

Giving and Receiving Care in the Adirondacks Community Empowerment Action Plan



A Plan of Community Engagement and Collaboration

Facilitated by Mercy Care for the Adirondacks
And Developed By
The Caregiving Working Group of Essex and Franklin Counties
March 2014



Mercy Care *for the Adirondacks*

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Mercy Care for the Adirondacks

History, Mission, & Values: Established in 2007, Mercy Care for the Adirondacks is a renewed mission of the Sisters of Mercy. The Sisters of Mercy first came to the Adirondacks in 1895 to establish Sanitorium Gabriels to treat tubercular patients and have provided love and care to elders and infirm people ever since.

It is love of God and love of neighbor that has brought about the founding of Mercy Care and continues to inspire it today. Mercy Care's mission is to enhance in every dimension the fullness of life of elders living in their communities.

Mercy Care is developing a new social model of extending mercy to elders living in their communities to relieve their isolation and loneliness and serving as a catalyst and facilitator of systemic change to empower older adults to age in place more

successfully. Mercy Care's mission is implemented through three interrelated strategies:

1) **Direct Service to Elders.** Mercy Care works to enhance the fullness of the lives of elders by responding to their needs in a holistic manner through direct service, including consultation, advice, or referral through its Friendship Volunteer and Parish Nurse Programs.

2) **Community Empowerment.** Mercy Care extends mercy to elders by encouraging each community to develop facilities, programs, policies, and practices that support a fullness of life of elders in the community. Mercy Care serves as a catalyst and facilitator for such community development and provides organizational support so that the community itself will become empowered to develop in a manner that will render the community more elder friendly.

3) **Education and Advocacy.** Through its educational forum program and other outreach activities, Mercy Care seeks to promote an understanding of issues and challenges in the lives of elders and of the impact on elders of the policies and practices of communities, the state and the nation. Mercy Care advocates for justice in the policies and practices that impact the lives of elders in the community and the wider society.

Acknowledgement

Mercy Care for the Adirondacks is supported solely with charitable contributions and grants. Since its establishment, grants to support Mercy Care's work have been received from:

Anonymous NYC Foundation, Adirondack Community Trust, Adirondack Health Foundation, Frances L. Carpenter Foundation, Thomas and Agnes Carvel Foundation, The Max and Victoria Dreyfus Foundation, Inc., Conrad L. Hilton Fund for Sisters, Infant Jesus of Prague, Inc., McCutchen Foundation, J. M. McDonald Foundation, Mercy Action Fund, NYS Department of Health, NYS Office for the Aging, The Glenn and Carol Pearsall Adirondack Foundation, Jacob L. Reiss Foundation, Sisters of Mercy Mid-Atlantic Ministry Fund, Vopicka Family Foundation, and the Charles R. Wood Foundation.

“There are only four kinds of people in the world: Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need care.” Former First Lady Rosalynn Carter

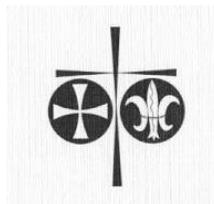


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Introduction

Building on its successful Aging in Place Community Empowerment Project, Mercy Care and its collaborating partners recognized the importance of caregiving and the need to develop a community empowerment action plan to determine and address the existing patterns of caregiving, the current and expected future needs for caregiving, and the personal and social needs of caregivers and care receivers themselves.

In the past elders were cared for by family members who continued to live with them in their family home or alternatively elders moved to live with their adult children and families. Although caregiving by family members continues to be the most common form of caregiving of elders, several societal trends have made its implementation more difficult. Some elders who may need the services of a caregiver value their independence and are reluctant to call upon any of their children who have their own families and careers to take care of. They often try to take care of themselves in their own homes even when they are not really able to do so.

In today's society before the age of 60 parents typically reach an "empty nest" phase when their children have left the home to pursue their own educations, careers, and/or marriage. With the increased life-span of older people this empty nest phase becomes longer, constituting a quarter or more of a person's total life-span. Geographic mobility of individuals and families in this country brought about by job or career, as well as by a new retirement destinations, often creates considerable distance between the homes of elders and their children.

A daughter or daughter-in-law, who in the past was the one most likely to care for a parent, is today more likely than in the past to be employed and less available for caregiving. As a result, sons, daughters and other family members are less likely to be in a position to become caregivers of parents no longer able to care for themselves. This is particularly the case in the Adirondacks where a high portion of the younger generation have been moving away for education and career, leaving their parents behind. It is one reason that elders constitute proportions of the populations of Essex and of Franklin counties that are among the highest proportion of any county in the state and nation. In addition, increasing numbers of elders are moving in retirement to the Adirondacks, where they may have vacationed in earlier years, separating themselves geographically from family and friends.

It is clear that, if Mercy Care and its collaborating partners are to be successful in helping to empower elders to live in their own homes for as long as possible, postponing or eliminating the need and greater costs of institutional care, it must seek with other organizations to insure that elders have available adequate caregiving in their homes to meet their needs.

Paul J. Reiss, PhD., President
Mercy Care for the Adirondacks

Background: The Caregiver in New York State
Excerpts from the *Report: Caregivers in Crisis—Why New York Must Act*
Published by AARP and New York State Caregiving & Respite Coalition
November 2013

“New York’s caregivers need help. A 2011 national report by AARP’s Public Policy Institute, the Commonwealth Fund, and the SCAN Foundation found New York ranked 48th out of 50 states with regard to support for its family caregivers.”

“Over four million family caregivers in New York State are providing unpaid care for a loved one. The New York State Office for the Aging (SOFA) estimates that unpaid caregivers provide the majority of all long-term care services to older adults and individuals with disabilities.”

“The need to help caregivers will only increase in the coming years as the baby-boom generation ages and the number of younger people proportionately decrease.”

“New York State policy on long-term care has been largely focused on slowing the growth of Medicaid. However, little discussion has occurred on how to slow the growth of Medicaid by investing in non-medical community based programs, particularly those assisting caregivers.”

Giving Care and Receiving Needed Care in the Adirondacks

Statement of Problem

In the Adirondacks, for those who are not eligible for Medicaid, but yet do not have enough income to hire home health aides and pay for other home and community based services, there is little assistance possible for family caregivers and those needing care. Family care may not be adequate, sufficient, or available.

Regardless of income, in many communities, there simply are not adequate home and community based services available to care for people in Essex and Franklin Counties in the Adirondacks.

Public policy is structured now so that elders who need caregiving services, in many cases, must spend themselves into poverty before they are eligible for financial assistance through Medicaid. With a change in public policy to assist elders with some financial assistance to help them cover some of their caregiving expenses before they are poverty-stricken, it might well be that elders will be able to remain at home longer thus delaying or preventing more expensive institutional or residential care at public expense.

Caregiving in the Adirondacks Community Empowerment Action Plan

This Caregiving Community Empowerment Action Plan illustrates the unique needs, findings, and potential solutions for elders who need and want home and community based care in Adirondack communities so that they might age in place more successfully.

Unique Caregiving Needs In Rural Adirondack Communities:

In addition to the cold and severe winters and long distances from services, people in Adirondack communities are not only older than national and state averages, but they have fewer personal resources to cope with aging. The 2010 Tri-Lakes Housing Study found the median household incomes in Essex County adjusted to 2008 dollars were \$44,374 in 2008 for all age groups and \$39,802 in Franklin County. The national median household income adjusted to 2008 dollars was \$52,029 (U.S. Census Bureau).

Population Served:

In the same Tri-Lakes Community Housing report, projections from the Cornell University College of Human Ecology Program of Applied Demographics concluded that the most significant finding from the population projections is in the period 2015 - 2035, particularly when broken down by age. **In terms of age cohort the projections indicated all cohorts below the age of 50 will experience double digit declines while the cohort of residents 50 and older will experience double digit increases.** For many years younger generations in this rural area often move away for education and careers, leaving the older generation behind.

Plan Goal: To foster adequate caregiving in elders' communities to enable them to age in place for as long as possible.

Plan Purpose: Building on the work of the Tri-Lakes Aging in Place Task Forces, the *Caregiving in the Adirondacks Action Plan* is meant to create the conditions for Essex and Franklin Counties to be good places for people to age in place more successfully by receiving adequate home and community-based caregiving services.

Caregiving Action Plan Values: Since a person is one integrated whole, care should be holistic, addressing the physical, social, intellectual, emotional and spiritual needs of the each person receiving care and giving care. It takes the community itself to help elders age in place more successfully.

Plan Development: Because of the change in public policy toward having elders who need care receive it in home and community based settings, rather than in institutions, every caregiving agency in Essex and Franklin Counties

came together as a community to respond. The number of nursing home beds in the Tri-Lakes area and the Malone area are declining significantly.

Understanding that government resources are diminishing and that adequate home and community based services are not yet fully developed to meet the increased caregiving needs in Adirondack rural communities, the Caregiving Working Group concluded that the community itself would need to create the conditions to respond to the needs.

Steps in Plan Development:

January 2013

- Caregiving Working Group established
- Set of goals and objectives adopted to develop Caregiving in the Adirondacks Action Plan

March 2013

- Set of Key Questions developed by Caregiving Working Group to conduct Focus Groups & Interviews with caregivers and care receivers in Essex and Franklin Counties

May 2013

- Educational Forum - Paul Smith's College—*Elder Caregiving in Rural Communities*; Linda Lindsey Davis, PhD., Anne Henshaw Gardiner Professor of Nursing, Duke University; Nationally recognized Expert—*R.U.R.A.L. Model for Community Based Elder Care Programs*

May 2013 - August 2013

- More than 50 personal interviews conducted with caregivers and care receivers by Caregiving Working Group Members and Mercy Care for the Adirondacks

September 2013

- Community-wide Caregiving Needs Assessment Survey drafted by Caregiving Working Group

October - November 2013

- Caregiving Needs Assessment Survey disseminated and collected

December 2013

- Caregiving Needs Assessment Survey results analyzed by Caregiving Working Group

January - February 2014

- *Caregiving in the Adirondacks Community Empowerment Action Plan* Drafted

March 2014

- Caregiving Action Plan adopted by Caregiving Working Group

Next Steps

- Work Plans to implement the actions called for in the plan will be developed and implemented over the next two years

The Action Plan Giving and Receiving Care in the Adirondacks

Introduction: As we age, we cannot know what will be our health conditions and our abilities in the years ahead and those of others who are important to us. If you need care one day or if a loved one needs care from you or someone else, new actions need to be taken to ensure people have access to the care services they will need to age in place successfully for as long as possible.

After conducting an initial set of more than 50 personal interviews with caregivers and care receivers and then conducting an extensive caregiving community needs assessment in Franklin and Essex Counties, it was found that new actions are needed to foster adequate caregiving in elders' communities to enable them to age in place for as long as possible.

Plan Organization: The Action Plan is organized into three different sections:

1. Caregiver and Care Receiver Needs
2. Caregiver and Care Receiver Concerns
3. Barriers to Needed Care

1. Caregiver and Care Receiver Needs:

Caregiver and Care Receiver Needs	Actions Identified
<ol style="list-style-type: none"> 1. Socialization for care receiver, respite for caregiver 	<ol style="list-style-type: none"> a. Continue to develop and grow new and existing Friendship Volunteer Programs to visit care receivers and provide respite to caregivers b. Use invitation for socialization as a method to help caregivers connect with each other, learn about informal and community support services; include respite care for care receiver, while caregivers participate in social engagement. c. Develop an emergency

Caregiver and Care Receiver Needs	Actions Identified
	<p>planning tool for caregivers in case their own health declines or other circumstances prevent them from fulfilling their caregiving responsibilities.</p> <p>d. Work with health care providers, independent living, assisted living, and health and human service agencies to assess the need for overnight or longer-term respite care. Develop services to meet respite care needs.</p> <p>e. When respite services are more fully developed, create a “Caregiver and Care Receiver Guide to Respite Services.”</p>

2. Caregiver and Care Receiver Concerns

Concern	Actions Needed
<p>1. Concern that care recipients (and their caregivers) will have available the guidance and advice they need, especially if their condition worsens.</p>	<p>a. Advocate for the development of a Caregiving hot-line or phone-in center in an existing agency or organization.</p> <p>b. Develop program of coping strategies, training, spiritual comfort care, and family counseling for the</p>

Concern	Actions Needed
	<p>caregiver and care receiver to better understand what to expect and what to do, if the care receiver's condition worsens.</p>
<p>2. Services are not available</p>	<ul style="list-style-type: none"> a. Further develop the capacity of organizations like Mercy Care to serve caregiver needs with volunteers, including respite care and door-through-door transportation b. Mercy Care and Collaborating Partners to develop a program of options counseling for care receivers and caregivers when services are not available in the community c. Caregiving Working Group to identify which additional home and community based services are necessary for elders to age in place for as long as possible, especially when family members are not available for caregiving. d. Develop advocacy agenda for development of

Concern	Actions Needed
	<p>additional home and community based services to enable elders to age in place successfully.</p> <ul style="list-style-type: none"> e. Caregiving Working Group to promote strategy to plan for continued aging in place for those already receiving care. f. Caregiving Working Group to advocate for the establishment of shared housing opportunities g. Develop a “pilot caregiving program” to meet the most pressing needs of caregivers now before the Action Plan is implemented.

3. Barriers to Needed Care

Barrier	Actions Needed
1. Lack of information	<ul style="list-style-type: none"> a. Develop a Holistic Caregiving Needs Assessment Tool. The tool would be used by Mercy Care, health and human service agencies, healthcare institutions, physicians, and others to evaluate each individual’s unique needs for

Barrier	Actions Needed
	<p>caregiving.</p> <ul style="list-style-type: none"> b. Mercy Care to develop a caregiving empowerment model to assist caregivers and care receivers, with specially trained volunteers, to accompany them on their holistic journey of navigating the path of finding needed care or services. c. Develop a referral model to be used by physicians and other health care providers to health and human service agencies, when it is anticipated that a person’s health is declining to a point where they will need home and community based care services.
<p>2. Home health aides—work force is inadequate to meet the home and community based care needs of elders living in some communities; Nursing Home Waiver care receivers are not able to get the number of home health aide hours authorized due to lack of available home health aides. Without an adequate home health aide work</p>	<ul style="list-style-type: none"> a. Advocate to increase the number of home health aides in Franklin and Essex Counties b. Workforce development—Work with other organizations and institutions to research what needs to be done to attract and retain an adequate home health aide workforce, especially in rural areas. Implement solutions.

Barrier	Actions Needed
<p>force, the method of caring for elders by providing home and community based services collapses on itself.</p>	
<p>3. Inadequate finances</p>	<p>a. Advocate for increased funding and access to Expanded In-Home Services for the Elderly (EISEP services include non-medical in-home services such as housekeeping, personal care, respite, case management)</p>

Caregiving Needs Assessment Survey Results

Respondents



- 277 responses received
- Lake Placid 21%
- Saranac Lake 24%
- Tupper Lake 14%
- Other – Franklin County 11%
- Other—Essex County 30%

Excerpts From Caregiver Narrative Responses Caregiving in the Adirondacks Needs Assessment Survey November 2013

Hearing directly from caregivers and care receivers themselves through their responses in personal interviews and through their narrative survey responses compels us to act.

Who is most likely to be your primary caregiver, if you need one now or in the future?

- Unknown, depends upon whether I become blind.
- Not sure at this time.
- We have a home health care policy.
- I have long term and nursing home insurance
- Not sure because of income limitations
- No idea...I have no family in the area. My partner, if he is still living, would probably be my caretaker
- My spouse is older than I am. But it would be him first then children (hopefully)
- I'm not sure...will cross that bridge when it comes.
- We made our house handicapped accessible and have also prepared for the option of an apartment in the house so we can have live-in care if we need it.

As a primary caregiver, what supports do/did you have in place?

- Paid aide
- My church gave me good support. My mother's church did nothing-even when she died.
- Hired private care
- Essex County CHHA
- Round the clock- a group of related sisters- to be with my friend-each had a salary.
- North Country Home Services
- Franklin County CARES Unit
- Mercy Care Friendship Program
- North Country Association for the Visually Impaired
- Saranac Lake Voluntary Health Senior/HUD housing directors Tribal Services (Akwasasne) NYS Commission for the Blind
- While I was at work I had a Nurses' Aide to take care of my mother - once I came home from work I took over all of her needs and on weekends
- Public Health

Of the supports you have/had, which ones could be improved or be more helpful?

- Other than Mercy Care, which is great and Essex County home health-I don't really know what is available.
- My Faith Community needs no improvement; My Mother's Faith Community needs major improvements.
- I have a Mercy Care volunteer and I truly appreciate having her. Family members work and do not have a lot of time to spend with me.
- Would like caregiving training and coping strategies.
- I have no support in Lake Placid, but my children will come home for Christmas and holidays from across USA
- Dr. wasn't very helpful.
- My friend paid each person- each week for their services which were greatly needed and a job well done by all of them
- I had to constantly change "aides"
- I hired aides
- North Country Home Services (home health aide service)
- Home delivered meals
- Hospital emergency room doctors and staff, the hospital staff Doctor—need to listen and hear what the caregiver is telling them and not ignore our observation and knowledge of the meds our loved ones are on and how long they have been on them.

What barriers do you have related to transportation?

- Busy schedule
- Going out in winter alone is big concern because of physical problems
- I work and must take off to go to appointments with father
- I drive but my care receivers do not. There is no taxi or public transport in many communities, public transport has many limitations where it is available- stigma, long waits, long circuitous routes mean long rides, inconvenient hours, limited destinations, inability to connect with other public transport for cross county or inter county travel
- No buses
- Wheelchair transport needed - she is non-transferable
- I can't miss more time from work and can't afford to.
- I need to take off work to bring to appointments etc.
- I have to take time off from work to go to the hospital or appointment for the person I care for

As a primary caregiver, what are your biggest concerns?

- Injury to self or patient
- Elder abuse and neglect
- I physically can't handle my husband anymore.
- My consumers who are not in need of 24 hour skilled nursing care are unsafe in their own homes. They need someone to monitor their meds and/or transport them to medical appointments and/or provide meals or some other care but they do not qualify for services and are unable to self-pay. There is a huge monetary gap.
- I am no longer responsible for my father, as he passed away. However, now my biggest concern would be the fact that there are such limited nursing home spaces available in the vicinity.
- Need occasional respite. Also nervous about quality of bringing caregivers into home. Afraid my mother will be abused or mistreated as she is unable to communicate
- Not enough money to care for the family member.

As a primary caregiver, what would make life easier for you?

- Counseling to help other family members and the elder to understand each other, especially threats to independence.
- Reliable and good aides were hard to find back in the '80's.
- In those days Medicaid did not provide assisted living as an option, and very little home-health care. Better services may have greatly improved my father's prospects. He ended up in a nursing home, and bed sores on his heel made him unable to walk for the rest of his life.
- Only would use nursing home if it was really good with only caring people.

- Sr. Housing where meals etc. provided that is affordable on income of social security alone.
- Have other family help with assisting the person being cared for

What are the barriers to getting the supports you need to make life easier for you?

- Respite from full time care unavailable only through bringing people in, residential respite seemed out of reach, there in theory only
- Family members are geographically distant.

As a primary caregiver, how would you describe the quality of your life?

- We had children at home and it was hard for me to find time to do so much which included traveling to hospitals in Plattsburgh and Burlington. At times it was frantic trying to be in two places when I was needed by my mother and a small child. If Mercy Care had been available at that time, it would have been a much needed help.
- I am Italian. I was raised with the idea that we take care of our family when they need us.
- Been doing this for 10 years—I am almost 60 and I am so tired
- I have no life, other than work.

What do you enjoy most about your caregiving role?

- Satisfaction of helping someone in need
- To help my mother in anyway that I can. Anything I did for her was always appreciated, so I liked doing it.
- She is my sister, I love her and we get along with each other very well.
- It is good to know that everything is going ok and my "patient" is as happy as possible.
- Doing for ones I love and seeing them happy.
- Sharing ups and downs with my mom, grateful for time I have with her.
- My husband has FTD for 7 years. It's my mission to keep his cognitive skills, speech, writing intact. I try to take him for PT for gait and balance. His neurological deficit is making him weaker and harder for me to handle him. I don't enjoy all that I do, but I do enjoy the satisfaction that I have done my all for him.
- A great relationship with my Dad for me and my daughter
- I enjoy older people. I like their stories. I'm going to be there someday and I hope someone has time for me and my stories.
- Knowing that I was caring for someone I loved. That I was constantly being reminded how fragile life is and the good feeling of being there for her.
- Being there for family - Taking care of Mom as did for my husband many years ago
- I loved meeting people and helping them stay at home as long as possible. I hope someone will feel the same way about me.

- Meals on Wheels and Parish Nurses
- KEEPING LOVED ONE HOME
- I loved my mother - she cared for me during very difficult times in her life and this gave me a chance to "thank her".
- Nothing
- Being there for my husband, helping him feel secure.
- Nothing. You just do what you have to do
- Allowing her to be able to still live at home
- People out in the world are generally nice to those in wheelchairs. I know I'm doing the right thing even though it's really hard.
- I know personally he is cared for as I would want to be cared for.
- Giving back to mom some of the love she has given me
- Learning successful strategies from older people who have developed them as they aged over the years. Not worrying about death because at this stage it is not negative.
- The person I care for is my mother and would do anything possible for her.
- Knowing my parent is not alone and not going without.
- I get to keep my mother out of a nursing home
- Makes things easier for my husband
- I love both my parents it feels good to be available for them
- Do not enjoy it

What do you enjoy least about your caregiving role?

- Being so far away.
- Working full time (M-F) and being at my mom's (Sat & Sun.). No time to do certain things-make crafts, bake, etc...
- No chance to get better.
- That I could not be there 24/7 as she refused to live with me and my family at the time.
- Watching the deterioration of someone I love.
- Lack of physical energy to complete tasks.
- No time for myself and unable to visit my own son and daughter for any length of time. Both live out of town.
- Overwhelming at times, care receiver's dementia and decline.
- That some of my loved ones weren't closer at times to share the ups and downs with mom.
- Feeling that I have to be responsible for everything.
- Keeping him on task to go for appointments. It takes 2 hours of frustration for me to get him out the door and then it is very slow going to get into the car. Time means nothing to him. He won't go if I say too much about being late.
- That I am alone and feel it all falls on me to do.
- Isolation from community and friends.
- When I cared for my in-laws who had dementia and Parkinson's, I would get to feeling trapped and very tired as my mother-in-law rarely slept.

- Always being responsible for mother-in-law, cannot travel without hiring someone to stay in our home.
- Lack of agreement with spouse over moving out of big house.
- Being unappreciated
- The fact that I could not be there all the time or afford full-time home care and he had to live in a nursing home.
- Watching her giving up at times.
- Being tired all the time and having to do so much paperwork, which takes time away from my husband.
- Watching one's mind just slip away on them.
- No time to live life. Not able to travel, not enough time with my kids/grand kids.
- Being tied down.
- Dressing and showering my parent.
- Being the "Bad Guy;" Fighting about safety issues.
- In a lot of ways I'm giving up my life to make her comfortable.
- I'm not sure about that one. No time for myself and always tired.
- Lots of work - get tired easily. Frustration.
- Unappreciative and argumentative person.
- Lack of appreciation and personal responsibility on the part of the care receiver.
- Loss of freedom and independence.

Caregiving Survey Collection Results

Living Situation

Living situation	Age 60 - 69	Age 70 - 79	Age 80 - 89
Live alone	31%	46%	50%
Spouse	54%	50%	35%
Family	5%	2%	8%
Friend	2%	4%	11%

Half of elders age 80 - 89 live alone.

Housing Situation

	Age 60 - 69	Age 70 - 79	Age 80 - 89
Live in own home/apt.	90%	86%	68%
Friend or family	5%	4%	2%
Senior housing	5%	10%	29%

Only 5% of elder respondents are living with family or friends and those are people age 60-69. The older one gets, the less likely respondents are to live with family or friends.

Work By Age Group

	Age 60 - 69	Age 70 - 79	Age 80 - 89
Work Full Time	39%	8%	0%
Work Part Time	20%	14%	3%

59% of respondents ages 60 - 69 and 22% of respondents ages 70-79 are either working full or part-time.

Caregiver Need by Age Group

	Age 60 - 69	Age 70 - 79	Age 80 - 89
Within 5 years	2%	8%	16%
Within 10 years	2%	10%	13%
Have not planned for it	17%	18%	21%

21% of respondents age 80 - 89 have not planned for caregiving needs and 50% of them live alone.

Likely Caregiver by Age Group

	Age 60 - 69	Age 70 - 79	Age 80 - 89
Spouse	38%	29%	15%
Family	20%	31%	18%
Move to senior housing or asst. living	20% (22% will need other)	15% (25% will need other)	35% (32% will need other)

By age 80, only 15% of respondents are able to rely on their spouse for caregiving needs and another 18% are able to rely on family.

Caregiver Now by Age Group

Age 60 - 69	Age 70 - 79	Age 80 - 89
21%	29%	16%

Respondents in their 70s are most likely to be caregivers.

Anticipate Caregiving

- Yes, within the next 5 years 19%
- Yes, within the next 10 years 8%
- Not sure 33%
- No 41%

Note: 27% of respondents are definite they will provide caregiving to someone within the next 10 years—33% not sure

Long Term Care Insurance

- Yes 15%
- No 81%
- Plan to purchase 2%
- Can't afford 8%
- Note: Long term care insurance cannot be relied upon at this time as a solution to provide for caregiving needs for the vast majority of respondents

Caregiving Status

- 110 people answered this question
- Current primary caregiver 33%
- Primary caregiver - past 67%
- Note: 110 out of 277 responses or 40% of respondents are current or past caregivers.

Caregiving Status by Age Group

	60 - 69	70 - 79	80 - 89
Current primary caregiver	33%	36%	6%

Caregiving Assistance Role

- 121 responses
- Unpaid primary family caregiver 81%
- Volunteer caregiver 11%
- Private paid caregiver 4%
- Agency employed paid caregiver 4%

Health of Caregivers

	60 - 69	70 - 79	80 - 89
Excellent	33%	27%	14%
Good	56%	58%	43%
Fair	11%	12%	43%

89% of respondent caregivers consider their health either excellent or good.

Who do you care for?

■ Spouse	23%
■ Parent	59%
■ Child	3%
■ Other family	11%
■ Neighbor/friend	14%
■ Paying client	7%

Where do you provide care?

■ In my own home	49%
■ Within the same community	37%
■ Within 30 min. drive time	23%
■ Within 1 hour drive time	8%
■ More than 1 hour drive time	2%
■ Long distance caregiver	5%

Age of person needing care:

■ Age 50 - 59	5%
■ Age 60 - 69	7%
■ Age 70 - 79	25%
■ Age 80 - 89	47%
■ 90+	13%

■ Note: 60% of those needing care are over age 80

Caregiving Responsibilities (122 respondents)

■ Personal care	58%
■ Supervision	58%
■ Medication administration	60%
■ Transportation - medical	84%
■ Socialization	59%
■ Household chores	56%
■ Meals	63%
■ Shopping	81%

Other Responsibilities

■ Family Finances	66%
■ Home maintenance	56%
■ Medical ins. Claims	51%
■ Work	24%
■ Parenting	16%
■ Family contacts	50%
■ Social engagements	43%

Doctor helpful?

■ Very helpful	32%
■ Helpful	41%
■ Somewhat helpful	21%
■ Unhelpful	6%

Broader medical community helpful?

■ Very helpful	15%
■ Helpful	39%
■ Somewhat helpful	39%
■ Unhelpful	7%

Supports in place?

■ Family	79%
■ Friends	59%
■ Neighbors	33%
■ Volunteers	19%
■ Faith Community	26%
■ Aging Service Agencies	24%
■ NY Connects	5%
■ Hospice	20%
■ Other health/human services	11%

Transportation assistance needed now or in the future?

- Yes 17%
- No 67%
- In the near future 16%

Note: 33% of respondents need transportation assistance now or within the next 1 - 5 years.

Transportation barriers

- 13% do not drive
- 9% do not have a vehicle
- 9% difficulty home to bus stop
- 12% have difficulty carrying packages
- 9% Taxi not available
- 12% Taxi not affordable
- 67% no barriers to transportation

Biggest caregiver concerns:

Item	Most Concern
Condition worsens	58%
Services unaffordable	36%
Services not available	46%
Caregiver health decline	25%
Exhaustion	27%
Isolation and loneliness	27%

Supports Needed

More information about services	31%
Training	18%
Spiritual support	14%
Coping Strategies - support group	18%
Health ins. counseling	21%
Transportation	22%
Home health aides	32%

Someone to visit with me	4%
Someone to visit my loved one	35%
Move to senior housing	17%
Assisted Living	15%
Respite time	28%
No supports needed	21%

Barriers to need supports:

Inadequate finances	31%
Lack of agreement from care receiver	21%
Lack of information	33%
Maintain independence	22%
Unavailability of family	25%
No barriers	29%
Lack of available services	30%

Top 3 Barriers:

- 1) Lack of information
- 2) Inadequate finances
- 3) Lack of available services

Relationship with care receiver:

■ Very Good	63%
■ Good	29%
■ Fair	3%
■ Poor	0%
■ Mixed	4%

Caregiver quality of life:

■ Excellent	27%
■ Good	43%
■ Satisfactory	25%
■ Unsatisfactory	4%
■ Very unsatisfactory	2%

Plans in place:

■ Healthcare proxy	83%
■ Living Will	68%
■ Power of Atty./will	87%
■ Emergency Plan	24%*

*Opportunity to assist people with preparing emergency plan if caregiver becomes ill or unable to provide caregiving in the future

Caregiving in the Adirondacks Needs Assessment Survey Distribution Strategy

Introduction

Mercy Care for the Adirondacks and its collaborating partners initiated a study of caregiving for people in the Adirondacks to determine the existing patterns of caregiving, the current and expected future needs for caregiving, and the personal and social needs of caregivers themselves. Surveys were completed on-line and through hard copies.

Target Population	Partners Needed	Actions to be Taken	Timeframe
Faith Community Congregations	Parish Nurses	Parish Nurses to discuss the Survey with Pastors; Parish Nurses to distribute survey with their congregations	October - November 2013
	Pastors	“Message from the Pastor” during Church Service	October - November 2013
Volunteers	Mercy Care volunteers	Distribute electronically and by hard copy as needed	
Elders Living in the Community	Mercy Care Friendship Volunteers	MCFVs to provide and discuss the Survey with elders they are assisting;	October - November
	Office for the Aging Outreach Workers	OFA outreach counselors to	October - November 2013
	Nutrition Site Workers	Nutrition Site workers to announce the availability of the Survey at meal times	October - November 2013
	Adult Centers	Adult Center Directors to distribute	October - November 2013
	Senior Housing Facilities	Directors to encourage residents to complete	October - November 2013

Target Population	Partners Needed	Actions to be Taken	Timeframe
General Public	Adirondack Health	Social workers, case workers, HR Department	October - November 2013
	Other Health Care Facilities in Essex and Franklin Counties? Physician Practices?	Caregiving Working Group members to determine contacts and follow up	
	Human Service Agencies	Essex County Human Services Coalition and Franklin County Long Term Care Council to distribute to employees and others	
	High Peaks Hospice & Palliative Care	Patient Family Members; Hospice Employees	October - November 2013
	County, Town, and Village Governments	Through Personnel departments, encourage completion of the Survey by employees	October - November 2013
MC Constituents		MC to distribute	

Key Questions

Personal Interviews

Caregivers and Care Receivers

Developed by Caregiving Working Group

Primary Caregiver Key Questions - Focus Groups & Interviews

1. Who do you care for?
 - a. How long have you been a primary caregiver?
 - b. What were the early days of caregiving like for you?
 - c. Are there other caregivers involved—family members, neighbors, volunteers, etc.?
 - d. Do you work outside of the home?
 - e. Do you have health issues yourself you are managing?
 - f. Do you have other people in your life who need your care and attention?
2. What do you miss most about your “old” life before you became a caregiver?
3. Please tell us about your experience with having adequate input with providers (doctors, nurses, therapists, aides, etc.) to the treatment developed to meet the needs of your loved one needing care.
4. Please tell us about your experience in communicating with your loved one about the care they need or want or don’t want. How would you describe your relationship?
5. Please share with us the most satisfying aspects of being a caregiver.
6. Please share with us the most difficult aspects of being a caregiver.
7. What is your biggest concern?
8. What do you need to make your caregiving experience more manageable and satisfying?
 - a. What type of added help would ease your workload? What support would you need to feel that you are engaged and an integral part of your community?
9. What caregiver responsibilities do you manage? Check all that apply.
 - a. Personal Care (Bathing, dressing, feeding, transporting/transferring)
 - b. Medication management and administration

- c. Scheduling medical appointments
 - d. Transporting and accompanying your loved one to medical appointments and therapy
 - e. Other
10. What other responsibilities do you manage? Check all that apply
- a. Family finances
 - b. Home maintenance—repairs, yard work, etc.
 - c. Household chores
 - d. Household shopping
 - e. Medical Insurance Claims
 - f. Professional and work responsibilities
 - g. Parenting responsibilities
 - h. Family contacts
 - i. Social engagement for you or your loved one?
 - j. Other?
11. What supports to you have in place, if any?
- a. Friends
 - b. Family
 - c. Neighbors
 - d. Volunteers
 - e. Faith community
 - f. Aging service agencies
 - g. Other human service provider agencies
 - h. Other

Which supports do you find most helpful?

Which supports could be more helpful?

12. Have you planned ahead? Do you have in place?
- a. Health care proxy and living will for you and your loved one?
 - b. Emergency Plan
 - c. Legal arrangements—power of attorney, etc.

Key Questions for Care Receiver Interview

1. Are there people who help you?
2. Who are your caregivers?
 - a. How often are they with you?
 - b. Do you feel lonely or isolated?
3. How do your caregivers help you?

4. What else do you need, if anything?
 - a. If you had access to any and all resources to stay comfortably and happily in your home, what would they be? Please think of your physical, emotional, social, and spiritual needs that are presently not being met.

5. Tell us about your experience with having adequate input as to how you wish to be cared for:
 - a. With your caregiver(s)
 - b. With your doctors, nurses, aides, therapists, human service agencies

6. What would make it easier for you to receive the care you need or want?

7. What makes it most difficult for you to receive the care you need or want?

8. What are your biggest concerns?

9. Have you planned ahead? What does the future look like to you?