We've been hearing about PROJECT 2015. What is the project about?

PROJECT 2015 is about the future – the future of communities across New York. It’s about New York state government agencies, localities and other organizations planning for the impact of the significant demographic changes we’ll be seeing in the coming years, especially the aging of our population and increasing diversity in New York. These changes will affect policies, programs, services and practices of government agencies and of organizations, communities and systems. The New York State Office for the Aging (NYSOFA) is the lead agency in the initiative.

Why is PROJECT 2015 important?

New York’s changing demographic profile – both the aging and increasing diversity of our population – requires our attention.

We have an aging population and significant immigration and migration patterns in our state. This means that we have more people living in New York from more parts of the world, speaking a wide array of languages, and we have increasing diversity in family structure in our state.

This is societal change. The impact of demographics will have major effects on how New York State “does business”. The issue of population demographics is being raised and discussed across sectors. That makes Project 2015 more powerful.

For New York’s citizens, it means we are taking significant steps to consider the future and to prepare for New York State’s aging and changing society. We aren’t waiting for it to happen, we’re preparing for change.

How did New York’s PROJECT 2015 get started?

In 1998, Dr. Patricia Pine, then Executive Deputy Director of the New York State Office for the Aging, launched the initiative that would come to be known as PROJECT 2015. The initiative was designed to prepare New York State for the significant demographic changes that would take place in the coming years, particularly the aging of the population and increasing diversity.

We hope that this document serves as a resource for all interested parties and stimulates substantive dialogue and concerted action to address these issues.

— Karen Schimke
President & CEO
for the Aging, asked the State Society on Aging of New York (SSA) to assist in bringing the message of an increasing older population to policy makers, planners, and other leaders in the state. SSA members offered to work with staff from the New York State Office for the Aging (NYSOFA) to write articles concerning the effects of a dramatically increased aging population in New York State in such areas as housing, health care, long term care, mental health, legal issues, transportation, role transitions and other life areas. There are 24 articles and briefs written by more than 40 authors in Project 2015: The Future of Aging in New York State, which was released in 2000. The articles include recommendations on how to prepare for the increased demand for services that we likely will see in the future.

To accompany that publication, NYSOFA compiled a booklet on the demographic projections of the older population entitled Demographic Projections to 2025 (1999). This publication is based on 1990 US Census data and includes population projections by five-year age groups from 1995 to 2025, including 2015. This publication also points out the increasing number of minority older people who will reside in New York State.

NYSOFA then brought the idea of convening a state agency planning process to consider the impact of our changing population to the Executive Chamber, which launched PROJECT 2015 in early 2002.

What is Governor Pataki’s PROJECT 2015 initiative?

In February 2002, Governor George E. Pataki charged 36 cabinet-level state government agencies to review their major policies, programs, and structure in light of the State’s increasingly older and more diverse population, particularly the aging of the Baby Boom generation. The 36 cabinet agencies that are participating in PROJECT 2015 are an expansive group with an array of missions, responsibilities and service sets. Each state agency was responsible for writing its own brief as an initial planning activity.

Each participating state agency developed a policy brief that highlighted critical functions or issue areas that would be affected by the State’s shifting demographic profile and which should be addressed within the next 10 years. Through a prioritization process, each agency selected the three most important functions or issue areas, identified action steps, and forecast expected results.

The state agency briefs were compiled and published as Project 2015: State Agencies Prepare for the Impact of an Aging New York – White Paper for Discussion (2002), which also includes two articles about the changing ‘face’ of New York, and an analysis and summary of the briefs.

The 36 state agency briefs in the White Paper for Discussion can be considered both individually and collectively as a compendium of issues important in the state.

continued on page 4
American society is becoming older. Census projections indicate that the elderly, currently 12 percent of our population, will grow to over 20 percent of the general population by the year 2040. In addition, one of the fastest growing age groups is the 85-and-over category, individuals who generally have limitations in one or more activities of daily living (ADLs).

Accompanying the aging of American society are demographic changes in race and ethnicity. Hispanics/Latinos are now the largest minority group, and the Bureau of the Census projects that this group will continue to grow to about 24.3 percent of the population in the year 2050. While the elderly in this group are a small percentage presently (5.5 percent), the Bureau of the Census indicates that the life expectancy of this group will increase and the percentage of Hispanic elderly will increase to 16.4 percent by the year 2050.

An additional consideration is that persons with developmental and other types of disabilities are now living to old age. A number of these individuals will outlive their care-taking relatives and will need long-term care as their limitations in performing activities of daily living increase. Our nation’s inmate population is also increasing, and prisons have increasingly been forced to accommodate their aging population.

This is the time to consider the changing demographics and the effect on society’s approach toward long-term care. The ethnic, racial and socio-economic composition of those needing long-term care will require the system to adopt new ways of providing care. In addition, the numbers of people needing care will become a larger percentage of the population—meaning that fewer people will be paying into the system to support them. New York must consider new ways of financing, organizing and providing long-term care to meet these challenges.

For example, Medicaid has become the primary funding source for long-term care for the elderly. A substantial percent of Medicaid monies go toward this end, although the elderly do not constitute the majority of poor persons eligible for Medicaid.

Financing woes will increase as the number of elderly needing long-term care grows. Funding for Medicaid is derived from federal and state governments and, in New York State, with funding from counties. Consequently, not only is the federal budget affected, so are state and county budgets. These budgets are also stretched by health care costs for groups such as the homeless, TANF recipients, and the medically indigent.

A major eligibility criterion for Medicaid is that beneficiaries must be low income, forcing many elderly who do not qualify for Medicaid-supported, custodial long-term care to find ways to become eligible. These elderly are concerned about having to sign over assets to the government in order to qualify for Medicaid, especially when they thought they could leave these assets as inheritance. This dilemma has spawned a cadre of attorneys and financial advisors to help middle-class elderly protect their assets in some type of trust so that they can then qualify for Medicaid-financed long-term care.

The nation and New York State need to develop innovative ways to provide long-term care for the frail elderly. We must recognize that, in many families, women are no longer available to care for dependent elderly relatives due to employment outside the home. Families need to be provided with incentives to maintain elderly relatives in their own homes, but they must also be provided with support, such as home health aides, day care and respite care, so that they can carry out these responsibilities. We need to experiment with different models of long-term care that will provide high quality services while keeping down costs.

We cannot dismiss our responsibilities for our frail elderly and other dependent populations in our society. We need to recognize the nature of our interdependent society in helping one another. How we help others who need our help will reflect on the quality of society that we want for ourselves.

Dr. Garcia is Vice President of SCAA’s Board of Trustees and Professor at the Syracuse University School of Social Work.
What is happening now in PROJECT 2015?

PROJECT 2015 is continuing at the state, local and national levels. At the local level, the State Office for the Aging has launched a component of PROJECT 2015 called “Taking it To the Streets” in all of the counties of our state, complete with a comprehensive PROJECT 2015 Tool Kit for Community Action that was specifically developed for this purpose. Each area agency on aging has the Tool Kit to use in their leadership role with County Executives and a host of local partners. At the state level, NYSOFA and the 36 participating agencies continue to look to PROJECT 2015 to provide coordinated, streamlined, cross-agency approaches to preparing for the impact of New York’s changing demographics. Nationally, we are responding to inquiries about the project and sharing information about New York State’s project activities.

Are other states looking at similar issues?

There are some states that are looking at the impact of an aging population in their state, but very few have undertaken a planning project similar in scope and scale to New York’s. There are a number of examples of states looking at the impact of the aging population. Minnesota and North Carolina have reviewed the projections of an older population. Minnesota has undertaken major changes in the provision of long term care as a result of its predicted number of older people. California has developed a Strategic Planning Initiative for Older Californians, using New York State as its model. Texas has surveyed state agencies and developed a report about its findings. Florida and Pennsylvania have both looked at the aging of the population and its impact on services delivered in the aging network.

What do you think will result from PROJECT 2015?

PROJECT 2015 provides the foundation to assure that good planning and action take place to address issues associated with the impact of the population changes taking place, and to continue to improve the viability of the State’s communities in the future. That's really what this is about.

PROJECT 2015 is a living process, and we need to continue to work together.

The efforts of many people, including New York State government employees, other professionals, academics, community advocates and volunteers, have led to significant contributions to the work of PROJECT 2015.

A list of all Project 2015 materials may be viewed on the New York State Office for the Aging’s Web site: http://www.aging.state.ny.us.

ANITA’S STORY

Anita is a 67-year-old Latina who is experiencing some medical problems due to her years of working in low-wage, physically demanding positions. She would retire, but has no pension. While Latino traditions encourage children to take care of their aging parents, her children are raising their own families and don't have the room or the finances to care for her. She has been encouraged to apply for Social Security Insurance but is afraid. She tells her family that her poor English skills prevent her from understanding and completing the paperwork. However, the real reason is that she remembers, when growing up in south Texas, years of harassment by immigration officers, and she never asked her parents about her legal status. She is afraid of being deported, although she has spent the majority of her life in the United States. Like many of her immigrant contemporaries, Anita changed jobs frequently and occasionally used different Social Security numbers out of concern that her residency status might not be legal. This makes it impossible for her to collect Social Security. She would like to investigate her status and her legal rights but has not found any organization she trusts. She sees her only option as working to support herself until she is no longer able to do so.
Long-term care refers to a broad range of personal, social and medical services required by people with chronic illnesses and disabilities. Although some long-term care services are provided in institutional settings, most people receive their care at home and in community settings. Many rely on informal, unpaid help from family and friends.

Long-term care services allow chronically impaired individuals to function in their daily lives by providing assistance with activities over a long period of time. Services might include assistance with personal care such as bathing, dressing or eating, or with household chores like meal preparation and cleaning. For home-based care, they may include some home modifications like ramps or may extend to health care services provided at the home. Institutional care can include a range of services provided in nursing homes and sometimes in hospitals. Congregate settings, such as assisted living and continuing care retirement communities, are also available for people needing different levels of care over time.

KATHRYN’S STORY
Kathryn has Alzheimer’s disease. She is only in her 60s. Her husband, Robert, is already in his 70s and suffers from diabetes and heart disease. Robert wants to care for Kathryn in their home. He resents the in-home cleaning services and home-health aides that their children have lined up to help them. He is belligerent, disagreeable and has repeatedly fired the aides. He insists that he can do everything on his own. The children are concerned about the safety and health of their parents but aren’t able to negotiate with their father. They wonder where they can turn for advice and guidance.

People at any age may need long-term care services because of physical disabilities or other impairments. Alzheimer’s disease, heart disease, mental retardation, spinal cord injury and stroke are just a few of the chronic illnesses and conditions that cause impairment.

The range of services available, how they are organized and how they are financed are the critical policy issues facing the elderly who will need services, the families who care for them and the public and private entities responsible for payments and for regulation.

Policy Goals
• The service delivery system should be centered on the needs of the individual and the family.
• The service delivery system should be flexible to meet an individual’s needs for all medical and non-medical needs. It must be able to care for the elderly and non-elderly with disabilities and it must be able to adapt to the cultural needs of minority populations and their families.
• The financing system should be comprehensive, allowing individuals to receive care in the most appropriate setting. Ideally, financial resources should follow the person to allow for the most appropriate care in a setting that meets the wishes of the individual.
• Supports should be developed that encourage families and friends in the role of caregiver.
• Assistance in the education, training and support of professional and para-professional long-term care workers should be provided.

Financing
The largest payer of long-term care services in New York is the Medicaid program. Most of the cost is for skilled nursing facility benefits and home health care benefits. Still, 30% of long term care costs are paid out of pocket by individuals or their families.
Seventy-two percent of Medicaid expenditures are for elderly and disabled beneficiaries. Because of their complex conditions and extensive service needs, expenditures per elderly and disabled beneficiary are much higher than those for adults and children. New York’s Medicaid program has a far greater concentration of elderly and disabled beneficiaries than California’s (31% vs. 18%) and offers better coverage, which helps to explain the oft-cited differences in Medicaid spending between the two states. The more hospital-oriented structure of health care in New York City, along with New York State’s long-standing practice of shifting state expenditures to the federally aided Medicaid program, further explains the differences.¹

Structural gaps in coverage offered by Medicare have led state Medicaid programs to bear an increasing share of the overall costs of health care for seniors and people with disabilities. Medicaid has historically compensated for Medicare’s limited benefits and is often the only source of coverage for persons with a wide range of disabilities who are not eligible for Medicare.

Service Delivery

Most people want to stay in their own homes as they age. The extent to which this is possible is often dependent on the individual’s needs, the availability of caregivers and the source of reimbursement. It may also be dependent on which provider or agency serves an individual seeking assistance.

Unlike acute care, housing is a critical element of long-term care. Where people live – both the physical and the social environment – has a great impact on their ability to function. Some long-term care options, such as nursing homes and assisted living programs, integrate housing with health and social services. Since most people with long-term care needs live at home, services may include “home health care,” including some skilled nursing care and “home care” services such as personal and housekeeping services.

New York State is challenged to provide a range of housing and service options that meet the long-term care needs and preferences of the elderly and non-elderly disabled populations.

Appropriateness of services is critical to ensure that the health and social needs of the individual are being met. This can be complicated because reimbursement plays such a large role in directing which services can be provided in which setting.

Workforce

As important as financing and service delivery systems are to the future of the provision of long-

term care, a key component that is often overlooked is the availability of a trained workforce and the continued availability of informal caregivers.

There is already a shortage of physicians trained in geriatrics and that shortage will be exacerbated with an increase in the aging population. Only 8,800 physicians (1.2 percent) are certified in geriatric medicine but the country will need almost 37,000 by the year 2030 to care for the graying Baby Boomers.2

The lack of paraprofessional workers has already become a crisis in long-term care. The demand for these workers has increased with the aging of the population and the desire of people to remain in their homes. For many reasons, including low wages, lack of career advancement, injury and stress, as well as other job opportunities, there is a decreasing pool of workers and a high turnover rate.

Informal caregivers constitute a critical component of the long-term care system that cannot be replaced through the formal structure. The vast majority of the elderly and disabled living at home receive their care from family and friends. These informal caregivers provide 85% of the long-term care provided in the community. Most of these caregivers are women and many are employed but still provide an average of 12 hours of care a week.


---

**JOHN AND BEATRICE’S STORY**

John and Beatrice are a couple in their late 70s. Both have significant health problems. They have some savings and own their home. They have begun to think about the future and consulted an estate attorney. They were surprised at how little Medicare will cover when one of them needs long-term care. They also found out that Medicaid wouldn’t assist them at all unless they become impoverished. They know from what has happened to friends that the cost of nursing home care will bankrupt their estate within months and want to ensure that the other is taken care of and that, if possible, some of their hard-earned assets go to their children. The attorney counseled them to turn over their assets to their children immediately since state law contains a “look-back” provision that might disqualify them if they wait too long to make such arrangements.
Medicaid spending for people with disabilities who are under age 65 is a large and growing portion of the Medicaid program. Over the past twenty years, New York and other states have shifted the costs of services for populations that have historically been a state responsibility to Medicaid. Communities and policy makers need to consider the unique public health challenges and opportunities associated with serving this population both to improve quality of care and to ensure efficient spending of Medicaid dollars.

- Approximately 624,000 disabled people make up about 18% of New York State’s Medicaid census.³
- The disabled Medicaid population tends to be older, less formally educated and poorer than the overall adult population and the general Medicaid population.⁴
- Medicaid beneficiaries with disabilities are more severely disabled than the general disability population. Nearly three-quarters of Medicaid’s disabled adults need help with activities of daily living such as dressing, bathing and meal preparation.
- Individuals with disabilities have an ongoing need for a broad continuum of health care services and supports. In addition to routine preventive care and primary care services, often neglected with the disabled, there is a need for:
  - Rehabilitative services to maximize functioning;
  - Specialty care to prevent the emergence of secondary conditions that can be complex and expensive to treat;
  - Durable medical equipment; and
  - Long-term care services for full integration into the work force and community life.

³ New York State Department of Health website.

---

**EDWARD’S STORY**

Edward is 56. He has cerebral palsy and suffers from several other chronic diseases. His family is devoted to him and has always cared for him in their home. His parents are deceased and his surviving siblings are getting older and find it difficult to provide care since he is totally dependent. Through the Long Term Home Health Care Program (LTHHC) his family was able to secure all the nursing care, personal care and enabling services that allow him to stay at home. Edward is happy in the home environment and enjoys the companionship of his family.
Barriers to service that result in more expensive care can include: problems with access to providers, including specialty providers; transportation problems; communication barriers; and disability literacy gaps.

In 2002, New York passed the Medicaid Buy-in Program for Working People with Disabilities. It was established to make Medicaid coverage available to severely disabled people between 16-64 who are working and have net incomes up to 250% of the federal poverty level (FPL), and have countable resources that do not exceed $10,000.

Other Medicaid beneficiaries with disabilities are currently institutionalized or face institutionalization as a result of inadequate community-based long-term care and housing options. The Supreme Court’s 1999 Olmstead decision requires that people with disabilities receive their care in the “most integrated setting.” To meet this obligation, New York State signed the “Most Integrated Setting” bill into law in 2003. Since then, New York State has initiated two pilot programs under the Nursing Home Transition and Diversion Program to address the need for more appropriate community-based options. These programs focus on diverting people from institutionalization by ensuring appropriate community supports and identifying and implementing innovative methods for transitioning people with disabilities in nursing homes to integrated community living settings.

As a result of medical innovations, people with disabilities are living longer and are prey to the same chronic health problems as the general aging population. They also have a thinner margin of health. Despite these realities, health promotion practices are not necessarily accessible or tailored to meet their needs. Barriers to physical activity and other self-care interventions often prevent participation. The New York State Disability and Health program has chosen to address these issues by initiating a targeted health promotion intervention, “Living Well with a Disability.” Preliminary results indicate that participants experience a decrease in disability due to secondary conditions as a result of their involvement in the program.

These three promising initiatives: Medicaid Buy-in; Nursing Home Transition and Diversion Programs; and Living Well with a Disability suggest new directions in care for people with disabilities that can both promote community integration and reduce Medicaid expenditures.

---

**OFFICE EQUIPMENT AVAILABLE FOR LEASE ASSUMPTION**

SCAA is seeking an organization to assume the lease for either or both of the following items:

**Item 1**

Imagistics Digital Copier, Model DL 270 and maintenance agreement: Copies 25 copies per minute; maximum monthly volume is 12,000 copies per month; networkable; wheelchair accessible; plus many more amenities. This copier was originally leased February 2002 and currently has only made 18,000 copies. The monthly payment for the 60-month lease is $215 and has 39 months remaining.

**Item 2**

Pitney Bowes Mailing System: Model 6500. The quarterly payment for the mailing system is $429 and there are 24 payments remaining.

If you are interested in either or both items, please contact Kimberly Bobb at SCAA, (518) 463-1896, ext. 40, or e-mail kbobb@scaany.org.

---

As the population ages, attention must focus on sectors of the health care system that will be affected by burgeoning geriatric needs. For example, the mental health sector is particularly ill-prepared to meet the coming challenges.

According to the Surgeon General’s report on Mental Health (1999), the elderly are encumbered by many of the same mental disorders as are other adults, although the prevalence, nature, and course of each disorder may differ. A substantial proportion of the population, aged 55 and older—almost 20 percent—experience specific mental disorders that are not associated with “normal” aging.

Prevalent diagnoses among the elderly include depression and other mood disorders, anxiety disorders, and severe cognitive disorders such as Alzheimer’s disease. Older adults also have a higher suicide rate than other age groups. The clinical challenges such realities present may be exacerbated by the manner in which they both affect and are affected by general medical conditions or by changes in cognitive capacities.

Currently, care for mental illness in the elderly does not meet the need. For example, while adults 60 years of age and older constitute 13 percent of the population, their use of inpatient and outpatient mental health services falls far below what would be expected in the population. There are also existing systemic problems with the way mental health services for the elderly are delivered and financed. In addition, the elderly themselves often do not seek services. Without changes that connect more people to affordable, quality services, the percentage of the elderly who receive care will decline even further.

**Stigma and Denial**

Many elders or their family members resist the need for treatment as a result of outdated images of mental illness. The elderly deny problems, are often reluctant to self-refer to mental health providers and fail to identify symptoms to primary care providers. Because late-life mental disorders can disrupt relationships and strain patience, they can pose difficulties for family members who assist in caretaking tasks.

**Financing**

Most of the elderly find it difficult to afford needed mental health services and other related care without assistance from Medicare and Medicaid, making these systems the largest payers of mental health services for the elderly. The inadequacy of reimbursement and the inability of systems to use existing payment mecha-
Collaboration
There is often little or no collaboration between medical systems, mental health systems and agencies that provide services to the elderly. This lack of coordination makes it more difficult for the elderly to be identified as needing services, and inhibits or denies access to enabling services, such as transportation.

Service Alternatives
For a variety of reasons, there is often a lack of service alternatives in everything from housing to community-based and in-home services. Prevention and mental health education are also often missing from systems of care.

Treating the elderly with mental disorders offers many benefits. It improves overall health and strengthens an individual’s ability to participate in health care decisions. It also encourages family caregivers to provide care and allows for longer periods of living at home.

The mental health needs of the aging population is only one of the health issues that New York must consider as the state adjusts to an aging population. Planning for and implementing the systems changes that will meet the needs of the population will be a challenge for policy makers, state agencies, community providers and private practitioners.

Organizations and policy makers who have not yet considered the implications of New York State’s changing demographics should begin to think about what this shift in the populations will mean for future programs and policies in New York State.

Included on the SCAA website (scaany.org) are links to resources that provide statistics and other information about aging, disabilities and the future. It is not an exhaustive list, but a sampling of what is available.

We’d like to know what you think about the ideas presented in this, as well as other, SCAA publication. Write to us at www.info@scaany.org, or at SCAA, 150 State Street, 4th Floor, Albany, NY 12207.
Depending on your situation, you may prefer to contribute to SCAA now, in the future, or both.

✈ O U T R I G H T G I F T S  O F  C A S H

Cash and checks, the most common form of gift, are always tremendously welcome. SCAA is a tax-exempt organization. As such, your gift is tax-deductible.

✈ A P P R E C I A T E D  A S S E T S

With careful planning, you may find that donations of stocks, bonds, mutual funds, or certain other property that has increased in value and been owned by you for more than 12 months can yield extra tax benefits. Not only will you receive an income tax deduction, but you will avoid capital gains tax that could otherwise be triggered upon sale.

✈ L I F E  I N S U R A N C E ,  R E T I R E M E N T  P L A N S

Many individuals have substantial life insurance or retirement plan balances. In some cases, these assets total more than is needed for a comfortable retirement, and could eventually result in heavy estate taxes.

Consider using these assets to make charitable gifts after first providing for loved ones using assets that would be taxed more favorably.

A simple change of beneficiary form may be all that is required to complete such a gift.

✈ A  P R O V I S I O N  I N  Y O U R  W I L L

As part of your long-range financial and estate planning, you may wish to consider a gift to SCAA through a provision in your will.

Check with your financial or estate planning advisor about ways to plan your gifts while maximizing benefits for you, your heirs, and your charitable interests, like SCAA.