

Issue No. 1 • Vol. 2 • April 2008



☒ Opportunity

☒ Experience

☒ Ideas

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Special Issue on Caregiving

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The Dynamics of Aging and Our Communities

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Mission Statement

CCQ is an electronic and print public policy quarterly dedicated to looking at the aging segment of our society and region as it redefines itself and intersects with a wide cross section of demographic, social, cultural and economic features of society. In this light, we will consider subjects such as city and town planning, environmental advocacy, economic development, housing, work force, education, mobility, regionalism, governance, marketing, recreation, health care, social services, creativity, demographics, emerging technologies and the roles of nonprofit organizations. Our audience is public and private decision makers and all others seeking to understand a changing society. We will offer concise, thoughtful and interesting articles. Comments, including letters to the editor and recommendations from our readers, are welcome.

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Richard Iannello

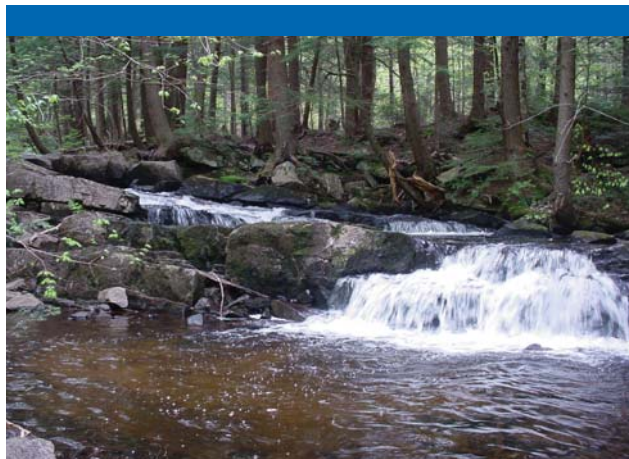
What's up? Actually, quite a lot

When Paul Bray and I first contemplated CCQ, we thought that each issue should contain a variety of topics. Later in the planning stages, we considered the possibility of occasionally publishing a theme issue when the time was right. Well, the time is right and let me tell you why.

On April 2, 2008, WMHT Public Television will be airing a documentary feature titled "Caring for Your Parents." It was produced by WGBH in Boston and it's about caregiving and caregivers. WMHT has assembled a coalition of organizations to promote caregiving throughout the month of April and Albany Guardian Society is pleased to participate by co-producing with WMHT another episode of "It's An Age Thing" that will focus exclusively on caregiving. Additionally, WMHT is producing a special edition of "HealthLink" that will focus specifically on caregiving.

When I told Vera Prosper from the New York State Office for the Aging about these activities, she suggested that if we were looking for a good theme issue for CCQ, the topic of caregiving could certainly give us plenty to work with. I agreed and immediately asked her to write one of the articles for this issue. I think you'll find she was right; we found an abundance of stories and themes and as a result, this issue is a little bit longer than previous issues.

Caregiving is a perfect example of what our sub-title, *The Dynamics of Aging and Our Communities*, represents. The New York State Office for the Aging created the Family Caregiver Council and this group has been meeting since September 2007 to identify better ways to support the estimated 1.9 million New Yorkers who are providing care to children and adults of all ages, including grandparents raising grandchildren. The Governor's budget includes \$5 million directed toward enriched social adult day care services, Caregiver Centers of Excellence, Community Empowerment Initiatives and Targeted Expanded In-Home Services for the Elderly. Additionally, the State Office for the Aging continues to promote NY Connects: Choices for Long Term Care. There certainly is a lot going on in the area of caregiving.




Alder Creek Preserve

As you read these articles, take a moment to reflect on your own situation. Are you a caregiver or do you require care? One of the most difficult things to acknowledge is just when these

situations are occurring. As you would guess, in most instances, it's a very gradual sort of thing. One moment you're going to your Mom's for lunch and the next thing you realize is that she couldn't prepare lunch without you taking her to the supermarket. One day you hope your father can give you some investment advice and the next day it strikes you that he's not doing a very good job of handling his checkbook. And you find yourself saying, "hmmmm . . . , how long has this been going on? Maybe I have to do something, perhaps become more involved in their lives."

Or you could be the person who is beginning to require care. How could it be that last week everything was so straight-forward, and today things aren't quite so clear? For many, it's a tough moment to experience. Several of the articles contained in this issue of CCQ are about that tough moment when the caregiving question first strikes you. How will you respond?

If you want additional information about caregiving or would like to attend one of the events being held in April, go to www.WMHT.org and check out their calendar of events. There are many excellent programs being offered by these organizations, not only in April, but typically year-round. 

Rick Iannello
Executive Director
Albany Guardian Society



Paul M. Bray

Learning from life

My parents were loving as well as independent. They were successful both in a long and mutually supportive marriage and in their professional lives. My father worked his way through the Albany public school system to become the Superintendent of Schools in the 70s. My mother was a full time mother for many years and then returned to college to finish her degree. She then had a satisfying career working for the State Education Department. They were dignified, self-reliant and caringly supportive of the independence of their two sons.

When the time came for them to need care in the last decade of each of their lives, it was a challenging and learning experience. I would like to share a couple of the many things I learned.

My mother developed Alzheimer's disease at a time when my father was strong enough to be her primary caregiver as her faculties declined. My father was retired and able and willing to devote all his energy to meeting my mother's needs. When the disease reached the point where hygiene and other needs called for professional support, my parents accepted the reality that my mother needed nursing home care. For many years thereafter, including when my mother had little consciousness, my father went to the nursing home on a daily basis. He was not shy to speak out if he saw any lapse in the level of care at the nursing home. Their sons' role was to keep an eye on things and show their support. Little else in caregiving was necessary.

The last decade of my father's life came under the long, slow cloud of dementia. Here I felt myself to be like an air traffic controller avoiding mishaps. My father clung to his dignity and was strongly independent even as he became increasingly dependent. My father did not want to show insecurity caused by his loss of short-term memory. He only felt comfortable with his sons, their family and an aide with whom he had bonded. Yet, he strongly did not want to be a burden on his sons. It was a clear example of a comment in the book, *Life is With People*, "The dignity of age can better endure the impersonal than the personal benefaction."

When it became clear that my father could no longer manage living alone in an apartment, I helped navigate with him through the chain of independent living to assisted living until finally in the last months of his life a nursing home. I was called by some a "caregiver," but I think it was more a manager being available but also separate enough so that my father did not feel dependent on his family, something he did not want.

The professional caregivers that helped or served my parents were caring even in the most difficult of situations. Yet, there were times when I saw caregivers being limited from helping

my father because of the institutional mentality of their employer. "Don't spoil the residents," they were told.

I also found caregivers that were not adequately trained to understand that one approach for all residents doesn't work. My father handled his dementia by asking caregivers and others basic questions about what he should do in this or that situation. Once I was with him when he was being given his meds in the morning. The aide gave my father a pill and a cup of water. My father asked the aide what he should do with the pill and was told to do what he did the previous day. Not helpful. My father could not remember what he did the previous day, got frustrated and threw the pill on the floor. If my father was told to put the pill in his mouth and drink the water, all would have been well. My father would then be his usual delightful self.



Blanding's Turtle

In the assisted living facility, an LPN told me he respected my father as an educator, but that it took him a while to understand why he was frequently asking simple questions like where he should sit. The LPN said it took a while to understand why these questions were being asked. He wanted to understand these things about residents and was happy when he connected with residents.

Caregiving has been ingrained in many, if not most, cultures over time, but I doubt it ever was easy and may be much tougher today with people living longer in a demanding and mobile society.

This is CCQ's first theme issue. It is devoted to looking at caregiving to help the reader identify policy issues related to caregiving and open the window on some personal experiences like Laurie Bacheldor, Pastor Victor Victorson and I are presenting.

In the last issue of CCQ, Anne Decker wrote "Help me" in her personal essay. When caregiving is needed, help is needed from all caregivers, be they professionals, family, friends or volunteers. Caregiving can never be easy. It is a public policy issue, but one that is also highly personal. We hope this issue of CCQ will have value at both the policy and personal level. 🐢

🐢 *Paul M. Bray is an Albany attorney who is a lecturer in planning at the University of Albany, a columnist and founding President of the Albany Roundtable civic lunch forum. His e-mail address is pmbRAY@aol.com.*

Feature Organization

Saratoga P.L.A.N.

By Amy L. Stock

Saratoga P.L.A.N. (Preserving Land and Nature) is a land trust working throughout Saratoga County to protect our region's exceptional quality of life through preservation of open spaces and special places for present and future generations. Our mission is to protect farmland, wildlife habitat and other open spaces, promote trail development and regional planning, and encourage community partnerships that foster a balance between economic development and open space protection.

Formed in July 2003 through a merger of the Saratoga Springs Open Space Project and the Land Trust of the Saratoga Region, Saratoga P.L.A.N. is a not-for-profit organization with two full-time and two part-time staff. As a land trust, Saratoga P.L.A.N. works with private landowners, local governments and other non-profits, to protect important open spaces.

As a community partner, Saratoga P.L.A.N. works with landowners, developers, and community and government agencies to develop strategies and guidelines for smart growth that reduce sprawl and preserve open spaces and view sheds.

We work with landowners to help them identify ways to preserve their land, like the Sweeney Family in Round Lake, with whom we are working to devise a comprehensive conservation strategy for over 200 acres of farmland and natural areas along Round Lake and the Anthony Kill. We protect farmland, like the Ritson Farm, owned by lifetime farmer Charlie Ritson, who recently placed a farmland conservation easement on his farm in the Town of Saratoga, and Howard Reilly, who in 2005 donated the development rights on his farm in the Town of Halfmoon through a farmland conservation easement.

We protect waterways like Alder Creek in the Town of Greenfield. A new 20-acre preserve established along the Kayaderosseras Creek, including state fishing rights, was donated by Bob and Barbara Thomas in the Town of Milton. The Ballston Creek Preserve protects important wetlands along Ballston Creek through a generous donation by Pat and Sven Peterson. We also preserve wildlife habitat, like the DesRoches Preserve in the Town of Galway, a 48-acre former tree farm bequeathed by the late Marshall DesRoches that provides habitat for migratory birds, coyote, deer and other wildlife.


We encourage and advocate for the creation of trails, like the mid-county Zim Smith Trail and the popular Bog Meadow Brook Nature Trail in Saratoga Springs and the Railroad Run Trail which connects the Beekman Street Arts District in Saratoga Springs to the new YMCA.


As an advocate for smart growth, Saratoga P.L.A.N. is concerned about the long-term viability of Saratoga County's quality of life, and the preservation of our natural, historic and rural character. As the lead advocate for the development of a county-wide Green Infrastructure Plan, we encouraged the county to complete this plan inventorying the county's existing natural, historic, cultural and recreational resources and prioritizing their protection. Saratoga P.L.A.N. is now working with the county and local towns and villages to identify ways to implement the plan and protect the trails, waterways, farmland and other open spaces identified as priorities.

We are proud of the conservation achievements we've accomplished including the protection of 3,030 acres of farmland, wildlife habitat and other open space to date.

As a community partner, Saratoga P.L.A.N. works with landowners, developers, and community and government agencies to develop strategies and guidelines for smart growth that reduce sprawl and preserve open spaces and view sheds. Our collaboration with New York Development Group on the planning for a Conservation Subdivision in the City of Saratoga Springs is a perfect example of this work. Saratoga P.L.A.N. has provided guidance to the developer on how to cluster the new homes while maintaining a large undeveloped tract of land, developing a trail system, and preserving wildlife habitat within the site.

We are proud of the conservation achievements we've accomplished including the protection of 3,030 acres of farmland, wildlife habitat and other open space to date. However, there is still much more work needed to be done. Saratoga County is the fastest growing county in upstate New York. The natural places, open spaces, and rural landscapes which draw so many people and businesses to the region are also threatened by this very same development.

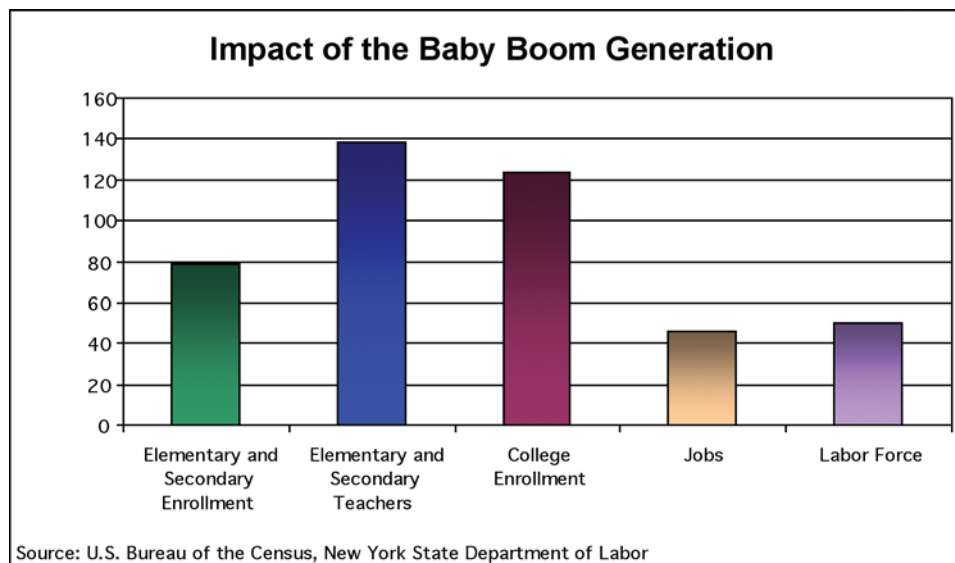
In order to continue the work we do to protect Saratoga County's quality of life over the next 20 years, Saratoga P.L.A.N. is embarking on an exciting new endeavor to build an endowment fund which will ensure that we have the resources to take care of the land we have preserved for the long term. By joining the Saratoga P.L.A.N. Legacy Circle, individuals have an opportunity to support the mission and work of the organization through bequests, charitable gift annuities, remainder trusts, lead trusts, life insurance or retirement funds. A permanent endowment will enable Saratoga P.L.A.N. to commit the resources to continue to protect and steward its existing sites and preserve new places. 

 To learn more about the organization, call 518-587-5554 or go to www.saratogaplan.org. Saratoga P.L.A.N. is located at 112 Spring St., Room 202, Saratoga Springs, NY 12866.

Demographic forces shaping the supply and demand for elder caregivers

By Robert Scardamalia

Between 1950 and 1970, the number of students enrolled in elementary and secondary schools increased from 28.7 million to 51.3 million, an increase of nearly 80 percent. During the same period, the number of teachers increased by nearly two and a half times. Between 1964 and 1985, the number of students enrolled in college more than doubled. The workforce expanded by one and a half times between 1968 and 1986 and the number of jobs the economy generated expanded by a corresponding measure. The single most important factor in each of these expansion periods was the impact of the Baby Boom generation; those born between 1946 and 1964. The Baby Boomers have strained the fabric of each of our institutions since their birth and the next milestone and challenge on the very near horizon is retirement and health care. It's no wonder, then, that providers of care for the elderly and those that finance these services are filled with concern.

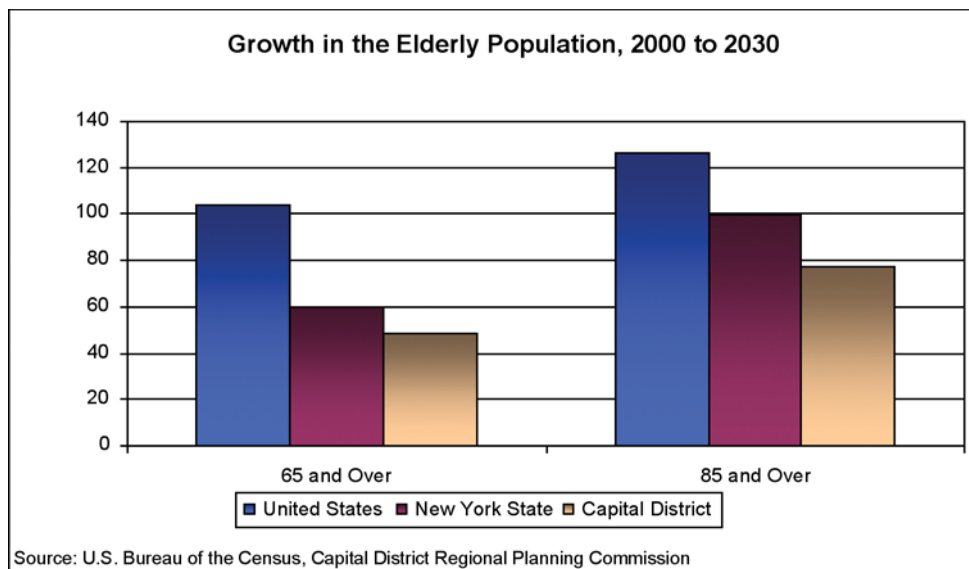


In retirement

The earliest Baby Boomers (born in 1946) will reach the retirement age of 65 in the year 2011. The last of this generation (born in 1964) will reach this age in the year 2029. Of course, this generation isn't necessarily waiting until 65 to begin retirement. Many are looking toward leisure time activities and travel. Others continue to work and have often begun second careers. Generally in better health than previous generations, the Baby Boomers look forward to a longer period of active life after retirement. In 1950, the life expectancy at birth was 68.1 years and a 65 year old could reasonably expect to live another 13.8 years. In 2005, life expectancy at birth increased to 77.9 years and someone reaching the age of 65 years old can look forward to another 18.7 years.

The combination of healthier lifestyles and advancements in care means this generation will continue to strain services for the elderly, whether for leisure or health care. Census Bureau

population projections show that the population age 65 and over will double between 2000 and 2030. In New York State, the increase is tempered because of previous out-migration, but this population will still swell by 60 percent. And based on Capital District Regional Planning Commission projections, this area will see an increase of nearly 50 percent. During this same period of time, the population age 85 and over is expected to grow by 125 percent nationally, double in New York State and increase by 75 percent in the Capital District. This scale of growth, particularly among the “frail” elderly has obvious implications for the state of health care and the supply of caregivers.



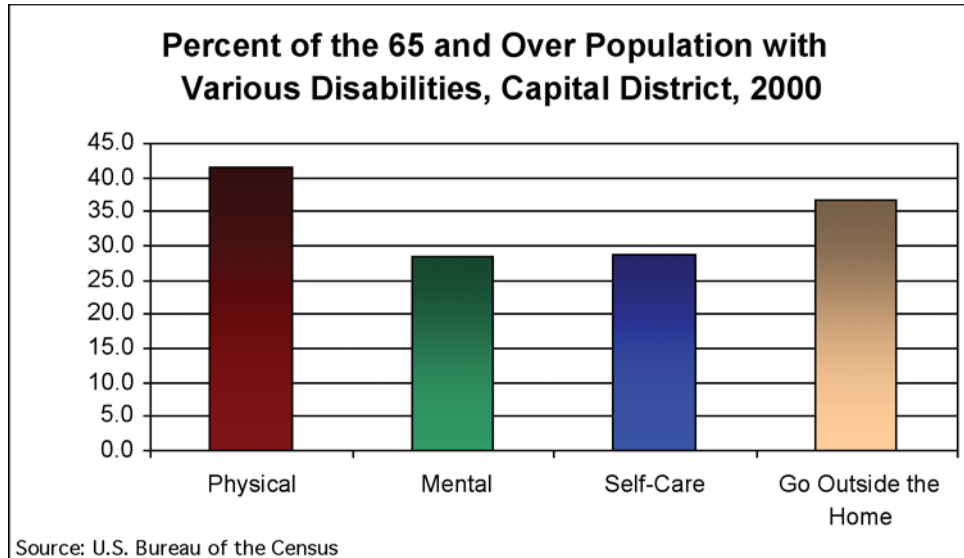
In need of care

Clearly, the demand for care is increasing rapidly based simply on the growth of the 65 plus population. Individuals with special needs will also increase rapidly as the 2000 Census data tells us that significant numbers of the elderly deal with a variety of disabilities. The Census defines disability in terms of whether the individual has a condition that makes it difficult to perform certain activities. These conditions represent physical, mental, self-care limitations, as well as, limitations on their ability to go outside the home.

More than 40 percent of the population 65 and over indicated that they had a physical disability though these disabilities (blindness, deafness, or physical limitation) may not be an indication of the need for care. Nearly 30 percent indicate having mental limitations such as learning, remembering, or concentrating while about the same number indicate that they have difficulty with self-care activities such as bathing or getting around the house. More than 35 percent have difficulty going outside the home for activities like shopping or going to the doctor.

Based on the 2000 Census data, just over 30 percent of Capital District persons 65 and over live alone while 60 percent in family households which means they live with at least one

other relative: a spouse, sibling, or child are the most common relatives. The remaining 9 percent are in group quarters settings or living with other non-relatives.



Caregivers – gap between supply and demand

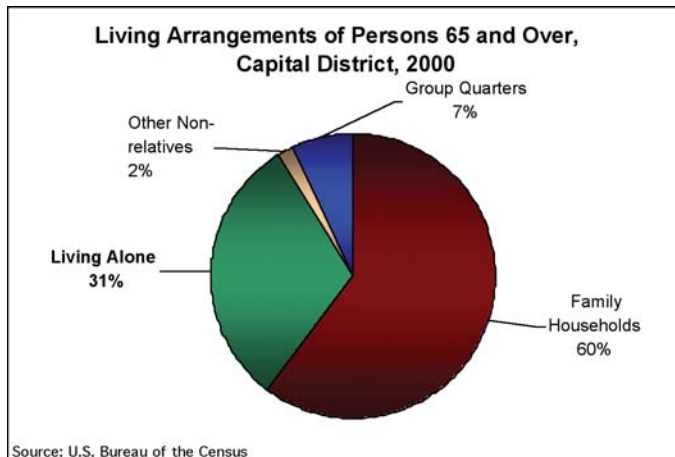
Formal occupational classifications in the Department of Labor don’t always capture all workers whom we might think of as caregivers. They certainly don’t capture informal, family caregivers, but they still illustrate the magnitude of the gap between caregiver supply and demand. Occupations classified as caregivers include: Personal and Home Care Aides, Home Health Aides, and Nursing Aides, Orderlies, and Attendants. The Department of Labor provides estimates of the number of workers in these occupations and projections for the need in the year 2014.

The 2004 Occupational Employment Survey estimates that there are just over 300,000 caregivers working in those three occupational classifications in New York State. The Labor Department projects that by 2014 the number of caregivers will have to increase by 23 percent to 370,000 statewide. In the Capital District, the number of formal caregivers was nearly 15,000 in 2004 and is expected to grow to more than 17,000 by 2014; an increase of 16 percent.

Another way of looking at the demand for caregivers and the potential supply is through changes in population by age. The National Health Policy Forum notes that the majority of long-term care workers are women between the ages of 25 and 54. Using that definition, the number of caregivers in the Capital District and New York State as a whole are expected to decline by the year 2030 while the number of persons 65 and over will increase by 48 and 60 percent, respectively.

Filling the gap

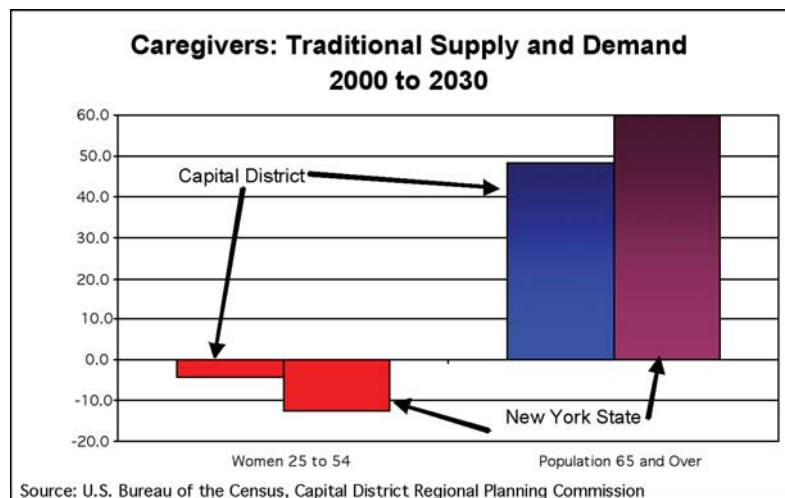
Unlike volatile short-term economic indicators, the demographic structure of a population



holds long-term implications. The Baby Boom generation is the perfect example of these long-term impacts and the greatest social, cultural, and economic challenges may be yet to come. The population requiring care is exploding nationwide and in our region. The number of potential providers of their care is at best stable and in most cases dwindling. Compounding the basic demographics are continued changes in employment and work

opportunities as fewer workers are inclined to enter the caregiver occupations that yield relatively lower wages. In addition, traditional family caregivers are being stretched as single parents struggle with work and childcare while spouses often both work. Time for care of our aging parents competes with many life struggles.

Public sector policy-makers and private sector interests must work together to seize the opportunities presented by a growing elder population. Such opportunities could lie in the expansion of living options for elderly couples and individuals and the significant potential for job creation if wages can match the needs. 🌿



¹ National Health Policy Forum, "Who will Be There to Care? The Growing Gap Between Caregiver Supply and Demand", The George Washington University, Washington, DC, January 23, 2002.

🌿 Robert Scardamalia is Director, Center for Research and Information Analysis, for the New York State Department of Economic Development.

Encouraging trends in caregiver support

By Renée Benson

Many more informal caregiving families are opting to keep cared-for family members at home for as long as possible. One reason, of course, is the enormous cost of being cared for elsewhere, in either hospitals or nursing homes. Another reason is that many families feel great satisfaction knowing that they are the ones to care for the loved ones who have provided and been there for them. Of course, taking care of mom or dad in later life at home is normal in many cultures, and families here in New York also feel that family responsibility.

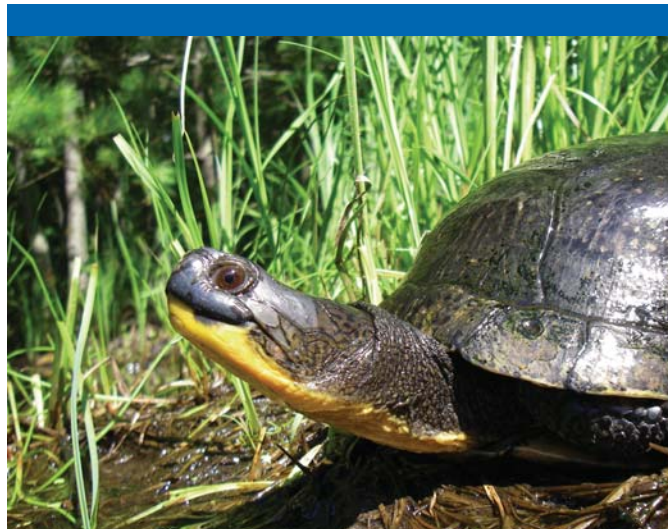
"Given this trend of caring for the elderly at home, it makes sense for us to change the way we view our informal family caregivers."

Family caregiving

The difficulty now, though, is that many more people are living much longer, and as baby boomers join the ranks of the elderly, New York, as well as the rest of the country, needs to find an effective way to address the needs of this burgeoning segment of the population. It needs to help build and reinforce a culture that supports family caregiving.

It is clear that the home setting offers the greatest possible chance for a loved one to receive the attention and care he or she both needs and deserves. It offers the best chance for preserving the loved one's dignity and independence as well. So it follows that the more support caregivers can be provided, allowing them to maintain their own health and balance as they perform these vital services, the more the family, the community, and the nation will benefit. The caregiving role can prove enormously burdensome, and when it does, caregivers themselves suffer—facing physical, mental, and financial problems that leave them feeling isolated and helpless.

Given this trend of caring for the elderly at home, it makes sense for us to change the way we view our informal family caregivers. They



Blanding's Turtle

are, in fact, heroes for taking on such high-risk work—work that is certainly analogous to, if not equal to, that which first responders encounter. In terms of the risk and stress they often face, our caregivers may be in many ways on equal turf with our police, firefighters, and emergency medical technicians. As with these first responders, they find themselves confronting crises and needing to make sense of chaos. They must help their loved ones recover from falls, dress wounds, and employ first aid. Figuratively, they run into burning buildings to rescue their loved ones every day. And they do this while struggling as well with all the emotional attachments to the individual that emergency personnel are counseled against developing.

“Our caregivers live in a world where the needs they must meet are multidimensional.”

New York State is beginning, in its budget, to recognize and respond to this caregiving need. Governor Spitzer’s proposed 2008-09 budget shows a firm commitment to older New Yorkers by increasing the State Office for the Aging’s funding by \$11.2 million dollars—a 9.5% increase—and by supporting new and existing initiatives that will enable older New Yorkers to remain as independent as possible, that support the role of caregiving, that empower communities, and that help promote new and innovative ways of delivering services.

Core ideas of caregiving

But innovative ideas aside, the core needs of caregivers remain basically unchanged. Studies show, and our experiences confirm, that the paramount needs are:

- Respite (a method to ensure that caregivers can take scheduled breaks),
- Counseling, and,
- Support-group participation;

all of which serve to keep caregivers balanced and energized.

Caregivers also need the following types of assistance, which often are provided through support groups and individual counseling:

- Training in how to be helpful and effective caregivers.
- Assistance in interacting with health professionals and the healthcare system.
- Assistance in handling transitions to and from nursing homes.
- Assistance in handling legal and financial problems.
- Support in dealing with and overcoming depression, anxiety, and guilt.
- Help in dealing with end-of-life issues.

With regard to these needs, we must not forget that our caregivers have all the human frailties that the rest of us possess. Issues of mental illness and substance abuse exist in both their population and the general population. Individuals who have had to battle addictions and illnesses often need even greater support when they are placed in the caregiving role. Note,

too, that those receiving caregiving who have these challenges often need specially trained caregivers and aides to assist them. Addressing these needs calls for substantial interagency partnership between the Office for the Aging, the Office for Mental Health, and the Office for Alcohol and Substance Abuse Services, as well as profound dedication by the individuals in these agencies.



Carver Farm

Our caregivers live in a world where the needs they must meet are multidimensional. Take for example the case of a 60-year-old grandmother with physical health problems who finds herself the primary caregiver for three grandchildren, one of whom has a developmental disability, another a behavioral or mental health diagnosis, and the third a physical disability, with all three suffering from issues of loss and adjustment. This grandmother lives in low-income senior housing and is not permitted to have children move in with her. She thus has to deal with problems of housing, finance, mental health, developmental disability, and physical health for herself and her grandchildren. Not only that, but she has to deal with the school system, special-education system, and legal system as she tries to arrange a permanency plan for the children. While she does all this, she must come to terms with what happened to her own child that resulted in the need for her to step in as the single caregiver for these children. Furthermore, grief and worry do not disappear just because there is no time to deal with them. If such a caregiver is not a hero, then I don't know who is.


"If such a caregiver is not a hero, then I don't know who is."

Availability of caregiving for children with or without special needs and for children with various other disabilities, keeps youth from having to enter foster-care placement and juvenile-justice institutions. Making this work requires a close partnership between state agencies such as the Office for Children and Family Services, the Office for Developmental Disabilities, and the Department of Health. It may also require the involvement of the Office for the Aging if the caregiver is more than 55 years of age. Each of these organizations, with their own funding streams, has its own way of operating, and accessing more than

one of these services when your situation calls for it is a real challenge. Often, providers are unaware that another service provider is involved and, therefore, don't coordinate services. Even worse, a service may not get linked to that could provide vital support. Add to all this the possibility that a person in need may not get access to services because a debate is ongoing among the funding sources as to which service that person is most eligible to use. This can occur, for example, when a child has both mental-health and developmental-disability needs. The difficulties that present themselves can be overwhelming.

Sometimes funding is not the problem. The problem may be a gap in the provision of services. Each year we deal with shortages in housing, in the number of available child psychiatrists, and more. When these shortages occur, families may come to believe they have no place to turn. This is when participating in support groups and getting counseling can help caregivers feel some degree of hope and even generate new approaches and possible solutions.

In helping all these caregivers, perhaps the most innovative and effective thing we can do is improve the coordination of resources and develop a comprehensive assessment of what would effectively and efficiently address all the vital needs of our caregivers.

If we remember that we, too, will likely need caregiving at some time in our lives and that none of us remains unaffected forever, we may just find ourselves inclined to turn our full attention to meeting the needs of these heroic souls who care for all our loved ones when they are most vulnerable and deserving. 

 *Renée G. Benson, MA, LMSW, is Executive Director, Catholic Charities Caregivers Support Services.*

Caregiving . . . and the workplace

By Vera Prosper, Ph.D.

How are families dealing with the burden of balancing the competing demands of work and family needs? In 1981, Carol Abaya coined the term “sandwich generation” to capture the juggling act of simultaneously caring for both children and aging parents. Today, in response to the increasing numbers of women in the work force, dual-income families, and single parents, the term “sandwich generation” has expanded to include a third demand-center in the juggling act, the workplace.

Extensive research has defined the picture and scope of the informal care that families and friends are providing for older people, including the health, social, and financial impact on caregivers and the economic value of these services that would represent costs to the formal services system if families and friends did not provide them. Comparatively, limited research has been devoted to identifying the various workplace-related impacts on caregivers or on the businesses that employ them.

Is the “working caregiver” phenomenon big enough, critical enough, to warrant greater attention? The National Alliance for Caregiving (2004)⁸ estimated that there are 44 million Americans providing unpaid care for someone aged 18 or over. Almost 35 million of them are caring for someone aged 50 and over, and 22 million of this latter group are working, the majority full-time.^{8,11} Sixty percent of employed caregivers make work-related adjustments because of caregiving responsibilities.⁷ Long-distance caregivers of older people are not immune from balancing work-family pressures. Eighty percent of long-distance caregivers are working full or part-time, and more than 40 percent had to rearrange their work schedules in order to take care of their long-distance caregiving commitments.⁹

A MetLife study¹¹ reports that caregivers do not adequately judge the time that will be required for caregiving or the impact of this commitment on their work. They

Albany: “I work full time and have two teenage boys. My parents live three hours from me, and my Mom also works full time. But my Dad needs regular care, so I help out quite a bit. I’ve adjusted my work schedule. Even so, days, evenings, late nights, weekends—every bit of my time is taken up.”

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“I needed to take care of Dad. I reduced my hours so much that management had to give my accounts to someone else.”¹¹

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Long-distance Caregiver: “The most difficult part is making time to go see them and spend quality time with them. Expense is not just a plane ticket, it’s also lost work time.”⁹ “You worry because they may not eat, or have anyone to look out for them in an emergency.”⁹

•

Latham: “My Mom lives in California; she’s 88 and needs daily care. I fly out there every four months to coordinate care and make sure a network of people visit her regularly. But it’s not the same thing as being there, so I call her on the phone every night to monitor her situation, check on her needs, and to let her know that she’s not alone.”

underestimate the years they will end up spending on caregiving and they underestimate the number of hours that will be required per week during these years. This underlies the variety of work-related adjustments working caregivers make in order to continue their caregiving obligations, including coming in late, leaving work early, taking time off during the day, using work time for care-related phone calls, taking unpaid leaves of absence, making up work on weekends and evenings, foregoing promotions, passing up special assignments or desired job transfers, missing training and educational chances, relinquishing work-travel opportunities, agreeing to take positions of lesser status and lower pay, using vacation and sick time for caregiving duties, changing jobs to move to the care recipient's city, reducing from full-time to part-time work, quitting work entirely, and retiring earlier than planned.

These adjustments result in substantial tangible losses in career advancement, professional skills development, salary and wage earnings, pension and social security income, savings, and health care benefits, as well as reduced discretionary income to spend on home improvements, investments, car and appliance purchases, grandchildren's college costs, vacations, charities, and more.

Such disruptions to work life intensify other caregiving impacts. Researchers have long recognized the primary stressors that lead to social, physical, and mental health problems— including the intensity of caregiving burden, length of caregiving time, care recipient's problem behaviors, relationship to the care recipient, etc. However, researchers have also identified factors that produce "stress proliferation," deepening the effects of these primary stressors. In addition to financial stress and family conflict, the work-family juggling act has been identified as a stress proliferating factor for many working caregivers.⁷

What about the other side of the caregiver-work equation? Is it worth it to the businesses themselves to take a closer look at the workplace-caregiver link? The 2006 MetLife

Glennville: "I turned down a professional promotional opportunity to work in Washington, DC . . . I couldn't see moving my Mother—she lived with me and had Alzheimer's."

•

"When I was full-time, I had to interrupt my job too much with phone calls and leaving work. With part-time, I am 'here' when working, and then I have more free time to help my father when I am off."¹¹

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"I went back to work because I needed the money for her. I was using my savings to take care of her. But then she had a stroke and I stayed there at the hospital with her. There was no way for me to be at the hospital and work at the same time. I had to quit because I wasn't there a year yet, so they couldn't give me a leave of absence."¹¹

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"I had migraine headaches and depression ... needed to take sick time ... my ability to focus on my work was affected so I wasn't as effective on the job."¹¹

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Male caregiver: "I am running myself ragged trying to take care of my grandmother and do a good job here at work. The only person I am shortchanging is myself."¹⁰

Caregiving Cost Study provides an impressive economic rationale. MetLife’s Mature Market Institute calculated annual productivity losses, directly tied to employee caregiving, of over \$33.6 billion to U. S. businesses.⁸ This figure includes only those caregiving workers who are employed full time.

United States - Lost Productivity Total Estimated Costs to Employers of All Caregivers Employed Full-Time and Caring for Someone Aged 18 and Over 2006		
Men: 8,285,160 (52%) Women: 7,647,840 (48%) Total: 15, 933,000		
	Cost Per Employee	Total Employer Cost
Replacement costs for employees who leave the workplace	\$413	\$6,585,310,888
Absenteeism (days not at work)	320	5,096,925,912
Partial absenteeism (late into work; leaving work early)	121	1,923,730,754
Workday interruptions	394	6,282,281,750
Eldercare crisis (several days off work due to crisis involving care recipient)	238	3,799,217,477
Supervisor time (supportive time associated with caregiving employees)	113	1,796,385,842
Unpaid leave (replacement cost of temporary employees or reassignments of other employees)	212	3,377,082,202
Employees’ work reduction from full-time to part-time (replacement costs of hiring employees to work during the remaining work time)	299	4,758,135,522
TOTAL	\$2,110	\$33,619,070,346
The MetLife Caregiving Cost Study: Productivity Losses to U. S. Business (July, 2006), MetLife Mature Market Institute and National Alliance for Caregiving		

How well are companies faring in responding to the challenges faced by working caregivers? A 2005 survey by the Society for Human Resource Management (SHRM) reported that 33 percent of large employers (1,000 or more employees) have some form of eldercare programs,⁸ many of which are limited to providing employees with lists of information about available community services. Small (50-250 employees) and mid-sized (251-999

employees) companies are less likely to have programs because of cost concerns. Anecdotal reports find that very small companies (fewer than 20 employees), because of their size and the nature of their work, often have the luxury of allowing caregiving employees to informally determine their own work schedules and task-sharing as long as the work is accomplished. Increasingly, employers are taking various actions to create caregiver-friendly work environments and have seen the benefits through increased productivity, reduced direct and indirect financial costs, and increased employee morale, satisfaction, and retention.¹⁴ Such actions include flex-time, job-sharing, compressed work weeks, temporary reduction of hours, telecommuting, both paid and unpaid leave, bereavement leave, gradual return-to-work policies, employee leave-sharing, shift-exchanging, employee assistance programs, elder care programs, information and referral, employee- and employer-funded long-term care insurance covering spouses and parents, flexible-spend and dependent-care accounts, adding hospice care to company-sponsored health insurance, travel discounts for long-distance caregiving, group legal and financial plans, and others.

While the number of employers offering eldercare assistance is growing,⁵ workplace bias against caregiving employees continues,¹³ some intentional and some because employers are aware of caregiver issues but do not know how to respond. Forty percent of working caregivers of older people are men,¹⁰ reflecting both the increasing caregiving roles men are assuming and the fact that if one spouse in a dual-earner family needs to quit work to assume a caregiver role, it is typically the wife who does so. Caregiver bias affects both men and women. Employers may perceive caregiving as typical for women but inappropriate for men, with men being denied benefits that are routinely given to female employees.¹³ Women encounter the “maternal wall bias” and are given disparate treatment after requesting to work part-time or a flexible schedule.¹³

Caregiver discrimination court cases increased from two in 1975-79 to 182 in 2000-05, reflecting a greater willingness

“People in higher authorities, when they realize that you’re a caregiver, they start looking for somebody else that doesn’t have those responsibilities—somebody younger, or somebody single ... who may not have children or have other responsibilities. So, it impacts you.”¹¹

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Chief Executive of Alysides Solutions: “Employees’ productivity suffers when they’re not happy. If your spouse or your child or your parent had a serious illness, how much attention would you focus on writing Java code?”¹

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Male caregiver: “Caring for a sick child is an acceptable reason to be off work, caring for a sick older relative is not given the same priority.”¹⁰

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Male caregiver: “All I hear from my supervisor is that I need to stop letting my personal life affect my business life.”¹⁰

•

Guilderland: “I had to reduce my work time to 80%. My supervisor’s change in attitude was subtle, but apparent . . . expecting me to still complete my full-time work load in the reduced schedule, monitoring my time more closely than my colleagues, questioning my commitment to my job.”

of claimants to file suit.¹³ However, these numbers do not reflect the greater numbers of discrimination victims who choose to say nothing. “Family-friendly work policies” often trigger severe stigma in the work place, a key reason for low usage of these policies by employees.¹³ In response, while “caregivers” have not been given “protected class” status, the Equal Employment Opportunity Commission did issue new enforcement guidelines in 2007 to spell out and warn employers of what it considers to be bias against caregivers, as well as the consequences of such behavior.²

Lisa Yagoda, Fannie Mae elder care consultant: “A lot of people come to me as a place to start their elder care search. They don’t know where to begin, and they don’t have the time to figure it out.”⁶

The 1993 federal Family and Medical Leave Act gives caregiving workers in companies with 50 or more employees 12 weeks of unpaid leave annually, including those caring for an older relative. However, because of eligibility and company-size criteria, only 40 percent of private sector employees end up being eligible for this benefit;¹² and three quarters of eligible employees need, but don’t take, family and medical leave because they can’t afford to miss a paycheck.¹ No federal legislation requires *paid* family leave. Even though paid leave policies are not universally supported by the business community, some states do see the benefits and are stepping up to fill the gap left by the federal government.³ By 2005, 24 states had some form of legislation mandating paid leave for various purposes.³ California (considered a model) was the first state to provide a *paid* family leave insurance program, and Massachusetts is considering an even more generous paid leave policy.¹²

Fannie Mae is an example of a company perennially recognized for the positive steps it has taken to accommodate employee caregivers, seeing clear benefits for the company, including enhanced recruitment, increased employee retention, reduced turnover costs, increased productivity, and enhanced community image.⁵ Through its Elder Care Initiative, Fannie Mae formed a partnership with IONA Senior Services, a community-based senior services organization, which offers Fannie Mae employees facilitated access to a broad range of resources and services; Fannie Mae has an on-site full-time elder care consultant who carries an average active caseload of 45-50 employees a month; the company provides in-house seminars and



Bog Meadow Brook Nature Trail

group legal services; an ElderKit of resources, information, and forms was created to help caregivers; and the company has a corporate-wide Flexible Work Options policy, including adjusted work schedules, telecommuting, part-time work, and compressed work weeks.⁴

According to Fannie Mae Vice President, Susan Holik, underlying the company's development of its employee programs is a strong belief in work-life balance. "We know our employees will confront important life issues, including the end of life. We believe it is important to help employees deal with the life issues that happen while they are doing their jobs."⁴

Resources

- MetLife's Eldercare Calculator, which provides a guide to help employers estimate their lost productivity costs related to caregiving employees: www.eldercarecalculator.org
- EEOC's newly-issued guidelines on caregiver discrimination in the workplace, with practical examples: www.eeoc.gov/policy/docs/caregiving.html
- Dobkin, L. (2008). "Caregiver Resources for Employers," *Workforce Management*. Irvine, CA: Workforce Management Research Center. www.workforce.com/archive/feature/24/85/10/248512.php

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A Capital Region forum on women's health and intergenerational caregiving

By Philip McCallion, Ph.D.

On November 9, 2007, over 100 people, caregivers and staff from not-for-profit and governmental organizations from the Capital Region of New York State, joined together in a Forum to gain a better understanding of concerns related to women's health and intergenerational in-home and community-based caregiving in the Capital Region.

The Forum brought together advocates, academics, policy makers and consumers to collectively consider public policy solutions to strengthen caregiver support capacity and to address unmet needs. The participants were divided into four work groups and focused upon issues facing women in caregiving roles, including poverty, immigration, their own health concerns, and the challenge of work-life balance.

Inspired by a portrait of caregiving in the keynote address of Laurie Bachelder, Vice President for Impact for the United Way of the Greater Capital Region (see this issue), and their own experiences, participants defined unmet needs and gaps in support services and identified strategies and best practice models to bridge those service gaps. The work of participants was presented to a panel of public policy partner respondents drawn from the legislature and executive agencies.

Major themes emerging from the discussions included:

1. There is an overall lack of informational, educational, and health related supports available to caregivers in the Capital Region.
2. Many Capital Region caregivers cannot afford to give up their jobs in order take on a full-time caregiving role. Businesses should, therefore, be more sensitive to the needs of caregivers.
3. NY Connects and other Single Point of Entry information and assistance systems being developed locally and statewide should be further promoted in an effort to raise awareness about the benefits of these systems.
4. Financial supports such as tax credits should be available to caregivers.
5. Services in the Capital Region should be available regardless of county lines.
6. For full-time caregivers in the Capital Region, lack of health insurance was a particularly critical concern.

A full report on the Forum and its findings may be downloaded from www.albany.edu/aging.

The Forum on Women's Health & Intergenerational Caregiving was made possible by a joint grant from the NYS Assembly, NYS Senate and New York State Department of Health awarded to the Research Foundation of SUNY to support activities and partnerships of the Elder Network of the Capital Region. The event was organized by the staff and partners of the Center for Excellence in Aging Services and the Center for Women in Government & Civil Society at the University at Albany.



Philip McCallion, Ph.D., is Director of the University at Albany Center for Excellence in Aging Services.

Caregiving . . . It challenges one's strength and forces tough decisions

By Laurie Bacheldor

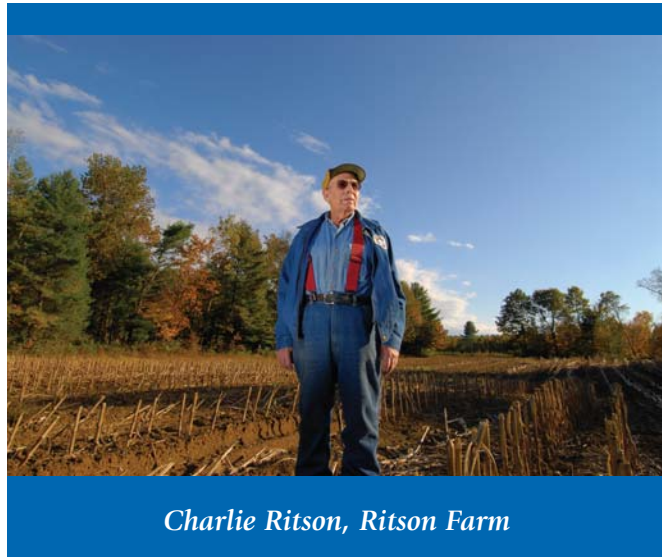
Portions of this article were presented at a workshop on the Ethics of Care Giving, 9/07. This article was updated 1/15/08 to reflect other caregiving issues.

My name is Laurie Bacheldor, and I'm a Vice President of United Way of the Greater Capital Region. In my position, I work collaboratively with many organizations that address senior and long-term care issues. This article has not been written to reflect my professional role at United Way, but rather to share stories of my personal role of caregiver of a mother-in-law, and only a short time ago, the caregiver of four elderly parents. Over the past several years, our family has had to address multiple caregiving and senior issues, which often lead to very difficult decisions, and sometimes ethical questions.

Approximately 15 years ago my parents and my husband and I bought a home that included an in-law apartment. The new home's purpose was to allow for my parents to age comfortably in their senior years, and to allow our growing young family to have a larger home. The three generation home seemed like it would work, and we expected that it would work forever. It did work for many years, and helped to create a very special bond between my parents and us, but more importantly with their grandchildren. In the last two years,

however, we lost my father and father-in-law, and only a month ago, my mother. We recently had to move our mother-in-law into an assisted living center after two months in a local rehab hospital. We received the word, the same week that my mother died, that our mother-in-law could no longer stay in her senior apartment, and needed assisted level care. She is recovering from elbow replacement surgery and pelvis fractures due to a serious fall.

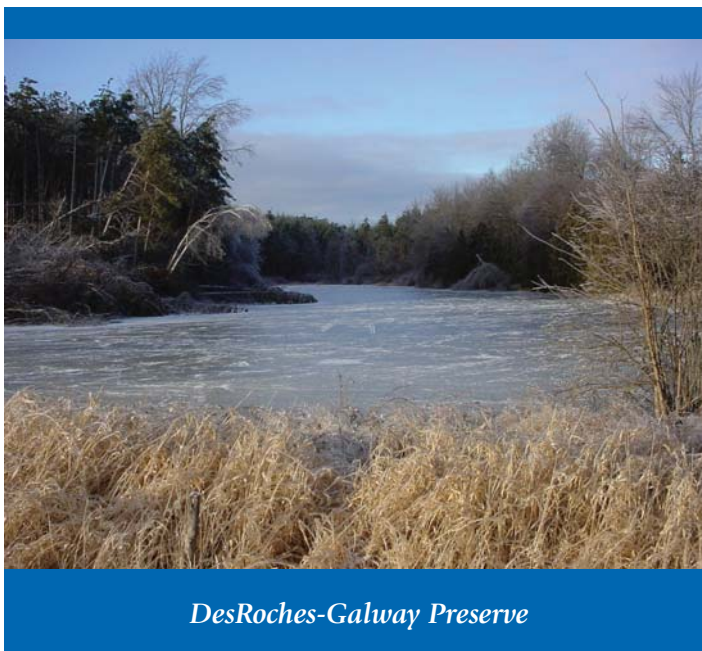
The problems, issues, and ethical questions families face as parents age are often difficult to imagine, let alone talk about. Although my generation is always talking amongst ourselves about elderly parents, we often don't discuss the details that are overwhelming, or even find the time to get personal help, join support groups, or find time to seek solutions for our own health. There just isn't enough time!



Charlie Ritson, Ritson Farm

As my parents aged, our home was slowly upgraded to include a handicapped entrance, grab bars, and it had an emergency intercom between the floor levels. In the early 2000s, my parents, in their mid-80s, were independent and active seniors who maintained their apartment, a Florida home and continued to travel. However, over the years, my father's health began to deteriorate, and we found ourselves facing caregiving challenges that were beyond our imagination. It is difficult to watch loving parents slowly disappear before one's eyes.

I am the youngest of four children and was the closest to my parents (so say my siblings). I want to make it clear that my siblings assisted with many of my parents' needs; they, too, provided care and assistance. However, our parents lived in our home, making us the primary caregivers. I thank God every day for my siblings and all they did to help. Not all families have other members assisting with care. In addition, my husband is an only child and is the only caregiver to his parents. We found ourselves with four elderly parents, all at different stages of senior care: independence, senior housing, in-home 24/7 care, assisted living, and eventually nursing home care.



DesRoches-Galway Preserve

The challenges began when it became apparent that my mother needed assistance taking care of my Dad—his body was slowly breaking down. My father was a brilliant and loving man, the successful owner of a Schenectady company, strong-willed, and not afraid to make decisions. However, he suffered from arthritis that slowly took away his physical body. Fortunately, or sometimes I want to think unfortunately, he never lost his mind. He always knew that his body was failing and he was dying a very slow death. My husband and I spent hours trying to help our mother care for Dad's physical needs; as a result, the decision was made (mainly by my Dad) that he needed care beyond our home.

When to drive and when not to drive

The first issue that developed was how to suggest that your parents should not be driving. How do you take away your parents' driving licenses? This was a problem we had to deal with for both sets of parents. Letting go of driving and that independence is very serious

business for seniors, and children find themselves having to force the issue and find ways to help (or make) their parents give up driving. My father recognized that he was no longer comfortable driving and he wanted to give up driving, but my mother fought him and insisted he was still a good driver. They battled this issue every day when he prepared to go out. It was difficult to watch them struggle and we knew Dad was correct—neither of them should be driving. We then sought out transportation options for our parents.

Insisting that parents should stop driving is the correct thing to do; however, it develops new problems for the caregivers. Suddenly we found ourselves having to add on new tasks for the parents—driving them to the banks, the stores, church, dinner out, and doctor office appointments. Now we were driving elderly parents and teens everywhere while still working full-time.

Transportation is a poor, if not, failing system. We live one mile over the Albany County line, but all of my parents’ doctors, stores, etc., were down the road in Schenectady County. I found a transportation company that would drive our parents to the doctors or take them to the hospitals, but only if they stayed in Albany County. We were told to switch all their doctors to Albany County. This was just NOT an option for my parents. We found transportation companies that couldn’t (or wouldn’t) cross county lines. This only complicated an already awful problem. Finally, I found an organization that quietly “broke the rules” for us, but their back-log of transportation appointments often prevented them from being able to pick up our parents when we needed it. A new era had arrived, all while we had three teens to care for and maintained full-time jobs.



Round Lake Preserve

At the same time, we were dealing with Dave’s parents. My father-in-law and mother-in-law were also showing signs of aging. This required us to take time off from work as we moved my in-laws from Florida back to the Capital District so they weren’t alone. We helped with the sale of their home and moved them into senior housing in Albany. After they arrived in Albany, within a few years, my father-in-law solved the transportation problem by selling the car without the consent of his wife. That ended their ability to drive.

When to seek new levels of home care

My Dad was an engineer/architect and approached all problems with methodical thinking and he always had to find the most logical answer. When the decision was made (nearly solely by my Dad and in consultation with the family) that the current shared in-law apartment, with family as the primary care support, was not working, he asked us to help them find assisted living facilities. We started to research and research and visit and visit facilities. We wanted to find a place that had multiple levels of care so they wouldn't have to move multiple times. In the Capital Region, we found only one place that had senior housing, assisted living and a nursing home all on the same campus. Unfortunately, the assisted living rooms were just that—ROOMS ONLY—no apartment, no living room, and no kitchen area. It looked like a fancy nursing home room, not an apartment. We also could not find a facility that they could move into that combined the services my Dad needed (assisted-level care) and the support my mother needed (social and recreational supports). We were told by that facility that one parent would be in their senior complex on one end of the campus, while the other was in the assisted living room. This was not to either of my parents' or family's liking.



Round Lake Preserve

We finally found an assisted living facility that appeared to meet both of their needs, but it did not have any future relationship for a nursing home. They moved in. Unfortunately, the assisted living for my Dad was not enough. He was failing physically and within four months of moving into the assisted living facility, more care was necessary. We were looking at nursing home or 24/7 in-home care. He chose to return back to our in-law apartment and we hired 24/7 care. My parents and siblings felt that Mom should remain in the assisted living center as the thought of her moving again was overwhelming her and she had begun to make friends. This was a very difficult decision. After 66 years of marriage, they separated for the very first time in their life—it was gut-wrenching.

In-home caregiving is not the answer to all situations. It worked for us, but only for about four months. Struggles began and issues developed. One main problem with in-home

care is the inconsistent professional workforce of such in-home agencies. Often we would have someone in our home, trained, and they would quit and leave the agency. When this happened, the agency often did not have back-up personnel and we found ourselves needing to call in at our own jobs in order to help our father. Workforce shortages are a serious problem. Furthermore, such in-home care requires that home-care workers must have a place to sleep when 24/7 care is required. We had to change the apartment to set up such living accommodations, and the workers often were surprised how often the 24/7 care did not allow them to sleep. My father struggled to sleep due to pain and discomfort, and required evening and night-time care. He fell and was injured during the night while one care worker struggled to catch a few hours of sleep. We knew the time had come to look at 24/7 shift workers or a nursing home.

After four or five months, the decision was made to move Dad into a nursing home. This decision was taken out of our hands, as my siblings decided this for us. They said that we had done enough and there would be no more 24/7 care in our home. Again, we were trying to find a place where my parents could be together; however, it did not exist and my Mom did not want to move.

Unfortunately, this final move did result in my father experiencing some early signs of dementia, but it was temporary and after a month or so, he returned to a more normal state.

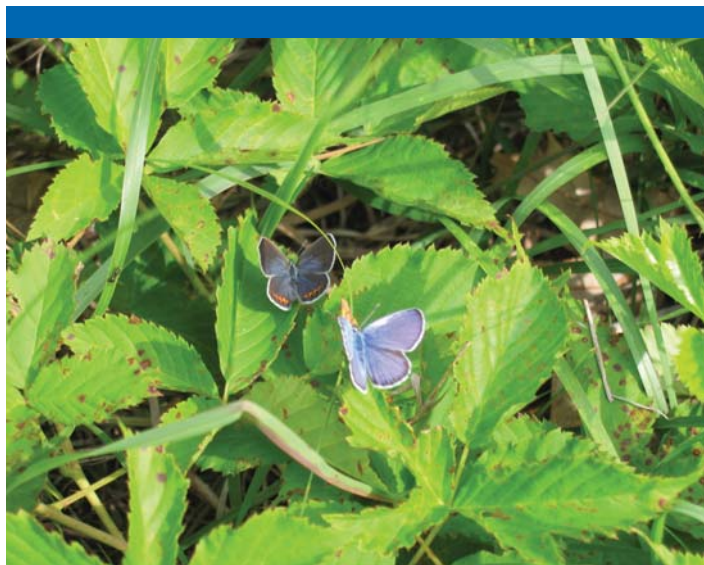
My mother, on the other hand, was able to stay at the assisted living facility nearly up to the time she died (a little over two years). However, within 13 months of her losing her husband of 66 years, she pretty much gave up on life, showed signs of depression, became very sad and expressed that she was tired of living alone; she prepared herself to leave this life. She commented in the last month of her life that she was seeing her husband nearly every day and she missed him terribly. The confusion and sadness led to her needing more care than could be provided by the assisted living center and the decision was made by her and my siblings to move her to the nursing home that my sister worked at in Massachusetts.



Orra Phelps Preserve

Unfortunately, the move caused her to give up further and at age 89 she died within two weeks of the move. Clearly moving elderly parents brings in confusion.

The housing issues for my in-laws took a different road. Despite the fact that our father-in-law was not a well man, he was able to stay in his senior apartment, primarily due to the daily care provided by his wife. She pretty much took care of him, with minor support from us. His story ended with regular visits to the local hospital and he eventually died at age 77 quietly



Karner Blue Butterflies, male and female

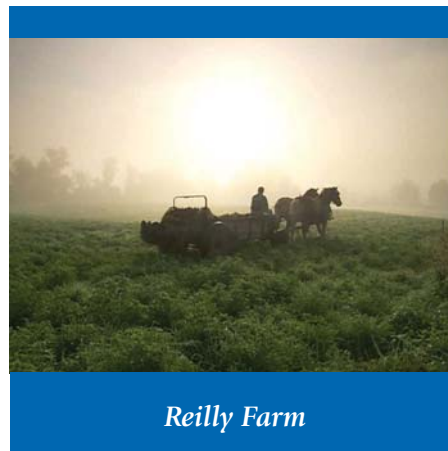
and quickly. My mother-in-law successfully maintained their senior apartment for another 15 months after the passing of her husband. Unfortunately, this past fall, she got off of a senior bus at a local supermarket and took a major fall, which landed her in a local hospital, followed by admission to a rehab facility for over two months.

The same week that my mother passed, we were told by the rehab hospital that our mother-in-law was being discharged. We had to find new housing for our mother-in-law while preparing for a funeral. Our solution was unique, but convenient. We found that our mother's assisted living facility was paid for through the end of the month and we were only given a week to find a new living situation for our mother-in-law. So the solution seemed obvious to both families. Empty out our mother's apartment, repaint it, downsize our mother-in-law, empty her senior housing apartment, and move her into the same apartment in the same facility. It is strange at times to enter the apartment and not find my mother, but rather to find my mother-in-law. Our mother-in-law also felt odd about taking over her apartment, but recognized that we were on a short time frame and she needed to move quickly. The most frustrating part of the move for our mother-in-law was that the rehab hospital only gave us a week's notice, did not help with placement, and expected that within a week, we would have her placed. There was no case management support in this situation despite someone with the title of "case manager." We were the case managers.

Religious values can get in the way or can bring relief

One particularly difficult issue that arose was when one of the in-home care attendants found out that my father was not a particularly religious man. It is important to understand that there was nothing wrong with my Dad's mind. He was very opinionated, well-read, and also a staunch agnostic. The home health aide, on the other hand, was a very religious

woman who believed that if they prayed together, his pain would subside and he could find peace. At first the religious bantering was fun for my Dad, but over time, she pushed for daily prayer and he didn't like it and it angered him. It finally ended when I had to stop her behavior and told her only to bring up the issue of prayer with my mother (when she visited) as she was very religious. When the in-home care attendant offered prayer with my mother, she found great comfort. The bringing in of personal values in the care of elders was most distressing to my Dad and to us, who had to deal with it. Bringing in faith in such situations must be done carefully and with an understanding of the senior's perspectives on faith.



Reilly Farm

Challenging medical recommendations

During my father's time in the nursing home (which was only six months), he was taken back and forth to the local ER for different medical issues. At one point, an ER doctor assumed, with no real examination, that my father was battling dementia or maybe Alzheimer's. The doctor started talking over my Dad and only to us (the siblings). The doctor determined that my Dad was depressed (who wouldn't be) and suggested that he have ECT (shock therapy). That announcement woke my Dad up and he turned to the doctor and said something to the effect of, "Are you talking about this for me? If so, talk to me, not them . . ." It certainly surprised the ER doctor.

A similar situation arose with my in-laws. Only in this case, our father-in-law assumed that his wife was developing signs of dementia. He insisted on tests for her without significant buy-in on the "problem" from her. We found ourselves between our parents, each telling us a different story about my mother-in-law's mental state.

Right to die

An issue that is very difficult to discuss is one's "right to die." My Dad believed in his right to choose when, where, and how to pass on. My parents filled out every type of form that was imaginable about end-of-life care including a living will and a health care proxy. One would think these forms would be universally accepted, but many times hospitals wouldn't recognize them and we had to fill out that facility's version of the form. Ambulances, too, had their forms and requirements. The worst time that this issue was ignored was when he was in the nursing home.

My Dad decided that he had enough of this "staying alive stuff" as he called it. He believed that the only way he could move on toward death would be to stop eating. He called his wife and members of the family in and told us that he was done and was ready to move on—that

he would not eat much. As a result, he dictated a memo to the nursing home, outlining (in detail) what care he would or would not accept. Included in his description was the choice to refuse food. The memo was signed by him, his wife, and our family’s health care proxy (who was my sister, a nursing home RN in Massachusetts). We gave the memo to the nursing home, which refused to accept it primarily because of the food item. They told us that no one on the staff witnessed it and they could not guarantee that the resident had written it. They interviewed my Dad and Mom about the memo; Dad only got angrier over not being believed. Multiple staff from the nursing home talked to him, and yet they refused to follow his wishes. The only recourse was for our family to engage the services of the State’s Ombudsman. Needless to say, that ended this issue and the memo was honored.

The final nightmare for us was during his last 24 hours of life. My father landed at the local hospital and it appeared that he had a small bowel obstruction. We refused a medical work up to verify this, and requested comfort care with hospice only. When I arrived at the hospital, I found health care workers force feeding him. I was not a nice person that day. I handed them all his right-to-die papers again, demanded to know why he was being fed, reminded them that we had already set up comfort care only with hospice and I wanted to know why there were IVs and forced eating going on. I had a verbal fight with a nurse who informed me that she would not starve him. I asked how they could feed him with a bowel blockage. All the time, my dad was yelling and begging me to make them stop. It was a terrible scene. Nothing changed until the hospice nurse arrived and took over the care. He died later that night.

Seniors’ decisions and feelings of guilt

The final issue that we have witnessed over the years is the struggle that seniors have with trying to decide when and how to make decisions that will lead to major changes because of health or home care concerns. Seniors suddenly find themselves having to let go of their independence and their understanding of who they are. Their sense of independence is severely challenged. We heard our parents ask such questions as: “How do you know when you need more care?” “How do you know that you need to give up your home/apartment and move to a more structured health care facility?” “What do



Karner Blue Restoration, Seed Collecting

you do when your solution to a problem is in direct conflict with a spouse or child?" There were many times we witnessed my Mom and Dad disagreeing on his care. She believed he could drive, he knew he couldn't. He knew he needed more care, she believed she was his nurse.

Another story was the day my father-in-law got it in his head that he was no longer going to pay out money on his senior apartment as he was throwing all his savings down the toilet. So he started visiting small houses as he decided that he would return to the role of home owner. This caused much distress and conflict for his wife and us as we knew he couldn't maintain a house, let alone move again.



Reilly Farm, Howard Reilly

There is also the sense of guilt that all four parents have stated over the years. Comments such as: "I'm such a burden." "I'm sorry to have to have you do all this work." "I hate seeing you do everything for me when you have your own family." "I can't believe I can't do this anymore—it frustrates me!" "I'm so dependent on you." It seems to be very difficult for the seniors and there seems to be no real words that can take that guilt away. To be frank and honest, it is difficult and burdensome at times. It does take time away from one's immediate family and work, and tempers can flare between parent and child. It is, however, part of the circle of life and for me, anyway, I would have done anything for my parents and in-laws to help them with these final years of life. They gave so much to me, I had to find ways to give to them and respond to their struggles.

We have dealt with the issue of driving licenses and when to insist that parents stop driving; in-home care shortages and services that don't work; religious values imposed on us; myths and assumptions about the elderly by medical personnel who assume that all elderly patients have dementia or other similar diseases; many systems insisting on their own paper work regarding a health care proxy and a living will; facilities that can't change as senior needs change; and the struggle to make the correct decision that often includes the "guilt factor."

My final comment is that I became the case manager to case managers in nearly every medical facility that we dealt with and are still dealing with. We regularly reminded case managers of our parents' doctor appointments, drug plans, insurance plans, and care plans. We helped parents sign up for Medicare Part D. We took over their bills and finances. We filled out all their paperwork. We drove them to the doctor and maintained their prescriptions. We downsized their life. We picked up their groceries. We arranged for their transportation—the case management goes on and on—all while raising a family and keeping full time jobs.

The only real solution that I can hope for is that we put together a good Point of Entry System that interfaces well with 2-1-1, and that full-range aging in place care or neighborhoods or some kind of comprehensive campus complexes are developed. I would hope that someday we will have facilities where couples can stay together and face their health issues together as they move along the continuum of elder care and that case managers have the time to really work through these difficult problems with the individual, couple, or caregiver.

We are a family that fortunately had the financial resources to handle the costs of these different levels of care. Hundreds of thousands of dollars disappeared VERY quickly over a two year period from my parents' estate; thousands of dollars are now disappearing from my mother-in-law's estate. I often wonder what families do that do not have such resources. However, having resources does not guarantee good care. No family should go through what we went through because of so many unnecessary problems. We recognize that even today we will still face new problems and challenges as we continue to help our mother-in-law age in place.

The caregiving continues

 *Laurie Bacheldor is a Vice President of United Way of the Greater Capital Region.*

Caregivers of our community

By The Rev. Vernon A. Victorson

As a pastor of a church, a congregation, a “faith based community,” I have been in and out of hospitals, nursing homes, rehabilitation centers, hospice settings and the individual homes of the homebound on a weekly basis for close to 40 years. It was all part of my seminary training, part of what it meant to be a pastor of the church, to visit the sick, to minister to the homebound, to bring the care of the church to those troubled by affliction of any sort. To visit the aged and the infirm calls for the pastor to see to not only their physical needs but to their spiritual needs as well. These calls were visit, a prayer, a reading from scripture, and a conversation concerning a person’s well being. In many places we call this “pastoral care,” hospitals have pastoral care departments and it can seem specialized. But this form of care is carried on every day throughout our area in all sorts of health related facilities and in people’s homes.


In the Christian Church we take our lead from the ministry of Jesus of which a significant part was healing with compassion and mercy. In the teaching of Jesus in St. Matthew, Chapter 25, he stated, “if you have ministered unto one of the least of these my people you have done it unto me.”

The call for such ministry is not just for pastors and religious leaders, but all people of faith. And they do respond. Churches maintain lists of their number who are homebound or alone. They will often work together to meet the needs of the residents of a particular nursing home. Month after month you can check the calendars of any health or assisted living facility to see the numerous activities and entertainments provided by churches, civic groups or caring individuals who have a talent to share. Walk into any of our hospitals to be greeted by the volunteers who take up the slack in important tasks such as staffing the reception desk or bringing information to families in surgical waiting rooms.

Many of these volunteers are active members of their faith communities and view this service as simply another way of living their faith. People who offer their time and talent in this manner as individual, church groups or in volunteer auxiliaries bring a great deal of care and compassion to the ministry they carry out.

I believe where some of this breaks down is when families seek to take care of a family member on their own at home. They, too, have need of volunteer help and cannot always get it because the systems are not in place, or unknown, that would provide such aid. It is especially important when the caregiver for an individual is that person’s spouse. They then become the 24/7 nursing agent and the toll on the health and welfare of the caregiver is gravely significant. As a community, we could invest more in helping families keep loved ones at home with the full care they need. Our area hospices can be fine examples of providing such comprehensive home care.

Another related concern that is troubling is that those on the staff of our health care facilities who provide the most basic of care, day in and day out for the people we love, are paid the least. It would seem that a society which says it values its older generation would take great care to see that the resources are there to provide first, the proper training, and then second, to allow those who work in this critical area of ministering to our aged and infirm the ability to make a decent living, in recognition of the significant work they do for the people about whom we care the most. We talk of these as entry-level positions and they are paid minimally. To scrimp at this level says something of the value we place on their work.

It is not that the community as a whole does not care; we see it every day in the countless volunteers and family members who care passionately. They want the care of family members and friends to be of the highest priority. Somehow, as a community, we must find the political will to provide that which is needed. In admiration of the caregivers in our community, we should vow as a community to do whatever it takes to recognize their efforts and their sacrifices and support them. 

 *The Rev. Vernon A. Victorson is Pastor of the First Lutheran Church, Albany, New York.*

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IMAGES: Each issue of CCQ will use images of architecture and natural features that make the Capital Region special. The cover for this issue has an image of an Albany streetscape with City Hall and the Capitol in the view, Kayaderosseras Creek Preserve in Saratoga County and the 18th century Johnson Map. This issue highlights Saratoga P.L.A.N..

CREDITS: The photograph on the cover of the Albany streetscape is by Richard Iannello. Photographs by Saratoga P.L.A.N are the "Kayaderosseras Creek Preserve", "Carver Farm", "Orra Phelps Preserve" and "Karner Blue Restoration, Seed Collecting". The photographs "Blanding's Turtle" are by Ryan Von Linden. The photograph "Bog Meadow Brook Nature Trail" is by Stock Studios Photography. The photographs "Charlie Ritson Farm", Round Lake Preserve", "Round Lake Preserve" on pages 25 and 26 are by Josh Gerritsen. The photograph "DesRoches-Galway Preserve" is by Laura Welles. The photograph "Karner Blue Butterflies, Male and Female" is by Dave MacDougall. The photographs "Reilly Farm" and "Reilly Farm, Howard Reilly" is by Elevation Films/Taylor Morrison.

CCQ is available in pdf format on [Http://www.albanyguardiansociety.org](http://www.albanyguardiansociety.org)

Organizations and their web sites that may be of interest to CCQ readers

Albany County Department for Aging

<http://www.albanycounty.com/departments/aging>

Albany Roundtable

<http://www.albanyroundtable.com>

American Library Council

<http://www.lff.org/about>

Capital District Regional Planning Commission

<http://www.cdrpc.org>

Center for Economic Growth

<http://www.ceg.org>

Civic Ventures

<http://www.civicventures.org>

Community Foundation for the Capital Region

<http://www.cfcf.org>

Federal Reserve Bank of New York, Buffalo Branch

http://www.newyorkfed.org/aboutthefed/buffalo_branch.html

Fulton County Office for the Aging

<http://www.fcfa.org>

Generations United

<http://www.gu.org>

Global Action on Aging

<http://www.globalaging.org>

Government Law Center at Albany Law School

http://www.albanylaw.edu/sub.php?navigation_id=668

Grantmakers in Aging

<http://www.giaging.org>

Greene County Office for the Aging

<http://www.greenegovernment.com/departments/aging/index.htm>

New York State Office for the Aging

<http://www.aging.state.ny.us>

Osher Lifelong Learning Institute

<http://www.usm.maine.edu/olli/national>

Rensselaer County Department for the Aging

http://www.rensco.com/departments_familyservices.asp

Rensselaer Polytechnic Institute

<http://www.rpi.edu>

Rockefeller Institute

<http://www.rockinst.org>

Sage Colleges

<http://www.sage.edu>

Saratoga County Office for the Aging

<http://www.co.saratoga.ny.us/aindex.html>

Schenectady County Department of Senior and Long Term Care Services

www.schenectadycounty.com

Schoharie County Office for the Aging

<http://www.schohariecounty-ny.gov/CountyWebSite/OfficefortheAging/ofaservices.jsp>

Schuyler Center for Analysis and Advocacy

<http://www.scaany.org>

Town of Colonie

<http://www.colonie.org>

U.S. Environmental Protection Agency Aging Initiative

<http://epa.gov/aging>

University Albany School of Public Health

<http://www.albany.edu/sph>

University Albany School of Social Welfare

<http://www.albany.edu/ssw>

United Way of the Greater Capital Region

<http://www.unitedwaygcr.org>

Warren County Office for the Aging

<http://www.co.warren.ny.us/ofa>

Washington County Office for the Aging

<http://www.co.washington.ny.us/Departments/Ofa/ofa1.htm>

Our Mission

Albany Guardian Society continues to seek opportunities to improve the quality of life for seniors as we carry out our Mission.

- The mission of Albany Guardian Society is to engage in a broad spectrum of endeavors that will improve the quality of life for seniors.
- We will devote funding to develop and support services for seniors.
- We will create an environment that will maintain the growth of creative and innovative ideas.
- We will fund the exchange of information to enable interested parties to learn how to create a better standard of living for our elders.
- We will attract additional resources to increase the impact we can make as we remain mindful of our mission to serve the elderly.