult day services if they were available.
- Potential interventions that could be carried out under this project include:
 - Making respite more available and affordable
 - Tapping local informal support networks and volunteers to provide respite and support for caregivers
 - Developing support groups and networking opportunities for caregivers
 - Holding public sessions on benefits and programs that are available for older adults and caregivers
 - Developing local, targeted trainings that provide information on resources, healthcare information, hands-on techniques for caregiving, and caregiver self-care
 - Developing training and outreach materials that are in attractive format for caregivers such as printed materials and/or internet resources
 - Addressing barriers to accessing programs and increase service coordination including developing networks of professionals that can exchange resources and increase coordination among each other
- Challenges to be considered in carrying out this work include: a lack of transportation options, a lack of resources in this area, and a tendency by residents toward independence and individualism.
- Assets that can facilitate these activities include: natural support networks that already exist, an inclination to help other community members, and existing programs and professionals who are viewed as resources.

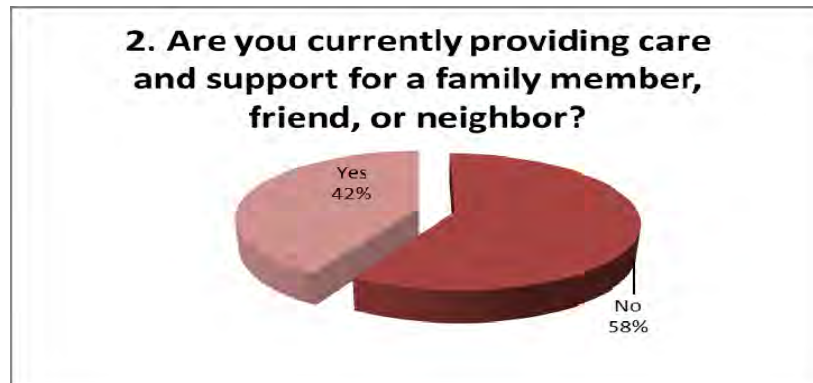
Survey Responses by Question

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

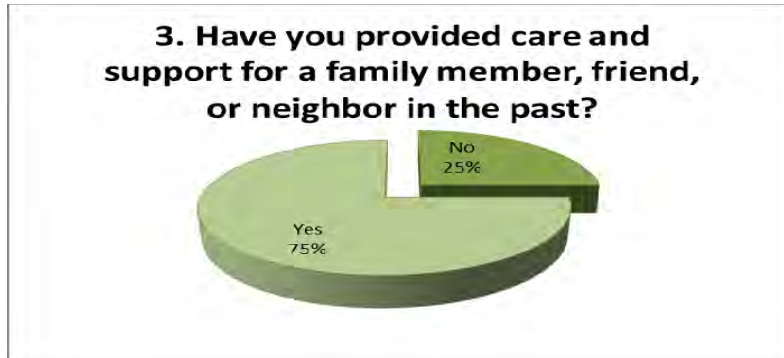
1. What is your position or job title? If you are a community member or retired, please let us know here.

Response	%
Retired	34%
Not working/receiving disability/community volunteers	7%
Currently working Examples in this category include (*top 4): <ul style="list-style-type: none">▪ Local or state government employee (11 people)*▪ Program director/coordinator/supervisor (10 people)*▪ Full-time caregiver paid and unpaid (8 people)*▪ Social workers (5 people)*▪ Administrative assistant/clerical staff▪ Nurses and healthcare staff▪ Teachers/instructors▪ Self-employed individuals	59%

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



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



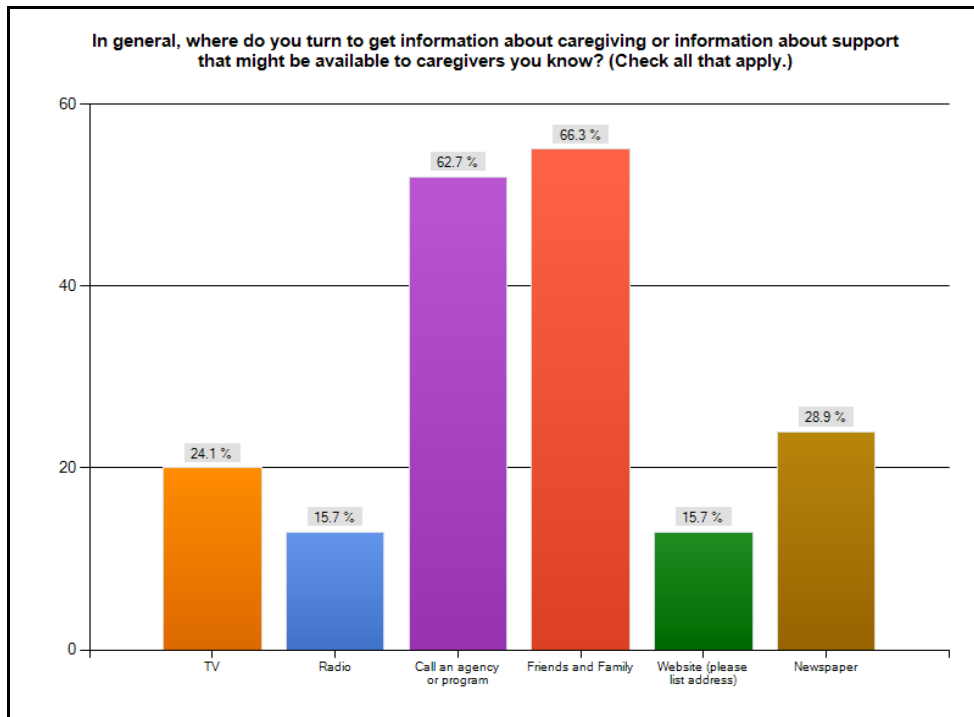
4. Do you know of other people in your community who are caregivers for a family member, friend, or neighbor?



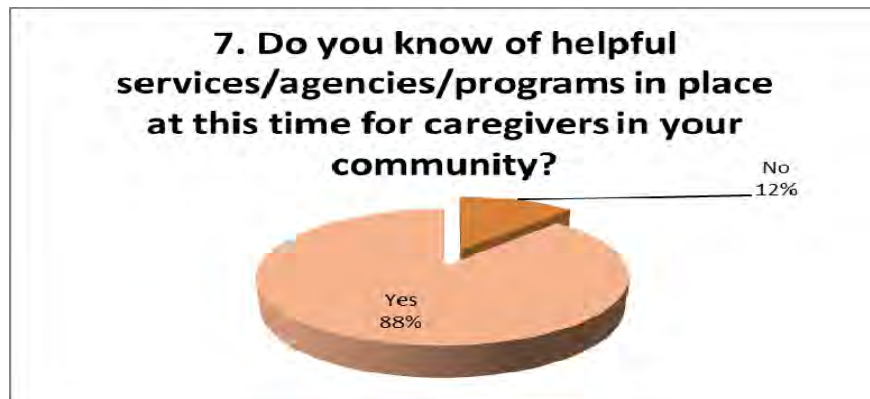
5. In which of these Washington County communities do you work or live? (Please check all that apply)

Locations	Response Percent
** indicates top 5 locations	
Calais**	29.6%
Machias**	27.6%
Lubec**	13.3%
East Machias**	11.2%
Baileyville**	9.2%
Machiasport	8.2%
Perry	7.1%
Robbinston	7.1%
Whiting	7.1%
Harrington	6.1%
Addison	5.1%
Cooper	5.1%
Dennysville	5.1%
Eastport	5.1%
Jonesport	5.1%
Marshfield	5.1%
Princeton	5.1%
Charlotte	4.1%
Jonesboro	4.1%
Northfield	4.1%
Pembroke	4.1%
Cherryfield	3.1%
Columbia	3.1%
Cutler	3.1%
Milbridge	3.1%
Pleasant Point	3.1%
Wesley	3.1%
Alexander	2.0%
Baring Plantation	2.0%
Columbia Falls	2.0%
Grand Lake Stream	2.0%
Indian Township	2.0%
Meddybemps	2.0%
Steuben	2.0%
Whitneyville	2.0%
Beals	1.0%
Beddington	1.0%
Crawford	1.0%
Roque Bluffs	1.0%

6. In general, where do you turn to get information about caregiving or information about support that might be available to caregivers you know? (Check all that apply.)



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



Agencies and individuals that were identified as helpful resources:

Health and hospice:

- Downeast Community Hospital
- Regional Medical Center at Lubec
- Public Health Nursing
- Calais Hospital
- Maine Veterans Home
- Gould
- Downeast Hospice
- The Beth C. Wright Cancer Resource Center

Homecare services:

- Community Health and Counseling
- Care and Comfort
- Catholic Charities
- Sunrise Home Care
- Living Innovations

Aging network:

- Eastern Agency on Aging/Family Caregiver Program/Meals for ME
- Elder Independence of Maine
- Senior Companions
- Elder Care of Maine
- Legal Services for the Elderly
- Eastport Senior Center
- Senior College Classes at UMM

Adult day programs:

- Sunrise Opportunities
- Robert and Mary's Place (adult daycare)

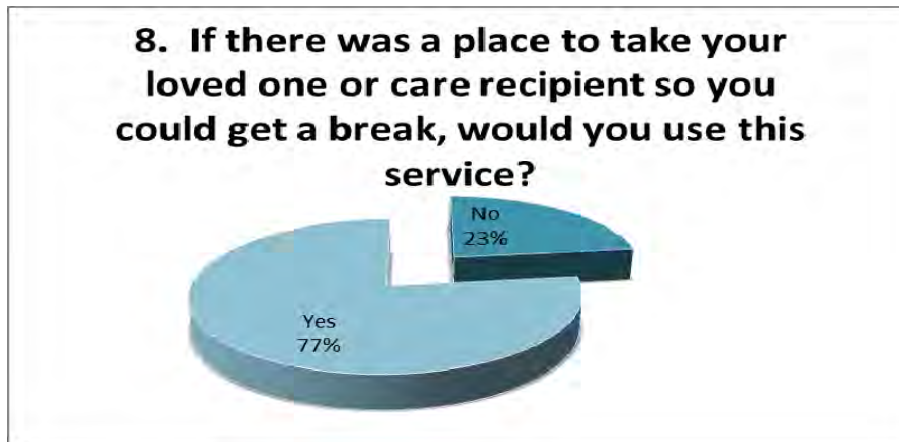
General social service and community-based programs:

- WHCA
- Maine Sea Coast Mission
- Cooperative Extension
- Pinetree Legal Services
- DHHS
- Alpha One

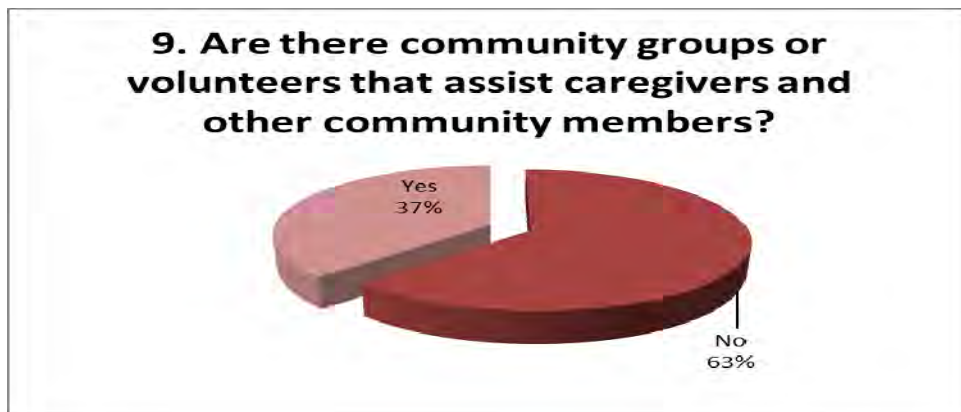
Other:

- Annual conference in Machias that addresses concerns of caregivers
- Food pantries
- Local churches
- Seniority group through Calais Hospital
- West Bus
- Dennysville Heights

8. If there was a place to take your loved one or care recipient so you could get a break, would you use this service?



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



Responses:

- Senior Companion Program
- Churches
- Friends and family
- Hospice programs in general
- Downeast Hospice
- University of Maine Cooperative Extension
- Catholic Charities of Maine
- Churches
- WHCA
- Local churches
- Local student council "adopts" seniors who need help with snow shoveling or just sitting and talking
- Nurses

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

Sample quotes:

- “I think they should leave more time for caregivers. 1-2 hours a day is just not enough time for what disabled people need. I realize the economy is bad but whoever is in charge should try to help more.”
- “We need a group that we can attend to talk openly regarding what we are going thru as AA has that is confidential. The emotions that a caregiver has with no one to talk to tend to sometimes get bottled up and are reflected in your attitude. One needs a physical or mental program to breathe thru these emotions.”
- “More people that come into the home and help the caregivers so they can have a break.”

Themes

Support groups/support opportunities for caregivers: Support groups and networking in general were requested to support caregivers in addition to support groups surrounding particular diseases such as Alzheimer’s disease and dementia.

Trainings: Training topics that would be helpful include: legal issues/ethics and how to assist a person with dementia.

Informational meetings/easy access to information: Informational meetings were noted as something that would be beneficial to inform community members about services and resources available to caregivers.

Transportation: Transportation is needed to medical appointments and to errands.

Respite care- Respondents recommended making home health and in-home respite more available and affordable in addition to developing more adult day service programs. A contact or resource list of potential private pay caregivers was also identified as a missing resource.

Higher pay: In general, higher pay for caregivers and community members was noted as something that is currently missing in this region of the state.

Supports for independent living: Various in-home supports were noted to be of particular value to caregivers including housekeeping services, meal prep, odd jobs, and home repair and maintenance.

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

Sample quotes:

- “Tell them what assistance programs are out there to help them.”
- “Come up with a program that would help caregivers to work outside the home (respite).”
- “Offer a comprehensive booklet of services with detailed descriptions of eligibility and services. Offer services to people that do not have MaineCare. Educate themselves to resources available in the community and be prepared to talk about the resources.”

Themes

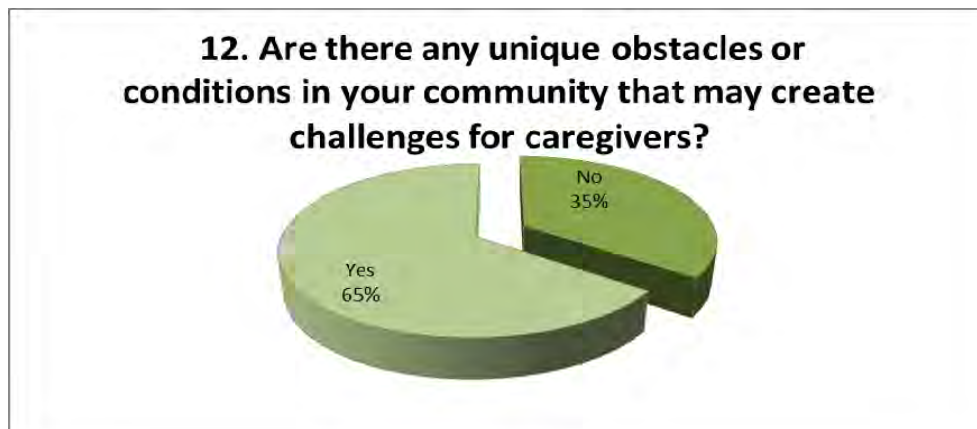
Advocate and support policy changes: Suggestions for supports that can be provided by politicians and decision makers include: cutting down on red tape that blocks access to services, increasing funding to rural areas; advocating for more assistance in Medicare and Social Security; decreasing taxes; and supporting health care reforms that place more care into people's homes.

Informing the public: Making information available to the public was identified as an important role that professionals can play in supporting caregivers. Information of interest includes services and resources available to caregivers and a resource list or a resource guide of what is available and the eligibility requirements for each service or resource.

More programs and home-based services: It was noted that more home-based services and programs are needed for the older adults and for caregivers.

More respite: Respite was identified as an area where more assistance could be provided including a list of volunteer respite providers and higher pay for private pay respite providers.

12. Are there any unique obstacles or conditions in your community that may create challenges for caregivers?



Sample quotes:

- “It is so large. Services are so spread out.”
- “Smaller communities without a lot of resources
- “Funding if you do not have MaineCare”

Themes

Transportation-Many people are living in rural areas of the county and do not have access to public transportation to get to necessary services and appointments.

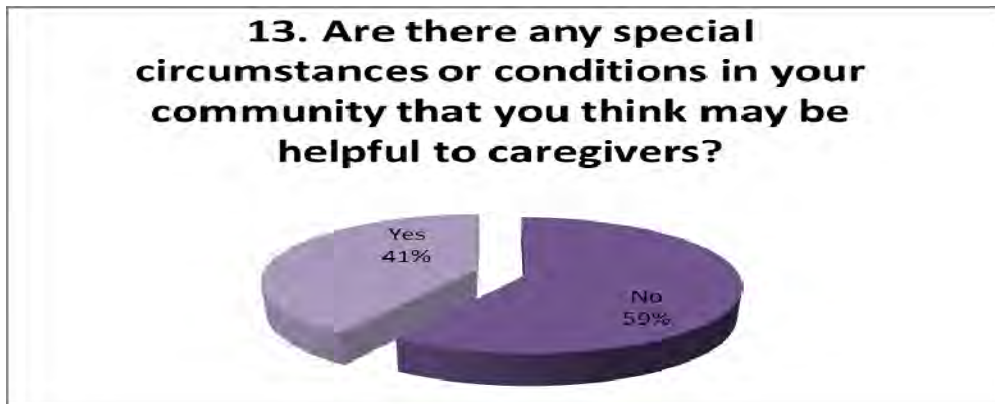
Lack of caregivers and volunteers: There was noted that there is a general lack of caregivers and volunteers who could help as well as a lack of caregivers who have the education and training to provide care.

Weather and distance: In the winter the roads can be very dangerous and take more time to travel throughout the region. In addition, the rural nature of this county and the great distance to services creates an added burden for caregivers.

Lack of funding: Lack of funding for programs and supports is of particular concern for people who do not have MaineCare and must cover their expenses on their own. In addition, lack of funding also translates into a lack of available services (medical and social services) for residents.

Individualism and independence: Several responses pointed to the notion that, in Washington County, there may not always be the approach of “neighbors helping neighbors.” Instead, some communities have a territorial perspective on working with other communities. Neighbors may not be willing to help on an individual basis.

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



Sample quotes:

- “Yes people in Washington County do care about their neighbors and are willing to help out so they could be mobilized to provide a volunteer force to provide help to caregivers. There are also a lot of hard-working, creative, and innovative people who live in Washington County and want to see their communities thrive.”
- “We have available a wonderful medical center which could be helpful to caregivers for support groups, workshops, etc.”
- “Small towns-neighbors and family help each other out.”

Themes

Neighbors helping neighbors: The majority of respondents noted a sense of community in local towns and that neighbors tend to help one another. Community members are needed to help with building wheelchair ramps, home repair, and meal preparation.

Providers and programs as assets: While respondents noted a lack of resources available in Washington County, it was also suggested that providers that are operating in this area are accessible and helpful and could serve as assets in helping caregivers.

Other: The Senior Companions was noted as a resource; the need for more volunteers; higher pay needed for workers and caregivers; more adult day programs for seniors, etc.

14. In your opinion, what kinds of workshops or trainings would be helpful to you or others who are caregivers?

Sample quotes:

- “All aspects of helping. Those that are homebound or need a little assistance.”
- “Classes for the caretaker on feeding, handling, and bathing.”
- “Resources that are out there. How to understand the different programs and who qualifies.”

Themes

Programs and resources: The majority of respondents expressed a desire to learn more about what programs and resources are available, eligibility requirements for programs, and how to access program and services that are available.

Hands-on and basic caregiving techniques: Workshops on hands-on care techniques such as bathing and feeding and general caregiving were noted as being beneficial to caregivers.

Disease-specific trainings: Disease-specific trainings requested included those that provide information on dementia, Alzheimer’s, depression, and cognitive disabilities.

Caregiver self-care: Respondents identified a need for caregivers to learn stress management techniques and have an opportunity to meet other caregivers and learn that they are “not alone in this journey.”

Local individualized trainings: Several respondents stressed a need for trainings to be carried out locally in easy to access locations. In addition, several respondents noted that findings from this project could be used to shape trainings provided to caregivers.

14a. Please list topics that would be helpful:

Health and disease information:

- Alzheimer's disease
- Dementia
- Parkinson’s disease
- Diabetes
- Seizures
- Understanding medical terms, jargon and medications
- Brain tumors and injuries
- Newer drugs for patient-specific illnesses
- How to deal and live with end stage congestive heart failure
- CPR
- Healthcare information
- Understanding the needs and actions of those with cognitive disabilities
- Caring for someone who has had a stroke

Hands-on care and techniques:

- Understanding and coping with dementia, incontinence, difficult behaviors
- Learning to proper lift techniques
- Guiding loved one when walking
- Fixing food so it will be easy to eat
- Bed sore care
- Having a trained nurse to give insights on hands-on care
- Classes on how to move and care of someone who is bed ridden.
- Basic hygiene for those with disabilities
- Medication maintenance and dispensing
- Basic first aid
- Home safety/setup
- Nutrition suggestions

Programs and resources available:

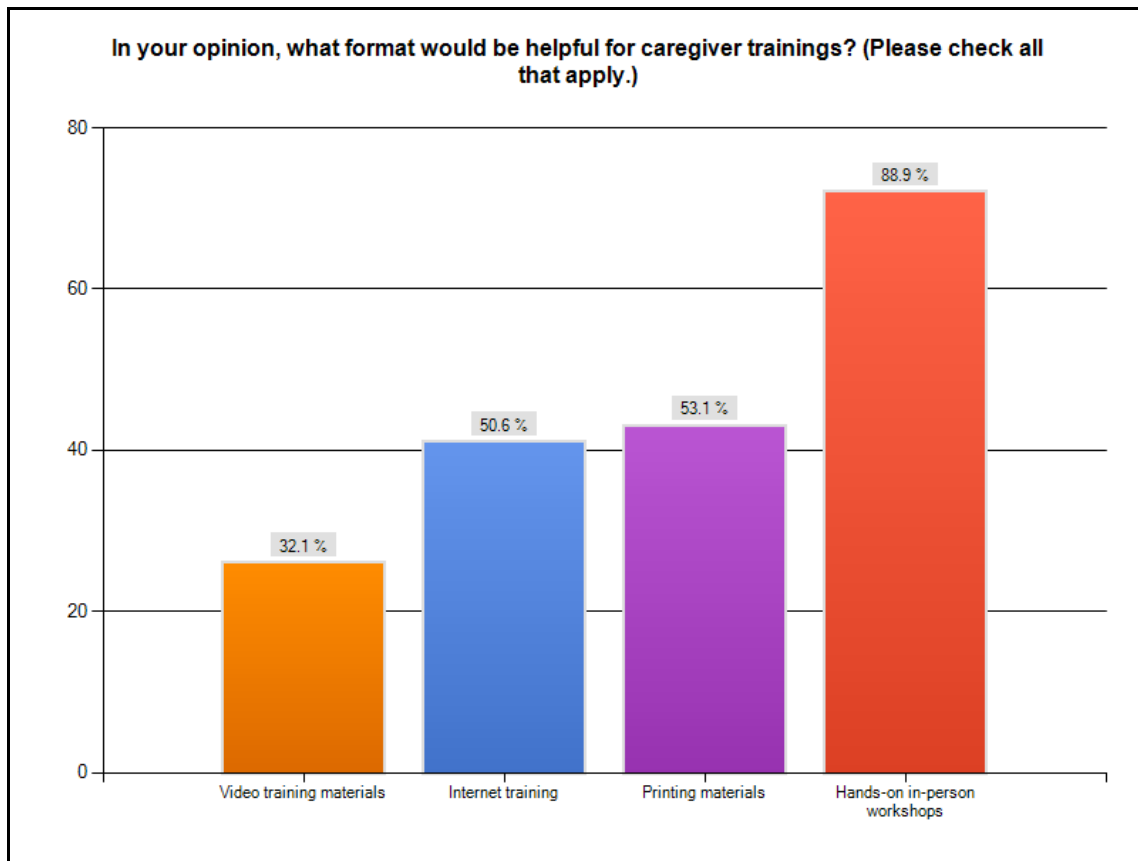
- Programs available
- Network of contacts
- List of services available and how to apply
- What agencies are out there and what they do to help
- How to navigate the healthcare system, who can help with navigating the healthcare system
- In-home respite options for those without insurance
- Social Security trainings
- Financial assistance available
- A listing of lawyers who have experience in elder law
- In-home services and assessments for those with Alzheimer's disease or dementia
- Transportation options
- Navigating the DHHS system for new comers.
- Support systems for caregivers
- Accessing appropriate care
- How to be a smart healthcare consumer

Self-care:

- How to not feel overwhelmed when trying to manage working, traveling for appointments, medical care, providing support at home and attending to one's own needs and recreation
- Stress management
- Handling guilt
- How to cope with your feelings
- Caregiver networking
- Importance of caregivers taking care of themselves

14b. In your opinion, what format would be helpful for caregiver trainings?

respondents were allowed to select more than one response



15. If you would like, please add any other comments or ideas you may have about this topic.

Sample quotes:

- “Needs of coordination of service, advocate for more supports and respite for care providers, financial planning, reimbursement for care, outreach services, needs for both elder and caretaker.”
- “Older people like me do not like getting out or even getting ready to go out.”
- “There needs to be a grocery delivery in the Washington County areas. More money and services are spent on drug addicts than seniors!”
- “Early intervention seems to be key with caregivers. Many, mostly women, get to the point of being too exhausted to act on accessing resources or help and end up with serious health problems themselves.”
- “If there were video training materials, it may be a good idea to contact local community TV stations to see if they would play them on their station.”
- “I was blessed with help from Community Health & Counseling Hospice program when both my mother and my husband were dying with cancer. They were outstanding! I don't know what I would have done without them. Downeast Hospice also helped with my husband. They were wonderful as well.”
- “This is a wonderful thing, and I am glad that it has come to Washington County, and I hope that some tangible results are realized for Washington County through this. There are young people up here who have old people's diseases who are not young enough to be children and therefore are not helped through the children's' programs, and they also are not elderly so, do not fall under that category. There is a desperate need for help with those who fall in between, if there is a way to combine to help all with this it would be so wonderful. Thank you.”
- “Having to drive 2 hours to Bangor or 4 hours to Portland, just to see a specialist, is extremely taxing. Having to wait 2 to 3 weeks for an appointment with a specialist is taxing to the patient and the caregiver. Having to wait 3 weeks for an X-Ray appointment (after having been to the emergency room in Calais) is unacceptable.”

Themes

In general, the comments provided under this section were diverse and touched upon personal caregiving stories, the lack of resources in Washington County, and an interest in seeing more services developed in the region.

Part 2: Washington County Community Focus Groups

During the spring of 2011, three focus groups were convened as part of the Caregiver Network Project caregiver needs assessment for Washington County. A total of 18 individuals participated in these focus groups. Two of the 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. The mixed groups were recruited through flyers and direct contact with service providers. The following section presents a summary of focus group findings.

Focus Group Participant Snapshot

There were a total of 18 focus group participants, 12 of whom returned demographic forms.

- The average age of focus group participants was 59.5 with a range of 40-72 years
- 75% were female and 25% male
- 58% were married/partnered, 8% never married, and 33% were divorced or separated
- 50% non-Hispanic white and 50% American Indian
- 8% reported their highest level of education as grammar school/grade school, 25% high school, 58% college, and 8% graduate school*
- 33% of participants lived alone, 50% live with spouse/partner, and 17% live with other relatives
- 33% of participants were employed, 42% retired, 17% unemployed, and 8% provided no answer to this question
- 42% of participants were currently serving as a caregiver and 67% knew of other caregivers in their community.
- 92% of all respondents are either currently a caregiver or have been a caregiver in the past.

*Proportions for education levels do not add up to 100% due to rounding.

From the focus groups held, it appears that the participants of the groups were lacking some key support that would assist them as caregivers. The caregivers expressed challenges of the financial burden, especially if they have no insurance, that caring for a loved one presents. They also expressed a need for more information regarding resources, in particular what they are and the eligibility requirements.

It was noted that being a caregiver subjects one to feelings of being overwhelmed, which can lead to depression. The lack of knowledge of resources and/or inability to access them due to obstacles can heighten a caregiver's stress level. Ways to manage stress, such as support groups and respite care,

were discussed. However, these, along with transportation to access resources, continue to be considerable needs for the caregivers in Washington County communities.

Many of the participants were not aware of, or do not know, how to find resources in their local area(s). More outreach is needed to ensure that community members know where to turn to find the resources need to support their caregiving. Many informal resources, such as family and friends, are limited and cannot be sustained long-term without assistance from the formal network. Formal resources are not always affordable or accessible to the caregiver. Caregivers asked for additional resources to become available to them such as workshops, trainings, and additional general information to aid them in their part of caregiving, such as ways to afford or access necessary services, and development or expansion of services.

Focus Group Questions and Responses

The term “caregiver” means different things to different people. What does this term mean to you?

When asked to define the word “caregiver”, focus group participants associated it with caring for an individual due to family relation or obligation. Participants stated that feelings of emotional stress and being overwhelmed were associated with being a caregiver.

Sample Responses:

- It’s a 24/7 job
- Hard – trying to work and give care simultaneously
- Financial Burden – Risk of losing one’s home in order to be eligible for Mainecare
- People see themselves as ‘spouses’, or ‘children’ taking care of their parents rather than as a “caregiver.” It’s just what they do.
- “Helping people who can’t help themselves”
- The caregiver doesn’t have to be related, they can be a neighbor or friend

In your opinion, what are the biggest challenges faced by caregivers in this area?

The biggest challenges facing the caregivers in Washington County are transportation, respite care, knowing what the resources are and eligibility requirements, personal care for the care recipient, and emotional support.

Sample Responses:

- It gets overwhelming when someone is dying and there is no money to pay a friend who helps
- Fear of losing home to become eligible for Mainecare
- Trying to find help and what someone is eligible for

- How to attend to personal care of loved one: hygiene, safety, etc
- Caregivers don't always identify themselves as such. They are family, see it as their role, and do not seek help
- Limited finances
- Stress of keeping the person home or looking at a nursing home
- Independence, stoicism – don't ask for help

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

Participants were generally aware of a few agencies that could offer assistance in some way. However, the general consensus was that they'd like a directory of resources listing what assistance are offered, contact information, and the eligibility requirements.

Sample Responses:

- Downeast Hospice
- Eastern Area Agency on Aging (EAAA)
- Janet Lewis (of EAAA)
- Home Health
- Department of Human Health Services (noted as “not helpful” by one participant)
- Care and Comfort
- Washington Hancock Community Action (WHCA)
- Community Health & Counseling
- Sunrise

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

In general, participants were not able to identify specific groups in the community that targeted helping caregivers. There appeared to be a lack of volunteer or service groups that could be tapped.

Sample Responses:

- Neighbors
- A volunteer group comes once a year from Massachusetts (Passamaquoddy Nation)
- Churches
- Masons
- Lions
- High School Students doing required community service (Lubec)

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

The participants identified home care, training, transportation, and support groups to be lacking. This type of assistance would be extremely beneficial.

Sample Responses:

- Training – To help people care for others
- Van for elder transportation
- Housekeeping Help
- Home Care, including overnight
- Support groups

Are you aware of any specific obstacles or barriers that could get in the way of providing support to caregivers locally?

The main obstacle that was identified in all focus groups was the lack of or inaccessibility to transportation and the lack of money. The other obstacle is inherent to the ‘Maine Way’ of being independent, proud and self-sufficient.

Sample Responses:

- People are stubborn – want to stay independent
- Proud – Don’t want to ask for help
- Lack of money for care
- Relatives can’t get paid for helping
- Isolation – the need to get out of the home
- Limited number of Personal Care Attendants
- Lack of knowledge
- Transportation unavailable, inaccessible, or unaffordable

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

The focus group participants felt that training, support groups and general information regarding resources would be of most benefit to the caregiver. There appeared to be a common request for a resource directory.

Sample Responses:

- Promote the WHCA bus that provides transportation for elders/caregivers
- Develop a resource list
- Use a caregiver advocate to assist in gathering resources and getting them to the community
- Establish support groups within the community

Do you know of any trainings or workshops offered in your area that would be particularly helpful for caregivers? What kinds of trainings or workshops could be developed to further support caregivers?

The focus group participants were not readily able to identify any known workshops or trainings other than a CPR course in the past (Passamaquoddy Nation). They did, however, feel that trainings in personal care, Alzheimer's, dementia, and caregiver wellness workshops would be beneficial.

Sample Responses:

- Focus on the caregiver
- CPR for all community members
- Alzheimer's and dementia
- Resource availability
- Legal Issues
- Respite opportunities

What is the best way to inform caregivers about available services and workshops?

Because Washington County is a rural area, participants responded that word of mouth was the primary source of information. Getting the information to key resources would be necessary. It could then be distributed through church bulletins, community socials, and friends and neighbors.

Sample Responses:

- Word of Mouth – a calling tree of sorts
- Church
- Information at Senior Centers

Is there anything we haven't covered yet that you would like to share about caregiving?

One focus group participant noted that some communities are adopting a type of co-op model, where people exchange services and support. That might be something that Washington County could pursue. Whereas Mainers are accustomed to taking care of each other,

neighbor-helping-neighbor, increased use of modern communication venues (e-mail, social networks), could be advantageous to caregivers.

Sample Responses:

- A Co-Op model being used in Hancock County could be beneficial
- Increased use of modern technology and communication media

Attachments

- I. Two Page Summary of Findings
- II. Asset Maps and Washington County Resources

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

Study background: The Washington County caregiver needs and resources assessment utilized surveys and focus groups to provide a greater understanding of the experiences of caregivers in Washington 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 particularly for health services, make 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.

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.

Informal networks: Informal networks were noted to be important to promoting the spread of information throughout Washington County communities. However, few community members could point to particular informal networks and volunteer groups who help community members with caregiving.

Lack of awareness of formal resources: Many caregivers and community members reported a lack of knowledge of available resources, programs, and benefits for which they may be eligible. However, many were able to identify at least one agency that serves caregivers.

Strengths

Friends and family willing to help: Many caregivers reported having friends and family members whom they could turn to in times of need.

Local resources: There are local resources in place identified by caregivers and community members that could be tapped to provide training and supports for caregivers.

Willingness to access resources when available: Community members pointed to a general willingness to use community resources or workshops if they were aware of such resources locally.

Resiliency and strength of caregivers: Given the rural nature of Washington County, many caregivers have had to be creative in developing solutions to the challenges they face, such as emotional stress and the physical difficulties of caring for another.

Recommendations

- Increase the availability and the affordability of respite through formal programs and initiatives
- Tap local informal support networks and volunteers to provide respite and support for caregivers
- Develop support groups and networking opportunities for caregivers to reduce isolation and combat the stress of providing care
- Hold public sessions on benefits and programs that are available for older adults and caregivers and increase outreach in rural communities when possible
- Develop local, targeted trainings that provide information on resources, healthcare information, hands-on techniques for caregiving, and caregiver self-care
- Develop training and outreach materials that are in attractive and accessible format for caregivers such as printed materials and/or internet resources
- Address barriers to accessing programs and increase service coordination including developing networks of professionals that can exchange resources and increase coordination among each other

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University of Maine Center on Aging

25 Texas Avenue, Camden Hall

Bangor, Maine 04401

Phone: 207-262-7923

E-mail: info@mainecenteronaging.org

Web: www.mainecenteronaging.org

Washington County Caregiver Resource Listing & Map

The resources listed below can be used as a guide to the various services in the Washington 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: Lisa King-Caregiver Support Specialist for Washington County
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
- Care Coordination
- 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

Friendship Cottage (Currently under development)
Machias, ME 04654

Proposed 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
- Caregiver support group
- Caregiver Resource Center
- 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 Caregiver 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*

Friendship Cottage*

*See above for more information.

CAREGIVER SPECIFIC RESOURCES

Support Groups

EAAA*

Friendship Cottage*

*See above for more information.

Robert & Mary's Place

72 Dublin Hill

Machias, ME 04654

(207) 255-4600 OR (207) 546-1255

Contact Person: Tanya Berry, Program Director

- Service: Support group last Friday of the month

Down East Community Hospital

11 Hospital Drive

Machias, ME 04654

(207) 255-3356

Contact Person: Rev. Bonnie Hasse

- Support group waitlist may apply

Adult Day

Friendship Cottage*

*See above for more information.

Robert & Mary's Place

72 Dublin Hill

Machias, ME 04654

(207) 255-4600 OR (207) 546-1255

Contact Person: Tanya Berry, Program Director

- Service: Adult day program

New Horizons Adult Day Care

144 South Street
Calais, ME 04619
(207) 454-3709

- Service: Adult day program

In-Home Respite

Friendship Cottage*

*See above for more information.

Sunrise County Home Care

11 Broadway
Machias, ME 04654-1141
(207) 255-3344
Website: www.regionalmedicalcenter.org

Living Innovations Home Care

89 Main Street
Machias, ME 04654
(207) 255-3733

Services provided include recruiting, screening, training, assigning, and supervising a variety of home and community support providers:

- Respite care providers (in/out of home)
- In-home companions and homemakers
- Supportive roommates/housemates
- Job developers/Job coaches
- Community integration specialists
- Transportation providers
- Host families (ISO home providers)
- Personal care service providers
- Home health aides and CNA's/LNA's
- Skilled nurses

Senior Companions

Helping elders stay independent can be a challenge in Maine's rural areas. Many older adults do not have relatives living nearby and must rely on others to help them. Through the University of Maine Cooperative Extension's Senior Companion Program, homebound elders are able to stay in their own homes longer thanks to regular visits from Senior Companions — dedicated, active individuals age 55 and older.

University of Maine Cooperative Extension
5741 Libby Hall
Orono, ME 04469-5741
Phone: 1-800-287-1542
E-mail: scpstateoffice@maine.edu
Website: <http://umaine.edu/seniorcompanion/>

TRANSPORTATION/MOBILITY

EAAA*

*See above for more information.

West Transportation

P.O. Box 82
Milbridge, ME 04658
1-800-596-2823
(207) -546-2823

Service:

- Transportation

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

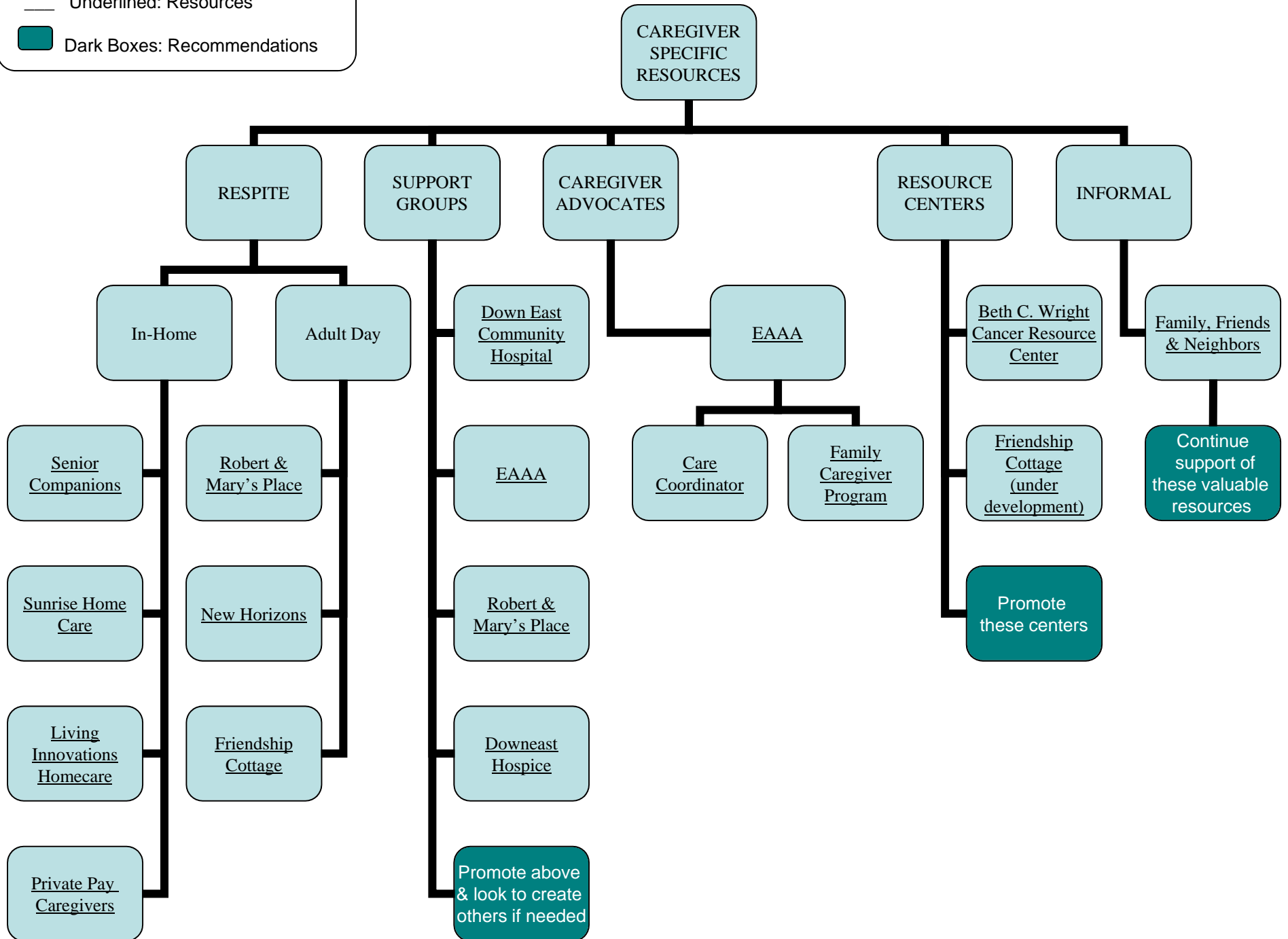
Services:

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

KEY:
— Underlined: Resources

■ Dark Boxes: Recommendations

Washington County Caregiver Specific Assets

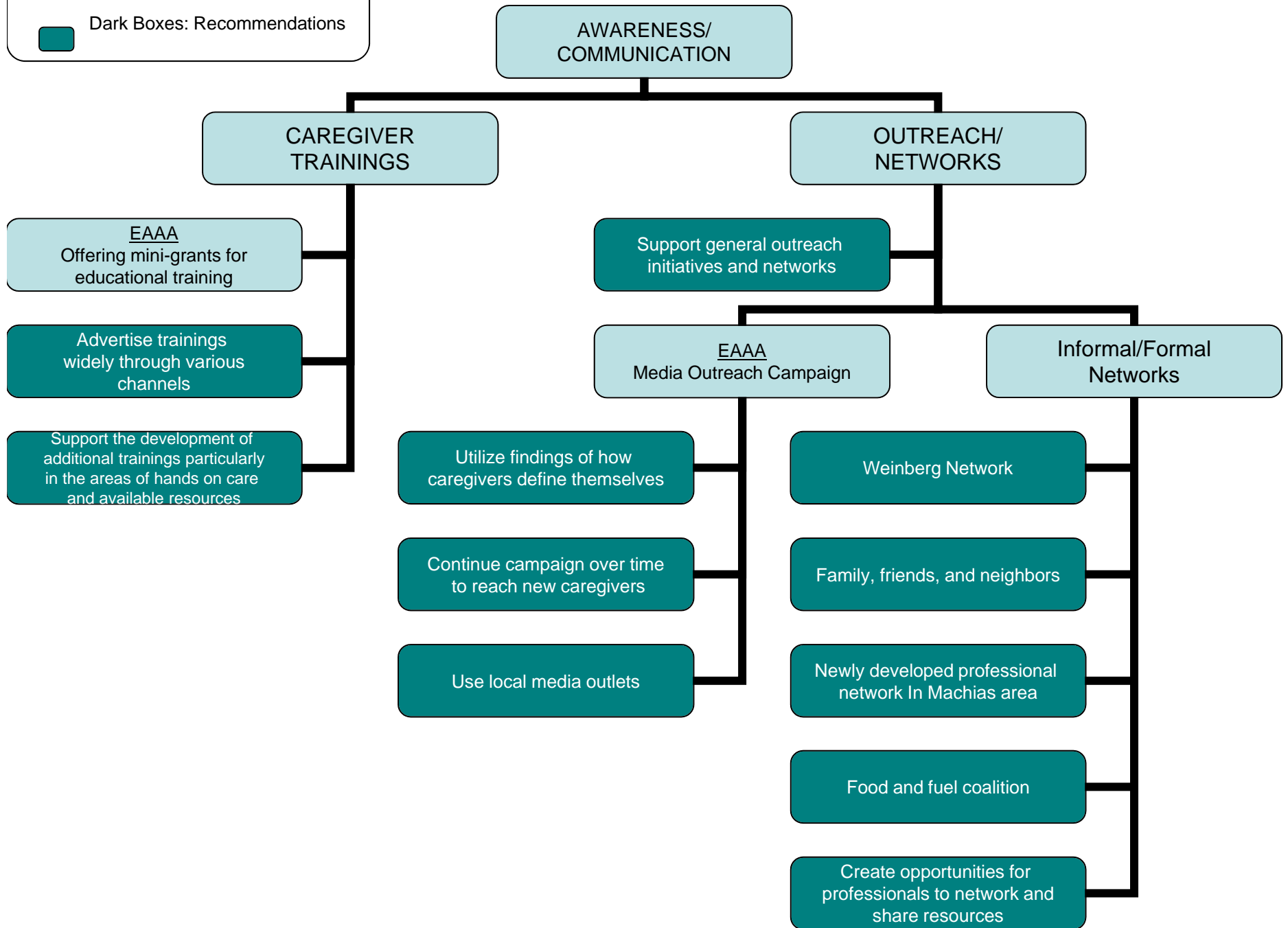


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Dark Boxes: Recommendations

Washington County Awareness and Communication Assets



KEY:

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■ Dark Boxes: Recommendations

Washington County Transportation Assets

