The Future of Aging In New York State

Articles and Briefs for Discussion

New York State Office for the Aging

George E. Pataki, Governor - Patricia P. Pine, Ph.D., Director

In Partnership with the State Society on Aging of New York

Project 2015: The Future of Aging in New York State, Articles and Briefs for Discussion is an initiative developed in partnership between the New York State Office for the Aging and the State Society on Aging of New York. The articles and briefs in this compendium, along with the report, **Demographic Projections To 2025** and public forums held throughout New York State during the year 2000 are intended to broaden public awareness and to encourage discussion and input into planning for the future aging population.

Public comments and suggestions about any of the topics in **Project 2015: The Future of Aging in New York State, Articles and Briefs for Discussion** are welcome.

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Project 2015:

The Future of Aging in New York State

ARTICLES AND BRIEFS FOR DISCUSSION

New York State Office for the Aging
and
The State Society on Aging of New York

STATE OF NEW YORK

GEORGE E. PATAKI
GOVERNOR

March 27, 2002

Dear Friends:

As the Baby Boom generation becomes the Elder Boom generation in the early part of the 21st Century, it will have a major impact on all of New York State. Preparing for this large increase in the number of older new Yorkers is a major challenge for the state.

Recognizing this challenge, we have initiated a planning effort to deal with the needs of this population. As a starting point in this endeavor, the New York State Office for the Aging and the State Society on Aging of New York have compiled a series of issue papers for discussion, recommendations, designs, and eventual implementation of new agendas and protocols in the Empire State.

Project 2015: The Future of Aging in New York State includes papers on health care, mental health, substance abuse, volunteer activities, transportation, and long term care as well as many other important topics. The papers are designed to gather information, commentary, and suggestions from teachers, researchers, planners, policy makers, and aging services providers.

The authors have contributed their expertise so that we can better prepare for the years ahead. I deeply appreciate their assistance, commitment, and interest in helping all of us shape the future for New York State. Their dedication will help ensure a brighter future for all New Yorkers, regardless of age.

Very truly yours,

George E. Pataki

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Governor

Patricia P. Pine, Ph.D.
Director

Two Empire State Plaza
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March 22, 2002

Dear Friends:

New York State's older population will nearly double by 2015. As this Baby Boom generation grows older and becomes the Elder Boom, it will make major contributions to, develop new expectations for, and foster critical changes in the State. In order to be prepared, we must begin now to anticipate how to best utilize our resources and their strengths.

With the support of Governor George E. Pataki, the New York State Office for the Aging and its 59 local Area Agencies on Aging continue to provide a quality lifestyle for current older New Yorkers. In order to prepare for the next generation of older residents, the New York State Office for the Aging and the State Society on Aging in New York have developed a series of issue papers on the potential effects of the aging of New York's Baby Boom generation. 2015 was selected as the pivotal year because it is when the largest number of that generation will be eligible for retirement and when they will become eligible for many government benefits and services. Project 2015: The Future of Aging in New York State offers an array of statistics, data, and recommendations about this older population.

These articles are presented to help broaden public awareness of the issues and to encourage discussion for planning for the needs of future aging citizens. This compilation has been assembled by the sponsoring agencies to assist in understanding the scope, content, and importance of the topics and ideas; however, the publication does not constitute an unqualified endorsement of all the materials presented by the authors, whose views reflect essentially their personal opinions.

It is my hope that through Project 2015: The Future of Aging in New York State, concerned New Yorkers will begin to discuss these important and exciting issues that will affect all of us throughout the 21st Century. We welcome your interest and comments.

Sincerely,

State Society on Aging of New York

Founded in 1972 as the New York State Association of Gerontological Educators (NYSAGE)

The State Society on Aging of New York is proud to partner with the New York State Office for the Aging on behalf of Project 2015, a joint endeavor begun in 1998.

These Project 2015 papers and issues briefs are the result of the forward-thinking and dedication of Dr. Patricia Pine and her staff and the enthusiasm and commitment of many authors (academicians, practitioners and researchers) who came together to share their expertise and insights. We are grateful to all that have contributed to this publication. By focusing on Older New Yorkers in the first quarter of the 21st century, they raise issues to be addressed and potential benefits to be experienced, challenging our thinking and assisting New York State to continue to meet the needs of our changing population, young and old.

The State Society on Aging is honored to participate in Project 2015.

Thank you for this opportunity to serve New Yorkers.

Rose M. Kriss
President, SSA

M. Joanna Mellor
Project 2015 Facilitator

Acknowledgements

The New York State Office for the Aging (NYSOFA) and the State Society on Aging of New York (SSA), partners in the development of **Project 2015: The Future of Aging in New York State, Articles and Briefs for Discussion**, gratefully acknowledge the generous contributions made by all the authors for this project. The authors include faculty representing a multitude of colleges and universities across New York and specialists from community organizations and state and local government, all of whom gave their time and energy to develop the articles and briefs for the Project. This publication offers a framework to engage New Yorkers in a discussion about the coming years and in planning for our aging society. Academicians, legislators, community leaders, individuals from senior citizens to young people, providers and government officials are welcome to contribute to this discussion.

We would like to take this opportunity to offer special thanks to Governor George E. Pataki and NYSOFA's Director, Patricia P. Pine, Ph.D., without whom this project would not be the dynamic reality that it is.

On behalf of the New York State Office for the Aging, Director Patricia P. Pine, Ph.D. wishes to thank Project Coordinators, Dr. Joanna Mellor, Past President (1998), SSA for collaborating on launching and effecting this high-caliber set of articles and briefs. Dr. Joann Reinhardt, Past President (1999), SSA and Dr. Rose Kriss, President (2000), SSA, have continued to support this project with NYSOFA, for which we are grateful. As Project Director, Marcus Harazin, Assistant Director for the Division of Policy and Program Development at NYSOFA has assured that the articles and briefs cover a broad spectrum of issues that will be discussed across the State. Paul Tazbir, Director for the Division of Policy and Program Development at NYSOFA, made the commitment of necessary staff resources to make this project a reality.

We would also like to express our great appreciation to all of the individuals at NYSOFA involved in the Project:

- Patricia Feeser, Assistant Director for Communications, has been responsible for overall production, including the design, formatting and printing for the Project.
- Jennifer Rosenbaum, editor, worked with all of the authors on their articles and briefs and coordinated responsibilities for developing article summaries and preparing the articles for publication.
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- Gay Jubrey provided support on all facets of the Project, including contact with authors, copying and distribution.
- Suzanne Novak assisted with tracking the status of articles and briefs for production.

Many individuals have worked to produce this Project that will raise awareness, encourage discussion and help New York plan for the aging of the Baby Boomers in the coming years. Thank you!

Project 2015:The Future of Aging in New York, Articles and Briefs for Discussion is dedicated to all those who are and will become older New Yorkers.

Project 2015: The Future of Aging in New York State
Articles and Briefs for Discussion

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Project 2015:
The Future of Aging in New York State

INTRODUCTION

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This new century brings one of the greatest challenges and opportunities facing all of society, including New York State: the aging of its population. Not only are older New Yorkers affected by the dramatic increases in numbers of elderly, but also their children and grandchildren, all of whose lives are bonded between the generations. Aging will have an impact on all aspects of our society, public and private.

The aging of America has been predicted and discussed for several years and media attention has made us all aware of the "graying" of society. In spite of this, we, as a country, have been slow to take the next step and examine what this aging population will mean to society and what, if any, planning must occur. At this time, as the ranks of the "Baby Boom" generation are about to burst into their mature, senior years, it is critical for New York State to step back, to re-examine the demographics, to note where we have been and to set forth policy directions for the next several years.

In the Fall of 1998, the New York State Office for the Aging[1] and the State Society on Aging of New York[2] shared their mutual concerns about the lack of preparation of New York State and out of this common cause, a joint project was conceived to establish a framework of facts and educated predictions of the future.

A beginning premise was that much of the needed knowledge was already known, owned, and studied by researchers, educators and practitioners focused in their specific areas of interest. Our task was to bring these individual centers of expertise and wisdom together in a format that would be easily accessible to others within and outside the gerontological arena. Several topic areas were identified, although they are not all-inclusive and can be expanded. Over the past year, experts in each content area, working sometimes in small groups, have taken responsibility to prepare a background or concept paper.

Identifying the concerns of an aging population was difficult and yet necessary. The new aging population will affect all aspects of our society. The characteristics, needs, and expectations of this aging population will differ significantly from those presented by New Yorkers over the past quarter century. As we enter a new century, we are already experiencing the "new" elders who are living longer, in better health and circumstances than their forefathers. The productivity, creativity and experience of New York State's elders offer an immense source of

[1]The New York State Office for the Aging was created by Executive Order of the Governor in 1961 and was one of the first State Units on Aging under the Older Americans Act. In 1965 the office was made an independent agency in the Executive Department and became the central state agency to plan and coordinate programs and services for the aging in all levels in both the public and private sectors.

[2]Founded in 1972, as the NYS Association of Gerontological Educators (SAGE) to provide leadership in the field of gerontology and geriatrics education, the State Society on Aging (SSA) changed its name in 1989 to reflect its membership of educators, researchers, and service providers. SSA brings together individuals from a variety of settings – health care, academia, government, and community agencies – providing a forum for interdisciplinary communication on behalf of older persons in NYS.

leadership and strength to the welfare of our society. While recognizing this, we will also be challenged to assist those older persons most in need of economic and health supports to attain a quality of life now denied them.

Today, there are almost 35 million Americans 65 years of age and older, representing almost 13 percent of the population and the number and proportion have been growing at a rate faster than the rate for younger cohorts. In the years between now and 2011, the older population will continue to grow but at a slower rate because of the low birth rate in our nation. The current group of older persons has benefited most from the medical advances and from the relative affluence of the economy since World War II, from the increase in retirement plans and the programs of the New Deal and the Great Society - Social Security, Medicare and Medicaid, the GI Bill of Rights, the Older Americans Act. Today's aged belong to the first generation of Americans in which a substantial number of women worked. Today's elderly have also benefited from the establishment of organizations for older persons, such as AARP, the founding of professional organizations, and the development of senior centers and opportunities for free and low-cost continuing education. Today's older population is in better health, better educated and more affluent than any earlier older cohort is. However, the relative affluence of most of today's elderly is offset by the existence of poverty and the increasing gap between the haves and the have-nots.

The Baby Boomers, arriving on the scene as older persons in 2011, are likely to differ in vital ways. The size of the Baby Boomer cohort has impacted on society at every stage and at the same time, membership in this cohort has affected its members' life histories and expectations. The size of the cohort will affect how its members age and the contours of the society in which they are growing older. Baby Boomers will be more likely than the preceding cohort to enter old age without spouses and more will be childless or parents of only children. There will be more single parents of long standing, more stepchildren and blended families. The delay in marriage and child bearing for this cohort will mean a longer span between the generations than that experienced by today's elderly. In addition, most of the women will enter old age with, like men, a work history spanning all their adult lives. This is likely to have economic consequences as well as affect the transition to retirement and other life roles.

In spite of these general characteristics of the coming aged cohort, it must also be recognized that this future older population will be more diverse than any preceding old age group in terms of ethnicity, income level, education, family configurations, living arrangements and health. This diversity is one of several crosscutting aspects, which feature in all of the content areas examined in these papers. These content areas will play major roles in our aging society in more ways than can easily be seen. These are diversity (ethnicity, class, and culture); technological advances; and intergenerational relationships and strengths.

Diversity. The older population in New York State will become more diverse. Population projections indicate that minority populations will increase by nearly 40 percent in the next quarter century. In addition, the variety of the customs of their cultures will make our society more complex.

Technology has become a major factor in our lives, both in communication and in assisted living devices. We can anticipate that further technological advances will continue to improve our quality of life and enable older adults to overcome barriers that now cause isolation.

Intergenerational Issues. As our society grows older, older adults increasingly will be requested to be more active in supporting their families and communities. Some of these responsibilities already are evident. Grandparents are raising grandchildren in the absence of their children. Retirees are the primary volunteers for most community projects replacing the non-working wives of the mid-century. These activities compel older people to remain connected to their communities, providing stimulation to themselves and role models for younger generations.

Today's elders and those to come have both experienced and created monumental changes in their lifetimes. They have participated in the process of catapulting the world from the era of the industrial revolution into industrial capitalism, from life on farms and rural towns to the era of cities and suburbia. They have witnessed and been party to vast changes in transportation and communication.

Life expectancy has been extended by several decades over this past century, reflecting revolutionary and evolutionary developments in science, medicine, economics and labor. This gift of extended life brings with it a range of promises and problems, which we have not yet adequately assessed. The State of New York has made great progress over the last quarter century in all areas of human services, including aging. Today we are challenged to understand, more profoundly than ever, the nature of aging and how elders may be integrated within the total society. Once we accomplish this, we can envision the agenda, which awaits the first generation of elders of the new millennium.

What can we envision for New Yorkers of all ages and this older population in particular? What new directions can be opened? Without abandoning those in need, we are faced with a broadened mandate for extended roles for older people. We will need to recognize the strength and potential contributions of elders to the total population. Our society will need to consider how to foster and accept leadership, participation, and active roles of our elders.

The graying of the Baby Boomers is forcing society to adjust its views and attitudes towards old people. We are being moved to:

a) acknowledge and eradicate ageism and stereotypes of aging;
b) acknowledge the commonality of human needs, integrating elders common cause with other age groups;
c) review and reformat our legislation and systems to meet needs;
d) accept and honor elders as role models; and
e) develop ways that enable and encourage elders to continue as respected participants in decision-making and problem-solving, holding a formal voice in policy and program developments.

The articles included in this compendium touch on only a few of the areas in which changes will occur and will need to be addressed. The authors and supporters of Project 2015: The Future of Aging in New York State hope that the concepts and recommendations in this work will encourage policy makers and planners to put in place some developments that recognize and make use of the wisdom and experience of older New Yorkers while also assisting all older New Yorkers to reach a lifestyle that supports their independence and dignity. We owe the population of New York State, young and old, no less.

Project 2015:

The Future of Aging in New York State

SUMMARIES OF ARTICLES

New York State Office for the Aging
and
The State Society on Aging of New York

Project 2015:
The Future of Aging in New York State

SUMMARY

LIVING ARRANGEMENTS FOR OLDER NEW YORKERS

Vera Prosper, New York State Office for the Aging
Susan R. Sherman, Ph.D., University at Albany, School of Social Welfare
and Judith L. Howe, Ph.D., Mount Sinai Medical Center

TRENDS

The primary housing-related preferences of older people are to age in place and to maximize privacy, autonomy, choice, familiarity, and flexibility. Older people's historical behavior patterns reflect a strong will to realize these preferences, and these behaviors will continue during the first quarter of the new century. Several continuing demographic trends make the housing implications of an aging population particularly relevant for New York State: (1) the State continues to have the second largest elderly population in the nation, (2) the State's well-elderly out-migration numbers are moderated by a significant number of frail-elderly returnees, (3) incidence of dementia rises to above 50% among those age 85 and over, (4) New York has a disproportionate ratio of elderly renter to owner households (41% vs. 59%) compared to the U. S. as a whole, (5) average entry age into purpose-built senior housing has risen to between 80 and 85, (6) the State's disproportionate share of minority and immigrant older people will increase dramatically in the coming years (minority elderly age 85+ will increase 285% between 1995 and 2025), and (7) we will continue to see an increase in nontraditional elderly family structures.

Continuing retirement housing trends include active adult communities targeted to young retirees, volatility in the private sector's development of assisted living models, a continuing gap in affordable housing/services models for middle- and lower-income people, greater involvement by the health care industry in senior housing development, evolution of diverse public and private financing mechanisms for housing and long term care, continued strong influence of market forces in shaping retirement housing models, consideration of naturally occurring retirement communities as viable retirement housing alternatives, and increasing attention to cultural continuity in retirement housing.

ISSUES AND RECOMMENDATIONS

- Focus on change and flexibility to adapt to changing markets and to respond to evolving social circumstances and economic conditions.

- Emphasis on an accommodating environment to promote viable aging in place and to maximize independence and autonomy for older persons.

- Greater variety in living environments to respond to the significant differences in needs and preferences found among the older population and to respond to increasing racial and cultural diversity.

- Focus on technology to extend the capacity of older persons to be self-managing, to increase opportunities for older persons to communicate and interact with the wider community, and to utilize opportunities for efficiency in service delivery.

- Focus on intergenerational matters to support interdependence and mutual support among generations, to maximize connections among age groups, and to optimize general community viability.

- Greater response to individual preferences for privacy, personal autonomy, self-determination, choice, and independence.

Project 2015:
The Future of Aging in New York State

SUMMARY

LIVING IN THE COMMUNITY: A RURAL AND NONRURAL COMPARISON

John A. Krout, Ph.D., Ithaca College, Gerontology Institute
Robert J. Maiden, Ph.D., Alfred University, Gerontology Program

TRENDS

Older people living in rural, urban, and suburban areas are different in a number of important indicators of quality of life, and they experience aging in different ways. Trends show a persistent widening gap in incomes between downstate metropolitan counties and upstate rural counties. Poverty rates among the elderly are highest in the most rural counties. A continuing trend that will have an increasing impact on quality of life is the shifting of local control of service delivery out of rural communities and to urban-based government or national and multinational corporations. Lack of public transportation means that rural older people must remain dependent upon private transportation even as they incur aging-related frailties. The oldest housing stock and the fewest alternative, affordable senior housing options characterize rural areas.

Compared to rural and urban elderly, older adults living in suburban areas are most advantaged regarding quality of life, including health, income, and housing status, as well as the availability of health and social services. Yet older adults in suburban areas face challenges in gaining access to services because of inadequate mass transportation systems.

Migration trends reveal the oldest-elderly moving to villages and urban centers for greater access to services, but cost and quality of services remain an issue for all elders, regardless of residence. Urban elderly are more likely to be non-white, have limited economic resources, and face cost barriers to housing, basic services, and especially health care. Typical of central city residents, older urbanites were less dependent upon automobiles throughout their lives and, in old age, become almost totally dependent on mass transit.

ISSUES AND RECOMMENDATIONS

- Assist rural communities in planning and developing more comprehensive and coordinated services for older adults, especially in the areas of transportation, housing, and income support.

- Collect more data on the health, mental health, and social service needs and expectations of aging Baby Boomers in all types of residential environments.

- Support the goal of allowing the elderly to live safely and independently in their own homes as long as possible by ensuring that all communities provide adequate and affordable in-home services, access to transportation, mental health services, home improvement programs, and protection of Medicare insurance and Social Security.

Project 2015:
The Future of Aging in New York State

SUMMARY

THE TRANSPORTATION MOBILITY OF NEW YORK STATE'S AGING BABY BOOMERS

Nina Glasgow, Ph.D.
Cornell University

TRENDS

More older drivers - more miles driven. With the aging of the Baby Boomer generation, New York State will see a 50% increase in older drivers by 2015. More will be female, and more will be dependent upon their personal automobile for mobility. Trends also show older persons driving greater distances for the necessities of life as once local retailers and services move to malls and commercial zones.

More crashes and fatalities. The projected increases in the number of older drivers, driving exposure and added crash injury risk from age frailty mean New York State will see a predictably normal increase in the number of older driver crashes and fatalities.

ISSUES AND RECOMMENDATIONS

- **Highway Safety:** Safe road initiatives, improved signage and markings, safer vehicles, and screening tests that accurately identify problem drivers of any age, are recommended safety directions.

- **Driver Safety:** For older persons residing in most parts of New York State, being able to drive is essential to their access to goods, services, and activities. Driver retraining when it would help to keep an older person driving safely, longer, is recommended.

- **Transportation:** Increasing numbers of older persons are using public transportation in metropolitan areas. Those who ride or wish to ride expect friendly, flexible, diverse, and secure transit options, including training on how to use those options. Many rural areas have only limited public transportation or none at all, and new systems to serve older rural residents should be developed.

- **Mobility Planning:** Since having to stop driving is a possibility in later life, older people should be encouraged to plan with their families and friends for their mobility needs after driving.

- **Community Planning:** Livable communities and pedestrian friendly neighborhoods should be encouraged through mixed-use zoning ordinances and land-use approvals that take into consideration the transportation needs of younger and older persons.

Project 2015:
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SUMMARY

LONG TERM CARE

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TRENDS

Long term care describes a variety of care settings and services for frail older adults and younger persons with disabilities, ranging from nursing homes to assisted living programs and from community-based services such as social adult day care to home care and family caregiving. Recently, long term care has grown as a concept to include rehabilitative and convalescent care (often called 'subacute' care). The retirement of the Baby Boom generation will coincide with tremendous advances in medical science and, with those, longer lives. Most Americans still do not believe they will need long term care services, do not save or become insured for this possibility, and this holds for the Baby Boom generation. However, the reality is that the need for long term care services, including in-home, community-based and nursing home, will increase in the 21st century.

ISSUES AND RECOMMENDATIONS

- Consumer Empowerment and Consumer Education: Baby Boomers, as caregivers of their elderly parents and later as consumers of long term care, can be expected to want an active role in participating in long term care decisions. Improving information and dissemination strategies that use innovative technologies will be crucial.

- Sustaining Family Involvement in Long Term Care: The family provides 80% of long term care services, yet few resources exist to help them cope. The stress on caregivers will increase as the dependency ratio changes (i.e., fewer caregivers available for more older persons needing care). Innovative skill-building, training and other support services need to be promoted and supported.

- Long Term Care Financing and Reform: A major challenge in long term care is to transform it from a system in which many people often impoverish themselves for care to one in which people plan in advance for long term care needs.

- Innovations in Long Term Care: Building on innovative models, continued development, implementation and evaluation of new approaches to long term care are needed.

- Links between Acute and Primary Care and Long Term Care: Linking long term care (funded primarily by Medicaid) and acute and primary care (funded primarily by Medicare) to create a more integrated approach, with the patient at the center, will need to receive attention in the coming years.

- Geriatric Case Management and Care Coordination: Geriatric case management and care coordination hold the promise of more cost effective and higher quality of care.

- Research: Several areas of focus are warranted: the role of families and consumers of long term care, the use of non-medical long term care services, dementia care, services in urban and rural areas, and several aspects of care in nursing homes. Basic research should continue, as should parallel research that evaluates the most effective ways of promoting prevention. Additional demographic research needs to explore how current and future trends of in- and out-migration in New York impact long term care service delivery.

- Professional Education: Educate health and allied health professionals on issues relevant to long term care.

- Regulation and Quality Assurance: Review current regulations of nursing home care to bring them up to date with current knowledge and practice in long term care. Emphasis will need to be placed on outcomes rather than process in all long term care service settings.

- Access to services: Individuals needing long term care and family members that assist them with care will continue to demand improved coordination of long term care services, better information about available choices, improved availability of service options, and a partnership approach to long term care decision-making.

INFORMAL CAREGIVING

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TRENDS

An estimated 15% of U.S. adults are providing special care for seriously ill or disabled relatives. Informal caregivers refers to unpaid family members, friends or neighbors who provide full or part time care to persons with disabilities. Nationally, seven million persons over the age of 65 need help with the tasks of daily living: feeding, dressing and bathing.

As Baby Boomers age and the number of elderly increases in New York, the need for services will have a fiscal and resource impact, and caregiver issues will raise ethical issues as well (e.g., end of life issues will likely become more prominent). Continual changes in family demographics and composition will have an impact on informal supports that are available. These trends cut across all ethnic groups.

The aging of Baby Boomers will no doubt produce a more educated cohort of the "young aged," with greater knowledge of resources, ready access to information from the Internet and possibly a more ready acceptance of public entitlements for themselves and their disabled parents. The higher incidence of multiple marriages, alternate family styles, and blended families will direct the way in which long term care is provided. Increasingly the identified needs of caregivers for respite, education and skills training, transportation and supplemental services for the older person will have to be met by a combination of public and private services.

ISSUES AND RECOMMENDATIONS

- Case management services, either public or private, should include an assessment of the caregiver as well as the care recipient since many caregivers need assistance to identify their own needs.

- Private and public funds should be dedicated to the development of additional adult day care programs.

- A literature review suggests that psycho-educational support groups are more effective than strictly support groups or strictly educational groups.

- The most effective programs that will reach rural and urban caregivers will incorporate all the technology available. Chat rooms and support groups on the Internet are also effective tools.

- Advocates for the aged and the aging network should consider how they may:
  - Encourage legislation to provide tax benefits for the costs of elderly dependent care;
  - Encourage businesses to incorporate stipends for elderly dependent care in their benefits package;
  - Encourage development of insurance programs that would cover custodial care; en courage businesses to include support groups, counseling, resources and referral information as part of their employee health programs;
  - Support the development of cooperatives and barter programs for service credits; and,
  - Encourage development of other innovative programs.

GRANDPARENTS AS FAMILY CAREGIVERS

Denise Burnette, Ph.D.
Columbia School of Social Work

TRENDS

Demographic and sociological changes have dramatically increased the number of grandparents who are rearing their grandchildren in the United States. New York State, particularly New York City, is one of several major epicenters of this growth. Public policy has been slow to keep pace with the changing roles and responsibilities of relatives as primary, long-term caregivers of young kin. Planning for this population is complicated by numerous interlocking, at times conflicting, needs of multiple generations of families, usually over the course of many years. Tailoring existing resources and programs to this growing family configuration and developing innovative programs and policies geared toward meeting already established needs will improve the quality of their individual and collective lives.

Grandparents who are rearing their grandchildren help preserve crucial kinship ties and provide an inestimable social and economic service to society. Most report a deep sense of satisfaction, gratification, and mastery from their caregiver role, but these gains are often at great personal and family cost. Over and above role-related demands, both current and cumulative disadvantages heighten risks of economic, health, and mental health problems for grandparent caregivers and challenge their current and continued ability to parent.

ISSUES AND RECOMMENDATIONS

- **Poverty:** The single greatest overarching problem facing grandparent caregivers is economic security. The current and long-term economic effects of welfare reform on grandparent-headed families should be monitored closely and addressed appropriately.

- **Physical and Functional Health:** Nationally, 36% of custodial grandparents rate their own health status as fair, poor, or very poor, and they are more likely than other grandparents to report limitations in Activities of Daily Living.

- **Insurance Coverage:** Grandparent-headed households are more likely than traditional households with children to have gaps in insurance coverage.

- **Mental Health:** The most significant mental health problem for grandparents raising grandchildren is depression, with one in four grandparent caregivers nationally experiencing a significant level of depression. Any efforts to increase the use of much-needed formal mental health services must address a wide range of barriers, including low awareness

of services, limited child care, lack of insurance coverage, cultural barriers and negative attitudes about mental health.

- **Information, Education and Support:** The chief source of education and support for grandparent caregivers is support groups, with more than 500 groups nationwide. Grandparents identify respite as a priority service need, and this service may be especially helpful for those rearing children who have special needs.

- **Legal Issues:** The legal status of the grandparent-grandchild relationship determines the type and extent of grandparents' rights, responsibilities, and authority on matters such as school enrollment, medical consent, access to official records, and health insurance eligibility. Existing arrangements vary widely in terms of level and type of economic and supportive services provided.

AGING PERSONS WITH DEVELOPMENTAL DISABILITIES

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TRENDS

There are an estimated 500,000 older persons with developmental disabilities in New York State, and the population is expected to double by 2030. New York State has long been a leader in program and service innovations for the growing population of persons living with developmental disabilities and more recently for the population of older adults with developmental disabilities. While much has been accomplished, major challenges remain. There is an ever-increasing need for innovative programs and services to meet the special health and service needs of these individuals and their families.

ISSUES AND RECOMMENDATIONS

I. Health

- Older persons with developmental disabilities should be screened for health risks on a routine basis.
- Special attention should be paid to age-related diseases that may present atypically in persons with significant communication problems.
- Physical environmental assessments need to be done to prevent injuries and accidents and enhance quality of life.
- Older persons with developmental disabilities should be educated in health and wellness activities.
- Caregivers need to be trained in observation of symptoms and in interacting with health care providers. They need to differentiate between disability and age-related changes and diseases.

II. Programs and Services

- Data needs to be collected on the numbers and functional status of older persons with developmental disabilities. Outreach efforts need to be made in order to identify older adults who are not known to the service system, but who may need care when their families can no longer do so.
- Programs and services need to become more flexible to fulfill the spirit of "person-centered planning." There needs to be better coordination between residential and day services in order to ensure flexibility as consumers age.
- The use of resources beyond those offered by the traditional aging and developmental

disabilities systems should be encouraged. Involvement in age-inclusive community activities, expanded retirement and leisure options need to be fostered.

- Paid caregivers need increased support in order to continue to care for the aging persons under their care. They need specialized training, as well as respite services for themselves in order to manage the increased dependency of their consumers.
- Adaptations to physical environments need to be made in order to allow persons with disabilities to continue to function as independently as possible.
- Day program activities need to be adjusted to accommodate the changing needs and abilities of consumers.

III. Caregiving

- Family support programs that are individualized and are tailored to the individual needs of the family need to be expanded.
- Long term planning, including family caregivers and the older person with a developmental disability needs to take place.
- A broader definition of "family" needs to be adopted in New York for persons other than parents or siblings to be eligible for needed services.
- Agencies providing services need to be culturally competent and be able to work with local cultural provider agencies.

GERIATRIC REHABILITATION

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TRENDS

Geriatric rehabilitation is commonly employed to: prevent impairment and disability; to support adaptation to or recovery from illness or disability; and to maximize functional independence. The geriatric rehabilitation team often includes the client, family, physician, nurse, occupational therapist, physical therapist, social worker and sometimes speech therapists, dieticians, psychologists and other allied health personnel.

Geriatric rehabilitation utilization has increased in past years. Hospital data indicate an 854 percent increase from 1985-1996 in hospital discharges prescribing geriatric rehabilitation. Certified home health agencies for the same period provided 134 percent more rehabilitation visits, and the Long Term Home Health Care Program recorded 394 percent more visits. Residents of skilled nursing facilities have offered an increased number of restorative geriatric rehabilitation services from 1986 to 1998.

New York State's older population will include greater numbers of those age 85 and older, which will increase the potential for chronic illness and disability among the oldest-old. The impact on the health care system will include a greater demand for more geriatric rehabilitation.

ISSUES AND RECOMMENDATIONS

- Provide greater access to an increasingly diverse aged population using a continuum of rehabilitation services, appreciating the role of environment and housing to promote functional capabilities.

- Support cost effective services, including community based preventive and restorative rehabilitation programs (including technology and supportive housing).

- Include families and communities in programs/services to support successful aging and community living.

- Increase the number of rehabilitation professionals knowledgeable about aging issues including understanding of multiple ways to utilize and fund rehabilitation services.

- Utilize multiple funding strategies including Medicare, Medicaid, managed care and other third party payer funding, Long Term Care Insurance, and government-private sector partnerships.

- Support partnerships among communities, families, volunteers and rehabilitation professionals to promote environmental supports, wellness, and preventive services to maximize capabilities of elders.

Project 2015:
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SUMMARY

HEALTH AND THE BABY BOOMER

Dorothy Hickey, MA, MPH, RN, CS
Clinical Nurse Specialist
SSA Board of Directors Member

TRENDS

Certain factors are important to consider in creating a plan to meet the health needs of Baby Boomers. These include but are not limited to: health characteristics of New York State residents age 50 and older; attitudes of Baby Boomers toward health; effects of health care costs and insurance on the Baby Boomer; emerging health needs of the Baby Boomer with aging; Baby Boomers' participation in their health care; and who will meet health care needs in 2015?

ISSUES AND RECOMMENDATIONS

- Compile and make available health behavior, health status, health care access and other health statistics for health care planning and marketing.
- Address chronic illnesses and supportive care needs in a variety of settings, including community-based, home and institutional.
- Develop and implement new initiatives for screening for men and women as they age for potential high-risk health problems and to enhance quality of life.
- Fund longitudinal research and more comprehensive data collection on the current cohort of Baby Boomers to make explicit projected health needs in 10 to 15 years.
- Combine public and private health insurance so as to provide opportunities for guaranteed health coverage for all children and adults. Continue support for collaborative prescription drug programs for those both acutely and chronically ill.
- Strengthen access to prevention, early detection and case finding by diverse health care providers.
- Include scientifically valid alternative and complementary therapies as covered services.

STEPPING OUT ON FAITH: GERIATRIC MENTAL HEALTH IN 2015

Martha Sullivan, DSW, Gouverneur Diagnostic & Treatment Center
Evelyn Lauriano, CSW, Neighborhood Self Help by Older Persons, Inc.
Angela Shen Ryan, DSW, Hunter College of Social Work
Maria Hodges, CSW, Brookdale Center on Aging

TRENDS

It is estimated that between 15 and 25 percent of people 65 and older suffer from mental illness or emotional stress. The current cohort of Baby Boomers has already shown relatively high rates of depression, anxiety and substance abuse. We can anticipate that these trends will accompany them into old age, resulting in a dramatic rise in overall prevalence of mental health disorder among older adults. The elderly population of 2015 will be a much more ethnically diverse population. The contemporary mental health service delivery system is struggling and falling short of the imperative to provide culturally competent services.

ISSUES AND RECOMMENDATIONS

Promoting Optimal Mental Health

- Mental health promotion should take a variety of forms including prevention, mental health education, etc.
- Sufficient services will need to be available and designed to meet the needs of older people who will have varied attitudes and preferences in regards to their care.
- There will be a need for a more age-affirming social environment. Provisions should be made to empower older adults as consumers of mental health services both as an ethical principle and as an opportunity to promote self esteem and social status.

Family Centered Care

- A greater emphasis will need to be placed on home-based and family oriented care in the community.
- Rather than organizing "clusters" of individuals, models of care should be developed to serve families.
- Families will need in-home services that promote independence and delay placement: health care, housekeeping support, and mental health care including crisis care and ongoing treatment in the home.
- Home based occupational therapy and recreational therapy should be increased and further developed in order to meet the anticipated demand.

Culturally Competent Care

- Practitioners will need to develop competencies in appropriate languages.
- Practitioners will need to understand immigration experiences, health/mental health practices and beliefs, acculturation differences, bicultural socialization and more.

Education and Training of Geriatric Mental Health Professionals

- In order to meet the demands of older people, specific programs need to be instituted to attract and train geriatric psychotherapists.
- New York State should create linkages between geriatric mental health programs and graduate professional schools in order to develop geriatric mental health traineeships across disciplines.

ELDER ABUSE AND NEGLECT

Pat Brownell, DSW, Fordham University, Graduate School of Social Work
Adele Welty, New York City Department for the Aging
Mark Brennan, Ph.D., The Lighthouse International

TRENDS

The last 15 years have been important in framing elder abuse as a significant social problem in New York State. Estimates on incidence and prevalence of elder abuse and neglect have ranged from 3 to 40 per thousand depending on the definition used and the population studied. Some estimates have risen as high as 100-120 per thousand. No estimates to date include institutional abuse. Assuming a conservative estimate of 40 per thousand, approximately 130,000 (out of over 3 million) elders in New York State may be victims of abuse or neglect. The actual number is thought to be much higher.

For the year 2015, New York needs to build on the foundation developed in recent years to move forward and more effectively address the problems of elder abuse and neglect. First, a common definition of elder abuse and neglect is needed that clearly defines and delineates what elder abuse/neglect is and how it is to be measured. New York also needs to consider how to address the current fragmentation among the criminal justice, social welfare and service systems that assist elder abuse victims and their abusers. This fragmentation is reflected in legislation, social policies and programs for abuse victims in New York State. The lack of a common definition combined with fragmented policies in elder abuse and neglect limit our ability to identify current trends and to better plan for the future.

ISSUES AND RECOMMENDATIONS

Definition of Elder Abuse

- Reconcile divergent definitions of elder abuse and neglect used by agencies and institutions that serve older adults and their families in New York State, and explore the feasibility of legislating a central reporting system for providers that protects confidentiality and does not trigger mandatory investigations.

Policies Concerning Elder Abuse

- Policies, funding streams and agency mandates mean that different agencies are responsible for different aspects of elder abuse and neglect. This fragmentation needs to be tackled so that effective services are available to address problems of elder abuse and neglect.

- Policies and programs to address elder abuse and neglect need to maximize the autonomy of victims without compromising their safety.

Services and Reporting

- Expand interdisciplinary service options within the criminal justice, social and health/mental health frames to better serve elder abuse victims and their abusers, including prevention services.
- Address service gaps to include special shelter facilities and voluntary financial management service programs for elder abuse victims.
- Consider an increase in service options for impaired abusers, including intensive case management, substance abuse, housing, and mental health services earmarked for abusers of older family members.
- Support outcome measurement research that looks at the effectiveness of services for both victims and abusers.
- Examine differences in reporting of elder abuse and neglect by race/ethnicity and gender to determine how best to address these reporting differences.

Training

- Increase professional development and training opportunities for workers serving elder abuse victims and their families.

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SUMMARY

ROLE TRANSITIONS

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TRENDS

Current institutional arrangements and policies about aging, work and family are outdated and lag behind the realities of the Baby Boom cohort. Organizational and occupational ladders provide a common understanding of social mobility and an identifiable pattern of progression through the life course. But this common understanding represents a set of practices and policies that no longer fit with the realities of a changing economy, changing gender roles, blurred lines between private and public roles, and a cohort of educated, introspective Baby Boomers newly valuing family life and uncertain about middle age. Many notions about roles are inconsistent with the growing number of two-earner (or single-parent) Baby Boomer families as well as with the leading edge of boomers moving into retirement. Identifying key "role transition" issues and structural lag can help New York policy makers and planners assist all older New Yorkers to lead satisfying, productive lives.

ISSUES AND RECOMMENDATIONS

Private roles and relationships:

- **Marital tie:** The marital tie provides a sense of connectedness and support. Social scientists have long ignored the substantial number of older adults who have, by choice or chance, not entered into a legal, marital relationship. Due to the increased possibility of isolation, we need a greater understanding of their ties to partners, parents, aunts, uncles, siblings, nieces, nephews, friends, co-workers and others.

- **Parenthood:** Little is known about the impact of parenthood on adults in later life. The number of children raised and the amount of one's life spent in raising children are important factors to consider when assessing later-life outcomes.

- **Grandparenthood:** Grandparents have very little control over this role¾the timing and process are in the hands of their children. Several factors influence the older adult's involvement in this role, including geographic proximity, number of grandchildren, stability of the children's relationships, and the health and financial status of both the grandparents and the grandchild's parents.

- **Care work:** Caring for others is one role that has a potential for "costing" a lot in terms of health and social/psychological outcomes for older adults. Whereas the care involved in the raising of young children is anticipated, frequently welcomed, and circumscribed in the life span, caring for an infirm parent (or spouse) or for a handicapped adult child can become an unexpected but absorbing role that may have many positive and negative outcomes.

Public activities in society:

- **Paid work** is the primary mechanism for many or most adults' active participation in the larger society, a fact that places many older Americans out of the mainstream. Knowing about current involvement in paid work may be less important than knowing the duration, spacing, and overall pattern of labor force participation throughout adulthood.

- **Post-employment lifestyle**. For some, this new lifestyle may involve additional periods of paid work in order to stay involved and feel integrated into the larger society. Others begin second careers; some work in their later years to help make ends meet. Leisure, travel, and community/family involvement are the main activities of those who have good health and adequate resources. Documenting the timing and process of these activities is difficult but important for understanding the public activities of older people.

- **Bartering or trading services** with friends, neighbors, and kin. How many older people participate in bartering or receive "payment under the table," and what are the reasons or motivations for this? One can assume that the underground economy is alive and well and will continue to flourish as Baby Boomers age.

- **Volunteer activities,** either through formal or informal involvement in the community, are associated with positive outcomes throughout the life course.

- **Political involvement**, ranging from running for office or serving as a public official to the mere act of voting also varies across the life course. Knowing a person's early experiences may be a good indicator of continued activity, but as Baby Boomers age we may see patterns of involvement that are different from those characteristic of the current cohort of seniors.

OLDER WORKERS: RETIREMENT OR CONTINUED WORK?

Patricia P. Pine, Ph.D.
New York State Office for the Aging

TRENDS

The retirement of the Baby Boom generation will double the number of retirees early in the next century. The timing of their retirement will affect the composition and the productivity of the workforce. The increased number of retirees will have an impact on the costs of entitlements, including increased retirement benefits, and a labor shortage with fewer workers to fill existing positions. When Baby Boomers retire, they will take with them their experience and knowledge, but recent trends indicate that Baby Boomers are more willing and able to work. Some will pursue continued employment for financial gains, others for emotional or psychological reasons. Three identified barriers to retaining and hiring older workers are (1) current policies that create financial disincentives to continued working; (2) discrimination practices in the workplace; and (3) the perception by employers that older workers are expensive.

ISSUES AND RECOMMENDATIONS

- Reform workplace policies and procedures to provide incentives for employee retention, appealing to both the financial needs and the quality of life of an employee. Popular options among newly retired workers are flexible work schedules, including job-sharing, flex time, and a reduced work week.
- Offer a diversified "cafeteria-type" benefits package to appeal to all generations of workers.
- Offer a phased or gradual retirement program.
- Combat negative stereotypes in the workplace.
- Promote training opportunities for older workers.
- Create recruitment strategies for older workers in new market areas.

ECONOMIC CONSIDERATIONS

Harvey Catchen, Ph.D., SUNY College at Old Westbury

TRENDS

The elderly in 2015 will be different from today's elderly. They will be better educated, have better health, and have greater financial assets than previous generations. At the same time, there also will be some elderly who are economically and physically disadvantaged.

Economic security for the elderly is provided primarily by federal Social Security, Medicare and Medicaid programs. Also there are social programs that offer supportive assistance, such as meals, transportation, part time employment, and home care. The future of Social Security is dependent upon at least two predictions. One is the number of older people and how many will collect retirement benefits. Two, the future of the economy of the United States will affect the financial stability of Social Security.

ISSUES AND RECOMMENDATIONS

To meet the economic security needs of the future elderly, there needs to be in place:

- Programs to support the needs of seniors who wish to continue to work. This will require redefining retirement, making it a gradual process during which employees can reduce their hours of work, depending upon economic, physical, social and familial constraints.

- Redefined education for a new generation of seniors. Courses can be offered at senior centers, churches and other public institutions to exercise mind and body as well as training for employment.

- Expanded programs for the disadvantaged elderly, including low-income, minorities and women. There will be a need for long term care assistance and expansion of community-based services.

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SUMMARY

LEGAL SERVICES

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Sia Arnason, C.S.W., Samuel Sadin Institute on Law
William T. Graham, Assistant Counsel, New York State Office for the Aging

TRENDS

The legal issues of older adults are often more complex and diverse than those of the population at large. They often involve planning for changes in life such as retirement, long term care for chronic and debilitating illnesses, loss of capacity and death. The solutions, like the issues, are frequently not simple. Attorneys need to look at many other disciplines in addition to the law in seeking the proper course. It is within this context that New York needs to prepare for the delivery of legal services to older adults in the coming years.

ISSUES AND RECOMMENDATIONS

- **Long Term Care Planning:** As the cost of long term care increases, the need to plan becomes ever greater. Long-term care insurance has been promoted by many and carries the possibility of greater choices for consumers. Also, those most in need of Medicaid will continue to require assistance in navigating the eligibility maze due to ever-changing eligibility requirements.

- **Housing - Particularly Assisted Living:** Increased life expectancy, cost of medical expenses, and demands on already limited resources require that state and local legislators and policymakers consider innovative ways to address the housing needs of New York's aging population.

- **Administrative Proceedings:** The elderly are often wrongfully denied or otherwise deprived of public entitlements and health care benefits on which they rely. Few elderly claimants are aware of their due process protections, nor are they able to pursue an administrative appeal without help from an expert.

- **Grandparents As Caregivers:** Many older New Yorkers are serving as parents a second time around. These kinship caregivers often face legal problems as they attempt to meet the needs of the children in their care.

- **Guardianship:** As the percentage of older New Yorkers increases in the next fifteen years, it is inevitable that more capacity problems will emerge. The absence of advance directives presents a major concern when the individual's capacity is questionable.

- **Develop Coherent Public Policies:** Policy makers must not use a piecemeal approach to legislation. Solving one problem could have unintended consequences if it is not thought through.

- **Increase Funding of Public Legal Services Programs:** A dedicated funding source for legal services programs would enable agencies to provide assistance to more mature residents.

- **Utilize Modern Technology:** Modern technology offers an opportunity for older New Yorkers and their families to obtain a wealth of information on legal issues. Technologies that are likely to see the greatest growth and usage in the next fifteen years or so are the Legal Hot Line and the Internet.

- **Education:** Lawyers, older New Yorkers and other professionals need access to information in order to resolve or avoid crisis.

NUTRITION

Arlene Spark, Hunter College of the City University of New York
Edward A. Frongillo, Jr., Cornell University

TRENDS

Helping Baby Boomers to adopt healthy exercise and nutrition habits now will significantly affect the need for and cost of long term care in 2015. When Baby Boomers reach old age, good nutrition will play a significant role in affecting chronic health conditions and illness. Health care professionals will require training to develop the skills and attitudes necessary to maintain older adults in an optimal state of health in their own environment.

ISSUES AND RECOMMENDATIONS

- The proportion of physician visits at which nutrition counseling and educational services are ordered or provided should be increased to prevent disease progression in Boomers who have already been diagnosed with nutrition-related conditions (e.g., type 2 diabetes, cardio-vascular disease).

- An active Web site should be developed and maintained that contains evaluations of food and nutrition products marketed to Baby Boomers. Products with implicit as well as explicit claims to promoting health and prevent disease should be included.

- Routine nutrition screening and interventions should be expanded beyond physician office visits: a) patients should receive nutrition screening and interventions at many points across the continuum of care, and b) nutritional assessment should include a diet/nutrition plan and recommendations regarding other important interventions (e.g., problems associated with multiple medications, dental and oral health problems, functional status, economic issues, and mental health concerns).

- Develop a method of identifying New York State counties with greater or lesser food security for resource allocation consideration.

- Ensure that people in greatest need are identified and served.

- Improve outreach and expand programs to reach more older people who are food insecure and homebound.

- Invite the Gerontological Nutritionists Practice Group of the American Dietetic Association to become a lead organization for food and nutrition training of health care workers who care for the older population in New York State.

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ARTICLES FOR DISCUSSION

New York State Office for the Aging
and
The State Society on Aging of New York

Project 2015:
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LIVING ARRANGEMENTS FOR OLDER NEW YORKERS

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Susan R. Sherman, Ph.D.,
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Introduction

In both the public and private sectors, economics underlie the ongoing shift to providing health and long term care in housing settings rather than institutional environments. This shift supports the living environment preference of older people to stay where they are and "age in place." Indeed, regardless of public and private sector actions, the historical "housing" behavior patterns of older people reflect a strong will to realize their housing-related preferences.

Housing Related Preferences

Age in place
Privacy
Autonomy
Familiarity
Flexibility
Choice

To a great extent, the behavior patterns of the past quarter century will continue during the first quarter of the next century as older people's living environments continue to reflect these major preferences. However, in New York, these continuing patterns will be colored by the characteristics of the State's diverse Baby Boomer generation, which will reshape both the concept of "staying where you are" and the means for ensuring viable "aging in place."

Rank Order

Housing Choices

Single family home
Family apartments
Senior apartments
Supportive housing
Assisted living
Institutional facilities

The housing implications of an aging population are particularly relevant for New York State because of several demographic characteristics. The state continues to have the second largest elderly population in the nation, and the state's "well-elderly" out-migration numbers are moderated by a significant number of "frail-elderly" returnees. All elderly age segments will increase significantly over the next 25 years, but the growth in those most vulnerable to impairment (age 85 and over) creates a critical need to attend to the design and cost of appropriate housing environments. New York has a disproportionate ratio of elderly renter:owner households (41% renters vs. 59% owners) compared to the rest of the country (20% renters vs. 80% owners), and this disproportionate ratio will continue into the future. New York's already disproportionate share of minority and immigrant older people will increase dramatically in the future. There is no reason to conclude that the proportion of elderly householders living alone will decline in the future. Finally, incidence of Alzheimer's and other dementias rises to above 50% among those age 85 and over. Many of these characteristics are related to poverty status. They have a significant impact on the public costs of housing and long term care, and they emphasize the need for appropriate living environment design.

POPULATION - New York State

% CHANGE: 1995 - 2025

	All Elderly	*MinorityElderly*
Age 60 - 74	+ 44%	+128%
Age 75 - 84	+ 29%	+165%
Age 85+	+ 41%	+285%

POPULATION — New York State

	60+	Under Age 60	Minority Age 60+
1995	3,152,046	14,984,031	629,643
2015	3,667,044	125,249,248	1,141,023
2025	4,402,269	15,427,571	1,541,181
% change 1995-2025	+40%	+3%	+145%

Past Housing Trends In New York

While there has been increasing variety in housing types for older people, the evolution of these types underscores the stability of older persons' housing-related preferences for privacy, autonomy, and aging in place.

New York State: 1990

HOUSEHOLDS AGE 60 +

Households	% Living Alone
Minority	42%
Homeowners	31%
Renters	60%
Below Poverty	74%
Age 60+	43%
Age 60-74	35%
Age 75-84	56%
Age 85+	68%

Prior to 1960, it was typical for older persons to live where they had always lived — in their own homes and apartments. Where this was not possible, they lived with family. For the frailest, or those with no families, nursing homes or homes for the aged provided an option. However, at any one time in New York, as well as in the rest of the country, nursing homes housed only five per cent of older people. Major involvement by the federal government in building senior housing for low income seniors and persons with disabilities began in the 1960s, and typical entry age for seniors was 60 to 70 years. This housing was designed for the well elderly, and government programs did not promote service enhancement. Retirement villages developed in several western and sunbelt states in response to private pay markets. These villages were targeted to active young-elderly couples; and climate, ease of maintenance, security, and recreational facilities were major attractions. At that time, a market among this group was too limited in New York to attract developers. Development of continuum-of-care campuses in western and southern states also began in the 1960s, providing independent housing, supportive assistance, and nursing home care. Specific nursing home regulations intended as consumer protection measures prohibited their development in New York State until 1989.

The proliferation of home and community based services in New York in the 1980s and 1990s gave older people increasing opportunity to exercise a choice to remain at home when frailty compromised independence. Despite the growing availability of both publicly funded and privately marketed housing models that included an array of supportive services and care, the average entry age into purpose-built senior housing rose to approximately 80 in the 1980s and hovers at 85 in the 1990s. This rising entry age characterized the private sector phenomena of supportive (congregate) housing, assisted living facilities, and life care communities which thrived as market-driven responses to the expressed preferences of affluent older people for a noninstitutional, supportive "housing" environment. The rising entry age was also found in public sector subsidized housing models which incrementally added services, staff, and activities to accommodate aging tenants. While the number of older people needing a supportive environment grew due to increasing longevity, the proportion of older people living in all types of senior housing has remained consistent at between 6 and 10 per cent across the country, and the proportion of older people living in nursing homes has declined in New York State.

The Future Impact of Evolving Trends In New York State

In planning housing for the upcoming cohorts, attention must be given to recent distinctive societal trends. These trends highlight either a need or a market among older people for housing that meets specialized needs or preferences. Much of today's senior housing is

Significant Baby Boomer Traits

More educated
Technologically sophisticated
More mobile
Cosmopolitan

Healthier
Greater attention to nutrition, fitness, & preventive care

Delayed retirement
Continued connection with the wider community

Significant Diversity

Many:
More buying power
Demanding a life style during the later years, not just alternative shelter

Many: Poor

single-purpose in design and targeted to specific subpopulations, effectively segregating these subgroups and creating housing that becomes unuseable as societal characteristics change. Often the regulatory frameworks around age-integrated housing restrict occupancy eligibility. The increasing types of non-traditional elderly family structures and the continuing ebb and flow of major subgroups emphasize the need for *flexibility* in creating housing environments that can successfully accommodate or adapt to evolving social and cultural phenomena. Examples of these growing trends include: (1) Grandparents who are raising grandchildren and who require a living environment that supports both the needs of children and the aging grandparent. (2) Persons with developmental disabilities who have been cared for at home by parents and who have historically not lived into old age. This group, like the rest of the population, are living much longer; they have lived their entire lives in a community setting but are unaccustomed to living alone; and their aging parents are dying or becoming too frail to continue the caregiving role. (3) Young-elderly and old-elderly children caring for an oldest-elderly family member, where multiple generations require support or assistance or may wish to live together. Baby Boomers are more likely than any previous cohorts to be older caregivers for elderly parents as their parents' life expectancies are elevated. (4) Increasing numbers of single older people who lack familial caregivers. (5) Emerging subgroups requiring housing with specialized care (such as older AIDS patients) or public policy attention (such as appropriate housing for older prisoners).

Many of the above phenomena characterize the current "young-elderly," who represent a transition cohort with traits that are similar to the Baby Boomers following them and who provide a taste of what to expect in greater proportions as the Baby Boomers enter the elder cohort.

Other social and economic conditions are currently shaping the design of housing environments for older adults, and the volatility of these conditions will have unpredictable impacts on the continuing viability of these designs for future cohorts. Some examples include:

(1) Active Adult Communities: The personal traits and interests of the Baby Boomer cohort, together with this group's increased buying power, have created an upsurge in the demand for "active adult" communities. What does the future hold for these age-segregated enclaves of large single-family homes targeted to those age 50 to 70 that include more rooms to accommodate second careers, hobbies, visiting grandchildren, fitness activities, and technology, but no supportive services to accommodate aging in place? The few such communities built in past years have quietly added services, but acknowledge the impact of this image-change on the marketing of these communities.

(2) Assisted Living: This generic term refers to a variety of models that integrate housing and a range of supportive assistance, long term care, and health services. Currently, assisted living represents a major noninstitutional choice of frail older people, as well as the cost-effective choice of policymakers. Changes in consumer demand, the capital investment community, and public regulations have repeatedly shaped and reshaped the assisted living industry and the design of its housing products.

Volatility in the private pay assisted living industry has prompted movement of individual companies in and out of the publicly traded sector, increased merging of community- and regional-based companies into national chains, and repeated modification of residents' housing/services agreements in response to regulatory restrictions and market competition. Creative assisted living partnerships are pairing traditional housing developers with the hotel industry, universities, health care providers, and aging services providers. Hospitals, nursing homes, and home health agencies are diversifying into assisted living development. The profitability of assisted living has spawned a growing national industry of single-purpose assisted living companies. Marketability and profit-niche issues have resulted in the development of dis-

crete dementia facilities, as well as housing models targeted to specific levels of functional ability. Such industry volatility creates both confusion and quality-of-care concerns for residents and families, and requires them to assume greater responsibility for understanding the lack of uniformity among models, the contractual promises of individual facilities, and the impact on their ability to age in place.

New York's licensed public Assisted Living Program is currently available only in limited settings and is available only to those assessed as being nursing-home-eligible. To date, in New York State, affordable housing/services integration models are available to middle income elders in very limited quantities. Availability may improve as the demand for private pay models is softening in response to near market saturation. The costs of models for low income older people results in the availability of this option remaining consistently and significantly behind the demand. The buying patterns of the looming numbers of Baby Boomers may have an influence on the development of models that are priced lower than current models. In both the private and public sectors, costs have prompted the design of models that include no kitchens or that consist of a single or shared room, reversing the desired goal of meeting consumers' preferences for full apartments and privacy.

(3) Naturally Occurring Retirement Communities (NORCs): These are age-integrated multiunit buildings that have evolved to include a disproportionate number (often, more than 50%) of households headed by persons age 60 and over. Conventional thought is that "staying where you are" means that seniors continue living in their single-family homes. However, among older renter households, greater numbers live in age-integrated than in senior rental housing. Aging renters who "stay where they are" have turned multifamily housing into NORCs. Because of New York's distinctive elderly owner:renter ratio, the State includes a large proportion of NORCs. In addition, there is a correlation between elder renter status and both poverty and minority status. The State's expected dramatic increase in minorities and immigrants argues for increased public sector consideration of NORCs as a potentially viable retirement option. With their congregated groups of older people, NORCs provide an opportunity for cost-efficiency in delivering social, health, and long term care services and in the cost-effective use of existing housing as an appropriate environment for older people to age in place.

(4) Negotiated Risk Agreements: Regarding safety and quality of care standards, an aim of New York's health-related regulations has historically been to create as risk-free an environment as possible for consumers and facility residents. Recent movement to moderate the State's regulatory environment has been in response to consumer preferences for greater autonomy in decision-making and industry's contention that onerous regulations increase operating costs. One result has been the increased consideration of negotiated (or, shared) risk agreements between supportive housing residents and operators to define accountability and shared decision-making about housing, service-use, and personal behaviors vis a vis safety.

(5) Private Resources: In both the public and private sectors, greater emphasis is now placed on the use of consumers' private resources to pay for long term care. A variety of financing mechanisms have recently evolved and will play an increasingly important role in financing housing and services in the future—whether in single family, multi-family, or senior housing. These include reverse mortgages for single family homes; one-time endowment/membership fees for supportive/assisted housing options; life care contracts for housing, supportive, and nursing care—in single family homes, family apartments, and senior housing; family subsidization of an older parent's housing and/or services costs; long term care insurance for in-home care and assisted living service packages; and managed care contracts for housing/service developments. Some strategies expand flexibility for consumer use;

others specifically define or restrict consumer use. There is no way to predict what future versions of these recent strategies will look like or which additional strategies will complement or supplant them.

The future of evolving housing models and financing strategies will be heavily dependent upon several things: (1) Market Forces. Because of their technological sophistication, mobility, life experiences, educational levels, and buying habits, the preferences of the Boomer cohort will be a strong influential force in shaping the choices developed. (2) Economics. Equally strong, but unpredictable, forces will be the availability of public dollars and political will to subsidize affordable models, the extent that consumers will be willing to use private resources/mechanisms to pay for housing/services, and the profit levels possible to sustain investment interest. The more that the design of housing environments and financing schemes can adapt to or accommodate diversity of needs and preferences, the greater is their potential for continuing viability as social and economic conditions change.

The Future of Housing Environments Vis a Vis the Baby Boomers

The Boomer cohort will expand the overall size of the older population, and longevity trends will continue to expand the segment most vulnerable to frailty, those age 80 and over. Thus, the design, availability, appropriateness, and affordability of housing environments will assume added significance in the expanding role that housing will play in the health and long term care delivery system and in the lives of growing numbers of older people.

Certain notable models and features that have achieved limited use by the current older population should gain greater use by the Baby Boomers because they reflect the social and cultural traits of the Boomers. Examples include:

(1) Co-housing: This is a planned age-integrated community which builds upon mutual interdependence among the resident generations to provide cross-community planning and support. Such communities can promote aging in place by providing the benefits and care of an extended family for older people who live far from their own family members.

(2) Shared living residences: Among the Boomer cohort, which perceives communal living in a more favorable light than previous generations, Shared Living Residences will provide opportunities for companionship and shared support among single older persons, particularly those who lack familial caregivers.

(3) Elder Cottages and Accessory Apartments: Caregiver Baby Boomers will take greater advantage of siting an Elder Cottage on their own home's lot, or incorporating a private Accessory Apartment into their own homes, as affordable options that provide privacy for an older family member and convenience for the caregivers.

(4) Senior Housing Cooperatives: The cooperative equity model will provide Boomers with the choice of continued home ownership, together with the convenience of supportive amenities and the opportunity to manage their own housing complex and design their own service arrangements.

(5) Naturally Occurring Retirement Communities: The preferences of minority populations to remain in their own communities to age in place will promote the support of Naturally Occurring Retirement Communities as viable ethnically relevant retirement options that promote a sense of community and intergenerational interdependence.

(6) Universal Design Features: The incorporation of universal design features in general construction, and in rehabilitating existing housing, will create "housing for a lifetime" that will accommodate the normal differing sizes and abilities of all age groups and will compensate for aging-related frailities to allow extended aging in place.

(7) Technology: Greater use of technology in housing environments will extend the time residents can remain self-managing, compensate for aging-related physical and mental

impairments, expand interpersonal communication and commercial opportunities from home, and simplify the provision of in-home health and long term care services.

(8) Service Industries: Increasing longevity, rising relocation ages, and increasing numbers of Boomers who will choose to not relocate will promote an upswing in convenience and service industries to support aging in place. Examples include housekeeping, home repair and maintenance, home modification, home delivered foods, shopping and delivery services, case management, transportation, assistive devices, safety and security, and "smart house" technology.

(9) Financing Options: Options such as tax credits, long term care insurance, accelerated death benefit plans, annuities, life care contracts, home equity conversion, and vouchers will allow the delivery of the total range of health and long term care to individuals regardless of the person's living environment, allowing people greater choice to stay where they are and to age in place.

These various models and features will make "staying where you are" achieveable in a viable way for older people of all income levels. For many Boomers, their mobility patterns due to college choices, job changes, second careers, and increased vacation and travel experiences will expand their perception of what constitutes "home" or "a familiar place" in which to spend old age. "Staying where they are" will mean staying in their latest "housing-of-choice" rather than relocating to a purpose-built supportive senior housing facility in order to get the assistance they need. Senior housing/service models will assume the role of today's nursing homes as the recent trends to counter the traditional lack of integration between housing and services become culturally ingrained.

If there is one principle to keep in mind when planning for the Boomer cohort, it is to incorporate flexibility in the development and financing of both housing and services—and in the zoning and regulatory frameworks that govern both. New York's aging Boomer cohorts will comprise all income levels, ethnicities, social circumstances, and abilities; and all will live in a future of continuing, rapid change. Flexibility accommodates such diversity and volatility, enhancing adaptation to demand-based environment models and assisting in creating environments to sustain aging in place.

To summarize, we recommend that the following principles be followed to successfully fulfill the housing needs of future elder cohorts:

- Focus on *change* and *flexibility* to:
  Adapt to changing markets;
  Respond to evolving social circumstances and economic conditions.

- Increasing emphasis on an *accommodating environment* to:
  Promote viable aging in place;
  Maximize independence and autonomy for older persons.

- Greater *variety* in living environments to:
  Respond to the significant differences in needs and preferences found among the older population;
  Respond to increasing racial and cultural diversity.

- Increasing focus on *technology* to:
  Extend the capacity of older persons to be self-managing;
  Increase opportunities for older persons to communicate and interact with the wider community;
  Utilize opportunities for efficiency in service delivery.

- Greater emphasis on *intergenerational matters* to:
  Support interdependence and mutual support among generations;
  Maximize connections among age groups;
  Optimize general community viability.

- Greater response to *individual preferences* for:
  Privacy;
  Personal autonomy;
  Self-determination;
  Choice;
  Independence.

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LIVING IN THE COMMUNITY: A RURAL AND NONRURAL COMPARISON

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Introduction

This paper provides an overview of the differences found among older New Yorkers based on community type-rural, urban or suburban. These designations have specific meaning to demographers, but their definitions are neither mutually exclusive nor used uniformly by researchers or policy makers (U.S. Congress, 1989). The U.S. Census Bureau defines urban as any place of 2,500 or more people and rural as anything else. Suburban areas are those parts of metropolitan areas not contained within the boundaries of a central city, which has a population of 50,000 or more.

Today, more than half of the population in the U.S. (including older adults) live in the suburbs. Because the urban definition of 2,500 or more is so broad, we will use the term urban when referring to the metropolitan cities of New York, such as Albany, Buffalo, Rochester, and New York City.

Residential Differences

These community designations refer to much more than just population size. Demographers, and more recently gerontologists, recognize that older people living in rural, urban, and suburban areas differ on a number of important indicators of quality of life and experience aging in different ways. Nationally, a significant body of research has found that, compared to their city counterparts, elders living in rural areas have: lower incomes; poorer health status; fewer housing and transportation options; and less well-developed health and social service systems (Krout, 1994; Coward and Krout, 1998; Peterson and Maiden, 1993). Transportation is generally identified by service providers as the number one obstacle to providing services to rural elders.

Although rural areas generally have some form of senior transportation, individuals without a car or others willing to drive them often find themselves geographically and socially isolated. Similar differences have been documented in New York in both government and academic forums (Krout, 1998, New York State Senate, 1980).

It also has been argued that important residential differences exist in attitudes, with rural elders being characterized as more independent and less accepting of assistance. Finally, although one of the strongest stereotypes of rural areas is that familial ties are stronger, researchers have not found a rural advantage in contact or support patterns between older adults and their adult children.

National data consistently show that older adults living in the suburbs have a better quality of life than in other residential settings, including health, income, and housing. However, suburban elders face challenges in gaining access to services if they cannot drive, as many suburbs do not have adequate mass transportation systems.

Residential Differences - New York State Data

Unfortunately, little current data on New York's older adults provide residential breakdowns. Gerontologists must rely on local studies or extrapolate from county level data. One source of information for New York State that uses 1990 census and other government data is the county profiles developed by Eberts (1994). Eberts uses a 6 fold typology that has 2 sets of metropolitan counties (downstate and upstate) and 4 sets of rural counties that are distinguished by the extent of urban influence on them. In New York State, any county of less than 200,000 population is defined as rural.

Using this definition, 18 counties are metropolitan and 44 are rural. Based on a combination of population size, size of largest place, percent rural population, and percent commuting outside the county to work, Eberts identifies these rural counties as: rural-urban-suburban; rural-urban; rural-suburban; and rural-periphery.

Eberts reports a number of county level facts and trends with implications for older adults and the aging services network. Rural counties have experienced a precipitous drop in the percent of their work force engaged in agriculture and manufacturing. Of importance is the finding that the percent of a county's population over 65 was greater in the rural as opposed to metropolitan counties, but this gap had gotten smaller from 1950 to 1990.

The greatest proportional growth in the percent of population 65 and over occurred in downstate metropolitan counties and the two most rural county designations. This suggests that the demands for formal services will increase fastest in these areas. All counties also experienced growth in the 85 and over group (1.5% of the state's population in 1990), but the percent was higher in the most rural counties.

Rural counties are found to be disadvantaged in ways that suggest fewer resources for elders to provide self-care or for communities to plan and provide for the growth in the older population expected as the Baby Boom begins to enter its seventh decade around 2015. For example, Eberts (1994) reports that rural areas had lower percents of population employed in health services. Data on socio-economic status also showed a rural disadvantage in per capita and inflation adjusted income with the gap between metropolitan and other counties widening significantly between 1970 and 1990. Eberts (1994,106) writes, "as trends..show the persistent and disturbing trend of a widening gap in incomes between affluent, downstate-metropolitan counties and less wealthy upstate rural counties". Poverty rates among those 65 and over are reported to be greatest in the most rural county types.

Education levels also were considerably lower in rural county groups. Eberts does not provide information on housing or transportation, but the data he does present certainly suggest that rural counties in New York will face considerable challenges in preparing for the needs of older persons in 2015. One of the last points made by Eberts is that as rural counties in New York become more integrated into metropolitan economic and social structures, their institutions will become increasingly dominated by metropolitan based marketing, management, and planning. This is the continuation of a decades-old trend where the locus of control has moved out of rural communities and shifted to urban based government or to national/multinational corporations. A good example, which will increasingly impact the quality of life of rural elders, is that of medical services. Metropolitan hospitals have reached out considerable distances to provide services to their rural neighbors. This is a mixed blessing. These programs give rural residents more access to specialists in cardiology, orthopedics, and oncology who hold office hours in satellite clinics once or twice monthly and allow them to be admitted to the generally better equipped urban hospitals for the treatment of serious illnesses or trauma. On the other hand, this reliance on outside services fosters dependency and formality in medical relationships.

Individuals no longer enjoy the close relationships they had with their doctors within their community. Now, the quality of their medical care is threatened as they are seen by medical practitioners who do not know them or their medical histories very well. On the plus side, because of their relatively sparse populations, rural communities have been spared from the worst excesses of the cost-conscious managed care industry. Their wealthier urban and suburban neighbors have not fared as well in this respect although they may have more of a selection of HMOs to choose from.

Residential Differences in Baby Boom Challenges

Health and Health Care

Research suggests that suburban areas are most advantaged when it comes to the availability of health (including acute care and wellness programs) and social services. This reflects not only the relative affluence of suburban residents, but also the increasing location of business and services outside of central cities. Many suburbs are no longer bedroom communities. Increasingly, suburbs are becoming naturally occurring retirement communities (NORCs) as their populations age in place.

While these relatively high concentrations of older persons will present service planning and provision challenges, the majority of older Baby Boomers living in the suburbs should benefit from the relative availability of health care opportunities.

Central city and rural Baby Boomers, on the other hand, will likely not be as fortunate. Although they avoid the cost-cutting effects of managed care, under-manned rural hospitals are under financial stress, which negatively impacts the availability of health services in general. Baby Boomers living in the central city, who are more likely to be non-white and have limited economic resources, face other barriers to health care.

Income

As noted earlier, residents of rural areas are less affluent than those in other areas of New York. This means that rural Boomers will enter retirement with smaller savings and pensions and, thus, fewer financial resources to pay for increased health care costs and other expenses. In addition, rural Boomers will find fewer opportunities for full or part time employment, as rural economies in New York are likely to remain sluggish over the next twenty years as the small farmer is fazed out.

Suburban Boomers will be best off in regard to economic resources. Central city Boomers, especially in New York City, will be faced with high costs for basic services, in particular in health and housing. Also, all three types of residences will require more mental health services as the Boomers cope with the inevitable losses and stressors associated with aging.

Current research shows only 5% of the elderly currently utilize mental health services although the need is far greater estimated to be about 20 to 25%. Boomers as a group show a greater willingness to use mental health services than their more reluctant elderly counterparts. They are not stigmatized by seeking help and many more of them will use mental health services in the future.

Access

Boomers in rural areas will be almost totally dependent on private transportation or community sponsored transportation given the limited alternatives. Large distances between services and people compound this problem. In 1990, twenty New York counties did not have a single community of at least 10,000 people. Many services are simply not supported by such a small population, requiring people to drive longer distances. In the absence of public transportation, those without the means or ability to drive will be at particularly high risk for isolation.

Suburban Boomers also will face access problems. Although suburban services may be near by, suburban developments have been built around the private automobile; mass transit often is very limited and taxi use can be expensive. Central city Boomers, many of whom were less dependent on the automobile throughout their lives, will now be almost totally dependent on mass transit. As they become frailer, this will present challenges as well.

Housing

Rural and Suburban Boomers will be more likely to be single family home owners and central city Boomers to be renters or owners of units in co-ops or townhouses. Rural housing is older and rural Boomers will be faced with home maintenance and repair costs with few formal

housing assistance programs to turn to. Perhaps the biggest problem facing rural Boomers will be the lack of housing alternatives. Few housing options other than the private home or nursing home exist in many rural communities. Relatively few assisted living, board and care home, or other congregate living units will be available especially in the rural villages where the aged are more likely to move to be closer to services when they become more frail.

Housing developers simply do not see rural areas as prime locations for senior housing. Suburban and central city Boomers should have more options available, but cost and quality will be of concern. Moreover, to maintain the elderly in their homes for as long as is possible more in-home services are necessary across all three domains.

Housing options may be further strained by changes in demography. Current trends in migration reveal that the senior elderly are moving to villages and urban centers where they have greater access to services. Other observers have noted an opposite trend. The younger elderly are relocating to more rural areas upon retirement where the cost-of-living is lower and their fixed incomes stretch further. These migration trends, if they continue, will tax already over burdened community service programs in these areas.

Summary and Conclusions

The Baby Boomers cohort will face many challenges in the year 2015. Residential differences will affect the quality of life experiences of the Baby Boomers in diverse ways. The data generally indicate that suburban dwellers will face more favorable conditions in terms of income, job opportunities, housing options, and have greater access to medical facilities than their peers residing in rural areas and inner cities. However, the suburban service system will be strained by the sheer number of suburban Baby Boomers and the need to provide access and in-home services. Older Baby Boomers living in rural areas will enter old age with lower incomes and will find fewer supportive service options and resources in their communities. Housing choices, in particular, will be limited as will access to goods and services. Rural Baby Boomers will be almost completely dependent on themselves, family and friends for transportation.

The aging service network in central cities will be challenged by aging Baby Boomers who will be more diverse economically, racially, and culturally. The need for affordable housing options such as assisted living and the provision of services in areas that have become NORCs will also need to be addressed. As is frequently found in anticipating the future, one needs to be very cautious as the issues and conditions are very complex and very changeable. Unforeseen circumstances can occur which obviate one's expectations.

When we examine the Boomers as a group, there are many positive indicators. They are better educated, wealthier, and healthier than the current elderly cohort. Because of the advances in medical science and technology, better behavioral practices, and medical insurance, the Baby Boomers will live longer healthier lives with fewer disabilities, as they approach the maximum life span.

Yet any unexpected (but probable) downturn in the economy may be devastating particularly to the rural elderly, the oldest-old, minorities, and women. Being prepared and making prudent public policy decisions in advance is the most rational way to the meet these needs and challenges posed by the Boomers in the year 2015.

Recommendations

- Assist rural communities to plan and develop more comprehensive and coordinated services for older adults, especially in the areas of transportation, housing, and income support.
- Collect more data on the health, mental health, and social service needs and expectations of aging Baby Boomers in all types of residential environments.

- Support the goal of allowing the elderly to live safely and independently in their own homes as long as possible by ensuring that all communities provide adequate and affordable in-home services, access to transportation, mental health services, home improvement programs, and protection of Medicare insurance and social security.

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THE TRANSPORTATION MOBILITY OF NEW YORK STATE'S AGING BABY BOOMERS

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Introduction

With the aging of Baby Boomers on the near horizon, older people's modes of transportation and the effectiveness of different modes in facilitating community-based residence of older individuals are increasingly important policy issues. Transportation mobility is a critical link between older people and their social and community activities, as well as to goods and services (Glasgow, 2000). To address transportation issues, I discuss recent trends in the travel patterns and capacities of older people, as well as the consequences of the use of different modes of transportation for older individuals' quality of life. I discuss these patterns and trends in an attempt to anticipate the transportation needs of New York's Baby Boomers during their old age.

When examining transportation issues among the currently old and future older Baby Boomers, it is important to keep in mind that New York is a geographically diverse state. New York City is among the world's largest cities; whereas many communities in upstate New York are in remote rural regions. One would anticipate higher rates of use of public transit, taxis, and walking among New York City residents compared to residents of metropolitan and non-metropolitan areas of upstate New York.

Nationally, 22.5 percent of the total population reside in non-metropolitan counties, but a higher percent (26.4) of people age 65 and older do (Glasgow, 1998). By comparison, 88 percent of both New York's total and age 65 and older populations reside in metropolitan counties and only 12 percent in non-metropolitan counties. Forty percent of New York's older population reside in New York City, 20 percent in New York City suburbs, 25 percent in upstate metropolitan counties, and 12 percent in non-metropolitan counties (Glasgow, 1998). New York State's older population thus is more concentrated in metropolitan areas than is the older population of the U.S., which suggests that transportation usage patterns are likely to differ among New York's older residents compared to their U.S. counterparts. Data on transportation mobility patterns and trends, however, are more readily available for the nation than for New York. Thus, I present findings for the U.S., but I supplement them with findings specific to New York.

Population Growth and Older People's Projected Travel Patterns

By 2025 all Baby Boomers will be over age 60, and by 2030 all will be over age 65. Between 1995 and 2025, the U.S. age 65 and older population is expected to approximately double in size (Siegel, 1993). During the same time period, the number of the nation's age 65 and older drivers is projected to increase by at least 2.5 times (Burkhardt, et. al., 1998). Among past and present older cohorts, driving was/is more common among men than women, but driving is almost universal among both male and female Baby Boomers (Rosenbloom, 1995). The large majority of both women and men of the Baby Boom generation will reach old age having driven automobiles as their primary mode of transportation throughout their adult lives. Thus, Burkhardt and colleagues (1998) project a faster growth rate in the number of older drivers than in older people.

Between 1995 and 2025, the age 65 and older population of New York is projected to increase by 35 percent (New York State Office for the Aging, 1999). Thus, the growth rate of New York's older population is projected to be lower than that for the U.S. If the number of older drivers in New York increases

proportionally to the increase in the number of older people, we would expect a 35 percent increase in the number of drivers age 65 and older, and, likewise, in the number of older users of other types of transportation. If New York's older drivers grow at a rate comparable to that projected for the nation, however, we would expect the growth in New York's older drivers to exceed 50 percent between 1995 and 2025.

Urban-Suburban-Rural Patterns of Mobility of Older Persons

The United States is an automobile-dependent culture, and travel by private vehicle is the primary mode of transportation of younger and older people. But when examining travel patterns of older people, we often do not know whether the patterns reflect preferences only, limited availability and poor quality of public transportation, or other environmental or personal constraints that impose patterns of use. For example, declining numbers of retail establishments and services in smaller communities necessitate greater travel distances to reach goods and services in neighboring communities, and, hence, reliance on automobile travel may be greater among rural and small town residents now than in the past. Suburban sprawl increases the distances that must be traveled to access community services or to participate in social roles and activities. Moreover, segregated-use zoning in communities is common, with some areas zoned for commercial/office use only, other areas for retail establishments, and still others for residential use. Such land-use patterns increase the distances that must be traveled to access activities, goods, and services. These attributes of places have contributed to driving becoming by far the most commonly used mode of transportation of older and younger U.S. residents.

Older people's increasing dependence on private vehicles over time (Rosenbloom, 1995) is exacerbated by the fact that public transit services are limited or lacking in many, especially rural, communities (Talbot, 1995). Fear of crime in core metropolitan areas inhibits older people's use of public transit and walking (Evans, 1999). That walking as a means of travel has declined over time also relates to the distances among activities and the absence of sidewalks in many suburban and rural communities of the U.S. (Rosenbloom, 1995). Health problems that tend to mount among older people may limit use of all modes of transportation.

As a percent of all trips, older age groups in the U.S. were more likely in 1995 than in 1983 to use private vehicles, either as drivers or passengers, as their mode of transportation (Table 1). Rural older people are somewhat more likely than their urban counterparts to travel by private vehicle, but travel by private vehicle is the dominant form of transportation among urban older residents as well. Public transit use declined from 1983 to 1995 among urban older residents but increased among older rural residents, where it went from zero to a still miniscule proportion of all trips. Overall, older U.S. residents make less than 3 percent of all trips on public transit (Rosenbloom, 1995).

Some communities do have high quality, relatively convenient public transit, and utilization rates among older people in such communities tend to be higher (Burkhardt et. al, 1998; Carp, 1989). In New York City and other large American cities, where traffic congestion is particularly high, driving and use of private vehicles may be comparatively low, whereas walking and use of public transit and taxis may be higher than the metropolitan average. But that is not necessarily the case. For example, the rate of driving among Los Angeles residents is high. The proportion of drivers among residents of metropolitan New York City age 16 and older is lower than the proportion of drivers in upstate New York cities or non-metropolitan areas (Table 2).

Among older men and women living in central city versus suburban areas of metropolitan counties throughout the U.S., private vehicle use is lower and transit use is higher in central cities (Table 3). Differences between central city and suburban older

residents in their modes of transportation, however, are strikingly small. Older people in most places travel primarily by private vehicle. When transit corridors radiate from a city's center and passengers must make transfers, trip distances as well as time spent making trips tend to be lengthy (Carp, 1998). In many communities, therefore, public transit use is unpopular, and it may be inaccessible to older people with health problems. Public transit's image is low in many communities, and often transit is perceived as primarily for low-income groups (Burkhardt et. al, 1998).

Older Drivers

Increased propensity to drive. Some evidence indicates that the majority of older people prefer driving as their mode of transportation (Burkhardt et. al., 1998; Eisenhandler, 1990; Glasgow, 2000, Forthcoming). Regardless, the proportion of older people who are licensed drivers has increased over time, as have average annual miles they drive (Burkhardt et. al., 1998; Rosenbloom, 1995). Between 1984 and 1992 licensing rates among both men and women in the U.S. increased in 50-59, 60-69, and 70 and over age groups, but rate increases were greater among women than men. Drivers' licensing rates among men were already high in 1984, and by 1992 almost 100 percent of men under age 70 held a driver's license. As Baby Boom women reach age 65, they will almost universally have been licensed drivers for approximately 30 years (Burkhardt, et. al., 1998; Rosenbloom, 1995). The licensing rates of older women thus are expected to approximate men's as Baby Boom cohorts enter old age.

The Centers for Disease Control's National Center for Injury Prevention and Control (1996) estimates that, in the past decade alone, the number of licensed drivers among persons age 70 and older in the U.S. increased by almost 50 percent. This increase, no doubt, reflects the fact that the older population is itself aging. But, as noted above, preferences, changing gender roles, and changing structures of communities also account for the rapid increase in drivers' licensing among old-old individuals.

Nationally, 77.5 percent of people age 65 and older hold drivers' licenses (Burkhardt et. al., 1998), but only about 60 percent of older New Yorkers do (New York State Department of Motor Vehicles, 1996). That the proportion of older drivers in New York is lower than in the nation, no doubt, relates to the large proportion of the state's older residents who live in New York City where the rate of driving is lower. In Glasgow's (2000, Forthcoming) study conducted in non-metropolitan counties of upstate New York, 85 percent of age 65 and older residents were drivers, which is a higher rate of driving than the rural U.S. average. These findings underscore the diversity of New York, and they suggest differences among various types of places in the transportation needs of older people.

Previous research has shown that maintaining a license and driving have great symbolic value for many older people in our society (Burkhardt et. al., 1998; Eisenhandler, 1990; Glasgow, 2000, Forthcoming; Glasgow and Blakely, 2000). Driving is an important part of many older individuals' self-concept in much the same way that driving is a rite of passage for younger people. To older people, driving symbolizes freedom, independence, and competence. Compared to other modes of transportation, driving is perceived as the most convenient and flexible mode (Glasgow and Blakely, 2000). Perhaps it is not surprising then that older U.S. residents' licensing rates have increased over time. The lower licensing rate among New York State's older residents is indicative of a city size threshold beyond which congested streets are problematic for driving. Moreover, public transit is extensive in New York City, and the New York City Department for the Aging (1999) contracts with non-profit vendors to supply paratransit rides designed specifically for older people, a type of service not all communities provide.

Although the majority of older people prefer to drive as their mode of transportation,

it is not uncommon for older people to reach a point where driving is no longer possible or safe. How problematic driving is for older people and the consequences of the cessation of driving are topics we discuss next.

Older drivers' crash risks. Driving entails greater hazards for older people than for most other age groups. But depending on which statistics are used, older drivers compare favorably or unfavorably to other age groups. If one analyzes crash rates per 100,000 licensed drivers, for example, older women and men have low crash rates, especially in comparison to drivers under age 25. If one analyzes the number of crashes per million miles of driving (older people drive fewer miles per year than other age groups), older drivers compare unfavorably (Burkhardt et. al., 1998). Data on crashes per miles of driving show people age 75 and older and under the age of 25 to have particularly high crash rates. Among older people, this seems to be because they drive more on local streets and roads, where most accidents occur, but where drivers also drive fewer miles.

Once involved in a car crash, New York's older drivers — especially those ages 75-84 — are at greater risk of injury than most other age groups. Older age groups, especially at more advanced ages, also have greater risks of fatality following a crash than younger age groups. The greater risk of fatality in a car crash is related to the fact that older people's bodies are frail in comparison to those of younger age groups. Re-engineering automobiles to make them more protective and less injurious of older bodies during crashes has been suggested as one way to address the needs of an increasingly older society (Waller, 1996).

When older drivers pose a risk to themselves and others. Diminished visual and hearing acuity, slowed reaction times, and cognitive impairments can accompany old age. Older individuals experiencing declines in their health and functioning may self-regulate their driving or cease driving, and, in doing so, they may not pose a particular risk to their own or others' safety. Cognitively impaired individuals, however, may not be aware of their impairment, and those individuals tend not to self-regulate or stop driving unless others intervene (Dobbs, 1996). Some older people resist curtailing or stopping driving because to do so would be psychologically painful and would reduce their transportation mobility (Burkhardt et. al., 1998; Glasgow and Blakely, 2000). Better screening tests to identify problem drivers of any age, as well as involving family, friends, physicians, and Department of Motor Vehicle personnel in identifying and counseling unsafe older drivers are among several efforts designed to address this issue (New York State Office for the Aging, 1997).

Self-regulation of driving. Older people drive fewer miles annually on average than other age groups (Burkhardt et. al., 1998; Rosenbloom, 1988; Rosenbloom, 1995). But older drivers report driving fewer miles currently compared to five years earlier because of less need to drive now than earlier (Glasgow and Brown, 1997). Older people often self-regulate driving by not driving on interstate highways, by driving only on familiar roads, only during daytime hours, only in non-rush-hour traffic, and on less congested streets and roads (Burkhardt et. al., 1998; Glasgow and Brown, 1997). Older women are more likely than older men to limit when and where they drive, and cessation of driving is more common among older women than older men (Eberhard, 1996; Glasgow, 2000, forthcoming). Older minorities are less likely to have a driver's license, and those who have licenses drive less than older whites with licenses. Minorities' lower socioeconomic status, differences in gender roles, and perhaps a greater acceptance of using public transportation are factors accounting for the differences (Rosenbloom, 1995). Self-regulation of driving often relates to older individuals' assessments of their driving capabilities, but it can also relate to cultural and economic considerations.

Cessation of driving consequences. The consequences of not learning to drive or the cessation of driving are both objective and

subjective. Comparing across several cities and smaller places in New York, average daily person trips by all modes of transportation among New York City older residents, particularly Manhattan residents, are lower than among older residents living elsewhere in the state (Table 4). Older residents of cities with lower driving rates (i.e., New York City) simply do not make as many trips from their homes. Among non-metropolitan older residents of upstate New York, drivers are more likely than non-drivers (former and those who never drove) to participate in a number of social roles (Figure1). Drivers also visit friends and neighbors more frequently than do non-drivers (Glasgow, 2000, Forthcoming). Thus, the risk of social isolation is objectively greater among older people who never learned to drive or who have stopped driving.

Even when warranted, the cessation of driving negatively affects older individuals' subjective well-being. Life satisfaction and morale are lower among former drivers (Cutler, 1975; Fengler and Jensen, 1981; McGhee, 1984), and former drivers are less satisfied than drivers with their transportation arrangements (Glasgow, 2000, Forthcoming). Older non-drivers report greater loneliness (Carp, 1998), and they are more likely to be depressed (Thompson, 1996) than drivers. The cessation of driving is problematic for older individuals and should not be encouraged or undertaken unnecessarily. In-home technology, such as computers, the Internet, and telephones, allow people to connect with ties and to perform many personal business functions from home, but most people value face-to-face human interaction, and viable transportation arrangements are important for that.

Interventions/Policies to Improve Older People's Mobility

Current transportation mobility trends and patterns, as well as projected transportation needs of aging Baby Boomers suggest consideration of the following policy options:

- Improve the safety of automobiles and roadways for older drivers.
- Re-train older problem drivers, if evaluated to be re-trainable.
- Develop screening tests that accurately identify problem drivers of any age.
- Develop a range of high quality, convenient transit and paratransit options for those who cannot drive or who wish to do less driving.
- Provide educational programs on available public transportation and how to use different options successfully.
- Encourage mobility planning among older people and the possible eventuality of their having to stop driving. Friends and families should be involved in the planning process, because oftentimes they must assist with the transition and may become responsible for providing rides.
- Encourage transit-oriented development that is user friendly to older people (e.g., kneeling buses, low-entry buses, and flexible routes).
- Implement mixed-use zoning to develop livable communities and pedestrian friendly neighborhoods.
- Clearly identify the link between housing, land-use choices and the transportation needs of older and younger people in our society.

Table 1
Modes of Transportation of Older Rural and Urban Residents of the U.S.: 1983, 1990, and 1995 (in %)

Travel Mode and Residence	Age Group and Year of Survey								
	65 – 74			75 – 84			85+		
	1983	1990	1995	1983	1990	1995	1983	1990	1995
Urban									
Private vehicle	83	90	90	79	85	90	75	77	86
Public Transit	4	2	3	1	3	3	8	3	2
Taxi	0	1	0	1	1	0	0	3	2
Walking	11	7	6	17	10	7	16	16	9
All others	1	0	1	2	1	1	0	1	2
Rural									
Private vehicle	88	95	95	85	92	94	80	86	83
Public Transit	0	0	0	0	0	1	0	3	2
Taxi	0	0	0	0	1	0	0	3	0
Walking	8	4	4	11	5	5	5	7	15
All others	1	0	1	2	1	1	0	1	0

Source: National Personal Transportation Surveys, 1983, 1990 and 1995.

Table 2
Drivers as a Proportion of Persons Ages 16 and Over by Place of Residence: New York, 1995.

Selected Places of Residence and Number of Persons Ages	Number of Drivers	Percentage of Drivers 16 and Older
New York City and Suburbs 8,627,165	5,838,614	67.7
Rochester 539,891	491,187	91.0
Syracuse 347,339	313,288	90.2
Poughkeepsie 200,300	180,160	89.9
Ithaca – Tompkins County 77,356	69,934	90.4
Small Urban Counties[a] 295,467	250,407	84.7
Small Rural Counties[b] 1,375,997	1,257,835	91.4
New York State 13,805,448	10,469,256	75.8

Source: 1995 National Personal Transportation Survey. Analysis conducted from data provided by the New York State Department of Transportation.
[a]Counties with urban places between 10,000 and 50,000 population but none larger.
[b]Counties with only places of less than 10,000 population.

Table 3
Total Trips by Selected Modes, Persons Ages 65 and Older, by Gender, Metropolitan Area, U.S., 1990 (in %)

All Modes of Travel	Central City		Suburbs	
	Men	Women	Men	Women
Private vehicle	88.5	85.1	91.5	89.1
Public transit	3.3	3.3	1.3	1.7
Taxi	0.3	0.8	0.1	0.3
Walking	7.0	10.2	6.7	8.0

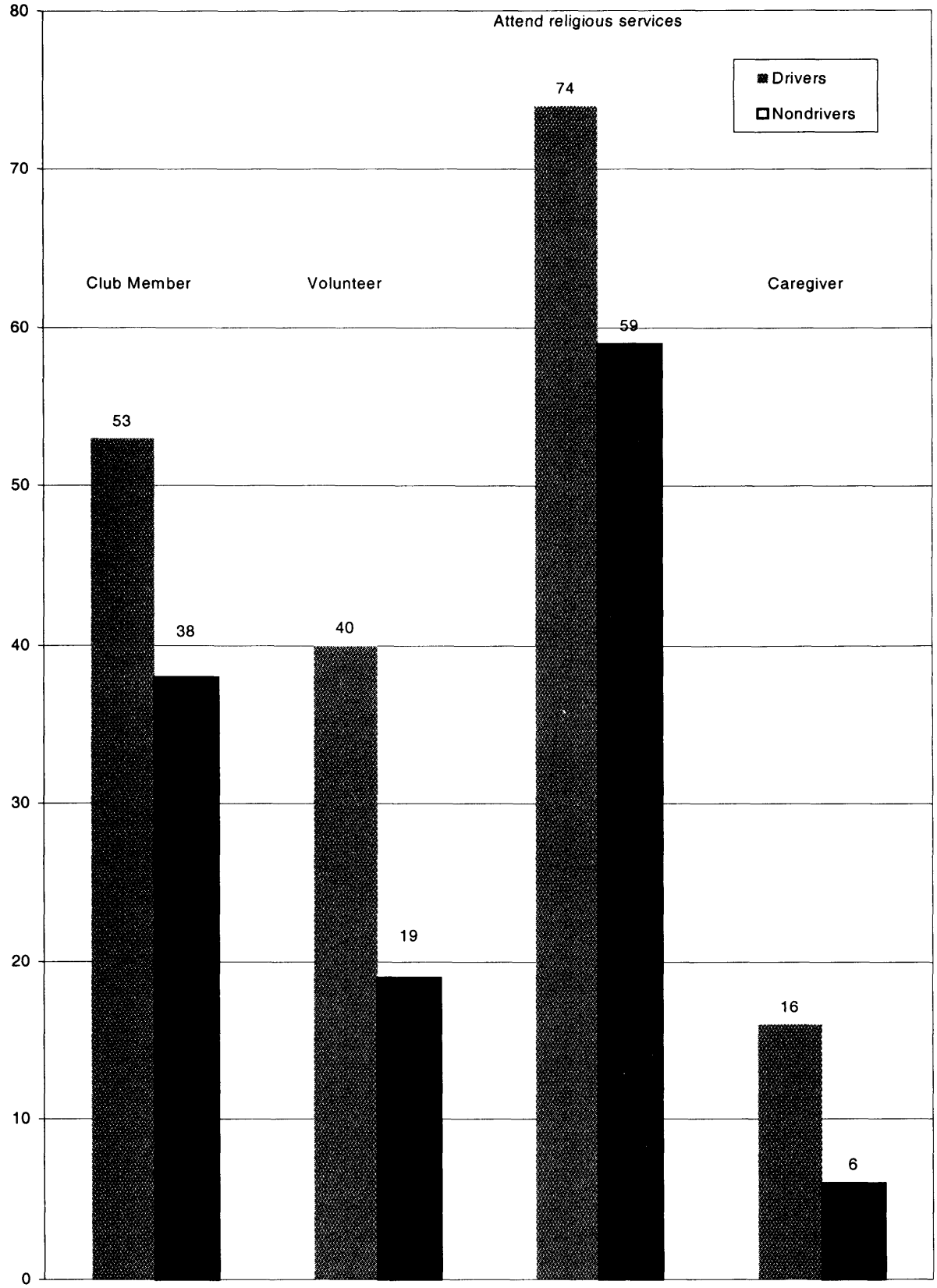
Source: 1990 National Personal Transportation Survey. Table adapted from Rosenbloom, Sandra. 1995. Travel by the elderly. In Office for Highway Information (Ed.), 1990 NPTS Demographic Special Reports, Table 14, p. 3-24. Washington, D.C.: US Department of Transportation, Federal Highway Administration.

Table 4
Average Daily Person Trips per Person by Age and Place of Residence: New York, 1995

Selected Places of Residences	Under Age 65	Age 65 and Older
New York City and Suburbs	3.81	3.22
New York City – 5 boroughs	3.65	2.95
Manhattan	3.89	2.62
Rochester	4.36	3.56
Syracuse	4.36	3.31
Poughkeepsie	4.03	3.20
Ithaca – Tompkins County	4.46	3.71
Small Urban Counties	4.14	3.34
Small Rural Counties	4.09	3.34
New York State	3.96	3.29

Source: 1995 National Personal Transportation Survey. Adapted from analysis conducted by the New York State Department of Transportation.

Figure 1 PERCENT PARTICIPATION IN SOCIAL ROLES AMONG OLDER NONMETROPOLITAN DRIVERS AND NONDRIVERS, 1995



Using chi-squares tests, drivers were significantly more likely than nondrivers (at the .01 level or better) to participate in these social roles.

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Project 2015:
The Future of Aging in New York State

LONG TERM CARE

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The year is 2015. Consider this vision for older New Yorkers. Long term care services and financing options are known to New York's older population. Housing and services are more fully integrated. Wellness, prevention and health maintenance programs are part of how we care for ourselves. The financing of long term care services has been restructured so those individuals will contribute to and benefit from reasonable packages and options. Persons who give care to a family member needing assistance on a regular basis have excellent supports to sustain them. Due in large part to good planning and foresight, the explosive numbers of New York's elders feel respected, part of the larger society and in the center of long term decisions about their health, well being and life choices.

Where are we now, and how do we get closer to this vision? What are the important trends to consider? What barriers do we face? What strengths and resources can we rely on? What are the next steps we need to take? We start by reviewing the background and emergent trends in long term care in New York State and close with a set of recommendations for the future.

Long term care as a term has evolved to describe a variety of care settings for frail older adults ranging from nursing homes to assisted living programs and from community-based services such as social adult day services to home care and family caregiving. Unlike hospitals, doctors' offices and outpatient clinics, which emphasize treating acute illness and managing chronic conditions, long term care focuses on providing custodial care to those who need assistance in caring for themselves and, more recently, has grown as a concept to include rehabilitative and convalescent care (often called 'subacute' care).

According to a recent report of the Congressional Budget Office, the U.S. will spend $231 billion on long term care in the year 2000, and this will increase to $295 billion in the year 2030 when many Baby Boomers will be in their 80's.

Background and Emergent Trends

The ideal, of course, is to promote the "successful aging" of the current and future cohorts of older adults, where health and vitality are maximized and sickness and loss of function are minimized (Project 2015: Health and the Baby Boomer).

With demographic and life expectancy trends, there will be an explosive growth in the over age 85 population in the 21st century. While this sounds positive, the real significance of this trend can be found in epidemiological data that focus on the active life expectancy, or the amount of 'remaining life' that one can expect to remain independent, without disability. Epidemiological studies show that more than 40 percent of people 85 years of age and older have lost the ability to perform one or more of the activities of daily living (ADLs), the self-care activities that include bathing and dressing, for example.

Loss of cognitive function, including Alzheimer's Disease, affects less than 5% of those over age 65, but the prevalence increases dramatically with age, so that about one-third of those over age 85 have dementia. This is especially relevant to nursing homes, where about one-half of the residents have dementia, and management of behavioral problems is a

serious concern. The inability of the family to care for a relative with dementia is one of the major reasons for institutionalization of older adults. The number of older adults with a loss of cognitive function also can be expected to increase into the 21st century. No cure is on the horizon, but a successful treatment for Alzheimer's disease that reduces the risk for the disease or even delays its progression would have dramatic implications for the need for long term care in the 21st century.

Baby Boomers initially will be affected by these demographic trends as caregivers to the current generation of older adults with disabilities and need for assistance. In about 2030, Boomers will be in the 85 and older age cohort and will experience first-hand the implications of these trends. Even if successful aging patterns continue in the Baby Boom generation, there still may be a significant need to care for increasing numbers of frail and dependent older adults well into the 21st century.

Who are consumers of long term care? Typically, they are and will continue to be primarily women over age 85, with several limitations in the ability to perform ADLs and Instrumental Activities of Daily Living (IADLs) including housework, shopping, laundry, transportation, meal preparation, and more. They, along with younger persons with disabilities, will be the primary users of long term care services in years to come.

Long term care services and financing have been changing during the past 20 years, with a growing recognition that the array of services and the financing of those services require review and restructuring. Up until the early 1980's the major suppliers of care in New York's long term care system were primarily nursing homes and some adult homes. Yet the cost for long term care services remains prohibitively expensive (nursing homes average $50,000 in New York State; round-the-clock home care approximates $20-40,000/year, and Assisted Living can be $24-60,000 a year.) This large, long term expenditure is exceeded in total cost on an individual basis only by the purchase of a home, of automobiles, or a college education. Policies of the 1980's and 1990's were designed to bring a balance to long term care services options, to meet consumer preferences to remain at home by expanding community-based long term care services, and to reign in costs. As a result, the use of home care, particularly Medicaid-funded home care, grew exponentially in our state well into the 1990's. This meant that most counties in the state saw an increase in the number of home care providers and the availability of trained home care aides and nurses.

Families: A Long Term Care Resource

Families are the number one long term care resource. Whether aging in place or living with relatives, fully 80% of caregiving assistance for frail older adults comes from family members (Project 2015: Informal Caregiving). Most informal caregivers are women, with one third of them participating in the workforce. The typical caregiving workload is four to eight hours per day. The length of time spent in the caregiving role usually is one to four years, but a substantial number of families (20%), provide care for over four years. The annual cost of caregiving provided by families with relatives who have dementia has been estimated at $18,256, with 29% of costs paid in cash, and 71% reflected in unpaid labor. The trend to minimize hospital stays also has resulted in older adults being discharged to home with more complicated care needs. This only intensifies and complicates the caregiving demands within families. In general, families are not quick to institutionalize their older adult relative. Lack of a social support network for the caregiver remains a major risk factor for institutionalization for the older person.

With demographic changes, the likelihood of a woman assuming a caregiving role at some point in her life is <u>increasing</u> compared to previous generations. Also increasing is the probability of adopting multiple caregiving roles. Employment <u>does not decrease</u> the likelihood of women adopting the caregiver role. Women who

are employed, compared to those who are not in the workforce, seem to provide the same number of hours of care, but the types of care may shift. The increased presence of women in the workforce, coupled with the findings that women do not "trade off" employment roles for caregiving roles is resulting in more women juggling work and caregiving roles. Recent legislative initiatives such as the Family Leave Act can provide some short term relief for caregivers that face acute problems, but does little to address caregiving over the long term.

Given the centrality of the family in providing long term care in the United States, caregiver issues and their impact on families should be of major interest to policy makers. Reviews suggest strong evidence that caregiving is associated with a variety of negative *psychological* effects for caregivers, including increased depression and anxiety. Major risk factors for negative psychological effects include family income level, caregiver's perceived quality of life, such as self rated health, perceived stress and life satisfaction, and a pattern of behavioral problems in the care recipient. Far less clear is the unique impact caregiving has on the *physical* health of the caregiver, with studies showing weak, mixed or no relationship between caregiving and measures of physical morbidity such as health care utilization or self reports of health problems.

Home and Community-Based Long Term Care Services

Many, if not most, older persons want to remain in their own homes. This demand has created the need for programs that can provide a variety of services and home modifications to make this possible. These include home delivered meals, transportation, personal emergency response systems, care coordination, homemaking/ personal care services, and social adult day services, to name a few. The demand also means that innovative, non-punitive ways to access equity in the home need to be explored (e.g., reverse mortgages), so that older persons may remain at home and use this resource to meet their long term care needs.

New York has a long history of providing home care through the Medicaid Personal Care Program, which grew significantly in New York during the 1980s, enabling approximately 90,000 individuals to obtain personal care services to remain at home each year. For many to qualify under the Medicaid program for home care, however, this means impoverishing themselves so that needed services can be obtained. Other programs were developed and expanded during the 1980s, including the Long Term Home Health Care Program, a Medicaid waiver program that enabled the expansion of the types of services that would be paid for and made available to a limited number of persons in New York. Certified home health care was another important component that expanded during the 1980s to meet needs and preferences of persons needing care to remain at home.

On the non-medical side of long term care, the Expanded In-home Services for the Elderly Program (EISEP), a cost-share program, was initiated in 1986 as an added component to the Community Services for the Elderly Program (CSE). It grew to become an essential program in counties throughout New York for older persons who are not Medicaid eligible and need home and community-based care services. This case management approach to providing home and community-based care has been tremendously successful in providing supports to help individuals to remain at home. These include informal supports, home care, minor home modifications and social adult day services, to name a few. The EISEP cost-sharing program is limited, with many counties bearing waiting lists for individuals needing and waiting for services.

In addition to the more established community-based long term care options, New York State has several innovative projects underway to test new directions in community-based long term care. Examples include: Managed Long Term Care (MLTC), initiated through the NYS Long Term Care Integration and Finance Act of 1996. The Act enabled the expansion of the MLTC concept that was demonstrated through

the Program for All-inclusive Care for the Elderly (PACE) model project, a federal initiative that provides supports and care to keep nursing home eligible frail older adults in the community. In the MLTC program, approximately seven current demonstrations or programs plus an additional 24 managed long term care plans will be allowed to serve up to a total of 50,000 persons including chronically ill and non-chronically ill in New York State. This will put more of an emphasis on what the consumer needs and less on the setting in which the consumer receives services. Providers will receive a fixed negotiated amount for each enrollee, and they, in turn, will be at risk to provide for enrollee long term care needs. Managed Long Term Care likely will expand in the future, because it is a flexible and potentially efficient way of providing long term care. In addition, it is less complicated for government and tax payers to fund services on a per capita basis rather than pay on a per service basis.

Localities are also testing innovations in community-based long term care. For example, the Health Care Financing Administration (HCFA) funded ACCESS/Monroe County Long Term Care, Inc. to conduct the Consumer Directed Care Demonstration Project that evaluates the effectiveness of a Medicare Voucher system and visits by a health promotion nurse in maintaining frail older adults in the community. Depending on the outcomes, innovative approaches like this one hold promise in developing cost effective long term care options for New York residents.

Incentives to expand non-medical supports likely will exist in the future. Resources could be shifted to meet what currently are often 'unfundable' needs. This includes home modifications, transportation, and caregiver respite services, to name a few. In addition, two of the more established community-based options from across the country are beginning to see an expansion in New York State: continuing care retirement communities and assisted living programs.

Continuing Care Retirement: Compared to other states, continuing care retirement communities have come to New York relatively recently. By paying an up front amount and a monthly fee consumers can reside in facilities that match their needs (initially an apartment, but potentially a nursing home). (Project 2015: Living Arrangements for Older New Yorkers).

Assisted Living: In the 1970s and 1980s most communities in New York State built apartment buildings for senior citizens. Today, the trend is to find ways of bringing services into these settings, as well as building new assisted living settings where a core of services, such as housekeeping and meals are offered as part of the package. Some industry analysts have called assisted living the "new long term care paradigm." It allows providers to be more responsive to consumer preferences, demand and incomes than nursing homes can. Assisted living is less regulated than nursing homes. While New York was slow to get into the assisted living market, it now is moving quickly.

Nursing Homes: Current Status and Future Trends

Current Status

Nursing homes, now and in the future, remain as one of the key providers of long term care, with demographic trends likely to increase the demand for nursing home beds. New York has over 600 certified nursing homes, with 120,000 beds. Nearly one-half of the homes are for-profit and about one-half are voluntary (not-for-profit). Currently, nearly three quarters of nursing home residents have their care paid for by Medicaid and about one quarter are private pay. Medicare pays a very small amount (less than 5%) of nursing home costs. As in other states, currently less than 5% of adults age 65 and over reside in a nursing facility in New York State. However, if one examines the percentage of adults who could expect to spend some time in a nursing home before they die, the percentage rises to over 40% of all adults and will continue to increase into the 21st century. The average length of stay is 19 months, with two-thirds of discharges accounted for by death.

For persons institutionalized because of dementia, recent research suggests that education and training of family members on management and coping techniques can delay institutionalization by a year (Mittelman. M.S., Ferris S.H., et.al.,1996). These studies show promising directions for future initiatives aimed at improving care and reducing costs associated with caring for persons with dementia, especially in nursing homes. Monitoring developments in dementia research and treatment will be critical.

Future Trends in Nursing Homes

Quality of care outcomes: The nursing home industry was dramatically reshaped by the Omnibus Budget Reconciliation Act of 1987 (OBRA 87). One of the major recommendations was the need to concentrate on quality of care outcomes achieved for residents, rather than on the processes used to achieve them. A comprehensive assessment of all nursing home residents using the Minimum Data Set (MDS) was required on admission and periodically thereafter.

Residents' rights: An additional major change resulting from OBRA 87 was the clear articulation of residents' rights in nursing homes, especially related to freedom from unnecessary medications and restraints. This focus on residents' rights reinforces the integral role of the long term care ombudsman and underscores the importance of this NYSOFA program in the future. Innovative approaches in New York and elsewhere, such as the "Nursing Homes Pioneer Movement," have set as a priority the reshaping of the nursing home by empowering nursing home residents and staff and giving them greater voice and control over their care and lives. The greater acceptance of health care responsibility and a rise in health care consumerism among Baby Boomers will create additional expectations for the nursing home industry. Staff and administrators will need to be prepared to satisfy these expectations, initially in response to Baby Boomers who are worried about their institutionalized parents, and later as consumers of nursing homes themselves.

Medical complexity of nursing home residents: Due to hospital trends to discharge patients before their illnesses have resolved, the rise of subacute care, and the trend for nursing home residents to be older and frailer, the nursing home residents of tomorrow will be more medically complex. In addition, the prospective payment system, geared to the case-mix of residents, creates incentives to institutionalize those who are frailer. Nursing homes are increasingly serving as sites for rehabilitation and recovery and are important resources to help transition patients back into the community. This mix of residents — frail individuals with potentially long lengths of stay with subacute residents who are undergoing rehabilitation and have short lengths of stay — creates more medical complexity of residents to be addressed in nursing homes than previously existed. This has implications for staff and for training staff to interact with residents with a variety of needs.

Currently, one half of nursing home patients have a length of stay of less than 6 months, but short stays only account for 5% of all nursing home days. A recent survey of New York nursing homes found 45% of facilities now provide subacute care, with an average of 21 patients (Eggert, G.M., Katz, P. Karuza, J. et.al., 1998). This likely will be an increasing component of nursing home care in years to come.

The nursing home of the future will be challenged to reconcile these imperatives. Key to meeting these challenges is appropriately defining and supporting the role of Medical Director in the nursing home, as well as the important role of the nursing staff, paraprofessional staff, family members and personal physicians.

The Future of Long Term Care Services

Several reviews document the current and projected future demographic landscape (Kramarow, E., Lentzner, H., Rooks R., et. al., 1999). Salient changes in marital and child rearing patterns, longevity, and women's labor force participation will continue to contribute to a

more diverse pattern of family and social relationships among older adults. With the sharp increases in fertility following World War II, the number of childless older adults will drop between now and 2015. However, because of reduced fertility, high rates of divorce and low rates of remarriage, the availability of spouses or children to provide care for the aging Baby Boomers will decline precipitously later in the 21st century.

Demographers have noted that the future family structure in the United States will resemble a "bean pole", as the number of living generations increases and as the number of individuals within each family generation decreases. This translates into fewer potential informal supports for older persons in the future, which has implications for possible increased need for formal long term care services. Compounding this pattern is the projected trend for New York to lose 5 million people through net internal migration between 1995-2025 (Demographic Projections to 2025, NYSOFA). With many younger and middle aged adults leaving the state, the number of family members available to provide hands-on or direct care is further reduced.

Even with the commitment to successful aging among Baby Boomers, lower fertility rates may increase the demand for formal long term care, including home-based, community-based and nursing home options for Baby Boomers and beyond. A major social policy issue for the 21st century is the impact that a smaller family size and an increase in single households will have on the social support network, quality of life and long term care of older adults.

Diversity in New York State

A trend also deserving serious consideration is the dramatic increase in the numbers of minority New York state residents, including older adults (Demographic Projections to 2025, NYSOFA). One implication of this is the increasing diversity of older adult consumers of long term care, whether in the community, alternative living environment such as assisted living, or the nursing home. Complicating the picture is, given current employment patterns, the likely increase in the number of minority and ethnically diverse health, allied health professionals and paraprofessionals who provide care in nursing homes and who provide home care in the community. Promoting cross-cultural and cross-ethnic sensitivity and understanding among professionals, paraprofessionals and long term care consumers of different ethnic groups, cultures, religions, and linguistic backgrounds will be needed. This will require health, allied health professionals and paraprofessionals to be more culturally competent, which is a training issue that will need to be considered.

Organization and Financing of Long Term Care

The different and multiple funding sources for long term care make it very hard to coordinate long term care services. Unlike health care for older persons, in which the federally funded Medicare program pays for most acute and primary health care, long term care is paid for out of a variety of sources, including out-of-pocket private pay, state-funded programs, long term care insurance, and Medicaid. Holding aside the long term care costs borne by families "out of pocket", the largest source of long term care funding is Medicaid. New York State now spends approximately 60% of the entire national Medicaid budget for home care and 80% of the country's budget for personal care. While long term care insurance has been available for some time, the number of persons opting to purchase it remains relatively small, due to high premiums.

The Baby Boom generation is uniquely affected by the structure of long term care service and financing. The retirement of the Baby Boom generation will coincide with tremendous advances in medical science and, with those, longer lives. Most Americans still do not believe they will need long term care services and do not save or become insured for this possibility, and this holds for the Baby Boom generation. Although Baby Boomers may retire with the

largest nest eggs in history, they likely will need to apply much of their hard-earned savings toward long term care services to remain independent. While it is a challenge to plan for the possibility of needing long term care, it is an essential challenge for Baby Boomers to take on. We cannot discuss a different vision for long term care financing and services, sustaining family involvement, and offering long term care options that meet individual needs, without recognizing this essential ingredient - - changing how we plan for long term care.

Recommendations

- Prevention and Promotion of Successful Aging: Better primary prevention of chronic illness and disability, and promotion of healthier life styles (e.g., exercise, better nutrition and smoking cessation) need to be encouraged. These approaches have the potential to reduce frailty and dependency among Baby Boomers, and should be promoted and facilitated by both the public and private sectors.

- Consumer Empowerment: Personal and family planning and involvement in long term care will be expected by most Baby Boomers and should be encouraged. Baby Boomers, as caregivers of their elderly parents and later as consumers of long term care, can be expected to want an active role in participating in long term care decisions.

- Information: With more choices than ever for long term care support, clear information about service choices and the long term care "market" will be a growing need. Improving information and dissemination strategies that use innovative technologies will be crucial to informing future long term care consumers and their families. Strategies include the Internet, existing private information resources (e.g., consumer groups, universities, and professional associations) and public resources (e.g., the New York State Office for the Aging and the local area agencies on aging). An integrated and user friendly database of information should be considered. Information accuracy will be a major concern and raises the need to establish an information certification or quality assurance mechanism. Whether the public or private sector best does this should be carefully considered and debated.

- Role of the Long Term Care Ombudsman: Once consumers are "in the system", an expanded Ombudsman role may be an important resource to help individuals to deal with issues of quality and residents rights.

- Sustaining Family Involvement in Long Term Care: The family provides 80% of long term care services, yet few resources exist to help them cope. Innovative caregiving skill-building, training and other support services (e.g., respite) need to be promoted and supported. In recognition of the major role families play in the long term care of older adults and the burdens of caregiving, development of more effective physician-caregiver relationships that consider the caregiver and patient as a single unit of care should be considered. Keeping in mind the demographic trends within families, including the multiple roles of working women, innovative programs that blend formal community services with informal caregiving should be created, expanded and evaluated.

- Long Term Care Financing and Reform: The need to develop stable, workable funding sources and to control long term care costs will be an important challenge in the 21st century. A major challenge in long term care is to transform it from a system in which many people often impoverish themselves for care to a possibility for which people plan in advance for long term care needs. It is important to consider whether the current financing system, primarily through Medicaid, can continue to pay for the care that will be needed in the future. Long term care

insurance is still an expensive and limited product. Innovative expansion of long term care insurance is needed (e.g., larger pools through employee/retirement benefit packages can help spread risk and reduce cost). Tax incentives and dependent care accounts should be considered for expansion to help finance long term care. Expansion of current services and more choices are needed for persons just above poverty level through middle income. These consumers generally are ineligible for Medicaid and can't afford to pay privately for all of their long term care needs.

- Links between Acute and Primary Care, and Long Term Care: A major stumbling block in making long term care cost effective is the difficulty in linking long term care (funded primarily by Medicaid) and acute and primary care (funded primarily by Medicare). Reforming the system to create a more integrated approach, with the patient at the center, will need to receive attention in the coming decade. This will require the active involvement of the federal government as well as states, consumers and providers of care.

- Geriatric Case Management and Care Coordination: Developing mechanisms for geriatric case management and care coordination across the levels of care hold the promise of more cost effective and higher quality of care. Training professionals to assure an understanding of the aging process and how to work with and communicate with older adults will become more important in the future.

- Research: Research that evaluates the effectiveness of innovative approaches to long term care is especially relevant, particularly those that maximize the role of families and empower consumers of long term care. The use of non-medical long term care services and the integration of various services and supports need to be evaluated and established in the mix of long term care. Worthy of special attention are the differences and similarities in delivering long term care in urban and rural areas. Within the nursing home arena, research in several areas is called for, including: defining appropriate benchmarks for quality, examining the role of families in creating a supportive environment, resident and staff empowerment, and the relationship between resident outcomes and several areas such as physician and nursing staffing ratios, open versus closed medical staffing privileges, and use of health care guidelines. Such research holds the promise for a leaner and higher quality of long term care in New York. Basic research should continue to explore more effective strategies to prevent chronic illness and reduce frailty. Parallel research that evaluates the most effective ways of promoting prevention among the New York State population is needed. Finally, additional demographic research needs to explore how long term care needs are impacted by current and future trends of in- and out-migration in New York. The impact of the Ombudsman also warrants further study.

- Professional Education: A priority should be placed on promoting the education of health and allied health professionals on issues relevant to long term care. Instrumental are the rich educational resources in New York State, including the federally funded Geriatric Education Centers, and professional associations such as the American Geriatrics Society and the American Association of Medical Directors. Equal emphasis should be placed on exposing health and allied health students and residents to long term care, and in providing high levels of continuing education to familiarize practitioners in the field with latest innovations in long term care. Especially noteworthy as a topic is promoting greater understanding and sensitivity to minority and ethnic diversity in long

term care. Given the increasingly complex care delivered in nursing homes, a special credential for medical directors should be considered. Additional training of nursing surveyors regarding quality of care can improve the consistency of the review process, and help promote quality assurance in nursing homes.

- Regulation and Quality Assurance: Emphasis will need to be placed on outcomes rather than process. For example, current regulations of nursing home care should be reviewed to bring them up to date with current knowledge and practice. The regulatory framework for home and community-based long term care, whether an assisted living program or home care also will need to reflect quality outcomes, promote a proactive approach to quality assurance, assure client satisfaction and preserve consumer rights.

- Access to services: Individuals needing long term care and family members that assist them with care will continue to demand improved access to service along several dimensions. These include coordination of long term care services, better information about available choices, improved availability of service options, and a partnership approach to long term care decision-making.

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Project 2015:
The Future of Aging in New York State

INFORMAL CAREGIVING

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Introduction

> "It is like living someone else's life—
> I feel like I'm in a 24-hour cocoon."
> "How do you decide how much time to give to your disabled husband, your children and your own needs?"

This is how several of the 13.3 million Americans who have a parent or spouse who is elderly and disabled describe their situation. An estimated 15% of U.S. adults are providing special care for seriously ill or disabled relatives. Informal caregivers refers to unpaid family members, friends or neighbors who provide full or part time care to persons with disabilities. Formal caregivers are volunteers or paid care providers who are part of a service system (Family Caregiver Alliance Fact Sheet).

Reference to the "sandwich generation" or "the woman in the middle" describes 20 to 40% of caregivers, which, in addition to caring for a relative with disabilities, are caring for children under eighteen. For many caregiver families the "empty nest" has been filled by parents and adult children who are divorced or no longer able to maintain themselves in their own home. Another dimension of caregiving, which is increasing at an alarming rate, is that of grandparents who are caring for grandchildren whose biological parents are incapacitated by substance abuse, incarceration, premature death, etc.

Nationally, seven million persons over the age of 65 need help with the tasks of daily living: feeding, dressing and bathing. Seventy-one percent of all long-term care is provided in the community, with 85% provided by family and friends. Seventy percent of all caregivers are married, but female caregivers are twice as likely as males to be widowed. The median age of the working caregiver of the elderly is 45 years while the average age of a caregiver is 57 years. Estimates are that between one third and one half of caregivers are employed. 72% of caregivers are women of whom half are employed.

The average amount of time spent per week by informal caregivers providing personal care assistance and household management is 12 hours. Twenty-eight percent of caregivers provide eight hours of care or less. Thirty-six percent of caregivers provide twenty-one hours of care per week, while the remainder of informal caregivers (11%) provides "constant care". When the place of care changes caregivers continue to give an average of 36 hours a month or 8.5 hours a week to care of non-community dwelling relatives. Most of the caregivers in the study of the National Alliance of Caregiving and the AARP (1997) had been providing care for less than 5 years, one in five for 5 to 10 years and 10% for at least 10 years.

Care Recipients

The average age of care recipients is 77. Of the 7.3 million Americans over 65, a quarter of the country's elderly population, the fastest growing cohort is the old-old, those over the age of 85. It is this group who require the greatest amount of care in the home. This group, as reported in New York State's Office for the Aging, Demographic Projections to 2025, will reach more than a third of a million people by the year 2015.

Reasons for Needing Care

Where do care recipients live? One fifth of them live in the same household as the caregiver; one half live in their own home or in

an apartment in a retirement community. The most prevalent reason for co-residence is the increase in the amount of care needed. Adult onset brain impairment from Alzheimer's Disease, stroke, traumatic brain injury, and Parkinson's Disease are some of the major reasons for needing care. Alzheimer's Disease affects an estimated 4 million Americans, 10% over 65, and nearly 50% of those over the age of 85. There are an estimated 2.9 million cases of stroke, and though difficult to track, from 1 million to 1.8 million cases of traumatic brain injury. Other reasons for needing care result from limits imposed by heart conditions, problems with ambulating (25% of care recipients are bedridden or use wheelchairs), limits on activity due to chronic conditions, osteoporosis, arthritis, sensory impairments, diabetes, special diets, high blood pressure and circulatory disorders, etc. Seven million persons over the age of 65 need help with the tasks of daily living: feeding, dressing, bathing, etc.

Satisfaction of Caregiving

Given the significant amount of care provided by family and friends and anticipating even greater demands of the informal sector, some exploration of the reasons behind their actions is helpful. The following have been identified by caregivers in support groups and/or educational sessions by the Brookdale Center on Aging of Hunter College: reciprocity for care in the past; respect for one's elders; love, admiration for the strength of the older relative, even in a dependent state; control of the quality of care; as a role model for their own children. There is also time for sharing of family history with more time together.

Stress of Caregiving

Caregivers report changes in most aspects of their life when they take on the role of caring for a disabled relative at home. They identify emotional stress as the most difficult including resolving the filial crisis when the parent is no longer the one to be depended upon and the parent depends upon the child (filial maturity), role strain due to conflicting demands; time constrains; reactivation of earlier sibling rivalry; the loss of the parent or spouse " who was," especially when there is dementia; guilt related to ambivalence; and negative reactions to the demands on them and other causes stemming from "unfinished business."

Caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the rest of the population (George & Gwyther, 1991). Being unprepared for the caregiver role, lack of information and difficulty in negotiating for services causes frustration and strain. Indications reported in the 1997 Survey of Family Caregivers by the National Alliance For Caregiving and the AARP are that 46% of caregivers suffer from clinical depression-49% of the females and 31% of the males.

The physical stress of caregiving, especially for the bedridden or wheelchair bound relative, often results in back or muscle pain. Caregivers report a worsening of their own health after becoming involved in caregiving and less medical attention for themselves. Employed caregivers often have a higher incidence of physical and emotional strain, frequent anxiety, headaches, and depression.

Financial stress is especially devastating for the dementia patient and his or her family, whether the care is received at home or in an institution. Since Medicare and private insurance pay less than 5% of the nation's long term care bill and many of the aged are above Medicaid eligibility, savings are quickly depleted. For employed caregivers approximately one third of both full time and part time workers lose time from work because of caregiving responsibilities, and some choose early retirement. 12% give up work entirely. The Family Leave Act, recognizing the need of employed caregivers for time off to care for a relative, assures them some job security and should ease some of this hardship. Financial stress is experienced by the caregiver at a distance as well. Caregivers report significant expenses for care related products and services. This generation of the aged

is often very proud of their independence and are reluctant to apply for public entitlements that could ease their financial stress.

Supports

Community supports are essential for the prevention of caregiver role strain and burnout and the provision of appropriate care for the care recipient. Community supports include respite, home care services, adult day care services, support groups, and educational opportunities. Respite care can be defined as any planned, ongoing, or periodic provision for community assistance to care for an elderly or disabled person so that the primary caregiver has the opportunity to leave the caregiving role temporarily to pursue his/her own interests and needs, whether it be for pleasure or work. This temporary relief from caregiving responsibilities provides the caregiver with the ability to continue in the role of primary caregiver. Respite can include home care services, residential services, and adult day care services (Table 1).

Table 1
Community Services Available in New York

Respite	Home Care	Day Care
-In-Home	- Certified Home Health Agency	-Social Model
-Day Care	- Licensed Home Health Agency	-Adult Day Health Services
-Adult Home	- Long Term Home Health Care Program	
-Residential Health Care Facility	- Hospice	
	- EISEP	

Support groups offer the informal caregiver the opportunity to gain a new perspective on their lives through interaction with others sharing the same experiences. This ability to share with others is another key to preventing caregiver role strain and burnout. Support groups are currently offered by organizations such as the Alzheimer's Association, other disease specific organizations, and other community agencies.

Informal caregivers require various skills to care for the care recipient and themselves. Learning these skills and becoming proficient in them eases caregiver stress. Mathis, 1992 and Krach and Brooks,1995, identified educational needs of caregivers to include community resources, aging, physical care, communication, information regarding mental incapacity of the elderly, stress management for caregivers, how to communicate with physicians, housing options, nursing home placement, how to communicate amongst family members, emotional acceptance of care recipients' condition, maintenance of caregiver physical self and ability to evaluate the care recipients' needs. Hospitals and other community agencies provide educational opportunities.

Family caregiving data as described cut across all ethnic groups. In New York State's Office for the Aging Demographic Projections to 2025, the rapid continuing increase in minorities among the aged is highlighted. Service providers need to be knowledgeable about and sensitive to this cultural diversity. Expectations and caregiver responsibilities and attitudes of trust and the formal system must be considered in focusing on service development and utilization. If the January 1999 proposed "National Family Caregiver Support Program" is passed and implemented, many of the identified needs will be addressed.

Future Issues/Trends

As Baby Boomers age and the number of elderly increase in New York, the need for services will have a fiscal impact as well as a resource impact. End of Life issues will become more prominent. Continual changes in family demographics and composition will impact what informal supports are available.

Ethical Issues

As we live longer and medical technology continues to advance, the Baby Boomers will face a multitude of life and death decisions. These decisions include such issues as Do Not Resuscitate Orders, quality of life vs. quantity of life, caregiver vs. care recipient beliefs, proxy appointments, service availability based on

ability to pay, and more. Bruce Hilton, Director of the National Center for Bioethics suggests that care recipients explore and define health beliefs with their caregivers. This may be difficult for Baby Boomers to do. A 1998 AARP study found that 68% of Baby Boomers have not talked to their parents about independent living issues. How much more difficult is it to talk about end of life issues?

Dementia

With the ever increasing life expectancy and the number of Baby Boomers, the number of dementia cases can be expected to increase proportionately since the incidence of Alzheimer's Disease increases as age increases. Dementia patients require labor intensive care, creating increased burdens on the caregivers.

Caregivers at a Distance

The mobility of the American family, both the caregiving generation and the older generation, has created another category and level of strain for both parties. The complications of travel, time, locating resources and learning about the support systems as well as monitoring home care for the out-of-town relative, can become overwhelming. Another level of knowledge and an enhanced network of support needs to be acquired. As longevity increases, caregivers often face another crisis that may include relocating the older person closer to the caregiver's residence. There are many implications to such a change, both concrete and emotional, for all individuals involved in this change. The older person in a more deteriorated state than when they relocated initially will require a range of both formal and informal services. The AARP publication, Miles Away and Still Caring, is a helpful guide. The specialty of Private Geriatric Care Managers targets the group of caregivers who can afford to pay for services.

Older Persons Caring for Older Persons

The households of siblings most frequently have one in the role of caregiver, often complicated by chronic illness affecting both of them. A major crisis in these cases and in spousal caregiving occurs when one of the partners needs hospitalization. If there are family members who can intervene, care in the community may continue. If not, this may be when placement becomes a plan of choice. Support services for the community dwelling population have increased in the past two decades and will need to accommodate these situations more often. Case managers will be challenged to acquire greater skill and understanding.

Community Supports

Despite the benefits of community supports, the caregiver does not always recognize the need for community supports, have the desire to use community supports, or have the financial resources to purchase community supports. Community supports may also be unavailable in certain areas. For example, in New York, according to Christine Fitzpatrick, Chairperson of the New York Day Health Council, there are still 17 counties without a medical model day care program (personal communication July 1999). Government funding has been decreased to all community support programs in recent years; thus services are being limited.

Residential respite may cost as much as $200 or more a day. Medical model day care programs cost more than a $185 a day (NADSA, 1999). Personal care aides may cost as much as $15 per hour. Currently, third party payers, other than Medicaid, do not cover care for the chronically ill. Therefore, many caregivers find that community supports are beyond their reach.

Projections

The aging of the Baby Boomers will no doubt produce a more educated cohort of the young aged, with greater knowledge of resources, ready access to information from the Internet and possibly a more ready acceptance of public entitlements for themselves and their disabled parents. The higher incidence of multiple marriages, alternate family styles, and blended families will direct the way in which long term care is provided. Increasingly the identified needs of caregivers for respite, education

and skills training and transportation for the older person will have to be met by a combination of public and private services. Implementing the concept of supplementing and supporting the informal supports, a major task, lies ahead for area agencies on aging, senior centers, the corporate sector and other employers of caregivers, unions, and religious institutions. Cross systems cooperation in designing resources will also have to become a reality in empowering caregivers.

Home Care/Hospice/Respite

Case management services, either public or private, should include an assessment of the caregiver as well as the care recipient, since many caregivers are unable to identify their own needs. Support should be given to the expansion of the Long Term Home Health Care Program, Naturally Occurring Retirement Communities and adult day care programs.

Private and public funds should be dedicated to the development of additional adult day care programs. Paul Arfin, Executive Director of the Community Programs Center of Long Island, Inc. (personal communication, July 1999) estimates that between 1 and 2% of those over the age of 65 could benefit from adult day care. Mr. Arfin also quotes Dr. Burton Reifer of Partners in Caregiving as stating that "any community with 25,000 individuals consisting of 25% over the age of 65 can support an adult day center of 36 members."

Education/Support Groups

A literature review suggests that psycho educational support groups are more effective than strictly support groups or strictly educational groups (Chiverton & Caine, 1989; Glosser & Wexler, 1985; Greene & Monahan, 1989; Mittelman, et.al. 1993; Toseland, Rossiter, Peak & Smith, 1990). C.A.R.E., a program developed by Lenore Hieler MS, RN, CS, which includes a nursing assessment, case management, phone consultation, and psycho/social educational support groups (Glassey, 1997) is an example of an attempt to provide a comprehensive service with goal of preventing caregiver burnout.

The most effective programs that will reach rural and urban caregivers will incorporate all the technology available. Programs such as those offered by Dorot University Without Walls, in New York City, and Stanley Isaacs Neighborhood Center in Manhattan provide prime examples of opportunities for caregivers to participate in learning activities and support groups through teleconferencing technology. Chat rooms and support groups on the Internet are also effective tools. All of these programs can be used as models for development of programs in other parts of the state. State and community partnerships could be encouraged to develop new initiatives such as the C.A.R.E. program. Resource packets that include web sites, long distance learning programs and support groups should be made available.

Policy and Public/Private Partnerships

Advocates for the aged and area agencies on aging should encourage legislation to provide tax benefits for the costs of elderly dependent care; encourage businesses to incorporate stipends for elderly dependent care in their benefits package; encourage development of insurance programs that would cover custodial care; encourage businesses to include support groups, counseling, resources and referral information as part of their employee health programs; support the development of cooperatives and barter programs for service credits; and encourage development of other innovative programs. They should also encourage the development of programs such as the Robert Wood Johnson Interfaith Health Program and Parish Nursing Programs.

Conclusions

Informal caregiving, often chosen, sometimes foisted upon an individual, is a vital part of our society. The services provided by the informal caregiver should be recognized and sustained. These individuals need the support of their family, friends, and community. Support—financial, emotional, hands-on, and educational, is necessary to ease caregiver strain

and prevent caregiver burnout. Public and private organizations should work individually and together to provide the resources so desperately needed. With the necessary supports, informal caregivers will be able to continue to provide invaluable care to their older family members and friends.

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Project 2015:
The Future of Aging in New York

GRANDPARENTS AS FAMILY CAREGIVERS

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Overview and Background

Families provide the vast majority of care for their dependent members throughout the life course, and grandparents, who have always served as a safety net for their grandchildren, are no exception. During the past quarter century, however, grandparents who are primary, long-term caregivers for young kin have emerged as a new, relatively vulnerable population of family caregivers. In 1997, 2.4 million, or 7% of the nation's families with children under age 18 were maintained by grandparents—up 19% since 1990. The lifetime incidence of surrogate parenting for grandparents is estimated at 10.9%, and care extends beyond 3 years for 56% and for more than a decade for one in five grandparents (Fuller-Thomson, Minkler, & Driver, 1997).

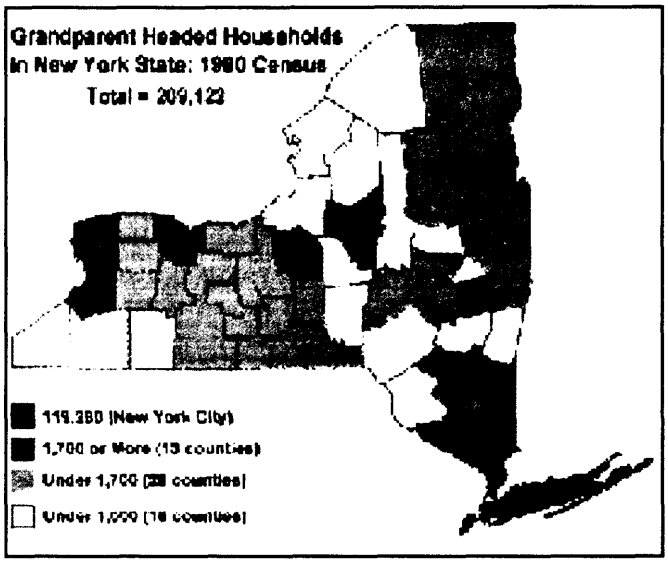
Data on living arrangements of children also reflect this trend. The number of children under age 18 who live with grandparents and other relatives has nearly doubled, from 2.2 million or 3.2% of all children in 1970 to 3.9 million or 5.5% in 1997– a remarkable 76% increase (Lugaila, 1998). About two-thirds of these children live in households in which one parent is present and nearly half (47%) reside with both parents. Importantly, the fastest growth rates in recent years have been for those children who live in grandparent-maintained households in which neither parent is present. Their numbers rose 6% between 1970 and 1990, then tripled from one half million to nearly 1.5 million in 1997 (Casper & Bryson, 1998).

The public policy significance of the rapid growth in grandparent-headed households is most fully appreciated in the context of contributing factors and, relatedly, the risk features of many families involved. Chief among the issues that have adversely affected the linking generation, and thereby accelerated the need for grandparents to expand their role to primary caregiver, are demographic changes in family structure. These include rising rates of teen pregnancy, divorce, and single-parent households. These also include a constellation of interrelated social and health problems, notably substance abuse (implicated in over 80% of all instances), mental and physical illness, particularly HIV/AIDS, and rapidly rising rates of incarceration for women of child-bearing age (see Burnette, 1997; Minkler, 1998).

Philosophical and practical shifts in child welfare policy in the past 20 years have contributed to grandparents and other relatives as a major source of care for children in families affected by these and other social problems. In *Miller v. Youakim, 1979*, the Supreme Court ruled that relatives caring for AFDC-eligible children could receive federal foster care benefits, and Title IV of the 1980 Social Security Act guaranteed them AFDC. The 1980 Adoption Assistance and Child Welfare Act (Public Law 96-272) mandated that children in need of out-of-home care be placed in the most family-like setting possible, and the Indian Child Welfare Act of 1978 was similar in intent and implementation. States responded by incorporating relatives into their child welfare systems through kinship foster care programs. These programs then burgeoned, especially in the primary urban areas of states that have heavy foster care caseloads, notably Illinois, California, and New York (Harden, Clark, & Maguire, 1997; Hegar & Scannapieco, 1999). More recently, the 1996 Personal Responsibility and Work Opportunity Reconciliation Act also mandated states to give preference to adult relatives over non-relatives when determining placement of a child (42 U.S.C. 671 (a)).

The demographic shifts, social problems, and public policy that coalesced in the 1980s to produce the rapid growth of grandparent caregivers yielded a disproportionate number of low-income, urban ethnic minority grandmothers in this population. Nationwide, three quarters (77%) of custodial grandparents are women, and African American grandparents are three times and Latinos almost twice as likely as their non-Latino white counterparts to be a primary caregiver (Fuller-Thomson, Minkler, & Driver, 1997).[1] Three quarters of children who live with their grandparents reside in standard metropolitan areas, up from 59% in the mid-1980s (Harden, Clark, & Macguire, 1997).

Data from the 1990 Census are useful for estimating the number of grandparent-headed households in New York State. Based on the Census definition of a grandparent-headed household as a family home in which both a grandparent and a related grandchild live, there were 209,122 grandparent headed households in New York State in 1990 (New York State Office for the Aging, 1999). There were no parents present in 50,576 of these homes (Wiener & Sconfienza, 1997). Nearly three quarters (72%) of grandparent-headed households in New York State were headed by a grandparent age 50+ and 57% were racial/ethnic minority grandparents. Whereas African Americans represented only 14% of householders in the state in 1990, one quarter of grandfather and half of grandmother heads of household raising their grandchildren were African American. Similarly, Latinos constitute only 4% of households statewide, yet 5% of grandfather and 7% of grandmother heads of household were Latino. Just under half (46%) of New York State's grandparent-headed households were minority grandparent headed households in New York City (see Figure).



Map - 1999
Source: New York State Office for the Aging

KEY ISSUES AND IMPLICATIONS

Grandparents who are rearing their grandchildren help preserve crucial kinship ties and provide an inestimable social and economic service to society. Most report a deep sense of satisfaction, gratification, and mastery from their caregiver role, but these gains are often at great personal and family cost. Over and above role-related demands, both current and cumulative disadvantages heighten risks of economic, health, and mental health problems for grandparent caregivers and challenge their current and continued ability to parent. Grandparent caregivers fare worse than spousal and filial caregivers in each of these dimensions of well-being (Strawbridge, Wallhagen, Shema, & Kaplan, 1997). Moreover, the formal services on which many depend are a fragmented pastiche of aging, child welfare, and public aid programs not designed for them or their families (AARP, 1995). In designating grandparent caregivers as one of 40 priority areas for increased attention, the 1995 White House Conference on Aging identified poverty, health, mental health, and legal issues as key areas of concern.

Poverty

The single greatest overarching problem facing grandparent caregivers is economic security. Almost half (46%) live on fixed incomes and 64% do so without public assistance. Nearly a quarter (23%) of grandparent-headed households have incomes below the federal poverty threshold, but this figure varies widely by sex and marital status of the householder and household type. Fifty-one percent of these households include a grandmother and a grandfather, 43% are grandmother only, no spouse present, and 6% are headed solely by a grandfather. More than half (57%) of grandmothers raising grandchildren alone have incomes below the poverty level. The mean annual income for these families is $19,750, as compared to $61,632 for those with both grandparents plus one or both parents (Casper & Bryson, 1998). In New York State, grandmother heads of household age 60 and over were more than twice as likely to have household incomes under $15,000 than their grandfather counterparts.

Recent welfare reform further affects the financial status of grandparent caregivers (Busch,1997; Mullen, 1996). The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L.104-193), which replaced AFDC with Temporary Assistance to Needy Families (TANF) (Family Assistance in New York), shifted responsibility for public assistance to states and emphasizes individual responsibility, work requirements, and benefit eligibility limits. Grandparent caregivers who receive Family Assistance, for example, must work unless they are ill or incapacitated, age 60 or over; or are needed in the home due to illness or incapacity of a household member. Those who apply for assistance for themselves and their grandchildren are subject to a 5-year lifetime limit on cash assistance, and prior receipt of aid for themselves may reduce or eliminate the amount of the grant.

These restrictions do not apply to "child-only" grants, which represented 10% of the national welfare caseload a decade ago but now constitute more than double that. In a growing number of states, nearly half of persons remaining on welfare rolls are children whose parents are ineligible for aid for reasons such as receiving disability benefits, removal from the rolls for failure to comply with rules, or are undocumented immigrants, though their children are U.S. citizens. Of the 336,857 families receiving Family Assistance in New York in August, 1999, 15.2% were child-only grants. Of the 645,788 child recipients, 5.5 % were grandchildren of the householder. One in five child recipients was white, 40% were black, and 36% Latino. Virtually all these families received medical and cash assistance (on average $417.00 per month) and 93% received Food Stamps (New York State Office for the Aging, 1999).

The current and long-term economic effects of welfare reform on grandparent-headed families should thus be monitored closely. Poverty rates are already high and adults in the 85% of Family Assistance cases which include an adult are subject to time limits and other restrictions unless exempted. Expulsion from the program would mean loss of medical and critical income support. Establishing a guaranteed minimum level of support for child rearing could help offset a worsening of the economic situation of this vulnerable group of family caregivers and their grandchildren.

Physical and Functional Health

Nationally, 36% of custodial grandparents rate their own health status as fair, poor, or very poor, and they are more likely than other grandparents to report limitations in Activities of Daily Living (Minkler & Fuller-Thomson, 1999). Physical and functional decrements affect grandparents' quality of life, increase their risk of comorbid mental health problems, compromise their ability to meet the physical demands of the caregiver role, and are likely to worsen with advancing age. Health problems may be especially troublesome for urban, ethnic minority grandparents (Burnette, 1999c; Burton, 1992; Minkler & Roe, 1993). In addition, there is evidence that grandparents tend to downplay the severity of their own health problems, prevent-

ing them from seeking needed medical attention (Minkler & Roe, 1993). Again, sufficient economic support and access to medical care could help prevent and reduce the exacerbation of acute and chronic health conditions and promote appropriate self-care.

Grandparent-headed households are more likely than traditional households with children to have gaps in insurance coverage; 19% of those responding to an AARP Women's Initiative Survey ranked health insurance as the biggest problem faced by households like theirs. Grandparents who work may be covered by employers, but policies are unlikely to cover grandchildren, especially if care is informal. If retired and on Medicare, they may have to purchase a private policy or seek Medicaid coverage. The New York State Child Health Plus program helps cover the needs of grandchildren, but grandparents need to be made more aware of this and other child health programs (Burnette, 1999a). The NYSOFA web site presents information on sources of coverage for grandparents themselves at http://hiicap.state.ny.us.

Mental Health

The positive mental health outcomes of rearing grandchildren are typically offset by considerable role strain that is often exacerbated by stressful life conditions such as emotional turmoil, social, leisure, and work role restrictions, and role conflicts due to balancing the needs of grandchildren with those of other family members. One quarter of grandparent caregivers in the U.S. report significant levels of depressive symptoms, a rate nearly twice that of other grandparents (Minkler et.al., 1997) and perhaps even higher for urban, ethnic minority grandparents (Burnette, 1999c; Burton, 1992; Minkler & Roe, 1993). Other notable mental health difficulties include social role restriction, isolation, anxiety, and loss of control and mastery. In addition, many grandparents are grieving the loss of an adult child, the circumstances of which may adversely impact its resolution.

Custodial grandparents are even less likely to seek help for mental than physical health problems. The considerable personal strengths that many bring to the role should be articulated and used to enhance their sense of mastery and competency. Informal support networks are often unreliable because family members are stretched to the limits meeting their own subsistence needs (Burton, 1992; Burnette, 1999b). The chief source of education and support for grandparent caregivers is support groups, with more than 500 groups nationwide. New York State groups are listed at: http://aging.state.ny.us/caring/grandparents/sgroups.html. The Grandparent Resource Center in New York City, a rich information and referral resource for the City, also maintains a list of support groups and provides training and support for group leaders. Grandparents also identify respite as a top priority, and this service may be especially helpful for those rearing children who have special needs. These services, which positively impact both physical and mental health (Tepper & Toner, 1993), could be delivered by charitable groups, community volunteers, churches, etc.

Finally, any efforts to increase the use of much-needed formal mental health services must address the wide range of dispositional, institutional, and situational barriers, including low awareness of services, limited child care, lack of insurance coverage, and cultural barriers and negative attitudes about mental health and professionalized care of mental health problems.

Legal Issues

The legal status of the grandparent-grandchild relationship determines the type and extent of grandparents' rights, responsibilities, and authority on matters such as school enrollment, medical consent, access to official records, and health insurance eligibility. Existing arrangements, which consist of informal care, legal custody, legal guardianship, kinship foster care, and adoption, vary widely in terms of level and type of economic and supportive

services provided. In New York, social workers are required to inform relatives of their choice to take a child informally with assistance from the TANF program, or elect to participate in federal or state foster care. The former option may preclude family strife associated with legal proceedings to transfer custody from a parent, but it carries far less economic and supportive services. On the other hand, the child must meet eligibility criteria for kinship foster care, the program has multiple rules and regulations, and legal authority over the child is transferred to the state (see Flint & Perez-Porter, 1997; Ginchild-Abeje & Perez-Porter, 1997).

These differential levels of support are noteworthy because the welfare and needs of children in kinship and non-kinship foster care (Berrick, Barth & Needell, 1994; Dubowitz, Feigelman, & Zuravin, 1993) and those in informal care (McLean & Thomas, 1996) are strikingly similar. States have thus begun to explore options to address the special legal issues of relative caregivers. Some have passed kinship care legislation which ensures grandparent caregivers parity with other foster care providers, while others are reorienting their social service systems away from a singular emphasis on family reunification toward policies based on the best interest of the child. Existing supportive programs, i.e. Medicaid, TANF, SSI, Head Start and Food Stamps–are also beginning to address the unique needs of grandparent-headed families. A few states, including Florida and Wisconsin, are also moving their child-only cases off welfare and into programs that pay relatives to care for children (Hushbeck, 1999).

In *The Dilemma of Kinship Care*, Gerald Wallace (1999) proposes amending the New York Domestic Relations Law to provide a statutory definition of "kinship custodian." This move would help bring unity to the myriad statutes that already invest kin caregivers in the state with some powers and responsibilities and would help clarify the rights, responsibilities, authority and liability of informal and formal kinship caregivers. Details on this proposal are available at http://aging.state.ny.us/caring/grandparents/letter2.htm

CONCLUSION

Demographic and sociological changes have dramatically increased the number of grandparents who are rearing their grandchildren in the United States. New York State, particularly New York City, is one of several major epicenters of this growth. Public policy has been slow to keep pace with the changing roles and responsibilities of relatives as primary, long-term caregivers of young kin, yet the well-documented vulnerabilities of this population clearly indicate an urgent need for long-range family-based programs and policies that will elucidate the definition, rights, and duties of custodial grandparents and ensure sufficient economic, health, mental health, and legal support for this challenging role. Planning for this population is complicated by numerous interlocking, at times conflicting, needs of multiple generations of families, usually over the course of many years. The final resolution of the 1995 White House Conference on Aging spelled out in detail what needs to be done to assist caregiving grandparents. The resolution called for:

- comprehensive programs for caregiving grandparents, including respite and day care, legal assistance, advocacy services, health care and substance abuse treatment and mental health support; financial, social and legal support for caregiving grandparents raising grandchildren;
- removal of the legal and regulatory barriers that make it difficult for caregiving grandparents to receive Temporary Assistance for Needy Families (TANF), food stamps and other safety net programs;
- programs through the U.S. Administration on Aging to provide supportive services for grandparents and their grandchildren and develop support groups in senior centers and other settings; intergenera-tional programs to strengthen the family unit in grandparent-headed households;
- legal surrogate decision-making authority for caregiving grandparents in cases where the parent or other guardian is absent;

- education for human service providers about the rights of caregiving grandparents;
- protection of grandparents' visitation rights; and
- use of existing federal, state and local revenue streams to accomplish the above purposes.

The number of grandparent-headed households continues to increase steadily, and even if this growth remained unchanged, the current cohort of children in grandparent care will mature to adulthood with their grandparents before 2015. Establishing a mechanism to systematically track these families will help us to understand and plan for the changing needs of both grandparents and the children in their care as they age. Meanwhile, tailoring existing resources and programs to this growing family configuration and developing innovative programs and policies geared toward meeting already established needs will improve the quality of their individual and collective lives and, in Margaret Mead's (1970) words, ensure "a future for the oldest and the youngest among us who share the total round."

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[1] These estimates, which are based on the 1992-1994 National Survey of Families and Households, differ from Bryson & Casper's (1999) report on the 1997 Current Population Survey. In the latter, 62% of grandparent maintained families were headed by a grandmother, 56% of whom were married (as were 90% of custodial grandfathers). These discrepancies appear to be due to differences in sampling strategies.

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RESOURCES

General

AARP Grandparent Information Center, 601 E Street, NW, Washington DC 20049. Established in 1993 as a national resource center for grandparent-headed families, program providers, professionals, researchers, policymakers, and the public.
Telephone (202) 434-2296 (main line) ; (202) 434-2281 (Spanish language)
http://www.aarp.org/getans/consumer/grandparents.html.

Generations United, 440 First Street, NW. Suite 310, Washington, DC 20001-2085. http://www.gu.org
Offers training, technical assistance, and resource sharing to support intergenerational programs.

Grandparents Raising Grandchildren: An Educational Web Site Providing Follow-up to the National Satellite Video Conference. http://www.uwex.edu/ces/gprg/gprg.html

Intergenerational Connections
Offers information for grandparent caregivers, educators, researchers, and other interested individuals. Links to other grandparent caregiver web sites. http://www.nnfr.org/igen.

Legal Services for Prisoners with Children, 474 Valencia St., Suite 230. San Francisco, CA 94103. Telephone (415) 255-7036.

National Resource Center for Permanency Planning. Hunter College School of Social Work, 129 E. 79th Street, New York, NY 10021. http://hunter.cuny.edu/socwork/nrcppab.htm

New York Committee for Kinship Family Care. 1011 First Avenue, New York, NY 10022, (212) 371-1000 , #2258.

New York State Office for the Aging. http://aging.state.ny.us/caring/grandparents/index.htm.

New York State Citizen's Coalition for Children. http://nysccc.org/voice/s94/grandparents.html.

New York City Department for the Aging. Grandparent Resource Center. Services include an information hotline, mayoral conferences, technical assistance, and a support group facilitators network. Telephone (212) 442-1094.

Educational Needs

National Information Center for Children and Youth with Disabilities www.nichcy@aed.org
ADD Action Group (non-drug interventions for children and adults with attention deficit disorder, learning differences, hyperactivity, dyslexia, and autism.

The Educational Resources Information Center. http://www.accesseric.org/.

Legal Issues

Grandparent Caregiver Law Center. Institute on Law and Rights of Older Adults. Brookdale Center on Aging of Hunter College. Financial and legal issues affecting grandparent caregivers and their grandchildren. Targeted to professionals. 425 East 25th Street, New York, NY 10010 Telephone (212) 481-4433. http://www.hunter.cuny.edu/~aging.

Grandparent caregivers: A national guide. From the Legal Services for Prisoners with Children, on-line resource guide for information on various legal issues, focusing on kin care, foster care, and grandparents rearing grandchildren. Features frequently asked questions and provides model answers to assist advocates. http://www.igc.org/justice/cjc/spc/manual/cover.hml.

Grandparents Guide to Navigating the Legal System. Topics include reasons why grandparents may go to court, advantages and disadvantages of representing oneself, how groups can ease the financial burden of raising grandchildren and who to contact for more information. National Committee to Preserve Social Security and Medicare, Suite 800, 2000 K Street, NW, Washington DC 20006; (800) 966-1935.

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Respite Services

National Resource Center for Respite and Crisis Care Services. Chapel Hill training outreach project includes information on grandparents raising grandchildren. http://www.chtop.com/archfs45.htm.

Curriculum Guide / Videos

AARP Grandparent Information Center Packet of 5 publications: Starting a Support Group; Grandparents Raising Their Grandchildren; What to Consider and Where to Find Help; Raising Healthy Grandchildren; Welfare Reform and Your Family; and, GIC Fact Sheet. Free if 10 copies or less.$4.00 per batch of 50. Grandparent Information Center, AARP, 602 East Street NW, Washington DC, 20049; (202) 434-2296.

Second Time Around–Grandparents Raising Grandchildren. Eight chapters cover new role, personal well-being, parenting skills, building relationships, school and community, finances, legal issues, and looking to the future. $75.00. Western Michigan University, 3018 Kohrman Hall, Kalamazoo, MI 49008, (616) 387-3704.

Going to Grandma's House... To Live. 18-minute video interview with several grand parent caregivers about their situation. $50.00 plus $5.00 postage. The Parent Place, 2211 Wabash Ave., Springfield, IL 62704. (217) 546-5257.

Grandparents Raising Grandchildren. A 25 minute video based on a grandmother's support group. Addresses the mental ad justment of children, difficulties of chi dren with disabilities, changes in the gran parents' lives, and their need for respite and support networks. $145.00 (no shipping if prepaid). Terra Nova Films (800) 779-8491.

Grandparents raising grandchildren: Implications for professionals and agencies. National Satellite Video Conference, Janu ary 12, 1999. University of Wisconsin Co operative Extension - Family Living Pro grams. Videotape of the program can be ordered at $28.00 plus $6.00 postage and handling. Total amount due $34.00. Make checks payable to University of Wisconsin. Send requests to University of Wisconsin Extension Publications, Room 170, 630 W. Mifflin, Madison, WI 53703 (608) 262-3346.

Self Help and Professional Guides

AARP Consumer Information: Welfare Reform and Grandparents - Get the benefits you qualify for. http://www.aarp.org/getans/consumer/welfare.htm.

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Service Program Initiatives

Brookdale Foundation RAPP (Relatives as Parents Program) http://www.ewol.com/brookdale/rapp1.html

Project 2015:
The Future of Aging in New York State

AGING PERSONS WITH DEVELOPMENTAL DISABILITIES

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Introduction

During the 20th century, vast changes occurred for older persons with developmental disabilities. While in the first part of the 20th century many persons with a developmental disability were not expected to reach adulthood, their life expectancy now is approximating that of the general population (with the exception of persons with severe disabilities).

The term developmental disability refers to a group of conditions that occur prior to, at birth, or during childhood and affect normal growth and development. The condition must interfere with functioning in several life activity areas, such as learning, mobility, speech, caring for oneself, making life decisions and earning an income. The impairment should first have occurred prior to age 22, and be of sufficient severity to require long time services. These conditions include mental retardation, cerebral palsy, epilepsy, autism and sensory or neurological impairments. By current estimates, there are about 3 million persons with this overall diagnosis in the United States.

It is estimated that four out of every 1,000 older adults have a developmental disability. The total number of elderly persons in the United States who are developmentally disabled is estimated to be as high as one-half million persons. This population is expected to double by 2030. This dramatic increase is due to improved habilitation, better medical care, age-appropriate physical environments, and a change in treatment philosophy. In the past, persons with developmental disabilities were regarded as a burden, a menace or a threat, and were segregated and "warehoused" in large institutions. During the past 30 years a shift has occurred to community based services and integration into community life.

This has presented special challenges as well as special opportunities for the service system, the caregivers as well as for these older persons themselves. The service system has had to adapt to this "new" population, by retraining its workers and designing innovative programs that promote integration between services providing for persons with developmental disabilities with those providing generic services for the elderly. Older caregivers have had to plan for the time when they themselves become too frail to take full responsibility for the care of their family members. Older persons with developmental disabilities have had to adapt to their own aging process. In many instances their quality of life has been compromised by long-standing physical or mental impairments as they age. They are in need of adapted housing, day-programs, and other supportive services in order to "age-in-place."

Historical Background

Prior to the middle of the 20th century, it was common practice to place persons with developmental disabilities in large institutions that were overcrowded, under-funded and under-staffed. As a result, living conditions in these facilities became a cause of great concern, and demands for reform gained increased public attention.

In the 1960's a new approach to providing services to persons with disabilities emerged. This approach became known as normalization, with an underlying philosophy that persons with disabilities should be fully participating members of society. This meant that they should have the same rights and responsibilities as all citizens while still needing supportive services. The 1970's saw the beginning of the de-institutionalization movement, aided by the advocacy of parents groups, legal intervention by civil rights groups, and by politicians needing to cut budgets.

As it became increasingly clear that persons with developmental disabilities were aging, attention began to focus on how to adapt the service system to accommodate their social and health needs. In a number of states, agreements were signed between state units on aging and state developmental disabilities agencies to engage in joint planning, to share technical resources and to provide technical assistance. The joint endeavors resulting from these approaches were meant to benefit older persons with developmental disabilities and their caregivers. Funding was made available to develop training and education programs through university affiliated programs (UAPs), as well as to develop integrated community programs through developmental disabilities planning councils (DDPCs). Generic budget allocations in various states made funds available as well. This resulted in a number of innovative programs in the country, promoting adapted day and residential services as well as specialized health and mental health services.

Focus On New York

In New York over 7,000 persons over age 45 are served by the system caring for persons with developmental disabilities. It is estimated that for every person known, 3 more individuals have developmental disabilities but have no connection with service delivery systems (Seltzer & Krauss, 1987). Since 1985, the state has focused attention on the state's growing population of older adults with developmental disabilities. New York has been a leader in this area. The New York State Office for Mental Retardation and Developmental Disabilities (OMRDD), the New York State Office for the Aging (NYSOFA) and the New York State Developmental Disabilities Planning Council (DDPC), have undertaken a number of special initiatives since that time. They have involved local provider agencies as well as university programs, resulting in an extensive network of linkages, a systematic approach to provide ongoing continuing education programs, workshops and conferences, as well as new program models to serve seniors, both in the aging and developmental disability networks. A number of coalitions are now in place that provide networking, technical assistance and resource exchange between the developmental disabilities and the aging services networks (Bishop and Lucchino, 1994, Mellor, 1996).

Innovative day programs have become an integral part of the service system. Cooperation between a University Affiliated Program (Strong Center for Developmental Disabilities at the University of Rochester School of Medicine and Dentistry), the State University of New York at Plattsburgh, the Institute of Basic Research on Staten Island, and two state agencies (OMRDD and NYSOFA) has facilitated statewide in-service training on an ongoing basis. Particular attention is being paid to early detection of signs of dementia of older persons with developmental disabilities.

Much has been accomplished, yet major challenges remain. There is an ever-increasing need for innovative programs and services to meet the special health and service needs of these individuals, and their families. Some of the key issues are identified below in the areas of Health, Programs and Services, and Caregiver Issues.

Health

Studies have shown that the causes of death for older persons with developmental disabilities are similar to those of the general population: cardiovascular disease, respiratory disease and cancer (Janicki, Dalton, Henderson, & Davidson, 1999). However, older persons with a developmental disability are at greater risk for age-related chronic diseases and health related functional impairments than persons in the general population. Preliminary studies indicate that older persons with developmental disabilities may exhibit relatively high rates of mobility impairments, fractures and osteoporosis (Evenhuis, Beange, Chicione & Henderson, 1999), visual and hearing impairments (Evenhuis, 1995) and mental health conditions (Day & Jancar, 1994), as well as psychotropic drug polypharmacy. Medications started in childhood may have

serious adverse effects after prolonged use (Anderson & Polister, 1993). Some of these impairments may have been the result of life long conditions; others may have been a combination of early onset and late life problems.

A large proportion of persons with mental retardation have Down's syndrome. Older persons with Down's syndrome have an increased risk for the early development of age-related visual and hearing disorders, seizure disorders and Alzheimer's disease (Burt, Loveland, Chen, Chaung, Lewis, & Cherry, 1995, Evenhuis, 1995, Janicki, Heller, Seltzer & Hogg, 1996). They are also at risk for specific endocrine, infectious and skin disorders (Evenhuis, 1995).

A significant number of persons with developmental disabilities have associated conditions, resulting from central nervous system abnormalities. Two examples are persons with cerebral palsy and epilepsy. Persons with cerebral palsy are at risk for osteoporosis, arthritis, chronic pain and skeletal deformities. In some cases their gastrointestinal disorders may lead to bowel and bladder problems. Swallowing disorders can result in a poor nutritional status and recurrent pulmonary infections (Overeynder & Turk, 1998, Turk, Overeynder & Janicki, 1995). Persons with epilepsy are at risk for falls and injuries, aspiration episodes and the specific short and long-term adverse effects of specific anticonvulsant medications (Evenhuis et. al., 1999).

In New York, several initiatives are focusing on the health needs of older New Yorkers with developmental disabilities. The Strong Center for Developmental Disabilities at the University of Rochester School of Medicine and Dentistry, the Institute of Basic Research on Staten Island and the State University of New York at Plattsburgh have each established an assessment clinic for the detection of dementia in older persons with developmental disabilities. The State University of New York's Health Science Center in Syracuse is specialized in caring for older adults with cerebral palsy. The Institute for Basic Research in Staten Island is conducting groundbreaking research in the causes of Alzheimer's disease in persons with Down's syndrome. Mount Sinai Medical Center, Hunter Brookdale Center on Aging and New York University all have health care providers trained in working with this population. In Rochester, the Finger Lakes Geriatric Education Center, in collaboration with the Strong Center for Developmental Disabilities, is providing specialized training for health care providers regarding the aging of persons with developmental disabilities.

Programs And Services

In the past 20 years, service provision for persons with developmental disabilities has shifted from institutional care to community living and integration. It is thought that residential, employment and day services options are provided best in a community setting. The principles of normalization and active treatment have guided the transition to community based services (Factor, 1993). Active treatment requires staff to provide specialized training, treatment and services to a particular individual in order to function with as much self-determination and independence as possible. A new approach, called "person-centered-planning" promotes community membership by creating individualized networks of informal and formal supports for persons with developmental disabilities (Factor, 1993, Bradley & Knoll, 1990, Mount, 1994).

In New York a variety of integration models and service practices have been put into place on behalf of older persons with developmental disabilities. OMRDD, NYSOFA, and the DDPC were among the first in the country to promote the integration of elders into generic community programs. A series of demonstration projects, model programs and training sessions were initiated in 1987 (LePore & Janicki, 1993). Initially, the aging initiatives were directed at retirement oriented, day activities. Senior centers were encouraged to serve a limited number of aging persons with developmental disabilities in their centers. Subsequently, New York's senior day program initiative was added to serve older individuals with more intensive

needs in social adult day care. These projects initially were funded as demonstration projects, and later through annual state and private agency budgets.

In 1991, OMRDD began participating in the federal Home and Community Based Waiver, a funding mechanism within Medicaid allowing for the redesign of the service delivery system. This made it possible to divert federal Medicaid dollars from institutional care to home and community based services for persons with developmental disabilities. Each eligible applicant could request the supports and services necessary to live, work, socialize and participate in the community. The waiver made it possible for state and private not-for-profit agencies to be much more flexible in the way in which they offered residential and day services. Many older adults with developmental disabilities applied for and began to receive services through the waiver funding. These services include a range from transportation and integration in a community center to supported apartment living and personal care services.

Currently a number of coalitions in various parts of the state are firmly in place. These coalitions consist of representatives of aging and developmental disabilities provider agencies, university faculty and state agencies. They have been able to achieve community integration in many locales, using available program resources, shared staff and joint expertise.

In-service and pre-service training have been provided since 1986 by specialized university training programs, such as the Strong Center for Developmental Disabilities at the University of Rochester. In addition, other academic institutions, including Utica College of Syracuse University, the Ringel Institute of Gerontology at SUNY Albany, Hunter-Brookdale Center on Aging and Mount Sinai Medical Center in New York are involved in outreach training programs.

Caregiving

Persons who have the responsibility to care for a person with a developmental disability are in need of special support themselves. Such persons may include parents, siblings, grandparents, other relatives, friends, or neighbors (Bishop, 1998). In many instances they have provided lifelong care and because of their own aging, may need services to help them to continue to do so. Often, elderly parents of an adult with a developmental disability are not using day services available from local developmental disabilities agencies (Smith & Tobin, 1989). Most of these families remain "hidden" from the formal service system. They have been reluctant to become associated with services, in many cases based on experiences in the past, when they may have felt pressure to place a child in an institution. They have always been self-reliant and have coped for many years with the demands and challenges of caregiving (McCallion & Toseland, 1993). Some find it difficult to anticipate the possibility that their adult son or daughter with a developmental disability may outlive them (Heller & Factor, 1991). Therefore, they have not made any firm plans for that eventuality. Even if caregivers have wanted services, the available services often have not been able to meet the immediate and long-term needs of these families.

To address these concerns, the New York Caregiver Assistance Project was formed in 1996 (Janicki, Bishop, Force, Grant-Griffin, Hacker, Lawrance, LePore, Lucchino, McCallion & Schwartz, 1996). It was supported by the DDPC, OMRDD, NYSOFA, the New York State Association for Retarded Citizens, the University of Rochester, Utica College and the State University of New York at Albany.

The project successfully tested the feasibility of incorporating outreach and linkages to support households of older members with a developmental disability into local area agencies on aging. It also focused on supporting distinct cultural populations, with whom the regular service system had little or no contact. The project located a significant number of

families not previously known to developmental disabilities service providers.

As to be expected, there were many mothers serving as primary caregivers for their disabled sons or daughters. In addition to elderly mothers providing for their adult son or daughter, many other caregiving situations were discovered. Fathers, siblings, other relatives, as well as neighbors and members of extended families were either primary caregivers, or played a major supportive role. The project demonstrated that area agencies on aging could be very successful in their outreach efforts if they closely cooperated with local disability agencies. In some instances more intensive services were required, needing extra resources.

Future Trends

◆ Health

The life expectancy for persons with developmental disabilities (with the exception of persons with severe disabilities and those due to organic causes) will continue to increase, and many of them will live as long as their peers in the general population. Older persons with developmental disabilities manifest the same age-related changes and age-related diseases as their non-disabled peers; it is not known whether the onset of age-related diseases occurs earlier in the life cycle.

Physical decline accompanying advanced age and an increased frequency of dementia and chronic illness of older persons with developmental disabilities will have a significant impact in the health care system (Janicki et al, 1999). Health care providers will see increasing numbers of persons with developmental disabilities in their practices. Extensive research, training and dissemination about possible risk factors, the particular ways in which age-related diseases manifest themselves in this population and best treatment practices is an ongoing task.

◆ Programs and Services

"Dual aging," the aging of persons with developmental disabilities as well as that of their caregivers (family members and paid staff members) will continue to put more demands on the service system. The need for services and the length of time these services need to be provided can be expected to increase.

Thus far, increased flexibility in funding has not always been followed by increased flexibility in services. For example, retirement options have been designed for this population in senior centers and social adult day care. However, retiring also means being able to stay at home and take it easy from time to time. The latter is not possible under the current system. Also, many current staffing patterns are not designed to provide coverage in an agency residence during daytime hours.

Residential options, while more varied than in the past, still do not allow renovating and renting apartments in New York. One critique is that the main emphasis for agencies is still on buying and owning houses or apartments, which diminishes consumer choice and flexibility.

Activities in day programs for persons with developmental disabilities are still not always age-appropriate for an older clientele. Many people continue to be exposed to the same curriculum that they followed when they were younger. This does not do justice to the concept of treating older persons with developmental disabilities with the dignity they deserve.

There is a need for increased flexibility in service delivery as well as a continued emphasis on creative design of these services. Continued training needs to be provided to alleviate the effects of staff turnover and to bring the latest information from gerontology and geriatrics to the field of developmental disabilities. Cross-training to aging services providers about developmental disabilities also needs to continue.

◆ Caregiver Issues

There will be more families who are caring for an older person with a developmental disability. These families will provide this care for a longer period of time. There will be an increase in multigenerational caring (grandparents caring for adult grandchildren with a

developmental disability). More families from different cultures will be identified who will present a challenge to the mainstream service systems. There will be more aging caregivers who are becoming too frail to provide care for their adult sons or daughters. More families will age who have had positive experiences with the service system and who will expect that service system to meet their needs as they age. Long term planning efforts need to be responsive to these families and work with them in ways that meet their specific needs. Specialized outreach training needs to continue, using caregivers' day-to-day expertise as a resource.

Recommendations

Health

- Research needs to be conducted in the area of best practices for health care for older persons with developmental disabilities. Health care providers need specialized training in the area of geriatrics and developmental disabilities.
- Older persons with developmental disabilities should be screened for health risks on a routine basis (e.g., older women should have routine breast cancer screenings).
- Special attention should be paid to age-related diseases that may present atypically in persons with significant communication problems (e.g., vision and hearing problems).
- Physical environmental assessments need to be conducted to prevent injuries and accidents, as well as create environments that enhance a person's abilities.
- Older persons with developmental disabilities should be educated in health and wellness activities.
- Caregivers (family members and paid staff) need to be trained in observation of symptoms and in advocacy for obtaining proper health care. They need to differentiate between age-related changes and age-related diseases.

Programs and Services

- Data need to be collected on the numbers and functional status of older persons with developmental disabilities.
- Outreach efforts need to be made to identify older adults who are not known to the service system, but who may need care when their families can no longer do so.
- Planning needs to occur that leads to supports being available that assist families to maintain their independence.
- Program and service delivery needs to become more flexible in order to fulfill the spirit of "person-centered planning". There needs to be better coordination between residential and day services in order to ensure flexibility as consumers age.
- The use of resources beyond those offered by the traditional aging and developmental disabilities systems should be encouraged. Involvement in age-inclusive community activities, expanded retirement and leisure options needs to be fostered.
- Adaptations to the physical environment need to be made to allow persons to continue to function as independently as possible.
- Day program activities need to be adjusted to accommodate the changing needs and abilities of aging clients, as well as to allow for periods of rest and reflection.

Caregiving

- Family support programs need to be expanded that are individualized and can be tailored to the individual situation of each family that provides care for an older adult with a developmental disability.
- In some situations, the older person with a developmental disability may be providing care for the "caregiver" and this needs to be taken into consideration when planning for family assistance.
- Long term planning, including family caregivers and the older person with a developmental disability needs to take place.
- A broader definition of family needs to be

adopted for persons other than parents or siblings to be eligible for needed services.

- Agencies providing services need to be culturally competent and be able to work with local cultural provider agencies.
- Paid caregivers need increased support to continue to care for their aging clients. They need specialized training and respite services for themselves so that they may manage the increased dependency of their consumers and possible resulting "burnout."

For additional recommendations for health and caregiver related issues see Appendix A.

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Appendix A

Health:

Several of the health recommendations are adapted from Janicki et al (1999) "Mortality and morbidity among older adults with intellectual disability: health services considerations"

- Develop preventive programs that minimize the impact of age-related changes, and age-related diseases for older persons with developmental disabilities.
- Screening protocols available for the general population should be instituted on a routine basis for older persons with developmental disabilities.
- Population of adults with developmental disabilities at risk for specific conditions should be identified and appropriate screening schedules implemented.
- Every effort should be made to take family histories of older persons with developmental disabilities.
- Adults with developmental disabilities need to be educated to engage in health and wellness activities.
- The health care system needs specialized training in the area of geriatrics and developmental disabilities.
- Research needs to be conducted in the area of best practices for this population, in the area of age-related conditions as they affect older persons with developmental disabilities, as well as the impact of secondary conditions, related to the presence of a life-long disability.

Caregiving

Several of the caregiving recommendations are adapted from Janicki "Help for Caring (1996, New York State Developmental Disabilities Planning Council) and Bishop " A study of caregiving and persons with developmental disabilities (1998, unpublished). Ph.D. dissertation).

- Caregivers need to be able to request the specific services they need for the particular problem they are facing.
- Reciprocity of caregiving between family members and persons with developmental disabilities themselves needs to be acknowledged.
- Families need to receive services allowing them to remain functioning with their developmentally disabled son or daughter in their midst.
- A broader definition of family needs to be adopted, in order for persons other than parents or siblings to be eligible for needed services.
- Agency personnel need to include older caregivers in their planning process.

Project 2015:

The Future of Aging in New York State

ARTICLES FOR DISCUSSION

New York State Office for the Aging
and
The State Society on Aging of New York

Project 2015:
The Future of Aging in New York State

GERIATRIC REHABILITATION

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Geriatric rehabilitation is commonly employed to prevent impairment and disability and to support adaptation to or recovery from illness or disability to maximize functional independence (Bottomley, 1994). Another primary goal is to improve or maintain the biopsychosocial status of frail elders experiencing decreasing capabilities to enable frail elders to remain in their communities or to maintain capabilities wherever they reside (Harris, O'Hara, & Harper, 1995). Given the crucial role of families in the rehabilitation process, rehabilitation programs increasingly focus on client and family education to optimize capabilities and health to support community living (Bottomley, 1994).

While the vast majority of older persons 65-74 are independent community members (89% report no disability), aging increases the likelihood of chronic illness, often with concomitant impairments (Lindbloom, 1993; Rowe, 1997). However, the proportion of persons over 85 who need assistance due to disability is more than double those under 84 years (National Academy on an Aging Society, 1999). Disability, with its impact upon functional capabilities, often results from interactions of disease processes when the magnitude of impairment compromise functional capabilities, commonly in combination with aging processes (Manton, Corder & Stallard, 1997). However, recent evidence finds plasticity in functioning, even in old age, challenging a fixed relationship between disability and chronic illness, supporting prevention and rehabilitation approaches for older persons (Jette, 1995).

The geriatric rehabilitation team commonly includes the client, family, physician, nurse, occupational therapist, physical therapist, social worker, and sometimes speech therapists, dietitians, psychologists and other allied health personnel. A team approach is optimally utilized for complex evaluations where expertise from different disciplines is needed for comprehensive interventions (Gallo, et.al.1995; Satin 1994). The most common referrals for rehabilitation are to physical therapy for strengthening and ambulation programs, occupational therapy to increase functional self-care capabilities and speech therapy to improve language skills. Rehabilitation programs are provided in acute care hospitals, in-patient facilities, long term care facilities, home care programs, or outpatient programs for medically stable individuals. Geriatric rehabilitation is commonly provided to persons with diagnoses of: cerebral vascular accident, Parkinson's disease, arthritis, amputation, cardiovascular disease, pulmonary disease, low back pain, fractures, and Alzheimer's disease (Bottomley, 1994).

Utilization of Rehabilitation Services in NYS: 1985- Present

To best understand changes in geriatric rehabilitation utilization in New York State, utilization patterns from the mid-1980s to the present were differentiated into 3 categories and reviewed; rehabilitation services provided by hospitals, long term care agencies, and certified home health agencies, each with its own funding criteria and data collection system. To understand trends, the most commonly utilized geriatric rehabilitation services, occupational therapy, physical therapy and speech therapy were grouped.

1985 hospital discharge data for NYS adults 60+, finds 1,803 discharges with primary rehabilitation codes (N = 2,784,541 total discharges). By 1990 acute care discharges with

rehabilitation codes jumped to 9,487, increasing to 13,864 in 1995 and 17,210 (N=2,431,215 total discharges) in 1997 (Table 1, New York State Bureau of Biometrics, 1999). Utilization of rehabilitation services by certified home health agencies also saw major increases during this time period, 761,747 total (OT, PT, SP) therapy visits in 1985, 680,043 in 1987, 789,838 in 1990, and most current data for 1996 noting 1,790,013 total rehabilitation visits (Table 2). In regard to rehabilitation services in long term care, rehabilitation services provided through long term home health certified programs (LTHHCP) finds 38,562 rehabilitation (OT, PT and SP) visits in 1985, 74,142 in 1988, 92,023 in 1990, and 169,075 in 1993. Most recent data finds 190,377 visits made in 1996, nearly a 5 fold increase (Table 3). While increased frequency of rehabilitation services were noted in all disciplines, physical therapy shows greatest growth within certified home health agencies (New York State Office of Continuing Care, 1999). Within skilled nursing facilities, data is collected on utilization of occupational therapy and physical therapy "specialized services" (Table 4). The percent of NYS nursing home residents receiving maintenance physical therapy (PT) to stabilize or slow functional deterioration was 12.3% in 1986, was reduced to 5.6% in 1998; however the percent of residents receiving restorative PT was 6.1% in 1986, rising to 15.5% in 1998. Data for occupational therapy (OT) find similar shifts; 4.2% received maintenance OT in 1986 while in 1998 only 2.2% received such services. However, in 1986 2.9% received restorative OT services but by 1998 10.6% received restorative OT (New York State Department of Health, 1999). This shift reveals increased utilization of rehabilitation services for limited numbers of nursing home residents, typically admitted for short term stays in separate sub-acute rehabilitation units, to improve functional capability, with a plan for discharge to home. This population can be contrasted to long term residents who may need maintenance rehabilitation services to support capabilities and prevent deterioration but whose ultimate functional outcomes are not expected to change.

Changes in utilization of rehabilitation services reflects multiple variables, including increased: awareness of rehabilitation's benefits for older persons, consumer information, appreciation of rehabilitation services by the medical community, and funding formulas that support restorative rehabilitation with limited support for long term or maintenance rehabilitation programs.

Perspectives on Geriatric Rehabilitation

Consensus is found among geriatric rehabilitation experts regarding the benefits of geriatric rehabilitation, including preventive geriatric rehabilitation to support community living for aged persons. New York University Hospital's Center Geriatric Nursing Advisory Board (personal communication, May 10, 1999) stresses the importance of a team approach, especially in long term care, patient and family education, follow up post discharge, increased use of integrative medicine (including Tai chi, yoga, and relaxation programs), patient education and preventive services, and caregiver supports, particularly for caregivers of persons with Alzheimer's disease. Occupational therapy tenets focus on assisting persons to maximize capabilities in self-care, work and leisure. Toward this end occupational therapists stress preventive rehabilitation and wellness programs with attention to the biopsychosocial needs of older persons, both well elderly and those with chronic illness and/or disability, often including assistive technology and environmental strategies to maximize physical, mental and social capabilities, and support community living (Clark, Azen, Zemke, Jackson, Carlson, Mandel, Hay, Josephson, Cherry, Hessel, Palmer, Lipson, 1997; Horowitz, 1997). The American Physical Therapy Association identifies 5 elements of patient/client management (examination, evaluation, diagnosis, prognosis and interventions).

The physical therapy roles particularly pertinent for older persons include focus on injury/fall prevention, including environmental assessments, and collaborative health education programs with local, state and federal agencies (J. Edelstein, Columbia University College of Physicians and Surgeons, personal communication, May 14, 1999).

However, recent developments in health care delivery, including prospective payment for long term care and managed care, are of significant concern to many rehabilitation professionals given their impact upon the needs of the most impaired and efforts to provide older persons with appropriate care at the most suitable time (J. Edelstein, personal communication, May 14, 1999; New York University Hospitals Center Geriatric Nursing Advisory Board, personal communication, May,10, 1999).

Similar concerns were voiced from an administrative perspective by David Glaser, Administrator of Parker Jewish Geriatric Institute for Health Care and Rehabilitation (personal communication, March, 1999), regarding nursing home reimbursement for comprehensive geriatric rehabilitation, including community based services such as adult day programs. Cost containment impacts efforts to provide comprehensive geriatric programs, including community-based care. This is of particular concern given future long term care and geriatric rehabilitation needs of tomorrow's aged Baby Boomers, supporting need for increased attention to use of Long Term Care Insurance by some population segments given the financial burden of long term care. While estimates vary, projections of the number of older persons who will need long term care by 2030 range from 10.8 to almost 14 million, as compared to 7 million in 1997 (National Academy on an Aging Society, 1999)

From another perspective, Sheldon Goldberg, Director of the Jewish Home and Hospital for the Aged, addressed the importance of housing and environment within the long term care continuum to support health, social needs, overall well being and community living, as well as preventive geriatric rehabilitation and supportive housing to reduce the consequences of isolation to promote community living and delay need for admission to skilled nursing facilities for the oldest old. In order for successful aging in place for tomorrow's aged Baby Boomers, old housing in many locales will need adaptations. To design for tomorrow, agencies will require access to capital to plan and build new facilities to meet future need with appreciation of financial risks involved (S. Goldberg, personal communication, May 7, 1999).

Given our growing aged population, and current appreciation of the benefits of geriatric rehabilitation by the medical community and public, coupled with Medicare/Medicaid and other third party coverage for rehabilitation services, it is not surprising to find increased utilization of rehabilitation services. Numerous studies find exercise is important to maximize physical functioning and reduce falls for elders (Chandler & Hadley, 1996; Province, Hadley, Hornbrook, Lipsitz, Miller, Mulrow, Sattin, Tinetti & Wolf, 1995; Schnelle, MacRae, Ouslander, Simmons & Nitta, 1995). Research supports the efficacy of geriatric rehabilitation and finds geriatric rehabilitation can positively affect surgical outcomes for aged patients by restoring physical capacities and functional abilities, and is beneficial for aged persons with arthritis, stroke, joint replacement and amputation (Richardon, Daly, & Adelman, 1989; Silver & Siebens, 1994; Weber, Fleming & Evans, 1995). Inpatient geriatric rehabilitation is associated with significant gains in functional abilities for persons with diagnoses of stroke and primary diagnoses of "general deconditioning" (Harris, O'Hara, & Harper, 1995; Liem, Chernoff, & Carter, 1986; Wilkinson, Buhrkuhl & Sainsbury, 1997). It is also an important component of long-term care, particularly to restore function for discharge to home (Goldstein, Strasser, Woodard & Roberts, 1997; Kochersberger, Hielema & Westlund, 1994; Penington, 1992), although there is lim-

ited evidence of impact upon long term survival and function (Evans, Connis, Hendricks & Haselkorn, 1995).

In addition to restoring physical and functional capabilities, geriatric rehabilitation has been found to return patients to home more frequently than non-participants (Evans, Connis, Hendricks & Haselkorn, 1995). While there is some debate regarding the cost-effectiveness of some kinds of rehabilitation interventions, there is a body of research that finds geriatric rehabilitation programs overall are associated with higher functional abilities with resulting reduced nursing home placement (Harris, O'Hara & Harper, 1995; Hoenig, Nusbaum & Brummel-Smith, 1997; Liem, Chernoff & Carter, 1986; Penington, 1992). Intensive post-fracture rehabilitation for aged community living cognitively impaired persons at risk for nursing home placement have also demonstrated improved functional performance, such that intensive rehabilitation may promote increased likelihood of discharge to home for this population as well (Goldstein, Strasser, Woodard & Roberts, 1997). Despite the intensive services and costs of geriatric rehabilitation program, given the limited time of rehabilitation programs, data suggests appropriately targeted geriatric rehabilitation is significantly less costly than nursing home care, even for individuals with severe disability or advanced age (Penington, 1992).

Challenges

Tomorrow's New York State elders will be more numerous, will include greater numbers of persons 85+,from 276,526 in 1996 to a projected 370,281 in 2020 (U.S. Bureau of the Census, 1996), will be very diverse, and generally more educated than older persons today. This may result in significant numbers of well educated elders living longer with reduced impairment and disability due to understanding of the impact of lifestyle and prevention on aging. However, increased numbers of older persons, also increases potential for chronic illness and disability among the oldest-old. Additionally, substantial inequalities exist and are expected to increase. These disparities are likely to impact on individual health and functional capabilities, and our health care system, including geriatric rehabilitation, with likelihood of greater demand for rehabilitation services to support elders' functional capabilities.

In addition to the overall challenges faced by geriatric rehabilitation, we have a growing elderly developmentally disabled population due to factors including policy changes, improved medical care, and advocacy for this historically marginalized population (Kornblau & Hinds, 1998). These individuals have pervasive developmental needs and may have secondary diagnoses of cerebral palsy, Down's syndrome or childhood psychiatric syndromes. Many have long experience with rehabilitation services provided to maximize physical, social and cognitive capabilities to maximize self care skills, independent living and quality of life. A common problem for persons aging with developmental disabilities is reduced independence in self care activities commonly due to long standing impairments and high incidence of disability, compounded by aging and increased likelihood of age associated conditions (Watkins & Weiner, 1997).

Thus, the challenges we face in geriatric rehabilitation are multiple. We need to:

1. Provide greater access to an increasingly diverse aged population using a continuum of rehabilitation services, appreciating the role of environment and housing to promote functional capabilities.

2. Support cost effective services, including community based preventive and restorative rehabilitation programs (including technology and supportive housing).

3. Include families and communities in programs/services to support successful aging and community living.

4. Increase the number of rehabilitation professionals knowledgeable about aging issues including understanding of

multiple ways to utilize and fund rehabilitation services.

5. Utilize multiple funding strategies including Medicare, Medicaid, managed care and other third party payer funding, Long Term Care Insurance, and government-private sector partnerships.

6. Support partnerships between communities, families, volunteers and rehabilitation professionals to promote environmental supports, wellness, and preventive services to maximal capabilities of elders.

Table 1
NYS Hospital Discharge Data
with Rehabilitation Codes (60+ yrs.)
(New York State Bureau of Biometrics,1999)

Date	Discharges with Rehab codes	Total discharges
1985	1,803	2,784,541
1990	9,487	2,532,069
1995	13, 864	2,521,355
1997	17,210	2,431,215

Table 2
Rehabilitation Visits Provided by
NYS Certified Home Health Agencies
(includes OT, PT & SP visits)
(New York State Office of Continuing Care, 1999)

Date	Rehabilitation visits
1985	761,747
1987	680,043
1990	789,838
1993	1,262,981
1996	1,790,013

Table 3
Rehabilitation Visits in NYS Long
Term Home Health Certified Programs
(OT, PT & SP visits)
(NYS Office of Continuing Care, 1999)

Date	Rehabilitation visits
1985	38,562
1988	74,142
1990	112,023
1993	169,075
1996	190,377

Table 4
Percent of NYS SNF Residents Receiving Physical & Occupational Therapies
(Level 2 (Maintenance) and/or Level 3 (Restorative)
(NYS Office of Continuing Care, 1999)

Date	% Receiving PT			% Receiving OT		
	Level 2	Level 3	Total	Level 2	Level 3	Total
1986	12.33	6.10	18.43	4.17	2.91	7.0
1988	12.57	6.10	18.41	4.41	3.10	7.1
1990	12.06	6.76	18.82	4.21	3.47	7.6
1992	11.36	8.46	19.82	3.63	4.45	8.0
1994	9.55	10.54	20.09	3.30	5.59	8.0
1996	7.59	13.60	21.19	2.64	7.81	10.0

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Project 2015:
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HEALTH AND THE BABY BOOMER

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The title "Baby Boomer" brings a particular image and behavior to mind. They represent a large birth cohort, encompassing a diverse group that has a unique way of being and acting, and yet with many important differences related to gender, culture, financial and personal experiences. The Boomer is definitely an individual. This individuality will likely extend into the way she/he approaches health and health care as she/he reaches age 65 in 2015. Because of the very size of the cohort and the impact it will have on health care in New York State, it is particularly important to examine the group as a whole so that policy makers and legislators can plan effectively and efficiently for all people in the group as it ages.

Certain factors are especially important to consider in creating a plan to meet the health needs of this cohort. These include but are not limited to: data concerning health characteristics of New York State residents age 50; attitudes of the Baby Boomer towards health; effects of health care costs and insurance on the Baby Boomer; emerging health needs of the Baby Boomer with aging; Baby Boomers: participation in their health care; and who will meet health care needs in 2015. With this as an organizing framework, each point and policy implication will be highlighted.

Data Concerning Health Characteristics of New York State Residents Age 50

There is an imperative to know more about the health of those New Yorkers age 50, the Baby Boomer. The Behavioral Risk Factor Surveillance System (BRFSS) includes a number of health related data on New York State's population. The BRFSS includes modifiable health behavior, health status, health care access, and immunizations, and demographic data such as age and gender. The New York State Department of Health (DOH) does not publish results from all the data it has collected but does publish a number of reports about New York State's population. These can be found on DOH's Web site at http://www.health.state.ny.us/nysdoh/brfss/main.htm.

POLICY IMPLICATION: Health insurance companies and HMOs may use these data for marketing and long term planning. These companies also are a source of useful data. A joint project with public and private funding would be beneficial for both parties in identifying a profile of New Yorkers in this age group.

There are two programs in New York State that have collected data about aging populations and their attitudes toward the aging experience: the Gerontology Institute at Ithaca College and the Bronfenbrenner Life Course Center at Cornell University, both in Ithaca, NY. The Consortium of Geriatric Education Centers statewide along with the Hartford Geriatric Program in the Department of Nursing at New York University is developing a format for collecting health status and other data statewide.

There are specific areas of research that may be particularly fruitful to study in the Baby Boom cohort. For example, statistics show that puberty occurred earlier in this cohort than in earlier cohorts, and there is a question about whether this affects menopause. This is important because changes that take place during menopause have a significant effect on the potential development of osteoporosis, heart disease, certain forms of cancer and perhaps dementia in women.

POLICY IMPLICATION: Funding for longitudinal research in addition to more comprehensive data collection about the present health status of the

cohort is needed to make more explicit the projected health needs of the aging population in 10 to 15 years.

Attitudes of the Baby Boomer Towards Health

As a group, Baby Boomers are more knowledgeable about health and health resources than prior generations and are more "choosy" or "picky" consumers. This is a more highly educated group on the whole with a predicted longer life expectancy. The Baby Boomer has been exposed to allopathic and complementary or homeopathic methods of care and many are involved in a variety of methods to address their health needs.

As the public is given more and more information about their physical health, so too is the individual expected to take more responsibility for maintaining his or her own health. Consumers have to have knowledge about many issues such as: whether exercise has the predicted effects, the importance of antioxidants in foods, and the primary issue about how much individuals will be held responsible for the consequences from their lifestyle choices.

There is an increase in stress secondary to external societal effects as well. Women are a large part of the workforce and many, in pursuit of education and a career, have chosen to have children later in life or to remain childless. Women have had more opportunities and increased possibilities for self-care as a benefit of employee health care insurance.

POLICY IMPLICATION: Ongoing and new screening initiatives are needed for men and women in their senior years for potential high-risk health problems, including but not limited to cancer, osteoporosis and dementia.

Effect of Health Care Costs and Insurance on the Baby Boomer

As health insurance benefits that once were associated with employment benefits have decreased in coverage or may have ceased completely for many, more of the cost of health care is being borne by the individual. Critically important to the individual and the public's health is that many people cannot afford to pay for health insurance. The scope of covered services provided by health maintenance organizations (HMOs) and other insurers has been reduced for many individuals. A possible result may be delayed intervention and minor health care needs may evolve into catastrophic events, with catastrophic costs.

It is not realistic to explore health care cost without taking into consideration the multiple groups that make up the Baby Boom generation. A large number are better educated, grew up in the 60's feeling that they were "special" and that anything was possible. They have changed many of society's policies and laws regarding women and minorities. They have high expectations that they will remain healthy, and have invested in nutritional plans and exercise programs. They use the Internet to "surf" for information to ensure they are up-to-date on the most recent health discoveries.

Others, including a growing population of new immigrants, have not had the same opportunities or experiences, and have different expectations. They may be forced to use the hospital emergency room for care, instead of paying out-of-pocket for health insurance for treatment for their acute problem. The growing uninsured and underinsured may not be able to gain access to prevention strategies, and without these, the result may be decreased life expectancy secondary to unattended acute care issues, which may evolve into chronic illnesses. To illustrate, untreated asthma may become debilitating chronic pulmonary disease and result in multiple, costly hospitalizations.

The Scudder Kemper Baby Boom Generation Poll indicated that Boomers are concerned about their own health as well as the associated costs. Those surveyed expressed concerns about deteriorating health as they grew older, with 79% of Boomers polled citing ill health as their main fear about growing older.

POLICY IMPLICATIONS: Joint planning between government programs (Medicaid and Medicare) and the private sector to provide opportunities for guaranteed health coverage for all children and adults is crucial. Health promotion and disease prevention strategies throughout the life cycle should be covered by health insurance. It is important that there is continued support of programs such as the Elderly Pharmaceutical Insurance Coverage program (EPIC) and collaboration between community providers and pharmaceutical companies who provide access to needed medications for acutely and chronically ill persons.

Emerging Health Needs of the Baby Boomer with Aging

Older single women, statistical projections reveal, will continue to be the largest group of the aging Boomer cohort as we move deeper into the 21st century. Women, as a result of their increased role in the labor force, will benefit from their own social security and pensions. However, they may be witness to their parents' increasing longevity and find themselves in a caretaking role. The demographer James Vaupel has proposed that the aging process may actually slow down in very old people and he projects that old-age death rates will slow to a crawl early in the next century (Stipp, 1999).

The generation following the Baby Boom generation, the so-called "Generation X," is a comparatively smaller cohort. Boomers had fewer children than their parents and many delayed childbirth until well into their 30s and 40s. This may affect the availability of caregivers for aging Baby Boomers.

Baby Boomers realize their cohort will vote and they will vote in number to secure their future. Boomers perceive that they can effect their lives by being personally involved. To a large extent, this generation has rejected many of the images of middle and old age and sought to redefine these later life stages. Significant advances in the prevention and treatment of chronic diseases have led to a decrease in disability.

POLICY IMPLICATIONS: Access to prevention, early detection and intervention must continue to be a priority in our health care planning. Future policy needs to include state and local partnerships in setting health goals in tune with initiatives such as Healthy People 2010, which was released on January 25, 2000 by the U.S. Department of Health and Human Services and sets the health agenda for the nation.

Presently we know that older persons face more chronic than acute illnesses. The medical model, however, is directed toward treatment of individuals who have acute, short-term conditions that can be addressed. Chronic illnesses, such as arthritis, already have an effect on the working 50 year old and these needs are not met nor linked well with the medical system in this country as it currently is structured. As Boomers age, there will be even greater long-term effects that will require holistic, supportive and environmental care.

POLICY IMPLICATION: Health policies need to consider chronic care needs and supportive care provided in a variety of settings including in-home, community and institutional locations. Linking chronic care and acute care is important now and will be even more so in the future, for all economic groups of Baby Boomers.

Baby Boomers: Participation in Their Health Care

In a recent New York Times article the author noted that the American Association of Retired Persons is now known as its acronym, AARP. It is part of AARP's effort to retrofit itself for Baby Boomers, the first of whom started to turn 50 in 1997 and thus became eligible for membership. A recent poll by AARP of Baby Boomers found that 80 percent expected to continue to work during retirement, possibly part-time, in a new career or in their own business.

POLICY IMPLICATIONS: When programs are being designed for Baby Boomers it must be remembered that they want to have input and control in their lives - they need to be consulted. The old ways, the old images will not apply to many of the cohort. It will be necessary to "think out of the box!" Policy needs to reflect the well elderly, ensuring them access to stay that way. There are health models in existence that nursing and health educators have been using for years. Collaborating with a professional association or including professionals with a unique perspective as staff members can open a new way of seeing.

Who Will Meet Health Care Needs in 2015?

Providers who address themes including partnering for health improvement, eliminating health disparities, increasing quality and years of healthy life and harnessing technology for health, are part of the vision of the future. This includes establishing reimbursement for primary health care provided by clinical nurse specialists and nurse practitioners as cost-effective providers. Services provided by other holistic providers should also be reimbursed.

We need to create programs that are inclusive and cost-effective. Naturally Occurring Retirement Communities (NORCs) support people over age 60 to safely "age in place" in their own homes by providing health and social service resources. Social Adult Day Care programs provide clients with mild/moderate dementia with social support and respite for primary caregivers. NORCs are cost sharing programs with state funding that is matched by the housing unit and uses the services of a multidisciplinary team of professionals. Both are examples of continuity of care that stresses and supports independence and increases access to a broad variety of health practitioners who support that independence - very much an issue of importance to the Baby Boomer. Because Baby Boomer women may not have adult children to support them in their later years, nursing home placement may be the only resource for Boomers with moderate medical and nursing needs that cannot sustain themselves at home. Planning for creative nursing homes programs needs to start now.

POLICY IMPLICATIONS: It is not possible to address health care now and in the future without commenting on health system reform. Health insurance restrictions that require individuals to get through the structure that has been set up in for-profit managed care, for example, means that many New Yorkers, including those who are poor, sick and/or elderly are unable to gain access to needed physical and mental health care in a timely fashion.

In the 21st century we need to continue to discuss and address issues such as access to care, consumer satisfaction and commitment to evaluation plans with increased determination.

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Project 2015:
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STEPPING OUT ON FAITH: GERIATRIC MENTAL HEALTH IN 2015

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Introduction

This paper will focus on mental health and diversity issues in relation to the elderly. Considerable interest has developed in looking forward to the year 2015 when the growing elderly population is expected to reach record proportions and double in size. Concurrent with this growth comes the challenge to examine the growing mental health needs of this population.

Just who will comprise this cohort of people age 60 and over in 2015? A significant portion will be NY State residents who are currently in their mid-thirties to mid-fifties and commonly referred to as Baby Boomers. This is an extremely diverse group, including not only the segment of cohorts born in the United States between 1946 to 1964, but also recent immigrants who have come to this country as adults.

Of great concern, is the fact that the fastest growing segments of the elderly are also the most vulnerable: the very old, women, minorities and elders living alone. These subgroups of the elderly experience psychosocial stressors which impact mental health: the highest rates of poverty, the poorest perceived health status and the highest levels of impairment with regard to ADL (activities of daily living) capacity. In addition, the impact of declining physical health, subsequent dependency and loss of autonomy affects their mental health and places them at risk.

Future Trends And Issues

A large proportion of older people, even when they are exposed to stressful conditions, have the capacity for coping and are satisfied with their lives (Moody, 1998). But it is estimated that between 15% and 25% of people 65 and older suffer from mental illness or emotional stress (Buchwalter, Smith and Caston, 1994).

The current cohort of Baby Boomers has already shown relatively high rates of depression, anxiety and substance abuse. We can anticipate that these trends will accompany them into old age, resulting in a dramatic rise in overall prevalence of mental disorder among older adults (Gatz, 1995).

Cognitive Impairment

Cognitive functioning is a primary determinant of mental health in old age. Cognitive impairments related to organic mental disorders such as Alzheimer's disease and multi-infarct dementia are a critical mental health concern. It is estimated that 10 percent of people over age sixty-five may have some degree of cognitive impairment and this rate increases with age (Citywide Geriatrics Committee, 1995). Living longer increases the likelihood of dementia and need for long term care. While there is a trend toward healthier lifestyles reducing the risk of strokes and organic mental disorders, increased longevity raises critical questions about the mental status and frailty of the oldest-old in the next decade.

Diversity and Multiple Jeopardy

The trend toward increasing racial/ethnic diversity among the elderly can be expected to continue. African-American, Latino, and Asian American populations are increasing more rapidly than the white population. By the year 2030 ethnic minorities are projected to make up one fourth of all older people. Patterns of inequality involving social class, race or ethnicity, age, gender, or sexual orientation create disadvantages that are cumulative.

It is anticipated that the year 2015 minority aged will continue to face multiple jeopardy as they deal with oppressive forces of

racism, sexism and ageism. As such, oppressed groups within the year 2015 aged continue to be most vulnerable to mental health problems.

Immigrants who differ from the mainstream culture in terms of languages and cultural values will also be at risk. In the absence of improved housing, income and access to health and human services, racial/ethnic elderly will require mental health services and the restructuring of health and mental health systems designed originally for a homogeneous population.

Living Alone

In New York State, 27 percent of those 60 years and older are currently living alone (New York State Office for the Aging, 1995). This number is expected to grow substantially within the next decade. This is because a larger proportion of those born from 1946 through 1964 have remained single and more of those who have married have not had children (AARP, 1998). Extended life and fewer children will create greater strains for older people in need of care and support. Older adults who live alone are more likely to live in poverty. Additionally, lack of social supports may make it difficult for them the cope with depression and overcome it.

Chronic Illness

Chronic illness is most prevalent among older persons and has a major impact on their emotional well being. The most common medical problems afflicting the aged are arthritis, hypertension, heart disease, diabetes, and sensory loss (Rowe & Kahn, 1998). In fact, health factors often lead to depression and depressive symptoms which are considered the most common mental health concerns among the aged (Butler, Lewis & Trey, 1991). The presence of a chronic ailment is closely tied to functional capacity. Age and the presence and duration of chronic disease significantly decrease the ability to perform activities of daily living. Dependence on others in regard to shopping, bathing, and dressing has a negative impact on one's self-esteem and self-worth.

Role Changes: Caregiving and the Evolving Definition of the Family

Role changes within the family structure impact the mental health status of all family members. In late life, the social roles carried out in middle age, such as that of spouse, employee, or parent, are altered. The older person seeks to adjust to the stressors of life changes and find new roles consistent with their age and lifestyle (Moody, 1998). Being a part of the labor force has been a significant feature in the lives of those in mid-life today, especially for women. This cohort is expected to have multiple careers and will most likely retire at a later age than their counterparts today.

Widowhood and the loss through death of a significant other have a profound impact on mental health. Loss through death of significant people who are part of the emotional support system of an older person may compromise that individual's mental health status (Gatz, 1995).

In the future, families will be increasingly expected to be responsible for the care of their elderly; yet there is evidence to suggest a decline in the number of family members available to provide care. The increasing longevity of older persons, especially those with chronic disabling illness that require a range of supportive services, will place greater demands on families to be responsible for their complex needs. By the year 2015, as the number of old old slowly expand, we will likely see an increase in the proportion of the very old who are cared for by their young old children. Aging caregivers, especially those without adequate financial and psychological assistance will be at risk.

A growing trend is the significant increase in grandparents providing full-time care for young children. The unexpected role of primary caregiver to grandchildren has its own set of challenges; dealing with multiple issues related not only to their surrogate role, but work responsibilities, financial concerns, and dealing with the emotional loss of the adult child who is unable to fulfill his or her roles as parent

(Minkler & Roe, 1996). Studies indicate that this group reports an increase in physical and emotional health problems after they assumed the role of full-time caregiver (Pruchnol & Johnson, 1996). At the same time, the grandparenting role is one that is acquired later in life, and can offer meaning, connection, status and increased self-esteem.

Options And Alternatives

Promoting Optimal Mental Health

Efforts should be undertaken to promote optimal mental health for future elders. Mental health promotion can take a variety of forms including prevention, mental health education, etc. It will be important for sufficient services to be available and designed to meet the needs of elders who will have varied attitudes and preferences in regards to their care. Furthermore, it will also be important to create a more age affirming social environment. Provisions should be made to empower elders as consumers of mental health services both as an ethical principle and as an opportunity to promote self-esteem and social status.

Service Access

Vast literature supports the fact that mental health treatments are effective. Currently, the emphasis is on identifying which of the plethora of treatment approaches is most effective for which problem or condition. However, attitudes toward mental health and mental illness and attitudes toward treatment clearly play an important role in accessing care.

Immigration/acculturation status are additional factors which play a significant role in utilization patterns and are known to influence early detection of mental health problems and early intervention. Although clinicians are witnessing a slight shift toward more openness toward treatment among the elderly, many elders, especially immigrants, often do not get needed services because of language, cultural barriers, lack of information, and financial resources, and difficulty with transportation. By 2015, elders will demand mental health care, insisting on a variety of treatment options such as clinic/hospital-based care as well as private treatment and a variety of treatment modalities. The challenge will be to provide sufficient, specialized geriatric mental health services to meet the needs of the underserved and the educated middle class.

Consumer Empowerment

Consumers are playing important roles in practically all areas of mental health service delivery, attacking stigma, helping to shape mental health policy and demanding roles in the community such as that of peer counselor and worker. Countervailing regressive movements based upon a fear of people with mental illness due to stereotypes of mentally ill people as violent and dangerous are cause for concern. Elder recipients of mental health services and their families have been far too silent. Mental health policy should require demonstrated participation of elders in mental health planning in the form of program advisory groups, boards, consumer organizations, etc.

Attitudes Toward Aging and the Elderly

The dominant society's attitudes towards aging and the aged will be important in shaping elder's self-esteem and opportunities. In addition to the ongoing stressors that accompany growing old, the negative valuation placed on aging and being old reinforces feelings of isolation, uselessness and mental deterioration. Ageist attitudes in our society have created an environment that is unsupportive of older people. There is an obsession with the avoidance of old age; through plastic surgery, drugs, beauty products, psychological defenses and outright denial. The preoccupation with youth and subsequent resistance to becoming old places the aged and mid-lifers in an emotional bind. For many, looking forward to growing maturity is tempered with the fear of decline and closeness to death and this can lead to psychological problems in late life. It is hoped that the increasing proportions of elders will propel social movement toward a more positive, affirming view of aging and of older people.

Programs and policies, which attack ageist stereotypes, prohibit age discrimination and promote acceptance and appreciation of aging for all ages should be encouraged.

Family Centered Care

A greater emphasis on home based and family oriented care in the community is recommended. The current shift toward community care rather than institutional care for the seriously and persistently mentally ill is a positive one that reflects not only advances in mental health treatment but also a positive shift in our attitudes toward mental illness and those who are mentally ill. Families are grappling with how to integrate persons with mental health issues into community life. Empowered mental health consumers are insisting that this change come about quickly.

Rather than organizing "clusters" of individuals, models of care should be developed to serve families with more than one elder, e.g., middle-old adult and young old adult child(ren) or older adult children caring for very old parent(s). We can speculate some of the needs families will encounter. In-home services that promote independence and delay placement: health care, housekeeping support and mental health care including crisis and ongoing treatment in the home. Home based occupational therapy and recreational therapy will be in demand as elders in 2015 challenge the rocking chair stereotype and seek support to remain as active as possible. Communication technology will play a major role in this regard while also providing continued educational opportunities and on-line relief from social isolation.

Moreover, the rationale for providing care should change. Supporting an elder to continue to work out of the home; minimizing caregiver stress or the simple notion of being entitled based upon life-long monetary contributions or social status as an elder citizen should be viewed as appropriate.

Culturally Competent Care

The elderly population of 2015, however, will be a much more ethnically diverse population. The contemporary mental health service delivery system is struggling and falling short of the imperative to provide culturally competent services. Sadly, the geriatric segment is faring no better. Aging advocates have been of little help in advocating for culturally competent geriatric mental health services as the aging professional community is far behind mental health in this regard. Cultural competence includes, diverse ethnic representation at every level: direct service, administrative, advocacy, and policy development.

It is critical to note that the issue here is not only language which is obviously key. Practitioners will need to be competent to understand immigration experiences, how slavery impacts health/mental health practices and beliefs, acculturation differences, bicultural socialization (as distinct from bilingual) and more. All practitioners, including those of color will need to learn to work cross-culturally.

Education and Training of Geriatric Mental Health Professionals

Changes in attitude and approach to the seriously mentally ill will further the already evident shift to a more accepting attitude toward psychotherapy among middle income and working class middle aged adults. This cohort is much more apt to seek private psychotherapy using health insurance or even sacrificing from their modest income to pay for it. At the same time, poor elderly, recent immigrants and others will continue to rely on clinics and hospitals for care.

The demand for psychotherapists with geriatric expertise will be great. In fact, unless specific programs are instituted to attract and train psychotherapists to the field, a major gap will exist. Already, the very few geriatric mental health programs, which exist, are unable to meet the needs of today's elderly population and find it difficult to recruit staff interested in geriatrics, let alone staff experienced or trained in geriatrics. These few programs, in fact, have become the training grounds for geriatric mental health. NYS would do well to develop

linkages between these programs and graduate professional schools to develop geriatric mental health traineeships across the disciplines, which include incentives and supports for racial/ethnic minorities. Family oriented programs should receive special attention given that current knowledge already stresses the importance of family-centered care of the elderly and future trends emphasizing the family as a point of service.

Conclusion

The mental health projections for the year 2015 aged population presented here are based upon current trends and may be impacted by intervening factors. Nevertheless, we have forged ahead optimistically "stepping out on faith" as it were, utilizing what is known in the present and what can be seen even dimly on the horizon. It is our view that the marginalization which geriatric mental health policy has suffered will finally be overcome as today's middle-aged cohort ages. We have faith in the power of the sheer growth in numbers of elderly, and faith in that sub-group who came of age in the US in the 'sixties' era to do what they have done at every other stage: transform it in some significant way. In particular, we expect that this generation will place geriatric needs front and center in mental health.

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Project 2015:
The Future of Aging in New York State

ELDER ABUSE AND NEGLECT

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Aging in New York State and Implications for Elder Abuse/Neglect

There has been a growing recognition of the problem of elder abuse during the last 20 years (Wolf, 1988). Estimates on incidence and prevalence of elder abuse and neglect have ranged from 3 to 40 per thousand among those age 60 and older, depending on the definition used and the population studied. Some estimates have risen as high as 100-120 per thousand (Tatara, 1995; Pillemer & Finkelhor, 1988; U.S. House of Representatives, 1990). No estimates to date include institutional abuse. Assuming a conservative estimate of 40 per thousand, approximately 130,000 (out of over 3 million) older adults in New York State may be victims of abuse or neglect. The actual number is thought to be much higher. The National Elder Abuse Incidence Report (NEAIS), mandated by the Family Violence Prevention and Services Act of 1992 (P.L. 102-295), states that abuse and neglect of older adults living in the community have been largely ignored. This can be said for institutional abuse as well. Increasing consciousness of elder abuse is likely to bring more cases to the attention of service providers and the public (DHHS, 1998).

Definitions of Elder Abuse and Neglect in New York State

The definition formulated by the New York State Governor's Task Force on Elder Abuse includes physical, psychological and financial abuse, and active and passive neglect. This definition, also used by the New York City Elder Abuse Coalition, is adapted from Wolf & Pillemer (1984). Physical abuse is defined as the infliction of physical pain or injury, or physical coercion, including confinement against one's will. Psychological abuse is defined as the infliction of mental anguish, through name-calling, infantilizing, intimidating, humiliating, threatening, or isolating. Financial abuse is the exploitation and/or improper use of funds or other resources. Active neglect is defined as the deliberate refusal or failure to fulfill a caregiving role, and passive neglect is defined as the unintentional refusal or failure to fulfill a caregiving role, because of inadequate knowledge, ability or capacity. This definition assumes that elder abuse is a form of domestic violence, perpetrated against older adults age 60 and above by family members or significant others.

Incidence and Prevalence of Elder Abuse in New York State

The authors were stymied by the challenge of even attempting to quantify elder abuse for this issue paper. One challenge that must be addressed before the incidence and prevalence of elder abuse in New York State can be determined in a meaningful way is the resolution of conflicting definitions of this social problem by organizations and systems that serve elder victims and their perpetrators.

Community-based Aging Service Agencies (including Area Agencies on Aging and Adult Protective Services): While the Older Americans Act defines elder abuse as domestic mistreatment of an older person age 60 years and above by a family member or significant other, Adult Protective Service agencies define elder abuse as a subset of adult abuse (for those 18 years of age and above).

Law Enforcement: The police view elder abuse as those violations, misdemeanors and felonies that are linked to domestic violence (defined as spouse or partner abuse), when the victim is 60 years of age or older. This may exclude financial abuse, as well as abuse of an older person by a child, grandchild, other relative or friend,

and most instances of neglect. The State Attorney General and county-based District Attorneys define elder abuse as any crime against an adult 60 years of age or older. These may include crimes committed against older adults by strangers and formal caregivers such as home care and nursing home aides, nurses and other health professionals, as well as family members and significant others.

State Health Department and Health and Mental Health Care Providers: Health care providers may view elder abuse only as physical abuse or neglect. Mental health and substance abuse providers will likely not identify abuse or exploitation of older family members by impaired clients under treatment as elder abuse, because the focus of those provider systems is the impairment of the abuser. The State Health Department is mandated to investigate reports of elder abuse and neglect in nursing homes, which it licenses. While in theory any form of abuse may be referred for investigation, in practice the State Health Department investigates primarily complaints of physical abuse.

Implications for Service Systems in New York State: The conflicting definitions of elder abuse currently used in New York State are linked to different frames through which this social problem is viewed. For the purpose of this discussion, we will define them as the criminal justice frame (police, district attorneys and the Attorney General); the social frame (area agencies on aging, not-for-profit agencies providing community-based services to older adults, and adult protective services programs mandated by the New York State Social Services Law); and the health and mental health frame. Other service providers also may come into contact with elder abuse without identifying it as such. Examples are child welfare agencies that oversee kinship foster care cases involving grandparents; probation, parole and juvenile justice departments; and domestic violence programs funded and structured to serve younger victims of domestic violence and their children.

Overview of Elder Abuse/Neglect in New York State

Elder abuse, like all forms of domestic mistreatment, is usually hidden; profiles of abuse emerge through formal and informal reporting systems.

Institutional Abuse: In New York State, there is mandated reporting of elder abuse and mistreatment in nursing homes. The numbers of older adults entering nursing homes in New York State have been stable over the past few years, and may be expected to remain so with increasing home-based alternatives. However, the 5 percent of the State's population age 60 and above residing in nursing homes are among the most frail and vulnerable among older citizens.

The New York State Department of Health (SDOH): Mandated reporters of elder abuse and neglect in nursing home settings must report suspected or actual incidents of elder mistreatment to the State Department of Health, the state licensing entity for nursing home facilities. While anyone, including family members, can report abuse or neglect of nursing home residents to SDOH, employees of nursing homes are mandated reporters and can be sanctioned for failing to report known or suspected abuse or neglect of an older nursing home resident. Mandated reporters in nursing homes are required to report physical abuse, neglect or mistreatment of nursing home residents.

The Long Term Care Ombudsman Program: NYSOFA is mandated under the Older Americans Act to implement the Ombudsman Program for residents living in long term care facilities. The Long Term Care Ombudsman is an advocate and voice for residents of nursing homes and adult care facilities needing someone to speak on or in their behalf. The primary function of the Long Term Care Ombudsman is to receive, investigate and resolve complaints. In New York State, the Ombudsman program is administered in the counties through area

agencies on aging or not-for-profit agencies. For counties that do not have a program, the Office of the State Ombudsman is responsible for receiving and investigating complaints. The heart of the Long Term Care Ombudsman Program is its corps of over 600 specially trained, certified citizen-volunteer ombudsmen. The Ombudsman Program is mandated through federal and state regulations to report any occurrences in nursing homes or adult care facilities of physical abuse, mistreatment or neglect to the New York State Department of Health.

Domestic Abuse in the Community: Older New Yorkers who are abused or mistreated by family members and significant others in the community represent a much more diverse population than those in nursing home settings. They may range from healthy and vigorous older adults, possibly with caregiving responsibilities for impaired adult children or grandchildren, to frail elders with severe cognitive as well as physical disabilities. Agencies that have responsibility for addressing elder abuse in the community include:

Adult Protective Services: Older adults who are at risk of abuse or neglect due to physical and/or mental impairments are eligible for services through Adult Protective Services, as defined by the New York State Social Services and Mental Hygiene laws. Services may be provided directly or under contract by not-for-profit agencies.

Area Agencies on Aging: A number of area agencies on aging in New York State have programs that respond to calls by or on behalf of seniors who are victimized by crimes and domestic abuse by family members and significant others.

Victim Services Agencies: Some not-for-profit agencies in New York State are funded to provide assistance to victims of crime and domestic violence, including elder abuse victims. As an example, Victim Services in New York City operates the domestic violence hotline under contract with the Human Resources Administration (HRA), a social services arm of the municipal government, and an elder abuse hotline under contract with the Criminal Justice Coordinating Council.

Law Enforcement and the Criminal Justice System: The police, District Attorney's offices, and the State Attorney General's Office investigate reports of elder abuse and neglect and may prosecute when the abuse rises to the level of a crime as defined by the state penal code.

Discussion

While there are a number of general issues related to elder abuse in New York State as discussed above, it is important to recognize the special issues and considerations of subgroups of abused elderly and the implications for policy and practice. An overview of some of the issues related to elder abuse and neglect in New York State that have implications for policy development and change in New York State are presented below.

Special Issues related to Elder Abuse in New York State

Incidence and Prevalence of Elder Abuse in New York State:

As noted, one problem in projecting the incidence and prevalence of elder abuse by 2015 is the lack of a common definition among all the sectors that may come into contact with older people who are abused, mistreated or exploited. For example, is elder abuse a form of domestic violence, or can it include mistreatment through the formal network (home care providers, nursing home attendants) as well? Should self-neglect be included in a definition of elder abuse? What about crimes committed against the elderly by strangers? Are telephone, mail, and mortgage scams forms of elder abuse when perpetrated against older adults?

Issues of Gender and Sexual Preference in Elder Abuse: Numerically, older women continue to be at higher risk of victimization than are men (DHHS, 1998). There is some suggestion in the

literature, however, that older men share a risk of abuse equal to older women (relative to their proportion in the population) and are at much greater risk of victimization by family members and significant others than is commonly assumed (Kosberg, 1998). Initiatives that address the needs of older male abuse victims must be considered, as well as those reflecting the traditional profile of spouse abuse. The ages of both victim and abuser may preclude interventions – such as mandatory arrest and incarceration – which are indicated for younger spouse or partner abuse situations.

As social acceptance of gay and lesbian relationships increases, abuse among partners within this population of older adults may become more visible (Cook-Daniels, 1997). While the social acceptance is a positive trend, increased case finding may generate a need for specialized service programs that reflect sensitivity and understanding of abuse among this and other special populations of older adults.

Cultural Issues: Race/Ethnicity and Elder Abuse: Research on elder abuse and cultural diversity is at a preliminary stage. There is no evidence from the literature that any one race/ethnic group or social class experiences more elder abuse than any other does. However, findings from research nationally suggest that certain forms and patterns of abuse may be differentially experienced by older adults and their family members based on ethnicity, country of origin, degree of acculturation, and values and beliefs regarding family obligations, including norms of reciprocity (Tatara, 1997).

Those working with elder abuse victims and their families should recognize cultural and ethnic factors that may complicate effective service delivery to abused elders. They should also have a knowledge base about cultural values and traditions. Provider agencies should ensure that outreach is conducted in languages understood by elders and their families in communities served. Continued research on the interaction of ethnicity, family mistreatment of the elderly, and successful intervention models is important as New York State's older population continues to diversify.

Immigration and Welfare Reform: Implications for Elder Abuse in New York State: Implementation of welfare reform legislation makes it more difficult for older immigrants without citizenship to obtain needed social welfare benefits and services. This in turn may invite more psychological abuse and/or neglect of the needs of this population by family members who are struggling to care for multiple generations within a single household. Unless the psychological abuse or neglect results in a health emergency, it has always been difficult for service providers to assist older adults without legal immigrant status to obtain other health care and income support benefits.

This problem has been exacerbated by the passage of the Personal Responsibility and Work Opportunity Reconciliation Act (PRA) of 1996 (P.L. 104-193), which eliminates eligibility for most categories of legal immigrants to receive federally funded social welfare benefits like Medicaid, food stamps and Supplemental Security Income.

New York State policy has addressed the needs of immigrants better than most states. Also, immigrants are not disentitled by this legislation for Older Americans Act-funded services. In addition, immigrant older adults and their families may resist accepting needed government benefits and services for which they are eligible, fearing reprisals from immigration authorities. Therefore, enlisting the help of immigrant community leaders as well as religious leaders for education and outreach efforts could help identify elder abuse in all its forms and assist culturally competent service providers to address it. This is significant because our aging population in New York State is projected to continue diversifying as we move toward 2015.

Aging, Dementia, Managed Care and Elder Abuse

Dementia, while not synonymous with increasing age, is correlated with it. Because dementia is a medical problem, it is often treated within health care settings. An increase in the number of older adults could also mean an increase in the number of cases of dementia. Studies have identified mental confusion and dementia as risk factors in elder abuse and exploitation (Goodrich, 1997). Health care settings should incorporate programs to detect elder mistreatment, particularly among high-risk older patients. These programs should seek to both prevent and intervene in elder abuse situations, either directly or through contracts with other service providers. The aggressive implementation of managed health care by private health insurance carriers and government may create disincentives to the establishment of these services in the interest of making profits or cutting costs. New York State should look closely at managed care policies, particularly as they affect mentally incapacitated older patients, and devise ways of addressing any barriers to treatment.

Intergenerational Issues in Elder Abuse and Neglect: Elder abuse and mistreatment, like all forms of domestic violence, is usually a family affair. While some studies have identified spousal abuse as the most prevalent form of elder mistreatment, findings from most studies suggest that adult children are in fact the most likely perpetrators of abuse and neglect (Quinn & Tomita, 1997). With the increasing numbers of grandparents and older family relatives providing kinship foster care for abused and neglected children, the hidden problem of abuse of grandparents by older grandchildren is likely to become more visible (Brownell & Berman, 2000).

Mentally Impaired Abusers: Abuse of older family members by mentally impaired perpetrators is an emergent area of interest and study. Categories of abuser impairment can include dementia, mental illness, substance abuse, and mental illness in combination with substance abuse (mentally ill/chemically addicted or MICA). According to a recent study conducted by the New York City Department for the Aging, substance abusing and mentally ill abusers are significantly more likely to have a forensic history than abusers with no reported impairment (Berman & Salamone, 1998). Most impaired abusers lived with their victims. In addition, elder abuse victims of impaired abusers were found to be less likely to accept services than victims of unimpaired abusers. Since so many impaired abusers live with their victims, and are supported and protected by them, it may be necessary to assist these abusers in order to protect their victims (Berman & Salamone, 1998).

Models, Perspectives and Remedies

Ethical Issues in Elder Abuse and Neglect: Professionals working with elder abuse victims and their families are challenged to confront professional ethical mandates to respect the autonomy of their clients or patients. The State is judicious in defining the circumstances in which and the extent to which it can intervene into the private lives of individuals and families. Two areas of intervention legislated to date are (1) when a serious crime has been committed against one family member by another, and (2) when victims lack the capacity to protect themselves from harm. Overriding the autonomy of unimpaired abuse victims because of their age alone is a matter of serious consideration for professionals and lawmakers. However, not to attempt to intervene in suspected or known instances of abuse is also troubling, particularly for those in the helping professions.

This issue is especially critical in legislation proposed by the State Senate and Assembly. To date, most State elder abuse bills have focused on reporting elder abuse and prosecuting abusers. However, studies have suggested that community education is more effective in identifying, and more importantly, preventing, elder abuse than mandatory reporting systems (Tatara, 1995).

Mandatory Reporting of Elder Abuse and Neglect: New York State is one of only five states nationally that does not have state legislation mandating reporting of domestic (as opposed to institutional) elder abuse and neglect to a central registry. State mandatory reporting systems are modeled after child abuse and neglect reporting systems. They are based on the assumption that elder abuse is a form of domestic violence perpetrated on impaired and frail elders who are unable to protect themselves from harm. State legislation mandating reporting of domestic abuse of older adults living in the community generally includes provisions for mandatory investigations as well, and sanctions against professionals who are mandated reporters and based on professional judgement choose not to report. Often state mandatory reporting statutes do not take into consideration the fact that most people 60 years of age and older are physically and mentally vigorous. In addition, older adults, unlike children, are legally entitled to make decisions about their own lives – however unsound these decisions may appear to an outside observer - unless adjudicated as lacking capacity by a court of law.

Studies from states with mandatory reporting of elder abuse report that mandated reporting systems are expensive and underfunded (Zorza, 1999). In addition, elder abuse victims, once identified, are entitled to refuse services if found able to understand the consequences of their decisions. Third, appropriate services are often lacking or inadequate even if the victim agrees to accept them. Finally, substantiating and intervening effectively in elder abuse situations requires staff with professional education and training in social work and gerontology.

Models of Elder Abuse Intervention: The following are examples of intervention models that fall within the three frames discussed above (criminal justice, social, and health/mental health). The criminal justice system provides access to legal and law enforcement remedies when the abuse perpetrated against the older adult rises to the level of a crime as defined by the New York State Penal Code. Some intervention models that have been developed include teaming law enforcement professionals like police and District Attorneys with social workers to address service needs of the victim and often the abuser as well. Training for Domestic Violence Police Officers by social workers to identify elder abuse is provided in some localities.

The social frame includes all the case management program models like Adult Protective Services, area agencies on aging, and those community-based organizations, including senior centers, one-stop programs, and meals on wheels, operated by voluntary (not-for-profit) and government agencies. Innovative programs like self-help groups as well as more traditional ones like home visiting and financial management programs are included in this approach. Not-for-profit community based organizations and Adult Protective Services (APS) agencies are important components of the continuum of community-based interventions for older people who may be victims of abuse or neglect.

While existing service and law enforcement systems offer many important services and remedies for elder abuse victims and their families, fragmentation among these services can limit their effectiveness and generate hidden or unseen costs. Coordination among the "frames" would help to reduce these costs as well as improve service effectiveness.

Partnerships need to be developed to effectively meet the needs of elder abuse victims. Some initiatives have been developed that can bring service providers with diverse perspectives together to develop a common language, coordinate services and solve problems related to service barriers. Examples include the New York City Elder Abuse Coalition and the TRIAD program in Seneca County. Local and state service coalitions represent one model of public-private collaboration among providers of services for elder abuse victims and their families.

The New York State Office of Children and Family Services (formerly State Department of Social Services) has funded a number of

innovative community-based elder abuse demonstration programs through the Children and Family Trust Fund. One example is the East Side Elder Abuse Prevention Project, which represents a collaboration of five agencies serving the elderly in a relatively service-rich community on the Upper East Side of Manhattan. Another is the Lifespan Elder Abuse Program in Rochester. The New York City Department for the Aging (DFTA) Elderly Crime Victims Resource Center is a model program serving the five boroughs of New York City that accepts referrals for any community-based elder abuse incidents. The DFTA Center also provides training to community providers of services to elder abuse victims and their families. Coalitions of public and private service providers, and programs like the DFTA Elderly Crime Victims Resource Center and those funded through the Trust Fund, can serve as models for service integration as we move into the 21st Century.

Health and mental health service systems provide access to health and mental health services for both victims and abusers. Home attendant, home health, and skilled nursing care can provide respite and support for overwhelmed caregivers and protective oversight in instances where there is an impaired perpetrator in the household. There is also a need to provide additional public information and outreach on recognizing potential abuse and how to report it.

Use of Technology

Computers and teleconferencing are two forms of technology that can be utilized to both educate older people about elder abuse as a preventive measure and to address problems of isolation for older victims of mistreatment. If available, computers in the home can provide both information on elder abuse, and allow a victim to communicate with others about their situation through e-mail, making it more difficult for the abuser to overhear a conversation. Teleconferencing can be used by homebound victims of elder abuse, assuming they are not residing with their abusers, enabling them to participate in elder abuse support groups.

The use of cellular phones and personal emergency response buttons, already in use with younger victims of partner abuse with orders of protection and home bound people with disabilities, can be used by elder abuse victims to seek assistance from the police if the abuser approaches them. The Internet can be more fully utilized to publicize reports of abuse and neglect in nursing home settings. Interested consumers can be alerted to problem facilities. In turn, facilities may be more motivated to ensure the safety of residents if poor supervision or training of staff results in negative publicity. The Internet is one way to educate the public on elder abuse issues.

The New York City Coalition on Elder Abuse's webside was noted by the American Society on Aging (ASA) as one of the best in the county. Another way technology can be used to improve coordination among systems serving older victims of abuse and their families is through the development of common reports across systems that can provide valuable information on incidence and prevalence of abuse, as well as assist in service coordination (DHHS, 1998).

Service Gaps in New York State

New York State has a rich array of services for older people. However, there are significant service gaps that should be addressed as we move toward 2015. They include:

Lack of access to appropriate shelter services on an emergency basis: There are plans for building the first shelter in New York City for elder abuse victims. Elder abuse victims utilizing this facility once completed will include those older men and women with emergency needs for shelter beds in a supported living facility. It is important that New York State ease its regulatory requirements to support the design and implementation of a shelter model that meets the needs of our aging population. Admission criteria should reflect the current definitions of elder abuse and not definitions of domestic violence specific to younger spouse or partner abuse.

Lack of Sufficient Long Term Housing for Elder Abuse Victims: In addition to elder abuse shelters, there is a need for additional long term housing, including supported living facilities, for older New Yorkers who are victims of family abuse. Without housing options, older victims of mistreatment and exploitation may be forced to remain in abusive family situations, or return to them after emergency shelter stays.

Emergency health, mental health, and home care services: Coverage for emergency health, mental health, and home care services should be considered for elder abuse victims without medical insurance or active Medicaid.

Voluntary financial management services: Financial management services for older adults at risk of financial exploitation and who are willing to accept this service is also an important issue. There is little if any funding for such programs for those older people lacking the means to engage a private financial manager or the social network to obtain one informally.

Increased preventive measures: More research is needed on the etiology of elder abuse and the effectiveness of programs designed to instill prevention within society. For example, mandatory educational programs in schools and professional training programs should be emphasized. Reduction of elder abuse should be a common community goal. New ways of increasing community collaboration need to be explored. Regrettably, Chapter 85 was unfunded: community education should be reemphasized.

The service needs of elder abuse victims extend beyond the traditional aging service network. Practice experience and studies have both demonstrated that often older victims of family abuse will not accept services for themselves if services are not also offered to their abusers (Dundorf & Brownell, 1995). Intensive case management, substance abuse, mental health, housing, and counseling services must be expanded and earmarked for abusers. With younger spouse/partner abuse, traditionally there has been serious opposition to spending service dollars on abusers instead of victims. This is counterproductive with elder abuse, as often services must be made available for the abusers (who may be adult children, grandchildren, and impaired spouses or partners) before the victims will consider accepting

Continuation and support of interdisciplinary programs and coalitions are essential for ensuring that representatives of the many disciplines and service sectors coming into contact with elder abuse continue an ongoing dialogue. This should include the review and drafting of legislation that relates to elder abuse. This effort should not only be targeted to those bills that relate specifically to elder abuse. It should also target those that address the needs of abusers. One example is the New York State law on involuntary medication of selected mentally ill patients who – as an unintended consequence of deinstitutionalization – are in the community and may present a danger to others unless medicated. This is especially pertinent to elder abuse as almost half of all mentally ill adults in New York State live with elderly parents after discharge from hospitals or prisons, according to Joy Braun, New York City National Alliance for the Mentally Ill - Families and Consumers Together (NAMI FACT) (Personal Communication, June 15, 1999). Legislation should be preventive as well as protective, and empowering in that it preserves the autonomy of elder abuse victims as much as possible.

The gaps in service identified here illustrate the limitations of taking a single focus approach to elder abuse and neglect. Criminal penalties for the abuser may serve as part of a protective strategy or as deterrents to further abuse, but they are not always appropriate. Other policy areas have an impact on this problem as well. In fact, most existing policy and legislative remedies to date are at best bandages. Many service interventions used to address elder abuse are after the fact; little is done as a preventive measure.

If prevention is a goal, we must extend the target of services beyond older people to include the larger network and community. Education and outreach, and engaging other types of community organizations such as churches, synagogues and mosques, as well as Tribal leaders, and libraries, is essential. Legislation like the law passed in August 1999 giving the New York State courts new authority to order former mental patients to comply with treatment is controversial, but at least attempts to take a proactive approach to violence prevention. This is important not only for the general public but also for families of the mentally ill.

Conclusion

There have been many achievements in the last 15 years in framing elder abuse as a significant social problem in New York State. The challenges we identify for New York by 2015 are three-fold.

First, we must develop a definition of elder abuse and neglect that clearly defines and delineates what elder abuse/neglect is and how it is to be measured. The lack of a common definition that transcends the cultural and institutional mandates and boundaries of agencies and institutions limits our ability to understand current trends in elder abuse and neglect. As a result, it is difficult to project future trends, recommend preventive measures, and plan for the kinds of services needed to reduce the incidence and prevalence of elder abuse and neglect in New York State.

Second, we must continue to search for new and effective ways to address the current fragmentation among all the existing criminal justice, social welfare and service systems that assist elder abuse victims and their abusers. This fragmentation is reflected in legislation, social policies and programs for abuse victims in New York State. Promising models to address issues of fragmentation that can be replicated include the DFTA Elderly Crime Victims Resource Center and coalitions of service providers.

Third, we are challenged to develop and implement a strategy for taking a comprehensive approach to elder abuse and neglect, drawing on models of synthesis to develop common ground among service providers, legislators and the aging advocacy community. With this foundation, we will be ready to move forward and address more effectively the problems of elder abuse and neglect in the new millennium.

Summary of Recommendations

1. Reconcile divergent definitions of elder abuse and neglect used by agencies and institutions serving older adults and their families in New York State, and explore the feasibility of legislating a centralized system for reporting elder abuse and neglect by providers that protects confidentiality and does not automatically trigger mandatory investigations.
2. Address social policies, funding streams and agency mandates that create barriers to developing effective services and integrated service systems to address problems of elder abuse and neglect.
3. Examine differences in reporting of elder abuse and neglect by race/ ethnicity and gender to determine why there are variations and how best to address them.
4. Evaluate the unintended consequences of implementing major social welfare policy changes through welfare reform and managed care legislation that create barriers to addressing elder abuse and neglect; consider modifications of legislation and regulations to address these barriers.
5. Maximize the autonomy of victims in setting policies and establishing programs to address elder abuse and neglect without compromising safety.
6. Expand interdisciplinary service options within the criminal justice, social and health/ mental health frames to better serve elder abuse victims and their abusers.
7. Address service gaps to include special shelter facilities and voluntary financial management service programs for elder abuse victims.

8. Increase service options for impaired abusers, including intensive case management, substance abuse, housing, and mental health services earmarked for abusers of older family members.
9. Continue and expand interdisciplinary programs and coalitions that address problems of fragmentation and needed policy changes related to elder abuse and neglect.
10. Develop and expand elder abuse preventive program initiatives and proactive legislative options.
11. Support outcome research that looks at the effectiveness of services for both victims and abusers.
12. Increase professional development and training opportunities for workers serving elder abuse victims and their families.

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[1] Definitions of elder abuse reflect the culture and mandate of these institutions. The service systems that may come into contact with elder abuse are complex and include many different players. In addition, each frame generates its own remedies. For example, the criminal justice system may generate legal remedies, but be unprepared for or unaware of the social consequences of these remedies. (The inclusion of social workers within the criminal justice system, including law enforcement, district attorneys and judges' chambers, to assist with family-related issues can mitigate against unintended consequences for domestic violence cases.) Within the social services system, Adult Protective Services - a potentially invasive service option as legislated in state social services and mental hygiene laws - may not view an unimpaired older victim of family abuse as a candidate for their services, much to the frustration of community based organizations serving the elderly. Health care systems may overlook stress-related health problems or undernourishment among older patients as related to psychological or financial abuse, and treat the symptoms instead of the cause. Mental health, substance abuse and criminal justice systems serving younger adults or adolescents may view older relatives as sources of social and financial support for their clients, and be unaware of the risk of elder abuse this generates. Child welfare systems overseeing kinship foster care caseloads may not recognize elder abuse perpetrated against grandparents and older relatives providing kinship foster care by older grandchildren and other household members if the children in care are not the targets of the abuse. Domestic violence programs, including shelters, may agree to serve elder victims of family abuse, but be constrained by funding mandates from offering age-appropriate programs and services.

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ROLE TRANSITIONS

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Women and men move through adulthood and old age in complex ways, involving a variety of social and psychological processes as well as biological ones. Role behaviors, role identities, and role transitions are major components of these complex processes. Traditionally, we have described changes in roles as if they could be captured in a snapshot—they occurred at a particular time and place and in a specified sequence. In reality we know that life is more like a multi-media show rather than a single snapshot. We are all involved in a series of entries into and exits from a wide variety of roles - worker, spouse, caregiver, and volunteer - in an ever-changing world.

The life course perspective challenges traditional snapshot views, focusing instead on life pathways, as individuals experience various role trajectories and transitions (Giele and Elder, 1998). A trajectory refers to "a pathway defined by the aging process or by movement across the age structure" (Elder, 1985:31). An individual life course is composed of multiple, interdependent trajectories (or "careers") of roles and relations. These career paths (e.g., work "career," family "career," volunteer "careers," or health "career") do not exist in isolation, but rather are interdependent, with changes in one often affecting all others. These trajectories are interrupted and altered by a sequence of successive life events and transitions. Thus an abrupt change (such as a sudden disability or widowhood) can lead to a series of other changes, large and small. Some transitions can be expected and planned for (such as the last child leaving the home or retirement); others (such as downsizing or having to provide care to an infirm relative) may catch people unaware. To complicate the picture, individuals may occupy different roles within these trajectories; in a work career, for example, an individual may be an employee, a boss, or an owner.

Four life course concepts are crucial to our understanding of role transitions for older persons: "timing," "process," "context," and "linked lives" (Moen, 1998a, Moen, 2000, Giele and Elder,1998).

- *Timing* refers to the duration of time spent in each role and the spacing or amount of time between two or more role transitions. For example, knowing whether an older person is employed at age 65 may be less important than knowing the duration and spacing of labor force participation throughout adulthood (Moen, Dempster-McClain and Williams, 1992).
- *Process* focuses on aging as a series of role transitions, rather than a single event. Role entries and exits are important, and process draws attention to the sequencing or order of these transitions over the life course. Older adults leave some roles (such as wife, husband, or worker), and enter others (such as widow, widower, or retiree).
- *Context* can be seen on two levels: personal and historical. The personal circumstances of people's lives—their education, income, social networks, marital status, family size, ethnicity, race, and age—will have important repercussions for their well-being as older adults. But historical shifts may matter as well, affecting the options and opportunities of people at different ages. Baby Boomers (born 1946-1964) were born into a different world than the current cohort of people over age 65. Expectations regarding their roles and lives have changed as we have experienced the major events of the last half of the twentieth century. Focusing on the context of lives draws attention to potential

differences by age within one cohort, as well as differences by race/ethnicity, educational background, prior health, household composition, economic situation, and exposure to major historical events.

- *Linked lives* acknowledges that individuals' life paths are played out in tandem with the life courses of parents, spouses, children, friends, and co-workers (Antonucci, 1994; Ryff and Seltzer, 1996; Moen, 2000). Increasingly, scholars of later life role transitions are studying couples and couples' decisions surrounding retirement, care giving work, and paid work. In addition, relational careers between parents and children, siblings, and friends are important pieces of the puzzle.

Another key concept is that of *structural lag,* defined by Riley and her co-authors (1994) as the tendency for the social structure of roles, norms, and social institutions to change more slowly and thus lag behind changes in people's lives. Most ideas and policies about aging, work, and family are grounded in the realities of the middle of the twentieth century, not the twenty-first. How do we fashion new templates, policies, and practices for growing older in a world in which older Americans are living longer, living healthier, and are more educated, yet are in danger of being on the sidelines of society? For example, the majority of people retire at around age 65; due to increased life expectancies, most people will live an average of fifteen to twenty years beyond retirement. But what roles or opportunities exist for retired people? What links do they have to the larger society? We as a society have lagged behind the changes in people's lives. We have not fashioned opportunities and responsibilities for this new life stage.

As documented in this paper, the Baby Boomers (early Boomers, born 1946-1953, and late Boomers, born 1954-1964) are currently deeply embedded in their communities – as workers, parents, spouses, caregivers, club members, and volunteers. But this role repertoire is both interlocking and ever-changing. While we can obtain statistical information about their current involvement in a single role (for example, percent employed/married/volunteering in the year 2000), it is almost impossible to obtain data about the complex movement in and out of various roles or the interdependency between roles. Thus, this essay focuses on selected roles and suggests interrelationships between role domains. Identifying key "role transition" issues and structural lag can help New York policy makers and planners assist all older New Yorkers to lead satisfying, productive lives.

Private roles and relationships

- The *marital tie* is a key role for most Americans, providing a sense of connectedness and support. Social scientists have long ignored the substantial number of older adults who have, by choice or chance, not entered into a legal, marital relationship. This group of "unmarrieds" is often left out of research and policy discussions. Due to the increased possibility of isolation, we need a greater understanding of their ties to partners, parents, aunts, uncles, siblings, nieces, nephews, friends, co-workers and others. Transitions and changes in these relationships are important and need to be recognized and acknowledged. The relationship status that receives the lion's share of attention is marriage, in particular the transitions in and out of marriage. Timing of the entry into marriage, exit from a marriage due to separation, divorce, or death and reentry into a second or third marriage is important. The negative effects of divorce and widowhood are well documented, but it is not clear whether the current state of non-marriage is the crucial factor or whether it is the recency of the transition from marriage to non-marriage (Esterberg, Moen and Dempster-McClain, 1994). Moreover, since widowhood becomes increasingly common in the later years of women's lives, being unmarried may have fewer negative impacts for older women than for women whose

marriages ended in earlier adulthood. If a marriage or relationship ends after age 60, what is the likelihood that a new relationship will be formed? Will the development of new relationships follow a sequence that is familiar? How have personal and historical contexts changed?

- *Parenthood* is a common role for men and women and, unlike marriage, it is one from which people rarely exit. Little is known about the impact of parenthood on adults in later life. The number of children raised and the amount of one's life spent in raising children are important factors to consider when assessing later-life outcomes. Our own research has shown that number of children is positively related to longevity among women who were wives and mothers in the 1950s (Moen, Dempster-McClain and Williams, 1989). The life course concept of "linked lives" has encouraged the study of the relational careers of parents and children. For example, parents who have provided economic support for their adult children in the past are more apt to be cared for by their children in their later years (Henretta, Hill, Li, Soldo & Wolf, 1997; Moen, 2000). Other forms of informal exchange, such as babysitting and providing transportation, are important avenues for investigation.
- *Grandparenthood* is another private role, one that links generations. Grandparents have very little control over this role—the timing and process are in the hands of their children. Several factors influence the older adult's involvement in this role, including geographic proximity, number of grandchildren, stability of the children's relationships, and the health and financial status of both the grandparents and the grandchild's parents. As discussed elsewhere, some grandparents become primary caregivers, while others rarely see their grandchildren. Linking the lives of grandchildren to their grandparents can be facilitated or hindered by the adult children.
- *Care work* for adult relatives is an excellent example of "linked lives" and illustrates the well-accepted fact that all roles carry obligations as well as benefits. Caring for others is one role that has a potential for "costing" a lot in terms of health and social/psychological outcomes for older adults. Whereas the care involved in the raising of young children is anticipated, frequently welcomed, and circumscribed in the life span, caring for an infirm parent (or spouse) or for a handicapped adult child can become an unexpected but absorbing role that may have many positive and negative outcomes (Moen, Robison and Dempster-McClain, 1995; Robison, Moen and Dempster-McClain, 1995; Moen, Robison and Fields, 1994).

Public Activities in Society

- *Paid work* is the primary mechanism for many or most adults' active participation in the larger society, a fact that places many older Americans out of the mainstream. Career paths shape both identity and financial resources and are also a source of relationships. Increasingly, couples are having to coordinate two work "careers" — along with their family "career" — and to plan two retirements. Knowing about current involvement in paid work may be less important than knowing the duration, spacing, and overall pattern of labor force participation throughout adulthood (Han and Moen,1999).
- As people age and exit from their "careers" or "jobs," they construct a *post-employment lifestyle*. For some, this new lifestyle may involve additional spells of paid work in order to stay involved and feel integrated into the larger society. Others begin second careers; some work in their later years to help make ends meet. Leisure, travel, and community/family involvement are the main activities of those who have good health and adequate resources. Documenting the timing and process of these activities is difficult but important for understanding the public activities of older people.

- Additional public activities performed by diverse segments of the population involve *bartering or trading* services with friends, neighbors, and kin. Others work for pay but the remuneration never enters the "formal" economy. How many older people participate in bartering or receive "payment under the table," and what are the reasons or motivations for this behavior? One can assume that the underground economy is alive and well and will continue to flourish as the Baby Boomers age.
- *Volunteer activities*, either through formal or informal involvement in the community, are associated with positive outcomes throughout the life course. In our research we found that membership in clubs or organizations is positively related to women's longevity. Using life history data for a 30-year period, we found that volunteering at various times throughout adulthood was positively associated with functional ability and occupying multiple roles in later adulthood; in addition, being a club or organizational member in earlier adulthood was positively related to functional ability and subjective health 30 years later, as well as to the duration of health. It may be that the degree of choice involved in social participation in community activities is beneficial for women. Variations in these connections may exist for men, as well as for people from different social classes. It is realistic to expect continual change in both the timing and the sequencing of all role transitions that are subsumed under the umbrella of volunteer activities.
- *Political involvement*, ranging from running for office or serving as a public official to the mere act of voting also varies across the life course. Knowing a person's early experiences may be a good indicator of continued activity, but as the Baby Boomers age we may see patterns of involvement that are different from those characteristic of the current cohort of seniors.

Dynamic Interconnections Between Private and Public Roles

The diverse strands of the life course shape –and are shaped by – one another. Thus, having a disabled spouse or parent may cause some people to retire earlier than expected, and retirement may free adult children to care for their parents. Dentinger and Clarkberg (1999), drawing on data from the Cornell Retirement and Well-Being Study, report that employed women who become caregivers in late midlife are more likely to retire from their jobs, while employed men who become caregivers are more apt to delay their retirement. Documenting and analyzing "linked" role transitions is a challenge for life course researchers over the coming decades.

Implications for Policy Makers

The life course perspective offers no simple interpretation of the relationship between role occupancy, role behaviors, or role transitions and positive/negative outcomes in the later years of adulthood. Rather it suggests that the connections should be viewed as a dynamic and possibly cumulative process, wherein the roles occupied in early and middle adulthood play out in patterns of involvement over the life course, which in turn are related to personal, social, and psychological outcomes.

Current institutional arrangements and policies are outdated and lag behind the realities of the Baby Boom cohort. Organizational and occupational ladders provide a common understanding of social mobility and an identifiable pattern of progression through the life course. But this common understanding represents a set of practices and policies that no longer fit with the realities of a changing economy, changing gender roles, blurred lines between private and public roles, and a cohort of educated, introspective Baby Boomers newly valuing family life and uncertain about middle age. Many of our notions about roles are inconsistent with the growing number of two-earner (or single-parent) Baby Boomer families as well as with the leading edge of Boomers moving into retirement. What is required are new institutional arrangements for helping Baby Boomers, as workers and as working couples, to manage their many interdependent roles (Moen,1998b, 1998c).

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OLDER WORKERS: RETIREMENT OR CONTINUED WORK?

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The impact of the Baby Boom generation on retirement timing and workforce change are important issues for the new century. The Baby Boom generation will double the number of retirees early in the next century. The timing of their retirement will affect the composition and the productivity of the workforce.

Retirement Trends

Using current retirement trends, the number of retirees in New York State will double by 2020. For several years older workers have been encouraged to retire at earlier and earlier ages. As a result, many middle-aged workers, age 50-55, anticipate early retirement and no longer being part of the workforce. The secretary general of the International Social Security Association, Dalmer Hoskins, states, "Within the space of about 100 years, people have not only accepted but grown to believe that retirement is a right somehow, a human right almost." (*New York Times*, 8/15/99). But the longer and healthier life spans result in their anticipating as many as 18 years in retirement as compared to 13 years only 30 years ago.

There are at least two concerns affected by the increased number of retirees. First, there is the concern of the increasing costs of entitlements, including retirement benefits, for this older population. As one multi-national human resources manager explained: "Funding retirement pension plans is a major liability of businesses and government today, and it will continue to present a barrier to economic growth into the next century." Both private and public savings will be reduced, resulting in diminished productivity.

Second, there will be a labor shortage with fewer workers to fill the existing positions. When Baby Boomers retire, they will take with them their experience and knowledge. The succeeding generation is less in number, so that there will be fewer younger workers to replace the Boomers. Often they lack the knowledge and valuable workplace experience. Replacing older workers is often costly. A recent study of employee-turnover expenses at 206 medium to large companies by William M. Mercer, Inc., an economic analysis firm, found that replacing a worker cost on average between $10,000 and $30,000 and often even more. One multinational business manager stated, "Losing our experienced employees because their perception of a quality of life will be improved in retirement has been costly to our business. Their knowledge of our customers' needs and our systems cannot be replaced inexpensively."

Older Workers

The number of older workers in New York State, aged 50-59 in 2020 is estimated to be about 2.6 million. Recent trends indicate that Baby Boomers are more willing and able to work. Some will pursue continued employment because their savings and pensions are not adequate to support their desired life style. Others will work because they are healthier and wish to remain active and productive. Women, who have established a career after raising children, often wish to pursue work even longer than men of comparable age do.

Businesses that have hired or retained older workers note that older workers are experienced human capital. Older workers frequently have more skills and more experience than younger workers and can provide a competitive edge in marketing and customer relations. Thomas Stewart in *Intellectual Capital* cites the value of the "Knowledge Worker" in the current and future workforce and points

out that information is the "most important raw material" needed for a job.

Barriers to Employment

There are at least three identifiable barriers to employment for older workers. First, current policies create financial disincentives to continued working. Private pension policies encourage workers to retire and receive pensions as early as age 55. Often there are financial disincentives for continuing to work after that age.

Second, discrimination practices in the workplace prohibit older workers from opportunities to receive training to upgrade their skills. There is the opinion that training is wasted on older workers because they will "retire soon." There also is the opinion that older workers are slow to learn new skills.

Third, employers often perceive older workers as expensive. Due to their number of years of employment, their earnings may exceed those of younger workers. In addition, their health insurance costs also may be higher. Cost cutting measures often encourage those older workers to leave the workforce.

Recommendations

There are a number of recommendations that if implemented could assist in recruiting and retraining older workers. First, reforming workplace policies and procedures can provide incentives for employee retention to appeal to both the financial needs and the quality of life of an employee. Popular among newly retired workers are flexible work schedules, including job-sharing, flex time, and reduced work weeks. These work options appeal to both older workers and younger workers with family obligations. Telecommuting also is an option and can allow the employee to contribute to work and maintain home life responsibilities of child or elder care. Many of these options can provide the employer with flexible plans and reduced expenses.

Second, offering a diversified "cafeteria-type" benefits package can fit the needs of older as well as younger workers. While a younger worker may select a "college savings" plan, an older worker may select a "deferred compensation" plan. Both selections may have identical costs to the employer, but better fit the needs of the individual employee.

Third, it is possible to offer a phased or gradual retirement program. This practice, successful in some companies, provides the older worker with ever-increasing non-work time while retaining their position in the company. This option provides the opportunity for training and mentoring a successor for the position.

Fourth, combating negative stereotypes in the workplace is critical to ensuring that older workers have equal opportunities. This can be accomplished by providing management and human services training on the value of older workers. It also is important to review interview and application procedures for ageist statements.

Fifth, promoting opportunities for older workers for training, older workers can be encouraged to upgrade technology and other work skills to remain equal with their co-workers. The Committee for Economic Development (1999) states that job tenure is higher for older workers after training than for younger workers. Other training, including life long learning opportunities, can be offered to provide new opportunities for growth and development.

Sixth, create recruitment strategies for older workers and test new marketing areas for job recruitment efforts. Senior centers and churches, as well as other places older people may gather can provide new avenues for worker recruitment.

Summary

Retaining valuable, trained employees is critical for economic productivity. A *New York Times* article (8/15/99) stated that unless people can be persuaded to work longer into old age, developed nations will have to accept a loss of productivity, creativity and even general economic health.

A major problem of older workforce recruitment and retention is the predisposing cultural expectations and the entrenched negative thinking about aging and older workers. If we recognize the current trends of today's retirees and their interest in remaining active, we can plan their needs and skills so that they can be merged with those of business, industry and government.

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ECONOMIC CONSIDERATIONS

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Introduction: The Elderly in 2015

It is safe to say that older Americans in the next century will be different from older Americans today. But in what ways will they be different? If current trends continue, then we can expect that the next generation of older adults will be better educated, will be in better physical shape and have greater financial assets than previous generations. As we discuss economic considerations for aging Baby Boomers, we need to think in terms of programs that support the health and economic viability of this next generation of seniors.

It is suggested that New York State consider and address at least three components in the area of economics for the future generation of seniors. First, programs to support the needs of seniors who want to continue to work part or full time. Second, programs that draw upon the unique resources of New York State to make the state a more attractive living environment for a better educated, healthier, retired senior population. And finally, programs to expand current services and provide new services to that sector of the senior population that will remain economically disadvantaged.

Economic Protection

The most important governmental programs that provide economic protection for the elderly are Social Security, Medicare and Medicaid. The federal government funds Social Security and Medicare, and Medicaid is funded jointly by the federal government and the states. In addition to its role in funding Medicaid, New York State and local agencies offer a wide variety of economic security programs for seniors that supplement the direct financial and medical aid provided through these three major entitlement programs. Some of these programs are: part time employment, energy/fuel assistance, homemaker services, elderly pharmaceutical insurance coverage (EPIC), financial counseling programs, transportation services, legal aid, real estate property relief, rent subsidy, and meals programs delivered to seniors in their homes and served at senior centers. Many other social services and recreational programs funded directly or indirectly by state agencies enable seniors to manage their incomes more efficiently.

Demographics and Social Security

The foundation of economic security for seniors in New York State and the rest of the nation is Social Security. The future viability of Social Security depends upon the number of older persons and the future health of the economy. Projecting future demographic and economic trends are both problematic. Demographers make projections of the future size of the population based upon past trends of three variables: fertility, mortality and immigration. At first glance such projections seem straightforward, since everyone who will be 65 or older in 2015 has already been born. Anticipating the future, however, is never simple. Future mortality rates will depend upon progress in treating and curing the many chronic conditions that currently plague the elderly. In addition, no one can predict whether new diseases or the reemergence of old diseases will develop in the next century and what the impact of such diseases will be on the older population. For example, no one could have anticipated the emergence of AIDS as a major cause of death or the reemergence of tuberculosis thirty years ago. It is also difficult to accurately predict future immigration patterns or their impact on the size of the older population.

If predicting the size of the population is difficult, predicting changes in the U.S. economy are even more problematic. In the early 1980s there was much talk about the "the Japanese

Miracle" and there were many suggestions that we study Japanese production methods before our economy was overtaken by them. Today, with the Japanese economy experiencing a severe down turn, fears of a Japanese challenge to U.S. economic supremacy are no longer expressed in the media. Similarly, few people in the 1980s predicted that the Dow Jones Industrial Average would pass 10,000 before the turn of the century. Currently economists are predicting a period of extended economic growth for the U.S. economy and politicians are debating how to spend the huge anticipated budget surplus. This may or may not prove to be as unrealistic a projection as that of Japanese economic supremacy in the 1980s.

Since the 1960s, the older population has doubled in size. During the same period the number and size of federal programs to aid the elderly increased dramatically. Programs such as Medicare, Medicaid, the Older Americans Act, The Employee Retirement Income Security Act and significant increases in Social Security were enacted without causing the federal government to become insolvent. We were able to expand our economic and social support to the elderly because of the dramatic expansion of our economy. Since 1960, the Gross Domestic Product (a measure of health of the economy) has increased by over 220 percent (Demography is not Destiny, p. 1-2). If the next fifteen years are a period of economic growth similar to what we are currently experiencing (roughly 2.8 percent growth per year), then the federal government will be able to absorb the cost of spending programs as the size of the older population increases. (Demography is not Destiny, p. 3) Some modification in the Social Security system may have to be undertaken to address the increasing older population as the Baby Boom generation begins to retire, but if the economy remains strong, we should be able to absorb the increased cost to the system.

The Dividends of Social Investment

When businesses want to expand and increase their profits, they borrow money to expand their production capabilities. They borrow the money with the anticipation that increased profits in the future will more than compensate for the principal and interest they will have to repay. Similarly, after World War II the federal government invested money in veterans to enable them to go to college and graduate school. Over time the higher taxes that these veterans paid, because they had better paying jobs as a result of their college training, more than compensated the government for its investment in their education. Similarly, New York State should consider a policy of investing in its educational and cultural resources to: insure that the next generation of seniors remain in the state after retirement and continue to pay state taxes; and to attract seniors from other states to visit and pay sales and hotel taxes. An effective way to do this is to build upon the unique resources that New York State has that make it a highly desirable place to live and visit: its work opportunities, extraordinary colleges and universities and cultural and environmental attractions.

Rethinking Retirement and Continuing Education

We will need to critically rethink our definition of retirement. If people live longer, healthier lives, and more jobs involve mental rather than physical skills, many individuals will want or need to continue to work part or full time into their 70s and perhaps beyond. This trend will be accelerated by the ability of individuals to work at home using personal computers, modems and fax machines. Retirement will come to be a more gradual process in which seniors slowly decrease their work hours depending upon economic, physical, social and familial constraints.

We also will need to rethink what education should be like for a new generation of seniors. The lecture and discussion model of education employed in colleges and universities for younger adults may not be appropriate for older adults and new teaching modalities need to be explored. More educated seniors will want different types of programs and support services.

Research has demonstrated that physical exercise and weight training can have a positive impact on health. It is not much of a stretch to suggest that mental exercises might have a similar impact on mental functioning. Courses could be offered at senior centers, churches and other public institutions to encourage seniors to exercise both their minds and their bodies. Courses will have to be given in ways and times that are attractive to seniors who continue to work. In addition, courses and support groups should be developed that will help seniors deal with issues they confront as older workers at the workplace. The content of such courses will depend upon the interests and needs of seniors.

For example, the elder hostel model of one-week courses needs to be reconsidered for a new generation of seniors who may want more in-depth courses. For many seniors, education will become a life long process of continual growth. New York has federally funded Geriatric Education Centers (GECs) that provide training and information to professionals working with the elderly. What we now need to consider are state funded educational centers to develop curriculum materials and educational programs to meet the needs of the next generation of seniors.

Cultural Resources

New York State is fortunate to have some of the best museums, a wide variety of concerts, and of course, many theaters all over the state. Transportation programs, traveling exhibits and summer theater projects could bring seniors to concert halls, museums and to plays. Programs to bring seniors to cultural events and to bring cultural events to seniors could be mutually beneficial. Imaginative use of satellite television and the Internet could be explored to bring cultural events to greater numbers of seniors and enable them to interact with each other, authors, actors, artists and musicians. Rather than have seniors leaving to live in warmer climates, educational and cultural programs might serve as a magnet to attract seniors from other parts of the country to New York State.

Prosperity, But Not for All

If current trends continue we anticipate that not everyone will benefit from the economic gains predicted to occur in the next century. Greater numbers of older persons will be living alone. Individuals over the age of 75 will be the fastest growing segment of the older population. Older single persons represent one of the most vulnerable groups in society, and frequently require extensive physical, social and economic supports. Women will continue to be a majority of the older population, although more and more men will probably live into their 80s and beyond. Since older single individuals tend to have lower incomes than married couples they may require more extensive public support. Minority seniors (Blacks, Hispanics, Asian and Pacific Islanders and Native Americans) also will increase in numbers in the next century.

Older age cohorts and minorities have lower incomes and assets than younger age cohorts. This largely is the result of lower lifetime earnings. This trend will probably continue into the next century but will decrease as younger age cohorts reach retirement. These segments of the older population will probably benefit less from the general prediction of increased prosperity for older adults (Older New Yorkers in 1990 New York State Office for the Aging, http//aging.state. ny.us/explore/ population/csummary/ index.htm). Policy makers at both the state and federal level need to be sensitive to the special needs of these groups.

Programs, such as job training and employment services, need to keep pace with market trends. These programs need to be structured to help older persons find part time jobs and to be retrained to be able to compete for jobs that can supplement low incomes. Meal programs, transportation and homemaker services will likely have to be expanded. A recent study in Little Rock, Arkansas found that seniors who received meals at home had shorter hospital stays than seniors of comparable age and diagnosis who did not receive meals. In a paper by Norman Daniels, he argues that the greater the social inequality within a society the

poorer the health of the most disadvantaged groups (Daniels, 1999). If Daniels' thesis is true, we can anticipate that those groups left out of the new prosperity will be in even poorer health as seniors of the future will than the present cohort of poor seniors.

There are two possible strategies to address this problem. Either we can enact legislation that makes Social Security more redistributive or we can develop medical and social programs to try to combat the increased poor health that we anticipate within more economically disadvantaged groups. Since the State has no role in reforming Social Security it should anticipate that disadvantaged groups will require more supportive social and medical services as the income of middle and upper income groups rises.

Conclusion

There are many programs currently in place that are designed to address the economic and social needs of older persons. The next generation of seniors will have a different set of social and economic conditions that need to be identified and addressed. It is suggested that New York State consider and address at least three components in the area of economics for the future generation of seniors. First, programs to support the needs of seniors who want to continue to work part or full time. Second, programs that draw upon the unique resources of New York State to make the state a more attractive living environment for a better educated, healthier, retired senior population. And finally, programs to expand current services and provide new services to that sector of the senior population that will remain economically disadvantaged.

With these considerations, New York can build on its assets to continue make the State an economically viable and appealing place to reside for its older citizens.

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Project 2015:

The Future of Aging in New York State

LEGAL SERVICES

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Overview and Background

The legal problems of older adults are often more complex and diverse than those of the population at large. They may involve planning for changes in life such as retirement, long term care for chronic and debilitating illnesses, loss of capacity, and death. Just as often they involve coping with an unplanned for event such as the death of a spouse or the sudden onset of a catastrophic illness. Because these issues frequently involve families in crisis, these difficulties often exacerbate social and emotional family problems. They also often present ethical concerns for attorneys, such as who is the client when the family seeks help and how to help a client of diminishing capacity.

The solutions, like the problems, are frequently not simple. Attorneys must look at many other disciplines in addition to the law, such as medicine, gerontology, and social work, to help their clients as they age. They have to be familiar with available resources to help the person remain in the community, access public resources and identify appropriate care.

Legal services should be available for all older adults to plan for or to cope with a crisis. New York needs to consider how to make this possible in the future. Many people may not recognize that they may need legal services as they age. They have made it so far without hiring an attorney and they do not expect to require one in the future. Still others may recognize their need for a lawyer but are deterred by the high cost of legal services. It is within this context that New York needs to prepare for the delivery of legal services to older adults in the coming years.

Delivery of Legal Services

Public Legal Services

History of Legal Services Corporation and Older Americans Act: In the early 1970's, a working paper and related hearings by the U.S. Senate Special Committee on Aging provided the first evidence that the legal needs of our elderly population were not being met. Many older persons simply did not perceive the legal nature of their problems and, absent special outreach and education, would not seek legal assistance. Many of the problem areas involved Social Security, SSI, Medicare, Medicaid, nursing homes, insurance sales, housing and consumer fraud, indicating that those elderly most in need were of limited economic means.

Congress responded in 1974 by establishing the Legal Services Corporation (LSC) in an attempt to ensure equal access to justice under the law for all Americans. The LSC had its roots in the Office of Economic Opportunity, which provided some legal services at the local level to low-income persons.[1] From that beginning came the LSC mission of providing civil legal assistance to poor persons of all ages. Elderly and handicapped individuals are specified in the LSC Act as groups of people who have difficulty accessing legal assistance and are in need of special consideration.

In 1978, Congress made legal assistance a priority service in the Older Americans Act (OAA), one that, absent a waiver, must be provided by every area agency on aging (AAA). Unlike services provided by LSC offices, OAA legal services are not means tested.[2] Nonetheless, as the competition for federal dollars has increased and the overall economic and social status of the older population has improved, Congress has increasingly directed that OAA services, and legal services in particular, be focused on older individuals with greatest

economic and social need, with particular attention to low income minority individuals.

For more than a decade, at the federal, state and local level, a debate took place over how much funding OAA legal services were to receive. Finally, in 1987, Congress required each state to set a minimum percentage of funds that every AAA must spend on legal services.[3] New York has required AAAs to expend 7% of their funding on legal services since 1991.

Funding Concerns: As with many other programs for older residents, funding has not been able to keep pace with the need. Cutbacks by the federal government have resulted in a loss to New York's Legal Services Corporation (LSC) programs of $8 million annually. A second major source of funding for LSC programs, the Interest on Lawyer's Accounts (IOLA) funds, has experienced lower interest rates. IOLA funding has decreased from $30 million in 1992 to $11 million in 1999. In order to continue to make legal services available to those in most need, alternate sources of funding need to be found.

Private Legal Services

Rise of Elder Law:" Elder Law" has come of age as a discipline within the private Bar. The American Bar Association has a separate commission, which studies the legal problems of the elderly, and virtually every state and local bar association has created an elder law section or committee. The fact that by the year 2030 more people will be over the age of 65 than under 15 fuels this increasing interest in elder law. Virtually all law schools in New York State as well as at the majority of law schools across the country offer one or more courses on elder law and related topics and several law schools have created certificate and clinical programs that offer students the opportunity to develop a special expertise in elder law. The American Association of Law Schools has a standing committee devoted to aging and the law.

National Academy of Elder Law Attorneys (NAELA): NAELA is a voluntary organization of attorneys dedicated to enabling one another to identify and meet client needs through self-education and through the exchange of ideas and information. NAELA is composed of attorneys in the public sector and private practice who address issues affecting the elderly and disabled. NAELA also promotes a process of certification for elder law attorneys to promote professionalism in their field.

New York State Bar Association: The membership of the New York State Bar Association's Elder Law Section has grown dramatically in the last 10 years.

Other Alternatives

The most common legal needs of older persons (housing, public entitlements, health care)[4] are frequently not recognized as "legal" by elderly clients [5] and, as a result, they often do not get addressed in a timely fashion so that, in the end, a fairly simple problem can deteriorate into a major crisis. For example, when an income check is misplaced, the rent may not get paid, the landlord may start eviction procedures, stress and fear may cause isolation and physical and mental deterioration, which in the end may lead to institutionalization.[6]

When an older person is faced with a problem that is not recognized as "legal" she may turn to a familiar social worker or other non-attorney professional for help, rather than contacting a lawyer — it is in this context that non-attorney advocates become pivotal parts of the legal services systems, either as information and referral specialists, entitlement advocates, or as care managers.

Non-attorney advocates are multi-disciplinary: they consist of social workers, nurses, psychologists, paralegals, law and social work students, and volunteers. What they have in common is an interest in "aging" and an understanding that the problems of elderly persons often require a team approach to being solved. These advocates have proven, during the past 30 years, that they are up to the challenge, provided they are knowledgeable about income and health care benefits, are adequately trained on due process rights and administrative procedures and hearings, and know when to refer the case to an attorney for legal representation.

Administrative Proceedings

The legal problems of the elderly include wrongful denials, reductions, or terminations of public entitlements and health care benefits on which many older New Yorkers rely for their livelihood. Although these entitlements and benefits are subject to due process protections and administrative hearings, few elderly claimants are aware of these rights, nor are they necessarily able to engage in an administrative appeal without help from an expert. Administrative appeals are legal remedies that do not require attorney representation (although they demand informed advocacy and expertise that is not always in the domain of non-attorneys) — it is this area of law that is most conducive to use of non-attorney advocates — Law school clinic students, "one-stop" advocacy program staff, I&R employees of area agencies on aging, and private geriatric care managers all play effective roles, representing clients at administrative appeals, provided they are well trained and informed about the specific legal requirements that pertain to the facts of the case; many do so successfully with the help of legal consultants employed in legal services programs, the elder law bar, and geriatric education centers.

Future Issues and Trends

In 1970, the National Council of Senior Citizens reported to the United States Senate Special Subcommittee on Aging that among the legal problems common to older adults were issues relating to the cost of long term care, housing, guardianship, and abusive nursing home care. These issues remain of concern and have been joined by many other issues that have arisen out of our societal and cultural response to growing old. This paper touches on the most significant of these issues.

Long Term Care Planning

Statewide in New York for 1998, the private pay rate for nursing home care averaged $76,000 per year or $208 per day.[7] For the period 1992 to 1996, the average annual rate increase for nursing home care was 5.6% in the New York City metropolitan area[8] and 5.4% for the rest of the state. In the year 2015, an older New Yorker could expect to pay nearly $180,000 annually, or $493 per day if the current rates of increase continue. When an individual's private funds run out, Medicaid is the payer of last resort at a current annual rate of $61,000 per person.

As the cost of long term care increases, the need to plan becomes ever greater. Long-term care insurance has been promoted by many as a means of preserving lifetime savings and reducing the strain on the state's Medicaid budget. Long-term care insurance is evolving as a product and carries the promise of greater choice for consumers. It carries with it, too, the possibility of greater confusion. Without adequately understanding the interplay between Medicaid and private pay for nursing home care, an individual may purchase a long term care insurance policy that is unnecessary or inadequate or that may not cover needed care.

It is likely that Medicaid eligibility provisions at the Federal and State level will continue to undergo change, including the need to address the issue of perceived abuses in Medicaid estate planning. Therefore, those most in need of Medicaid will continue to need assistance in navigating the eligibility maze.

Housing

Increased life expectancy, cost of medical expenses, and demands on already limited resources require that state and local legislators and policymakers consider innovative ways to address the housing needs of New York's aging population. Although most older adults would prefer to "age in place" maintaining their dignity and independence in their own home, for many, chronic illness, general frailty and loss of mobility present barriers to that goal. New York has seen the growth of a variety of options for older adults, including assisted living facilities and Continuing Care Retirement Communities, shared living residences, accessory apartments and elder cottages. As the older population continues to grow and entrepreneurs market these options to older adults, seniors and

their families will no doubt require assistance in working their way through the legal consequences to them as consumers of these various options.

Assisted Living

The concept has evolved as an alternative to the high cost and institutional setting of nursing homes, demands for more personal autonomy, the increase in the number of widows aged sixty-five to seventy-five seeking affordable residential programs and the desire to age in place. In the absence of regulations, however, many residents may find that their choice fails to meet their long-term needs. An alternative to regulation, the residency agreement, could establish the rights and responsibilities of both the assisted living resident and the provider. Yet, contracts can also be vague, confusing, and lacking in the information necessary to bind the facility to specific services, fees, accommodations, staff or procedures for appealing adverse decisions by the facility. Consequently, residents of assisted living facilities are likely to need legal assistance with issues pertaining to rates charged, services received, accommodations utilized, and personal autonomy and resident safety.

End-of-Life Decision-Making

Advance directives in the form of living wills, health care proxies, and do not resuscitate (DNR) orders, are slowly gaining acceptance in the United States. An estimated 40% of older Americans have executed an advance directive [9]; however, this group tends to consist of educated Anglo-Americans. Ethnic minority Americans, the economically disadvantaged, those who have fewer years of education, speak English as a second language, or who have recently immigrated, are less likely to have appointed a health care agent.[10] Notwithstanding the federal Patient Self-Determination Act which requires health care providers to offer community education, access to forms, and compliance with advance directives, recent studies indicate that the existence of an agent or directive does not guarantee that the patient's wishes and the peace of mind of the decision-makers are guaranteed.[11]

Even though families tend to be heavily involved in caring for their elderly relatives and most elderly patients expect that their families in the end will make decisions for them, too little discussion about health care preferences is taking place among family members, or between patients and their families and health care providers. Appointed agents are often not informed about the patient's preferences at the end of life and have great difficulty "speaking with the patient's voice," as required by law. In addition, the "legalization of end-of-life health care" has resulted in a fear of liability on the part of the providers and an excessive reliance on risk management that does not serve the patients or their families well.[12]

Many state Legislatures, including New York State, are now considering alternatives to advance directives, by relying less on the principles of *patient autonomy* and *agency*, and instead, developing surrogate decision-making laws that enable family members and friends to make decisions in the *best interest* of patients, and promoting the use of ethics committees in health care facilities.

Grandparents as Caregivers

Many older New Yorkers are finding themselves acting as parents a second time around. For a variety of reasons such as death of a parent, divorce, abuse or neglect, chronic or catastrophic illness or substance abuse –reasons that cut across economic and social lines— grandparents and other relatives are often obliged to undertake the full time care of grandchildren or other young relatives. Although New York's laws fully address the legal rights of parents in meeting the needs of their children, the laws are far from clear regarding the rights and obligations of kinship caregivers. Consequently these kinship caregivers often face legal problems as they attempt to meet the needs of the children in their care. The caregivers are often unable to obtain prompt medical care, access health insurance, or enroll the children in an appropriate school district. The laws governing guardianship, foster care, and custody offer little or conflicting guidance and are not well

understood by practitioners and judges across the state. Hence, the caregivers are uncertain about whether they should pursue a formal legal arrangement such as guardianship or custody or carry out their responsibilities in an informal way.

Guardianship

The shifting demographics that promise a greater percentage of older New Yorkers in the next thirty years is also the harbinger of the "statistical inevitability that more and more capacity problems will emerge." [13] While many people may engage in voluntary planning to avoid a crisis, many people will lack the education, the legal services or even the moral resolve to allow them to execute durable powers of attorney and health care proxies and living wills and do-not-resuscitate orders. The absence of advance directives presents a major concern when the individual's capacity is questionable. Banks, financial institutions, hospitals and nursing homes as well as other organizations want to identify a third party who possesses the definitive unimpeachable authority to make a decision.

Consequently, a court must make the appointment of a surrogate decisionmaker, known in New York as a guardian. A guardian is a person appointed by the court to make personal care and/or financial management decisions for a person who is determined to need such a decisionmaker and who agrees to the appointment or is determined by the court to be incapacitated. To be found incapacitated, a person must have functional limitations that prevent him /her from meeting his/her needs and must fail to recognize the harm that can befall him/her because of those limitations. Although New York has three different forms of guardianship for an incapacitated person: Guardian of an Incapacitated Person — Article 81 of the Mental Hygiene Law, Guardian for Veterans and Infant Wards of the United States Veterans Administration — Article 79 of the Mental Hygiene Law, and Guardian of a Person with Mental Retardation or Developmental Disabilities— Article 17A of the Surrogate's Court Procedure Act, the Guardian of an Incapacitated Person – Article 81 of the Mental Hygiene Law is the appointment most frequently sought for an older adult who has lost the capacity to make decisions on his or her own behalf.

The goal of Article 81 is to address diverse and complex needs of individuals with incapacities and to provide the court with the necessary flexibility to grant appropriate relief to meet those needs of the person and also allow the person to maintain "the greatest amount of self-determination and independence and participation in decisions affecting his or her life."[14] In so doing, the statute reflects the national trend in the reform of guardianship law. It provides for vigorous advocacy for the person alleged to need a guardian, the assessment of capacity based on a functional assessment rather than the diagnosis of an illness, use of the least restrictive form of guardianship and training and education for court personnel and guardians. Nevertheless concerns remain about the cost of guardianship and the provision of guardianship services for indigent individuals.

Additional protections in the guardianship process have come at a price that not everyone can afford. When the person in need of guardianship services lacks the assets to compensate the guardian, often for many services, it is difficult to find a guardian willing to serve *pro bono*. New York has enacted a community guardianship program but it has become effective only in New York City where three not-for-profit corporations have contracted with the Human Resources Administration of the city of New York to provide guardianship services to PSA clients for whom the court has appointed a guardian. Outside of New York City, there are no community guardianship programs and although some not-for-profit organizations do provide such services in other parts of the state, they are few and far between. Consequently, the courts are left to their own devices as they scour the landscape for someone willing to serve without compensation.[15]

Options and Alternatives

Interdisciplinary Approach

By recognizing each other's role in the delivery of services to the elderly, advocates of

many disciplines have become close partners with attorneys in legal services and elder law. In this new century in which the percentage of older Americans is likely to double, interdisciplinary approaches to serving the elderly will remain essential and need to be fostered and encouraged.

Coherent Public Policy

As New York faces this demographic surge of older adults, policy makers should not respond piecemeal. Well-intentioned legislation may solve one problem but have unintended consequences in another area if it is not thought through. A comprehensive approach to the legal problems of older adults would make the delivery of legal services less difficult. Likewise, as we plan for the future of older adults, we need to be mindful of all New Yorkers lest we offer up solutions that create problems for those left in the wake of the demographic wave.

Funding

In 1998, Chief Judge Judith Kaye's Legal Services Project proposed creating an Access to Justice Fund. A dedicated revenue stream of $40 million derived from the State's Abandoned Property Fund would support this fund. Bills based on the proposal have been introduced in both the Senate and Assembly.

As noted in the proposal of the Chief Judge's Legal Services Project, a loss of funding means staff reductions and a resulting reduction in the number of clients served. Many individuals with meritorious claims and most in need of assistance have to be turned away. A dedicated funding source, such as the Abandoned Property Fund, would enable programs to provide assistance to more older residents.

Modern Technology

Modern technology offers an opportunity for older New Yorkers and their families to obtain a wealth of information on legal issues. Those that are likely to see the greatest growth and usage over the next fifteen years or so are the Legal Hot Line and the Internet.

Legal Hot Lines: A legal hotline would allow persons 60 or over, or people calling on their behalf, to speak to an attorney about their legal problems or questions. A legal hotline would not offer actual representation but could provide a referral to a legal service program or a private bar member. Currently, 17 states have legal hotlines for people 60 and older funded by the U.S. Administration on Aging (AoA). This number is likely to increase and it is likely that New York will be among those states that will operate at least one hot line. The obstacle for any legal hot line is obtaining an ongoing source of funding once the AoA grant expires, typically after three years.

The Internet: The use of any common search engines to find elder law related materials will present literally thousands of results. Searching the Internet will allow an older New Yorker to acquire information and become familiar with an issue before seeing an attorney. Thus, the time spent with the attorney is more productive for both parties.

Some simple problems may even be resolved without attorney involvement. There are some pitfalls that need to be avoided, however. Laws can and do vary from state to state, so seniors need to make sure that the information they find on-line applies in New York. They also will need to make sure that the information they find is current and not outdated or superseded.

Training for Lawyers

Lawyers in New York have recently been required to continue their legal education after law school. Whether newly admitted or old hands, each attorney is required to complete a certain number of credits in courses related to ethics, skills, practice management and substantive areas of professional practice. This education requirement will help attorneys working with the elderly to keep up to date with many areas of the law, which are changing rapidly.

Other topics relating to the elderly are also becoming the subject of more education. For example, financial and physical abuses are serious problems among the elderly. Many banks, law enforcement agencies and other professionals who work with the elderly are educating themselves and members of the community

about how to spot elder abuse and what to do when elder abuse is suspected.

Educating seniors is also important. Planning for future care and financial management is critical for older adults. Learning what to do, how to do it and when legal services are necessary or appropriate will help pave the way for a smoother delivery of legal services and help families avoid crises.

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[2] The Older Americans Act was conceived in 1965 to address the needs of *all* older persons and its purpose was broadly directed at giving them an opportunity for full participation in the benefits of society. To this end, the regulations implementing the OAA specifically prohibit means testing. 45 C.F.R. § 1321.71(d)-(e).

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[14] NY Mental Hyg. Law § 81.01 (McKinney 1996).

[15] *See, e.g, Matter of JASA(Cedeno)*, 674 N.Y.S.2d 34 (1st Dept. 1998)(Community guardian program cannot be used when person is in nursing home); *Matter of Skinner (Lyle)*, N.Y.L.J. (Sup. Ct. N.Y.Co.) February 21, 1997, rev'd 1998 WL 255561 (N.Y.App. Div. 1st Dept., May 21, 1998)(court cannot require petitioner to pay fee of special guardian when person is indigent); *Matter of Gambuti, Bowser*, 242 A.D.2d 431, 662 N.Y.S.2d 757 (1st Dept. 1997)(special guardian not available when person is transferred to nursing home).

Project 2015:
The Future of Aging in New York

NUTRITION

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Introduction

Helping Baby Boomers to adopt healthy exercise and nutrition habits now will significantly affect the need for and cost of long term care in 2015. When Baby Boomers reach old age, good nutrition will play a significant role in affecting chronic health conditions and illness. In 2015, we will be able to classify Baby Boomers into three general nutrition categories:

1) *healthy* and *relatively healthy* older adults who are able to care for themselves;
2) those requiring varying degrees of support, whose residential arrangements range from living independently in their own homes to residing in facilities that offer long-term skilled nursing care; and
3) older adults who are *food insecure*. These groupings are *not* mutually exclusive.

Healthy and Relatively Healthy Older Adults

As Baby Boomers age, many will continue their commitment to preventive health and preventive nutrition. At age 65, the most common reasons for Baby Boomers' physician visits will be for general medical examination, post-operative visit, vision dysfunction, blood pressure testing, and cough. Their most common diagnoses will be hypertension, diabetes, cataract, chronic ischemic heart disease, glaucoma, and osteoarthritis and associated disorders. Nutrition is a consideration in many of these conditions.

Older adults who appear healthy are not necessarily in good nutritional health. Poor nutritional status includes excesses such as alcohol abuse, nutritional imbalances that result in obesity and under nutrition and nutritional deficiencies, and changes in physiologic functions that may compromise nutritional status.

For older Americans, risk factors for poor nutritional status include inappropriate food intake, poverty, social isolation, poor mental health, poor oral health, dependence/disability, acute/chronic disease or conditions, medication use, as well as advancing age. The greater the number of risk factors and the longer they persist, the greater the likelihood that poor nutritional status will ensue. Easy-to-use screening questionnaires (such as DETERMINE Your Nutritional Health developed by the Nutrition Screening Initiative) are useful to identify older adults who appear healthy, but may be at nutritional risk.

For Boomers who have already been diagnosed with chronic nutrition-related conditions, the authors recommend an immediate increase in the proportion of physician visits at which counseling and educational services are ordered. To identify nutritional risks in older adults, who appear healthy, the authors recommend using an easy-to-use instrument for nutrition screening, at least once a year.

Also, the authors recommend that an active Web site be available in the future that contains evaluations of food and nutrition products marketed to Baby Boomers, especially products with implicit as well as explicit claims to promote health and prevent disease.

Older Adults Who Require Varying Degrees of Support

Living arrangements for older adults who require varying degrees of support range from living independently in their own homes to being in facilities that offer long-term care. Maintaining the nutritional status for many of these older New Yorkers may include providing medical foods and enteral or parenteral nutrition therapy. Referrals to providers such as registered dietitians, pharmacists, dentists, social

workers, and mental health professionals will be crucial to alleviating compromised nutritional status.

Screening individuals routinely, at least once a year, is the key to using nutrition care to slow the progression of chronic disease. The goal is to catch problems in the early stages, not once someone is hospitalized. Year 2010 Healthy people is the United States' contribution to the World Health Organization's "Health for All" strategy. One of its objectives is to increase to at least 75% the proportion of primary health care providers who provide nutritional assessment when appropriate and to at least 75% the proportion that formulate a diet/nutrition plan for patients who need the intervention.

The Nutrition Screening Initiative (NSI, 1998) is a national initiative to promote routine nutrition screening and better nutrition care for the elderly. One of its objectives is to utilize existing aging service networks to promote nutrition screening and care. We support this initiative and endorse routine nutrition screening and interventions at physician office visits, to ensure that:

Patients receive nutrition screening and interventions at many points across the continuum of care, not just in a physician's office. With the fragmentation of care and increasing numbers of the elderly receiving health services at home, every health care provider should be alert for signs and symptoms of malnutrition. Home care and long-term care providers, for example, should assure nutrition screening is conducted to identify people in need of nutrition therapies before costly and preventable nutrition-related problems develop. Regardless of the particular diagnosis, the routine provision of nutrition screening and intervention across the continuum of care will improve nutrition status, enhance disease management outcomes, minimize complications, lower health care costs, and have a positive impact on health and quality of life.

Nutritional assessment includes a diet/nutrition plan and recommendations regarding other important interventions (e.g., problems associated with multiple medications, dental and oral health problems, functional status, economic issues, and mental health concerns), in addition to nutrition education and counseling.

The authors endorse routine nutrition screening and interventions at physician office visits and during home visits.

Elderly Adults Who Are Food Insecure

Food security, malnutrition and hunger are closely related. *Food insecurity* is the "limited or uncertain availability of nutritionally adequate and safe foods or limited or uncertain ability to acquire acceptable food in socially acceptable ways." (Hamilton et. al., 1997). Food security includes a third element in addition to the two in the definition (availability and access)—utilization of food. Elderly food insecurity follows a progression of severity beginning with compromised diet quality and progressing to food uncertainty, then socially unacceptable meals, use of emergency strategies, and finally, actual hunger (Wolfe et. al., 1996, 1998). Hunger is "the uneasy or painful sensation caused by lack of food." (Hamilton et. al., 1997).

Older adults, especially those with limited financial resources, are at increased risk of suffering health consequences as a result of food insecurity. Although aging itself does not cause malnutrition, older adults have a number of risk factors that contribute to food insecurity, increasing the likelihood that malnutrition will develop. Among these factors are diseases such as arthritis, chronic lung disease, heart disease, and neurologic diseases; disabilities, functional impairments, and dependency; sensory losses; impaired oral health; chronic use of multiple medications; use of specially prescribed diets; and social isolation. Food program participation, life experiences, food management skills, community characteristics and availability of family members, also relate to food insecurity in the elderly (Wolfe et. al., 1996, 1998).

Malnutrition is "a weakened, disordered condition brought about by prolonged lack of food." (Hamilton et.al., 1997). Malnutrition in older adults results in loss of muscle mass and

strength, which can affect very basic functions such as walking and standing, and also can lead to disability that may cause loss of independence. Malnutrition can compromise immune function in elderly persons, leaving them more susceptible to developing pneumonia and other infections that can be life threatening. Malnutrition may contribute to confusion and disorientation, which may lead to institutionalization (Codispoti, Bartlett, 1994). Nutritional risk is an important predictor of hospital admission and visits to physicians by older adults, which increase costs to the Medicare system. Food insecurity is associated with low intake of energy, protein, carbohydrate, saturated fat, niacin, Vitamins B_6, B_2, B_{12}, magnesium, iron, and zinc, as well as, lower skinfold thickness (a measure of energy stores). Also, food insecure elderly are 2.3 times more likely to report fair and poor health status than food secure elderly (Frongillo and Lee, 1999). Thus, food insecurity among older adults influences their quality of life in very important ways, and also has implications for society in terms of health care costs (Torres-Gil, 1996; American Dietetic Association, 1998).

The authors recommend: 1) developing a method of identifying counties in New York State with greater and lesser need as a resource allocation consideration; 2) targeting nutrition services to food insecure elderly; 3) improving outreach and expanding programs to more of those who are food insecure and homebound, and/or eat alone; and 4) developing training materials to prepare health care professionals who will be working with the food and nutrition issues expected to challenge New York's aging population.

Nutritional Health of Today's Elderly New Yorkers

Based on a statewide telephone survey to assess the extent of nutritional health risks among New Yorkers over the age of 60 years (NYS State Office for the Aging and NYS Department of Health, 1994): One out of every four elderly New Yorkers who lives at home is nutritionally at-risk of malnutrition (approximately 728,000), based on:

1) the presence of at least two NSI warning signs of poor nutritional health,
2) food insecurity, and/or
3) being homebound.

The prevalence of nutritionally-at-risk elderly is highest among those who are most likely to have functional impairments and lower incomes, i.e., women who live alone, minorities, and the "old old" (85 and older).

The presence of two or more warning signs of poor nutritional health is reported by 18.5% (approximately 539,000) of New York's elderly. Elderly New Yorkers most likely to have at least one of the factors associated with the risk of malnutrition include almost one-third of those living on incomes below the poverty level, 29% of minority elderly (including 29% Black and 28% Hispanic), one-fifth of elderly women, and those 75 or older. The prevalence of individual warning signs ranges from a low of 3% who have "3 or more drinks ... every day" to 42% who say they eat "alone most of the time." Elderly New Yorkers most likely to be at high nutritional risk include: 42% of elderly persons living on incomes below the poverty level; 39% of minority elderly (including 41% Black and 37% Hispanic), and 36% of those aged 75 or older. Based on the NSI warning signs, these high-risk elderly New Yorkers would benefit from nutrition education and intervention by qualified professionals.

When low income is coupled with fragility, the elderly may skip meals, may not be able to shop for food or to prepare meals, or may be forced to choose between buying food and paying for other necessities such as medicine, housing and utilities. The Elderly Nutrition Survey found 11.4% (332,000) of elderly New Yorkers experience at least one of the three food insecurities described above, ranging from 4% who skip one or more meals to 7% who had to choose between buying food and other necessities during the past six months. Food insecurity is significantly more prevalent among

minority elderly (24% in comparison to 8% of White non-minority elderly) and elderly New Yorkers in poverty (22% in comparison to 8% of those above the poverty level).

Food Assistance Programs

Service networks to provide elderly people with a continuum of home- and community-based long-term care allows them to avoid unnecessary and costly institutionalization (AoA, 1997). One very important component of any package of home- and community-based services for elderly people is the provision of comprehensive nutrition services.

Elderly persons most at-risk nutritionally are often those who, because of physical incapacity from chronic health problems or following acute hospital stays, are unable to shop, prepare meals or feed themselves. In many cases, family or other informal caregivers provide the assistance the elderly person must have. When such caregiving is inadequate or simply not available, the elderly person may require services that include home delivered meals (HDM — the delivery of hot meals to the older person's home), nutrition counseling, and/or shopping assistance. HDM services are needed by 6.6% (193,000) of elderly New Yorkers, including 3.5% (101,000) who rarely leave home and are almost entirely homebound and without informal supports. Less than one-third (2%, or 57,000 older people), however, receive such assistance (NYS; 1994). Elderly New Yorkers most likely to need HDM services include: 16% of those aged 75 or older; 14% of elderly persons living on incomes below the poverty level; 13 % of minority elderly (including 10% of Black and 16% of Hispanic aged), and 9% of elderly women.

Several food assistance programs are also part of the community-based services targeted to older individuals. The Food Stamp program is the most important program of USDA overall, but is under-utilized by older persons. In New York State, funding was provided for outreach to older persons eligible for Food Stamps and for a study to be conducted by the Nutrition Consortium of New York. Results from the study showed that older persons often exclude themselves from the Food Stamp Program, and do not see themselves as needing this resource. The study also showed that older persons expected their Food Stamp benefit would be lower than the actual benefit would be. While the Food Stamp program is an option for persons who are economically in need and food insecure, a challenge is in getting older people to use the resource. Doing so would take dispelling the myths held about the benefits of the program. For the elderly, congregate meals and HDM are also available, and USDA provides a substantial amount of funding to these programs, ($140 million in FY 1997), funding that is augmented in New York by State and local funds and participant contributions. These food assistance programs are targeted to those with the "greatest economic or social need." These targets are set to help nutrition programs provide services more efficiently and implement appropriate outreach activities. Food assistance programs for the elderly have succeeded in accomplishing their mission of improving the nutritional intake of elderly people, as well as decreasing their social isolation (AoA, 1997).

In New York, HDMs appear to have a positive impact on food security and dietary practices. For example HDMs for diabetics may lessen the risk of diabetic-related hospitalizations (Edwards et. al., 1993). However, it is estimated that there is considerable unmet need for elderly meals programs, and that 10-17% of program participants experience some food insecurity (Ponza et. al., 1996). In addition, increased national awareness of hunger and food insecurity in the elderly raises doubt about the reach of food assistance programs for the elderly.

Current Elderly Nutrition Programs and Services

The New York State Office for the Aging (NYSOFA) administers the Elderly Nutrition Program (ENP) under Title III-C of the Older Americans Act and the state-funded Supplemental

Nutrition Assistance Program. Other ENP services include nutrition education, nutrition counseling, shopping assistance and transportation. The services provided by the ENP are made available through local Offices for the Aging, which serve all New York State counties.

The ENP provides a mid-day meal, five or more days per week, to persons age 60 and over at congregate nutrition sites. Besides a nutritious meal, congregate nutrition sites provide social interaction and access to other services including health screening, financial counseling, nutrition and health education, and recreational activities. Other services of the ENP include shopping assistance and transportation services. Shopping assistance is provided to obtain food, medicine or other necessities usually in conjunction with transportation services.

The ENP also provides meals at the older person's home. HDM are appropriate for those individuals assessed incapacitated due to accident, illness, or frailty, unable to prepare meals, and lacking other support for meals. One or two meals five or more days a week may be indicated when other support is not available. HDM are a vital component of in-home supportive services designed to delay or prevent inappropriate institutional care. In NYC, the Department for the Aging provides nutritious HDM for elderly New Yorkers five days per week; Citymeals-on-Wheels [http://www.citymeals.org/] provides HDM on weekends, holidays, and times of emergency, when these vulnerable seniors would otherwise go without food. In other communities, similar programs are operated under the aegis of religious organizations, hospitals, and other humanitarian groups.

The goal of nutrition education and counseling activities is to improve eating habits by aiding participants to make informed food purchasing choices and to develop positive attitudes toward good nutrition. Nutrition education programs are presented to congregate nutrition participants, and nutrition education information is provided to HDM participants. Nutrition counseling is available to congregate and HDM participants identified at high nutritional risk. It provides guidance and information through interpersonal sessions to participants and/or their caregivers to improve health status through appropriate adjustments in dietary intake.

We recommend that the Gerontological Nutritionists Practice Group of the American Dietetic Association become a lead organization for training NYS health care workers who will be responsible for assuring the nutritional health and well-being of Baby Boomers as they enter old age.

Trends in the Food Industry

The food industry will produce more and more products targeting aging Baby Boomers who are health and nutrition conscious. A spike in wellness-related products is expected as boomers reach their sixties, with emphasis on economics, convenience, taste and nutrition. Nutritional fortification, for example, will become increasingly important to the elder market because:

Aging consumers need increased amounts of Vitamin D and calcium in their diets to combat the effects of osteoporosis. As there is an increase in lactose intolerance with age, calcium-fortified food products and calcium supplements should be expected to proliferate because milk may not be a regular part of the diet.

10-30% of older adults are estimated to have protein-bound Vitamin B_1 malabsorption. All people over the age of 50 years are at-risk for this condition, and recommendations to consume the majority of the Recommended Dietary Allowance for this essential nutrient as synthetic Vitamin B_{12} has been suggested. (Ho, Kauwell, Bailey, 1999).

Products will be formulated to compensate for losses of taste and smell, which are common in the elderly. These losses result from certain diseases (especially Alzheimer's disease), medications, surgical interventions, as well as from normal aging (Schiffman, 1997). Examples of products targeting seniors are: flavor-enhancement to amplify aroma; soups and vegetables flavor-enhanced with a variety of herbs; and added coffee and chocolate to mask bitter tastes.

Conclusions

In just 15 years, NYS will experience the largest number of residents turning 65 years of age in its history. Health care professionals will require training to develop the skills and attitudes necessary to maintain older adults in an optimal state of health in their own natural environment. As nutrition plays a critical role in disease prevention, health promotion, chronic disease management, and medical treatment of disease and injury, we propose the following:

1) The proportion of physician visits at which nutrition counseling and educational services are ordered or provided should be increased to prevent disease progression in boomers who have already been diagnosed with nutrition-related conditions (e.g., type 2 diabetes, cardio-vascular disease).

2) An active Web site should be developed and maintained that contains evaluations of food and nutrition products marketed to Baby Boomers. Products with implicit as well as explicit claims to promoting health and prevent disease should be included.

3) Routine nutrition screening and interventions should be expanded beyond physician office visits: a) patients should receive nutrition screening and interventions at many points across the continuum of care, and b) nutritional assessment should include a diet/nutrition plan and recommendations regarding other important interventions (e.g., problems associated with multiple medications, dental and oral health problems, functional status, economic issues, and mental health concerns).

4) A method should be developed to identify counties with greater and lesser need of food insecurity for resource allocation consideration.

5) Nutrition services should be targeted to food insecure elderly to address food insufficiency, thus preventing its adverse nutritional and health consequences.

6) Outreach should be improved and programs expanded to reach more older people who are food insecure and homebound.

7) The Gerontological Nutritionists Practice Group of the American Dietetic Association should be invited to become a lead organization for the food and nutrition training of health care workers who care for the booming older population in New York State.

Recommendations for Public Policies in Nutrition to Promote Healthy Aging

Public policies should:

- Emphasize screening for nutritional risk factors.
- Employ appropriate nutrition interventions to address risk factors.
- Focus efforts on reducing food insecurity, an especially strong risk factor.
- Encourage the food industry to fortify foods to help meet the greater nutrient requirements of older people.
- Emphasize exercise, especially resistance training, in combination with nutrition services.
- Provide greater availability and individualization of nutrition services, and specifically, provide more home delivered meals.
- Focus attention on the need for nutrition supplementation for undernourished people.
- Provide improved outreach for food stamps among the older people.
- Build better coordination/communication between aging network and emergency food programs.
- Perform better nutrition program evaluation to ensure that programs are meeting their intended goals.

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Project 2015:

The Future of Aging in New York State

BRIEFS

New York State Office for the Aging
and
The State Society on Aging of New York

Project 2015:
The Future of Aging in New York State

BRIEF
Gerontology and Geriatric Education: Professional and Paraprofessional Issues

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This brief will highlight educational trends, challenges and opportunities in the 21st century for gerontologists and geriatricians that will influence how professionals and older adults interact. In addition, health and long term care services for older adults, which include an increasing demand for care in the home and community, require a parallel look at educational trends with paraprofessionals.

It is tempting to assume that the health and human service professionals that serve the older adult population will be adequately prepared to meet the challenge of the demographic imperative. New York is one of the leaders in medical and health education, yet there is reason for concern about training of professionals to appropriately work with older adults.

Training professionals in health and human services disciplines in aging-related issues has been a topic of increasing importance over the years, yet there has been no consistently successful effort to infuse gerontology or geriatrics into the curriculum for professionals. Many disciplines do not have a required aging curriculum, nor do they have a gerontology or geriatric practice specialization. It is quite possible to become a physician, dentist, licensed physical therapist, speech therapist, clinical psychologist or social worker without course work or practical experience in the field of aging. Within nursing homes, there is no requirement that the medical director have any special certification in geriatrics.

In the 21st century, there will be a projected shortage of geriatricians. Current research by Reuben indicates that each year, more physicians abandon geriatrics than become geriatricians. Consequently, generalists, or primary care physicians will provide most medical care of older persons in the 21st century. Similarly, despite the growing demand for human services professionals with training in gerontology, not nearly enough students are pursuing careers in aging.

Rural areas are particularly vulnerable to the gap in trained professionals and availability of paraprofessionals. The creative use of technology and the reinvention of physician home visits (perhaps through 'virtual visits') are components that need to be considered. The increasing awareness of health promotion and disease prevention, including personal nutrition and importance of physical fitness, need to be included in the equation of training for professionals serving older adults, as does the fit of alternative medicine.

Academic programs in the health and human service professions should be encouraged to increase students' exposure to geriatrics and aging issues. The challenge is two-fold: to stimulate interest in working with older adults, and to enhance the aging-related knowledge and skill base of future practitioners with a general background who will continue to have a critical role in caring for older adults.

Along with the need for individuals to <u>enter</u> the fields of geriatrics and gerontology, there is a serious need for greater and more effective <u>continuing education</u> for professionals working with older adults. Work by Davis and others suggests that effective continuing education for physicians and professionals in other disciplines should be active, involving and empowering of the practicing professional, as it should for individuals entering the field.

New York State is fortunate in having several major public and private universities

with nationally known experts in geriatrics and gerontology. New York also has active professional associations such as the State Society on Aging, a statewide Area Health Education Center (AHEC) and two federally-funded Geriatric Education Centers (the Finger Lakes Geriatric Education Center and the Consortium of New York Geriatric Education Centers, based in New York City). The mission of the Geriatric Education Centers is to promote the geriatric education of faculty and continuing education of practicing professionals; as such, they serve as focal points for more comprehensive statewide educational efforts.

For health and long term care services in the home, community and institutional settings, the 21st century will see a continued, exacerbated shortage of front line workers - those workers that provide hands-on care (e.g., personal care aides, nurses aides). In the shifting locus of care and service delivery for individuals from institutions (hospitals, nursing homes) to home and community settings over the past 10 years, a major challenge has been the shortage of workers to provide needed care. This trend is growing in the tight labor market in which we live. Recognizing the impact of this shortage on the delivery of appropriate health and long term care services to older adults is essential to addressing the issue. Enhancing the relationship among service recipient, paraprofessional and professional provider will be critical to meet the growing demands of older adults for interactive health and long term care strategies.

There is a great deal to consider in the future of geriatrics and gerontology. Following are items for further discussion and deliberation:

As the shortfall of geriatricians continues, primary practitioners play a significant role in the medical care of older adults.

It is imperative that primary care physicians have the special knowledge and skill to work with older adults. In addition to being familiar with the presentation of geriatric diseases, syndromes and their management, physicians need to be skilled communicators. Whether or not a physician is a trained geriatrician, exposure to geriatrics and communication skills needs to be included in the curriculum of future physicians.

Active educational leadership and effective coordination are needed among geriatric centers, university departments, professional societies and state agencies (e.g., New York State Office for the Aging, State Department of Health, State Education Department) to develop educational priorities and to foster synergistic use of resources in the private and public sectors.

Trends in the labor market: Because of demographics, paraprofessionals and caregivers have become and will increasingly become stable components of the service delivery system. Yet recruitment, training and retention of paraprofessionals remains a major challenge in the tight labor market. Similarly, the ratio of informal caregivers to care recipients is declining. Because of their critical role, any consideration of education/continuing education in geriatrics and gerontology should include them. For example, how to interact with paraprofessionals should be part of education for persons planning to work on a professional level with older adults.

Development of career ladders for paraprofessionals within the network of services for older adults should be reintroduced as a means of attracting individuals to the field.

More and more, consumers expect to play a central role in care they may need. Education and training in geriatrics and gerontology should consider a strengths-based approach to working with consumers, in which the consumer is at the center of care. This approach better aligns service delivery with consumer expectations.

Trends in health care, such as use of alternative medicine, and trends in home and community-based services, such as consumer-directed care, should be considered in future curriculum development and implementation in New York.

Health promotion and disease prevention themes, especially nutrition and exercise for older adults, should be considered as part of geriatric and human service education.

The role of technology in future care delivery and information availability should be evaluated.

New York State should review available gerontology and geriatrics credentials used in other states for professionals at the state or professional level for the various disciplines, and New York should consider whether to establish which are best for professionals in New York.

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Project 2015:
The Future of Aging in New York State

BRIEF
Teaching Youth About Aging And The Aging Process

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In Japan, when older persons say they are 75, the traditional response is "congratulations on having achieved such an age."

In America, it is usually "you don't look your age."

The difference in these statements shows that Americans consider youth an asset and have underlying anxieties about aging. "Late life in America is to some degree still considered as a time of loneliness, ill health and decline." (Images of Aging in America, AARP, 1995.)

Introduction

By 2015, when many of today's youth will be well into the workforce, nearly one out of five persons will be over age 60 (Demographic Projections to 2025, NYSOFA, 1999). With the rapid growth of New York State's elderly population, all aspects of our communities are changing. The implications for the structure of families, social programs, workforce, health care, and economic security systems are tremendous. Increasing longevity also has implications for personal lifestyle and retirement planning for younger generations. All of these have implications for how society views the aging process and the "value" of older people.

Despite the "graying" of our society, children at all grade levels have negative images of older people. This is reiterated in AARP's Images in America (1995), which included a national random sample of teens and a survey of children ages 6-11. This study showed that children form negative stereotypes about the elderly at a very early age.

Children perceive growing older as a process of decline, without potential for growth and fulfillment. Images of aging as depicted in children's drawings emphasize disabilities, isolation, and dependency. Missing from children's images is the vision of physical and mental wellness in later life, involvement with others, independent living, productivity, and connection with the larger community (NRTA, NATLA 1997).

Despite the knowledge of children's negative attitudes about older people, children are exposed to very little about the aging process or to older people directly in order to promote a more realistic view, even a positive image, of aging. Several researchers have found that when schools have initiated programs at different grade levels to teach about aging, the results have been very positive on how children view older people and the aging process (Aday, 1996; McGuire, 1994). In addition, interactions with older people were found to be a factor in forming positive images of the elderly and reducing stereotyping (Jantz, et.al, 1977; Rich, et.al, 1983; AARP, 1995).

However, numerous barriers to teaching about aging have been identified (Aday, 1996). These include: inadequate resources and materials; lack of interest by teachers; lack of trained teachers; aging represents a nontraditional topic and has a low priority; attempts at content integration have been unsuccessful; difficulty in finding suitable volunteers; lack of transportation to intergenerational opportunities and events; and difficulty in gaining administrative support.

Workload and poor materials are also factors that prevent development of additional programs. Markson and Pratt (1996) point out that, on average, a public school high school teacher has five classes per day of forty-five minutes each. They prepare for their classes as many as 1,000 times each year. Given these limitations, teachers must rely heavily on text-

books that often don't include appropriate information about aging.

Another barrier to teaching children about aging is the lack of national or statewide policies and incentives to develop appropriate curricula. The 1995 White House Conference on Aging called for the development of programs that teach children about the elderly. However, only four states, Connecticut, Mississippi, Missouri and New York have developed or tried to develop aging curriculum (Lucchino, Lane and Ferguson, 1997).

Examples of successful programs in New York State include but are certainly not limited to:

Service Learning Projects. In service learning, students participate in volunteer community service projects that assist senior citizens and other needy groups. Service learning activities that involve older people can include friendly visiting, telephone reassurance and assisting at nursing homes. Some funding through the National Service Corporation's "Learn and Serve America Grants" program helps support this effort. Presently, 44 school districts in New York State receive funding through these grants.

Older persons in the schools: In response to the recognition of the critical link of strong reading skills to success in school, the New York State Rural Education Advisory Committee (REAC) has engaged in an intergenerational project to bring together rural schools and agencies/facilities serving older persons. In a school setting, intergenerational programs can link older persons with students to share common experiences and the love of learning. Older persons participate in school experiences daily, weekly or occasionally for special events. A Guide titled, "Generations Together: Reading for the Future" (REAC, 1999) includes descriptions of 23 of these programs found across the state.

Inclusion of gerontology in various high school curricula. There has been some success by New York State Office for the Aging Advisory Committee members in working with local school district health teachers in developing a part of their curriculum dealing with the aging process.

The State of Connecticut has developed a local planning process to implement education about aging in schools. They have also published a series of technical assistance materials that include models of curricula and intergenerational programming exercises.

Given the realities of a "graying society" and the positive results associated with K-12 programs that teach about aging, several gerontologists are suggesting strategies for consideration at the federal, state and local level.

For example, Lucchino, Lane and Ferguson (1997) suggest a multi-tier strategy that includes: development of a national and state policy to infuse elderly into primary and secondary school curricula; provision of aging content guidelines for key disciplines and different grade levels; provision of information about aging content in college level training for elementary and secondary teachers; and provision of in-service programs to help implement curricula on aging.

On a national level, the National Retired Teachers Association (NRTA) and the National Academy for Teaching and Learning about Aging (NATLA) have challenged authors and publishers to meet the need for the development of non-ageist instructional materials. They believe publishers and authors have an obligation to respond in the same way they did in dealing with gender, racial and cultural discrimination.

The advantages of teaching youth about aging and the aging process are numerous. Several of the key advantages include: offering young people a more positive, realistic view of older people and a chance to become familiar with issues of an aging society; providing children with clearer perspectives about their own futures as people who will also some day grow old; stimulating students to pursue further study in the area or to better understand how an aging society will affect their future employment; and mitigating the affects of intergenerational conflict.

Opportunities to improve teaching about the aging process include: studying the characteristics of healthy and successful older people (such as John Glenn) or using local older

individuals to teach lessons about health, science or prevention; utilizing older volunteers to mentor students and demonstrate programs; engaging students in intergenerational "service learning" projects such as friendly visitors, telephone reassurance, congregate or home delivered meals programs and nursing home visitors; utilizing teaching about aging in history class lesson plans; and utilizing intergenerational projects to help students learn in required subject areas (math, sciences, social studies, English, etc.).

To successfully teach children about aging, curricula-based programs must be supported with appropriate educational materials and teacher training, and combined with intergenerational experiences. Experts stress that intergenerational programs alone are not a substitute for infusing aging into key curricula (Connecticut Departments of Education and Aging, 1992; NRTA and NATLA, 1997). Aging network organizations and schools are encouraged to work together in assuring that our children learn about older people and the aging process. They can successfully develop and implement effective programs.

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Project 2015:
The Future of Aging in New York State

BRIEF
Lesbian And Gay Issues

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Introduction

Even as we enter the 21st century, Lesbian, Gay, Bisexual and Transgender (LGBT) subjects remain particularly controversial. According to the American Psychoanalytic Association, homophobia is our society's last permissible prejudice. Such societal attitudes must be recognized before aging professionals can appreciate the environment in which lesbian and gay seniors lived most of their lives. Present LGBT seniors were largely rejected by their biological families, called sinners by their religious institutions, unjustly fired from their jobs, criminalized by selective use of archaic laws, and pathologized by mental health professionals. Even though some of such stigmatization is now changing, the result is a severely scarred current generation of elders. They have internalized homophobia and have learned secrecy for survival. For example: a) Would a lesbian participating in her senior center reminiscence group feel free to admit that she dreads the holidays because she always has to choose between spending them with her life partner or her brother and sister who reject her partnered relationship? b) Would a gay man, facing a terminal condition and trying to protect joint property for his partner of 35 years, be open with Legal Services for the Elderly? c) In working with an EISEP aide would an elderly lesbian feel safe from ridicule or ill treatment (even in her own home) if her true identity were discovered? Indeed, training for service professionals in the field of aging includes little, if anything, about the background and problems of the LGBT community.

Based on the 1990 census, a conservative estimate is 150,000 to 300,000 LGBT seniors residing in New York State. Yet, there are only five programs targeted specifically to this population in all of New York State, four in New York City and one just emerging in Syracuse. Four of these, Sage, NYC, Sage/Queens, Griot Circle and Sage Upstate provide a meeting place for social activities and a variety of social services, while Pride Senior Network focuses on education and advocacy. Demand for all services already exceeds their capacities. Although the FY '99 NY State budget included a groundbreaking $1 million for lesbian and gay health and human services (non-HIV related), no funds were awarded for LGBT senior services. The distribution of the $2 million allocated for FY'00 has not yet been determined.

Additional stressors for these seniors include the fact that their lifetime relationships can put them at financial risk. They receive no social security survivorship benefits, private pension survivorship assistance, rarely family health insurance coverage, family leave coverage, tax advantages, or the same inheritance or property and visitation rights automatically assured under espousal or birth family definitions. While isolation is often a problem for seniors in general, 66% of LGBT seniors live alone as compared to 26% in the general senior population*. Interestingly, there are few such statistics available since fear of disclosure results in a less than accurate account of older gays and their characteristics.

The Future

The present generation of closeted LGBT seniors who will be living longer and becoming increasingly frail, will require more formal and informal caregiving. Some of the barriers to such support faced by the gay population are apparent in a recently published report by the Brookdale Center on Aging of Hunter College*.

Their data indicated that less than one in five elderly LGBT respondents reported living with a life partner whereas nearly half of the general

elderly population reported being currently married. It further shows that nearly 90% of gays/lesbians sampled have no children whereas only 20 % of the general senior population are without children. Losses from HIV/AIDS have also thinned the ranks of potential caregivers. Clearly the LGBT senior population will be deprived of an adequate informal caregiving structure unless creative interventions can be mounted within the coming decades. In terms of the more formalized caregiving structures such as home care agencies, assisted living facilities and nursing homes, the persistence of negative societal attitudes and uninformed aging service providers would continue to deprive LGBT elderly of safe, meaningful and respectful care.

LGBT Boomers are now beginning to face their own aging process as well as their roles as possible caregivers for partners, parents, friends and families (both biological and chosen). They can be expected to bring to the public arena a generally more self-accepting attitude, with greater expectations for open LGBT affirmative services and programs. While some areas of New York State and particular environments, i.e., certain religions and national cultures, may continue to be repressive for older lesbians and gays, a large percentage of the senior Boomer generation will not tolerate a "don't ask; don't tell" environment and press for more responsive public policy.

Options

As long as sexual orientation and gender identity remain a way of separating people out, of causing isolation, and closing ones eyes to the uniqueness and needs of a particular population, claims to support the diversity of New Yorkers are untrue. To encourage a more inclusive climate and meet the needs of this population, we urge the following:

TRAINING

Lesbian and gay issues to be a required part of training for any state supported programs providing services and oversight for the elderly. Curriculums should include: 1. An awareness of homophobia and its devastating consequences; 2. Factors that have shaped the lives of gay seniors, their needs, their unique family configurations; 3. How to create safe and welcoming service environments for gay clients; 4 . Legal, financial and sociological barriers in accessing appropriate services and 5. Information on accessing resources offered by the lesbian and gay community. These have not been included in requirements for diversity and cultural competency, and while organizations like Pride Senior Network offer training for the aging services system, the need is far greater then their present capacities.

FUND LGBT SPECIFIC PROGRAMS AND SERVICES

Considering that there will be a portion of seniors who, still out of fear of disclosing their sexual orientation, will access only gay services and will not be served otherwise, make adequate funds available for the creation and support of programs tailored accordingly. These might include case management, social programs, ombudsman, elder abuse, telephone reassurance, friendly visiting, adult day services, caregiver training, respite and enriched housing.

ENCOURAGE RESEARCH

Establish research initiatives able to reach and track a more representative sample of older gays, their caregivers and their needs. NYSOFA can partner with major universities and LGBT community based organizations. NYSOFA might also incorporate information on partnering and living situations in their intake and assessment forms. This will give an opportunity to clients to volunteer information such as being "Partnered" as a choice along with "Married", "Single", "Widowed" and "Divorced".

SUPPORT LEGISLATION TO END DISCRIMINATION

- Include sexual orientation in all anti-discrimination policies protecting employment, public housing and the access and delivery of services. The vulnerable gay senior population must be assured protection against

ridicule, neglect or harassment in health care facilities, public housing, senior centers, etc., and LGBT staff working in the aging services system should be free to "come out" on the job and offer their special experience in helping LBGT clients.

- Include sexual orientation in hate crime bills to send a clear message that violence against any individual or groups will not be tolerated.
- Provide the same legal and financial safety nets for all New Yorkers by giving legal recognition to gay and lesbian families. This will help assure equality in retirement benefits, insurance coverage, inheritance rights, nursing home regulations, health care decisions and hospital visitation rights to name a few.

The interdependence of all these issues will profoundly affect the health and welfare of New York's diverse population as it ages through the 21st century.

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BRIEF
Older Prisoners

Rozann Greco, MSW

Aging in prison has been virtually ignored by the medical staff and rehabilitative apparatus of the criminal justice system. The literature on aging in prison is remarkably lacking, especially on aging women in prison. The relative absence of such studies may stem from society's inability to accept the idea that "graying grands" are in prison.

The many facets of prison life and the problems confronting older inmates must be understood within a broad gerontological framework that requires investigating theoretical approaches to a range of issues about aging in modern times. The older inmates' care and well-being depends on the prison's degree of caring and its capacity to understand them.

Therefore, the New York State Department of Correctional Services (DOCS) and the prisons' medical staff must become educated in the fields of geriatrics and gerontology. And become better prepared to provide the information and education needed by persons aging in prison. Also, the prison must accept responsibility for understanding and fostering the well-being of older prisoners by becoming experienced in treatment of illnesses most prevalent in the aging population. To evaluate the lives of aged prisoners requires examining the bio/psycho/social aspects of aging as well as the exploration of issues that shape the quality of life for older prisoners.

An opportunity must be created to assess the present circumstances regarding their bio/psycho/social needs as they age and to anticipate some developing need. The development of a series of seminars that embraces the concept of holistic health care may be helpful. The seminars can provide education and information dissemination regarding aging processes and the inter-relationship of an individual's environment with his/her physical, mental, spiritual, and emotional states.

Personal growth issues are not the only problems confronting DOCS and state officials. The cost of housing older prisoners is huge, attributed largely to medical expenses and antiquated health care in prison. While the total state prison population has grown from 66,259 in July 1994 to 70,406 in April 1999, an increase of about 6%, the number of aged inmates increased 54% from 2,830 in July 1994 to 4,369 in April 1999.[1] The issue of elderly inmates is certain to be pushed to the forefront as New York State continues to sentence under the Rockefeller Drug Laws.

As a result of these sentencing practices, the growth rate of the older population in prison is expected to rise at an alarming pace. There are 4,369 inmates 50 years or older in our state prison system. While they comprise only 16% of the total prison population, the expense of housing them is huge, mostly because they suffer an average of three chronic illnesses during their prison stay. Providing care for senior citizens behind bars is making costs so great that New York State simply cannot ignore it any longer. Driven by medical expenses, the average annual tab for imprisoning an elderly inmate ranges from $50,000 to $75,000, at least twice the average for a younger prisoner.

Prison health care is based on an antiquated sick-call system originally conceived to treat common illnesses like flu. It is not designed to serve the large number of prisoners who are chronically, acutely, or terminally ill. There are signs that the system is overloaded. Triage is performed by whatever personnel are available that day, including correctional officers who have no medical training. Doctors and nurses must see dozens of patients in an hour. Most prison physicians have little training or experience in treating illnesses commonly associated with aging. Few, if any correctional

systems, require continuing education of their medical staffs. Given the rapid increase in elderly prisoners, geriatric and gerontological training and services should be provided.

Considerations

- State officials, experts in geriatrics/gerontology, and corrections need to take action for the future aging population, including those in prison. The investigation of alternatives to incarceration may be a potential solution to relieve prison overcrowding, save money in health care expenses, and/or make prisons more humane.

- Renovations to unused facilities such as military institutions or state psychiatric centers could meet the needs of elderly prisoners including specialized care, geriatric dormitory services such as special diets and wheelchair access, and protection from young and violent inmates.

- Alternatives such as the Project for Older Prisoners (POPS) can be instituted. This program sets up an electronic home detention system for those too old or frail to be a threat to society.

- Release aged inmates (60+) from prison but re-institutionalize them in long term care facilities in general society. This option could be for inmates with no family, or for those whose families are not willing to assume responsibility for them.

- The implementation of preventive health care measures is sorely needed. Overall, we need more effective methods for caring for our forgotten minority, the elderly prisoners.

[1] Statistics provided by New York State Department of Correctional Services

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BRIEF
HIV Over Fifty

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When older persons manifest symptoms of confusion, it should not be automatically assumed that the older person has a dementia associated with aging, such as Alzheimer's. The HIV disease trajectory is characterized by episodes of acute exacerbation, complex treatment modalities, and long periods of relative health. Inclusion of older persons in clinical trials for medications to treat HIV disease was not an identified recruitment goal nor is data available to determine if there were greater toxicities from the medications for persons over 50 (Huff, 1998). There is virtually no evidence to indicate whether pre-existing morbidities, which are more common in older persons with HIV/AIDS (Nokes, et.al., in review), increase side effects from the medications.

Nutrition is a key factor in the aging process and a key issue in dealing with HIV. Misinterpreting a nutritional or aging problem as an HIV-related illness is a common mistake. Although the problem may appear to be the same, their roots and solutions can be quite different. For example, we tend to exercise less as we age, which results in the loss of muscle mass, which could be interpreted as HIV wasting. Good muscle mass has a positive effect on appetite, metabolism, the working of insulin, energy level, breathing, ease of movement and self-esteem (Krales, 1996). Other symptoms that could be mistaken for symptoms of HIV disease are caused by nutrient deficiencies, for example, Vitamin B12, folate and Vitamin E. As more people with HIV disease live longer, it is hoped that there would be answers to the question, how do normal aging processes interact with HIV disease? While in 1996, persons age 50 or older were more likely to have died within one month of their AIDS diagnosis (13% versus 6%) (CDC, 1998),it is hoped that in 2015, being older and having AIDS will not be associated with premature death.

Considerations

- Baseline epidemiological data about sexual and drug use histories of people over 50 be available so that interventions can appropriately target older populations.
- Organizations such as AARP include HIV prevention messages within their commu nication mechanisms and also increase visibility about older infected adults who are living with HIV/AIDS.
- Sexual and drug use history be incorporated into routine assessments irrespective of person's age.
- Condoms (male/female) be readily available in congregate living situations including senior centers, nursing homes and assisted living housing.
- HIV infection be considered as a possible diagnosis in older persons with dementia or unexplained weight loss.
- Providers be knowledgeable about normal aging processes and HIV/AIDS, and develop treatment plans that reflect consideration of client preferences and pre-existing co-morbidities.
- Programs be developed to decrease the social isolation of older infected persons.
- Ongoing programs recognize that older caregivers of persons with HIV/AIDS might be embarrassed to share information about the diagnosis of the person for whom they are caring.

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BRIEF
Vision Impairment And Hearing Loss In Older New Yorkers

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Overview

Normal aging processes result in some sensory impairment that can largely be addressed through medicine, surgery, or the use of adaptive devices. Age-related vision and hearing loss due to disease can not be ameliorated. Common causes of late-life vision loss include cataract, glaucoma, diabetic retinopathy, and macular degeneration. Common causes of late-life hearing loss include heart conditions or stroke, head injuries, tumors, certain medicines, heredity or changes in the ear that happen with aging, smoking and second-hand smoke (Cruickshanks et.al., 1998).

Based on national estimates of vision impairment (using a broad definition of impairment) among adults age 65 and above (The Lighthouse International., 1995), there are about 509,000 elders in New York State age 65 and above (21%) with a self-reported vision impairment. Using a more restricted definition, there are approximately 222,650 older adults age 65 and above in New York State (9.4%) with self-reported, severe vision impairment (inability to read newsprint even with glasses or contact lenses including blindness in both eyes; Nelson & Dimitrova, 1993). Hearing loss affects between 730,000 (30%) and 2 million (85%) of those over 65 years of age in New York, depending on the definition used (Smith, 1992). Rates of vision loss and hearing impairment increase with age.

Age-related sensory impairment can have a devastating impact on elders' functional ability and life quality. Vision loss has been shown to be an independent predictor of disability in daily living activities, even after controlling for age, gender, and comorbidity (Horowitz, 1994). Vision loss can also impact general health as it affects the elders' ability to handle any necessary medications or procedures, and may be a contributing factor to falls among elders (National Vision Rehabilitation Cooperative, 1999). Hearing loss has been found to be associated with increased cognitive impairment (Maggi et.al., 1998), adverse driving events (Gallo, et.al.,1999) and occupational injuries among older workers (Zwerling, et.al.,1998). Both vision loss (Horowitz et .al., 1994; Reinhardt, 1996) and hearing loss (Ormel et.al., 1997) in old age have been associated with depressive symptoms, decreased morale, lowered self-esteem, and feelings of excessive dependence.

Specific rehabilitative services for both vision impairment and hearing loss are available which can result in the maintenance of some level of functional ability, the prevention of unnecessary disability, an associated increase in life quality, and less strain on both informal and formal resources. Vision rehabilitation services include low vision assessment and training in the use of devices, instruction in daily living skills and orientation and mobility, and counseling for adjustment to vision loss. Services for hearing loss also include assessment and training in the use of devices based on individual need (e.g., hearing aids, radio, television, and telephone amplifiers, alarm flashers). Unfortunately, research has demonstrated that rehabilitative services for vision loss (The Lighthouse International, 1995) and hearing impairment (Smith, 1992) are largely underutilized. This may be due to multiple factors including lack of public knowledge, denial, and lack of adequate funding to pay for needed services. Only about one fourth of those who need hearing aids wear them, and while consumer satisfaction and use have been increasing, a

significant portion still discontinue use after obtaining a hearing aid (Popelka et.al., 1998).

Future Trends And Options

Because vision and hearing loss are positively associated with age, the demographic trend of the aging of the population is likely to be associated with increased numbers of elders with sensory impairment. Further, increasing numbers in ethnic minority groups (Bureau of the Census, 1997) will also result in increasing percentages of visually impaired elders (Kirchner, 1999). Hispanics, African Americans, and Native Americans have higher rates of vision loss (after accounting for age differences) due to geographic and cultural barriers to educational information, health care, and rehabilitation (Kirchner & Schmeidler, 1999). While factors such as improved fitness among elders and medical advances may have an opposite impact on prevalence, demand for rehabilitative services is expected to grow due to increased availability of information about services (e.g., through the internet), greater acceptance of assistive technology, and increased effectiveness of rehabilitation services based on outcomes research (Kirchner, 1999).

Considerations

Suggestions for action include expanded funding for rehabilitative services for sensory loss. Specifically, to provide equal access to rehabilitation services, Medicare, Medicaid, and private health insurance must be expanded to include vision (NVRC, 1999) and hearing rehabilitation services in benefit packages, and qualified, specialized providers must be able to receive reimbursement. Expanded coverage would result in improved function and life quality for elders with sensory loss, reduced dependence on family caregivers and community services, reduced health care costs for treating excess disability, and consumer protection against inadequately trained providers (NVRC, 1999). It is also important to increase the number of trained personnel who will provide the various rehabilitative services to meet the increased need. Services for family members also need to be developed and expanded to include training of caregivers to manage vision and hearing losses sensitively, and effectively. Training of community service providers (e.g., bus drivers, and bank tellers) can help those with disabilities feel more integrated and better able to continue everyday activities. Finally, research in both the biophysiological mechanisms of vision and hearing loss, as well as psychosocial issues of adjustment and quality of life must be continued, especially studies focused on an increasingly elderly population and the special issues involved.

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BRIEF
Trauma And Aging

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Introduction

Traumatic events can occur at any point or during any period of the life cycle: some individuals may undergo long periods of traumatic stress, such as that experienced in combat or in prisoner-of-war camps; others may experience only one incident, such as a rape, or the Oklahoma City bombing. There is some evidence to suggest that early, repetitive trauma such as that experienced by children growing up in an abusive family may have permanent developmental effects, leaving the individual vulnerable throughout the life span.

Though reactions to traumatic events can vary widely among individuals, there is some evidence that as external and internal resources diminish in later life, prior trauma may renew its hold. Consequently, delayed onset, re-emergence, or exacerbation of symptoms and behaviors associated with post-traumatic stress may appear during the aging process. Indeed, aging may prove to be a risk factor for individuals who have been previously traumatized, but symptoms may be misunderstood and/or misdiagnosed, causing further distress. These symptoms can include, among others, anxiety, numbing of affect, depression, dysphoria, cognitive and memory impairment, somatic complaints, flashbacks and sleep disturbance. It is clear that these symptoms, and the behaviors associated with them could, especially when considering the elderly, suggest a range of diagnoses, both psychiatric and physical, which could lead to treatment or interventions that might both overlook the underlying cause of the post-traumatic symptoms and hinder recovery.

The study of trauma and its effects has evolved over more than two decades and it is now widely known that "shocking events or lengthy periods of stress can cause serious damage to individuals' health" (Aarts & Op den Velde, 1996). Empirical research in neurobiology, psychopharmacology, and behavioral and social psychology points to the importance of understanding the causes and behaviors associated with trauma reactions, becoming familiar with the symptoms of Post-Traumatic Stress Disorder (PTSD) and applying the concepts and principles of trauma theory.

Trauma cuts across all boundaries of age, race, nationality, culture, gender and class. People with PTSD suffer from an inability to come to terms with real experiences that have overwhelmed their ability to cope. Exposure to extreme stress is widespread, and a substantial proportion of those exposed develop symptoms and behaviors characteristic of PTSD. Recent studies of the incidence of exposure show that, for example, 76% of American adults said they had been exposed to extreme stress (Elliot & Briere, 1995); 9% of the population in a large North American city suffered from PTSD (Breslau & Davis, 1992); and more than 15% of Vietnam veterans continue to suffer from PTSD (Kulka et.al., 1990). The figures for other industrialized countries are compatible with those for the United States; data for the rest of the world are not available.

Considerations

Education:

Education and consciousness-raising about trauma are key to ameliorating its effects. This should occur not only through training of agency personnel and health professionals, but through community efforts. First, we can "depathologize" the person who is suffering from the effects of trauma and view our task as helping him or her to emerge from the after effects of incidents that would have been painful, terrifying or overwhelming to almost

anyone. Second, we need to recognize that there is much we can learn about "what happened" if we are aware of the characteristic ways in which the trauma is replayed and/or relived, whether communication is through words, behaviors, somatic phenomena, flashbacks, dissociation, or all of the above. In fact, once the trauma is revealed, the affective, cognitive and somatic baggage that accompanied the original event will likely resurface. We need a repertoire of interventions that can serve to diminish anxiety and help the individual regain equilibrium. Third, trust may be an issue, and the listener (relative, social worker, doctor, friend, senior center worker, volunteer, etc.) may have to tolerate descriptions of gory or horrific details of the original event in order to achieve it. The listener is in the position of "bearing witness" to a terrible, unspeakable experience.

Resources:

In addition to knowing what trauma is and how it is manifested, we need to know about resources. Linkages with existing systems that deal with survivors of trauma which currently include, in New York, the Red Cross (disasters), the Veterans Administration (combat related trauma), Victim Services (interpersonal trauma, including domestic battering, child abuse, and crime victims), the Gay and Lesbian Anti-Violence Project (partner abuse, bias crimes), and Rape Crisis Centers at St. Luke's-Roosevelt Hospital and Mount Sinai Medical Center in New York City (rape, survivors of child sexual abuse), among others--must include a process of sensitizing those systems to the existence of *elderly* survivors (often hidden) and collaborating in developing programs appropriate to this population.

Need for New Frameworks:

The assumption that during senescence a person's physical and mental resilience gradually diminishes, leaving the trauma survivor less able to ward off or master repressed memories and feelings, is increasingly being questioned (Coleman, 1986; Schmid, 1991; Solomon, 1991; Fields, 1996), but we lack conceptual models for assessing and explaining the effects of negative events on the elderly. Nonetheless, if we misconstrue or ignore observable post-traumatic symptoms, we may well deny aging trauma survivors an empathic understanding of their sufferings and adequate treatment. Life events that involve personal changes, such as retirement; death of or separation from relatives, friends and children; physical illness; and hospitalization, may precipitate a sudden onset or worsening of post-traumatic symptoms. Similarly, confronting evidence of racism, war, prison camps, or cruelty, whether through direct experience or through the mass media may retraumatize those who had experienced any of these situations earlier in life. However, these are only *triggers* for memories of *past* trauma, not the *cause* of trauma. Reminiscence is critical in post-traumatic recovery, as a more active and controlled remembrance of traumatic events is a key to successful recovery from trauma (Horowitz, 1976). " Survivors of trauma have to mourn not only the losses that accompany old age, but also the many losses at the time of their traumatization that have not been worked through" (Aarts & Op den Velde, 1996). Giving meaning to the traumatic experiences lessens distress, restores the sense of self-control and fosters coherence and continuity of the self.

Future Issues and Trends

What will be the elderly populations' risk for the reemergence of symptoms of traumatic stress in New York in 2015? Some might be obvious, others less so. A partial list follows:

- Those who have been victims of interpersonal violence. This includes those who have survived domestic abuse by spouse or boy/girlfriend; former victims of child physical and sexual abuse; those who have been attacked or harmed due to hate or bias crimes, muggings and robberies; survivors of rape; and relatives of homicide victims. Given the tremendous wave of crime and violence spawned by the drug wars of the '70's through the early '90's, as well as the mounting evidence of a high incidence of domestic and child abuse nationwide, we might

expect the elderly of 2015 in New York to include battered wives, incest survivors, grandparents raising grandchildren whose parents died as a result of violence or drugs, and aging gays who have been beaten or maimed. In addition, there may be a sizeable number of survivors of *recent* muggings or assaults, as well as those who are victims of physical and emotional elder abuse.

- Those who served in combat. Vietnam veterans from the late '60's and early'70's will be in their sixties and seventies in 2015. There will likely be a sizeable proportion of individuals among them with PTSD, many of whom have not sought treatment, have had other psychiatric diagnoses, or have been asymptomatic until older age. Those who served in Korea in the early 1950's will be among the "old-old" and may include not only combat veterans but former prisoners-of-war.

- Those who have immigrated to the United States, whether recently or many years ago, from countries where war, ethnic cleansing, political torture and other forms of political violence have caused large-scale social disruption and flight. In 2015, a sample of elderly survivors of such events might range from the "hidden children" of the Holocaust, through those who fled after the Soviet invasions of Hungary in the '50's and Czechoslovakia in the '60's as young people, through adult refugees from countries in Africa, Asia and Latin America that have suffered armed conflict and political repression more recently, up to ethnic Albanians who fled Kosovo as middle-aged and elderly individuals in 1999. New York has long been a haven for such refugees and their proportional representation will be large compared to many other areas of the country.

- Those who have survived natural disasters such as floods, tornadoes, hurricanes, and earthquakes as well as man-made disasters such as terrorist bombings, school shootings and train wrecks. In New York, in 2015, there may be fewer elderly individuals who have suffered the effects of natural disasters than in other regions of the country more prone to tornadoes, hurricanes, etc. However, there may be survivors of the World Trade Center bombing, those who have lived through serious subway, automobile and bus accidents, those who have suffered as the result of building fires or collapses, and many others whose loved ones were killed or maimed in disasters (such as the TWA crash off Long Island in 1996).

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Project 2015:
The Future of Aging in New York

BRIEF
Alcohol And Other Drug Problems

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Alcohol and other drug abuse among the older population are not new phenomena but tend to be undetected, misdiagnosed, ignored or untreated. Existing diagnostic criteria and models of education, prevention and treatment services do not adequately address a senior's developmental, medical and lifestyle needs. The fastest growing cohort is older adults, and it is imperative to address the needs of this population regarding alcohol and other drug use/abuse. If our policies and services are not improved and expanded to reflect older adults' needs, the financial and human costs will continue to mount. We hope to provide a brief background of the problem and offer some solutions to this issue.

Alcohol and other drug problems among older adults may be separated into three main categories: Alcohol and other drug misuse, abuse, and dependence (addiction). Approximately one-third of older adults are late onset substance abusers, which is often precipitated by life changes such as retirement, loss of a spouse or poor health. Two-thirds of older adults are early onset substance abusers with long - standing substance abuse resulting in severe medical, social and other life disruptions.

ALCOHOL: Estimates of alcohol problems among older persons vary widely, but it is generally accepted that anywhere from 10-15% of persons over 60 years of age can be defined as alcohol dependent. With 3.1 million New Yorkers age 60 or older, this translates into more than 300,000 persons. These numbers may be seriously underestimated due to the relative isolation of many older persons (living alone, retired) and the under-diagnosis and misdiagnosis by inadequately trained health and social service professionals. Family and friends are often reluctant to label their loved ones alcoholic, hesitating to interfere with drinking patterns that appear to comfort the older person. Studies show that just 3.8% of the admissions to New York's alcohol and substance abuse treatment programs were 55 and older. This is in marked contrast to available data regarding seniors in health care settings. In hospital settings where appropriate screenings are carried out, more than one-fifth of the older patient population were diagnosed as alcohol abusers. Nearly half the residents in nursing homes have been found to have medical problems related to recent or previous alcohol abuse and dependence.

An older person may have had a lifetime of drinking without serious problems, but as he/she ages, his/her metabolism also changes, resulting in an altered tolerance for alcohol. For an older person, even one or two drinks may have far more dangerous effects than the same amount of alcohol had when they were younger. Any alcohol use, combined with prescription or over-the-counter (OTC) medication in older adults can significantly impact their health and quality of life.

PRESCRIPTION AND OVER-THE-COUNTER (OTC) MEDICATION: Older persons consume over one-third of all prescription drugs in this country plus large amounts of OTC medication (including supplements). This fact places older persons in serious jeopardy as they are more likely than younger persons to be taking several medications, thereby increasing the risk of an adverse drug reaction. Until recently, few drug trials were undertaken with persons over the age of sixty so that the impact on the older body was often unknown. With the increase in life span and rapid introduction of new

pharmaceutical products, the risk of prescription and other medication problems for the Baby Boomers will offer a significant challenge to the health care system.

ILLICIT DRUGS: Problems with illicit substances (including the inappropriate use of controlled substances) may be long-standing or develop in later years. There have been very few studies on the use of illicit drugs in older adults, however, treatment agencies serving older adults have noted an increase in marijuana, cocaine and heroin use in the young-old. This problem will only intensify as the Baby Boomers age. They are the first generation of Americans to reach adulthood during an era relatively widespread with the use of mood-altering psychotropic drugs, e.g., barbiturates, sedatives, benzodiazepenes, and stimulants. Since this generation experienced the more relaxed "drug culture", which emerged in the 1960's, their perceptions and patterns of drug use are far different than previous generations of older adults.

COSTS: A national study on women over the age of 60 indicates that, in an acute care hospital setting, only 2% ($205 million) was spent to treat substance abuse. The remaining 98% ($10 billion) was spent to treat the illnesses and injuries that are a result of the substance abuse. Costs in hospital, nursing home, physician visits and home health care related to substance abuse will soar in the next 20 years (from $30 billion to $100 billion for women alone). Many insurance providers do not adequately cover the costs of alcohol and substance abuse treatment. Physicians report that 20% of the substance abuse treatment referrals they make for older persons are denied by managed care organizations or insurance companies. This is so despite the fact that research has shown that even brief interventions made by primary care physicians can reduce alcohol problems in seniors.

SUMMARY: A very positive note in relation to older adult substance abusers is that there is evidence of a better prognosis for successful outcomes with them than younger persons when provided with appropriate treatment. What is needed is improved identification of older adult's alcohol and other drug abuse by health care providers and others who interact with them regularly. This can lead to increased use of treatment programs and, as an end result an improved quality of life for older adults and their families, as well as a reduction in overall health care costs. Substance abuse problems are unlikely to diminish among the Baby Boomer generation without a concerted effort by health care systems, the community and the government.

The following crucial initiatives are recommended:

1. Education: Education on substance abuse and older adults needs to be offered to the public, health and geriatric care professionals and older persons themselves. A collaborative effort by the aging network, health care and chemical dependency professionals can be instituted within the existing systems.

2. Prevention: Assist the current generation of Baby Boomers to prepare for retirement and other life transitions and inform them about the phenomenon of late onset substance abuse. Develop more senior specific written material, videos and other tools to facilitate this process.

3. Treatment: Improved training of health care, chemical dependency and other professionals is needed to ensure adequate and effective treatment specifically developed for older adults.

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