

Report of the New Jersey Advisory Council on Elder Care



October 1999

In many ways, autonomy is the all-American value or virtue. It affirms that we ought to be the master of our own fate or the captain of our ship. Autonomy mandates a strong sense of personal responsibility for our own lives.

-- Thomas A. Shannon
An Introduction to Bioethics



NEW JERSEY ADVISORY COUNCIL ON ELDER CARE

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Commissioner
Susan C. Reinhard, R.N., Ph.D.,
Deputy Commissioner
Ruth M. Reader, Ass't. Commissioner

ASSEMBLYWOMAN CAROL J. MURPHY, *Chair*
101 GIBRALTAR DRIVE, SUITE 2D
MORRIS PLAINS, NEW JERSEY 07950
(973) 984-0922
Fax: (973) 984-8094

Theresa L. Edelstein, M.P.H.
Vivian E. Greenberg, A.C.S.W.
John Michael Heath, M.D.
Renee W. Michelsen, L.C.S.W.
Roberto Muñiz, M.P.A.
Joanne P. Robinson, Ph.D., R.N., C.S.
Bernice B. Shepard

October 1, 1999

Governor Christine Todd Whitman
Trenton, New Jersey

Dear Governor Whitman,

I am pleased to transmit with this letter the report of the New Jersey Advisory Council on Elder Care.

The Advisory Council was created by Executive Order No. 89 on September 28, 1998, to gather and evaluate information on the current and perceived future service needs of senior citizens and those caring for them, and to determine the current needs of independent elders and those anticipated during the next 25 years. The Advisory Council focused on the following issues: (1) the kinds of support or choices that caregivers need now and will need in the future to help their patients, parents or loved ones maintain their dignity and independence; (2) the expectations that middle-aged persons currently have about the kind of care they will receive as senior citizens during the next 25 year period and how they expect to pay for that care; (3) the service delivery system that needs to be established or modified to meet anticipated elder care needs, and the kinds of legislative or policy decisions necessary for this purpose; and (4) the kinds of accommodations that need to be made for senior citizens who want to utilize various long-term care options.

I would like to take this opportunity to thank all the members of the Advisory Council for giving so generously of their time and for their valuable contributions to this report. Their participation in the hearings and meetings and their careful consideration of the issues discussed were essential to the development of the recommendations included in this report. On behalf of the Council, I would like to express our deep sorrow at the loss of two of our members. Senator Wynona M. Lipman and Lennie-Marie Tolliver were extraordinary advocates for New Jersey's senior citizens.

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The Advisory Council held three public hearings, in Newark, Neptune and Vineland, in order to receive testimony from senior citizens, their relatives, caregivers and service providers. These people spoke of their immediate needs and wishes, and their own future goals and plans. Eight additional meetings of the Advisory Council were held to receive information from members of the Department of Health and Senior Services, hospital professionals and program providers about new and on-going programs and options available to today's senior citizens and about initiatives that look to the future of care for New Jersey's senior citizens. Assistant Commissioner Ruth Reader and Rick Greene, Program Manager, Wellness and Family Support Program in the Department of Health and Senior Services, in cooperation with the County Offices on Aging, made it possible for us to hold many of these meetings in senior citizen housing facilities in four counties. Other meetings were held in the Edison and Old Bridge municipal buildings, the New Jersey Hospital Association complex in Lawrenceville and the State House in Trenton.

What we found was that we are speaking about ourselves. This is not a question of "someone else"; these issues turned out to be discussions of our lives as we move forward. We heard that people want most to maintain their independence for as long as they are able to do so. We were impressed with the creativity and variety of housing and service options currently available in New Jersey. We learned that families, for the most part, do not engage in inter-generational conversations about aging and mortality. Many people related that once a conversation was begun, they felt better knowing that issues of options and costs had been discussed. Experts spoke to the Advisory Council on topics that ranged from future planning by hospital administrators to the relatively new options available in long-term care insurance.

New Jersey is a leader in the development of programs designed to allow its residents to age in place; however, it became increasingly obvious to the Advisory Council that more needs to be done in the following areas: (1) increased education for all State residents as to the options and their price tags available to tomorrow's seniors, and (2) all aspects of caregiving, from how to more ably support those who are currently in place as volunteers or paid professionals to how to plan to meet greatly increased future demands, in terms of numbers, training and costs. The establishment of an ongoing work group as defined in the final recommendation of this report should be a top priority. With appropriate allocation of staff and funding, this group would provide valuable assistance in the areas of monitoring, development of policy recommendations and further exploration of several of the more long-term suggestions from the Advisory Council. It also is critical that all areas of State government become involved in developing innovative and effective policies and programs to meet the needs of tomorrow's senior citizens.

On behalf of the Advisory Council, I would like to commend the work of the staff provided by the Office of Legislative Services. The professional services of Irene M. McCarthy,

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Senior Counsel, were invaluable during the many hearings and meetings and especially in the development and preparation of this report.

I sincerely hope that the recommendations of the Advisory Council will assist the Governor and the Legislature as they continue planning for the needs of the State's senior citizens in the third millennium.

Sincerely,

A handwritten signature in cursive script, appearing to read "Carol", with a long horizontal line extending to the right.

Carol J. Murphy
Chairman

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Honorable Samuel D. Thompson, Assemblyman, District 13

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**Susan C. Reinhard, R.N., Ph.D., Deputy Commissioner,
Department of Health and Senior Services**

**Ruth M. Reader, Assistant Commissioner,
Department of Health and Senior Services**

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Theresa L. Edelstein, M.P.H.

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John Michael Heath, M.D.

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Roberto Muñiz, M.P.A.

Joanne P. Robinson, Ph.D., R.N., C.S.

Bernice B. Shepard

Lennie-Marie P. Tolliver, Ph.D.*

*Deceased

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New Jersey Advisory Council on Elder Care

INTRODUCTION

The New Jersey Advisory Council on Elder Care was created by Governor Christine Todd Whitman's Executive Order No. 89 (1998) to gather and evaluate the current and future service needs of senior citizens in the State and those caregivers providing care to them. In particular, the Council was charged with focusing on: (1) the kinds of support or choices that caregivers need now and will need in the future to help their patients, parents or loved ones maintain their dignity and independence; (2) the expectations that middle-aged persons currently have about the kind of care they will receive as senior citizens during the next 25-year period and how they expect to pay for that care; (3) the service delivery system that needs to be established or modified to meet anticipated elder care needs, and the kinds of legislative or policy decisions necessary for this purpose; and (4) the kinds of accommodations that need to be made for senior citizens who want to utilize various long-term care options.

The number of senior citizens in the State is increasing dramatically. Currently, one in seven residents of the State is at least 65 years of age and it is anticipated that in 30 years, one in four State residents will be that age. According to the United States Census, between 1970 and 1990 there was an increase of 58% in the number of persons over 65 years of age living in the State; however, the overall population increase during those 20 years was only 7.8%. Relying on data from the

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1994 census update, it is anticipated that the overall State population will grow from 7.9 million to 8.3 million by the year 2005 and to 9.4 million by the year 2030. During the 20 years from 2010 to 2030, it is projected that the number of State residents over 65 years of age will increase by 68%. (A chart that highlights this demographic shift can be found in the appendix.) It is hoped that the work of the Advisory Council will help the State develop responses to the future needs of this aging population.

To fulfill its responsibilities, the Advisory Council held an organizational meeting on November 4, 1998; received a presentation by experts in the area of caregiving for elderly persons on November 13, 1998 at the State House in Trenton; and held three public hearings on the issue of caregiving at Newark Beth Israel Medical Center, the Senior Citizens' Center in Neptune and the Center for Health and Fitness in Vineland, on December 9, 12 and 15, 1998, respectively. An interim report, a copy of which is appended to this final report, focused on the needs of caregivers and their family members and was submitted to the Governor on December 28, 1998.

On January 20, 1999 the Advisory Council traveled to Somerset County to visit an adult day care center and an innovative type of residence for older adults, known as a shared living residence. In this type of residence, supervision and monitoring are provided, as appropriate, within the comfort of a traditional home that is situated in a family neighborhood. Each resident has his or her own private bedroom and bath, while sharing common areas such as a kitchen, living room and

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dining room.

In addition, on February 10, 1999 the Advisory Council heard from experts involved with the New Jersey Easy Access Single Entry (NJ EASE) project, which provides information and referral, assessment, care planning and care management to senior citizens and their family members through the use of standardized protocols, and from care managers in the private sector who help senior citizens and their families decide which particular elder care services meet their needs. At this meeting, there was a presentation by Deputy Commissioner Susan Reinhard of the Department of Health and Senior Services about the department's senior initiatives which are aimed at helping senior citizens in the community "age-in-place" through:

Community-Based Care Alternatives, which will be available to senior citizens who have been determined to be in need of nursing home level of care and will be implemented on a cost-sharing basis, and include a:

- Caregiver Assistance Program, which will assist caregivers of Medicaid recipients in the purchase of services and goods, which supplement family supports;
- Jersey Assistance for Community Caregivers program which will allow non-Medicaid recipients to receive services;
- NJ EASE Home Care program which will permit Medicaid-eligible senior citizens without family support to receive in-home services from home health and homemaker agencies; and
- funding increase to the New Jersey Statewide Respite Care Program which will include caregiver support training; and

Counseling About Choices, which includes the:

- Community Choice Counseling Program - Nursing Homes, which will provide health care professionals to work with senior citizens currently in a nursing home to determine if a different living arrangement might be more appropriate to that person's current needs;

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- and
Community Choice Counseling Program - Hospitals, which will provide senior citizens who are being discharged from a hospital an opportunity to discuss long-term care options with a health care professional.

Also, the Deputy Commissioner discussed the Governor's commitment of up to \$200,000 per year to award competitive grants to nursing homes (\$20,000 for ten nursing homes) to implement the Eden Alternative philosophy. Under the Eden Alternative, a nursing home creates a more independent, community-like setting by encouraging companionship, variety, spontaneity and the opportunity to care for other living things.

Next, the Advisory Council toured a nursing facility in Piscataway, the Francis E. Parker Memorial Home, on March 5, 1999. In conjunction with the tour, the Advisory Council received testimony from two nursing home administrators (one of whom, Roberto Muñiz, is a member of the Advisory Council), a certified nurse aide, a caregiver who placed her mother in a nursing home, and patients in nursing homes, in order to better understand the needed services that nursing homes provide to the most vulnerable of populations as a part of the continuum of care. At this meeting, the Advisory Council also heard from experts about the Medicaid program and the federal Medicaid waiver programs of Community Care Program for the Elderly and Disabled (CCPED) and Assisted Living/Alternate Family Care (AL/AFC). CCPED is a Statewide community care program that has over 3,300 slots available for providing the following eight services to persons who meet specific

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eligibility¹ requirements: case management, home health, homemaker, medical day care, non-emergency medical transportation, respite care,² social day care and prescribed drugs. The AL/AFC waiver allows for a total of 1,500 slots and provides the following services to eligible³ persons: case management, assisted living,⁴

¹To be eligible for CCPED, persons must be 65 years of age or older and be eligible for Medicare or have other health insurance which includes hospital and physician coverage. If under 65, persons must be determined disabled by the Social Security Administration and be eligible for Medicare or be determined disabled by Medicaid's Disability Review Section, and have other health insurance, including hospital and physician coverage. All persons must be assessed by the Department of Health and Senior Services as in need of a nursing facility level of care. Income must exceed the Supplemental Security Income (SSI) community standard up to the institutional cap (currently \$1,500 per month) or the person must be ineligible in the community because of SSI deeming rules. Resources may not exceed those required in the institutional program (\$2,000 for a person living alone). Persons who are currently Medicaid-eligible for community services are not covered under this waiver program. A spouse's income is not considered in determining eligibility, but the spouse's resources are considered.

²Respite care services are offered on an as-needed basis to temporarily relieve the family of caregiving responsibilities and include in-home services, such as homemaker-home health aide services, or up to 14 days of inpatient care in a nursing home.

³To be eligible for AL/AFC, a person must be 65 years of age or older, or from ages 21 through age 65 and determined disabled by the Social Security Administration or Medicaid's Disability Review Section and be assessed by the Department of Health and Senior Services as in need of a nursing facility level of care and be receiving SSI or be eligible for the Medicaid Only (institutional services) program, that is, income of not more than \$1,500 per month and resources of \$2,000 or less. Persons may have a cost-share liability if income exceeds the SSI level. In determining eligibility, a spouse's income is not considered but the spouse's resources are considered.

⁴Assisted living is provided in three settings: (1) A comprehensive personal care home, which is a licensed residential facility that provides room and board. Units are typically shared occupancy, by no more than two residents, and have locks on the

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alternate family care,⁵ and respite care for those in the alternate family care setting providing care.

The Advisory Council also visited the Morris Hall assisted living facility in Lawrenceville on April 15, 1999 to hear from experts on how the independent assisted living lifestyle fits into the continuum of long-term care. At this time, there was also a presentation about the special needs of Alzheimer's patients and dementia-specific staff training.

On April 9, 1999 the Advisory Council met at the New Jersey Hospital Association to learn how different hospitals in the State accommodate the needs of their patients and their families by providing care management and information when patients leave the hospital. Presenters explained the hospitals' integrated delivery systems and "front-end" care management, in which social workers and physicians collaborate with patients and families prior to hospital procedures so that care options are introduced to families and patients at the outset.

doors to the unit entrances. Bathrooms are shared and congregate dining is provided. (2) An assisted living residence, which is a licensed residential facility that provides apartment-style living and congregate dining. At a minimum, apartment units include one unfurnished room, a private bathroom, a kitchenette and locks on doors. They can be single or double occupancy. (3) Assisted living program, which is a package of assisted living services, including nursing and personal care, to be provided by a licensed agency to residents in publicly-subsidized housing.

⁵Under the alternate family care program, an unrelated individual who has been approved by a licensed sponsor agency and trained to provide caregiving, provides room and board, personal care and other health services to no more than three persons.

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At the Edison Municipal Complex on April 23, 1999, the Advisory Council learned about the relationship of hospice care to palliative care and the need for increasing awareness about these approaches to health care among health care professionals and the public. Palliative care is the active, total care of a patient whose disease does not respond to curative treatment. This care includes control of pain and other symptoms, and the goal is achievement of the best quality of life for patients and their families. Hospice care, on the other hand, is a part of palliative care and provides comfort care during a particular phase of end-of-life care, the final six months.

In addition, Dr. John Heath, a geriatrician on the Advisory Council, discussed educational needs and advised that medical knowledge doubles every five to seven years. In his presentation, Dr. Heath outlined the types of ongoing training that are necessary for physicians and other health care providers, including training that facilitates input from providers in determining in which areas ongoing training is needed, links the NJ EASE care managers with physicians' offices, and provides for cross-disciplinary training.

The Advisory Council received presentations about the role of long-term care insurance in planning for one's own elder care at the May 14, 1999 meeting in the State House in Trenton. Presenters included the architect of the long-term care insurance program that was established in California, representatives from the New Jersey Long-Term Care Insurance Committee and an attorney who practices elder

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care law. The Advisory Council also held an evening public hearing on May 17, 1999 at the Old Bridge Municipal Complex in an effort to reach out to middle-aged persons to learn about their expectations for their own elder care needs and how they will finance that care.

Finally, the Advisory Council gathered for a work session on June 9, 1999 to discuss recommendations for this report and a preliminary report was subsequently circulated for review and comment. At the last meeting on September 9, 1999, the members reached a consensus on the recommendations which are contained on the pages that follow.

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SUMMARY OF RECOMMENDATIONS

1. Home and community-based services, including medical and social adult day care, home health care, respite care and meals-on-wheels, need to be expanded and supported by increasing State funding and expanding the use of cost sharing for services based on a sliding-fee scale.

2. The Departments of Health and Senior Services and Labor should develop a plan to attract people to the homemaker-home health aide profession and investigate ways to encourage the provision of health insurance benefits to these health care professionals who might otherwise rely on publicly funded health care benefits.

3. The Department of Health and Senior Services should employ the concept of presumptive eligibility for community-based services, possibly on a pilot basis, in an effort to reduce stress on caregivers at the time that they need assistance.

4. The Department of Health and Senior Services should prepare and distribute to State, county and local agency elder care staff, training materials and seminars that would ease cultural barriers and promote a customer-friendly atmosphere to senior citizens and their family members who are seeking elder care services.

5. a. The Department of Health and Senior Services should continue to expand to all counties the NJ Easy Access Single Entry (NJ EASE) project, which provides information and referral, assessment, care planning and care management to senior citizens and their family members.

5. b. The department should promote NJ EASE by increasing awareness through the advertisement of the project to potential caregivers and their family members and by targeting some of its marketing to needy caregivers and their family members.

6. The NJ EASE project should receive increased funding for care management. As a means of outreach to the senior citizen community, care managers should be available periodically in senior centers and other places frequented by senior citizens.

7. The monitoring component that oversees the delivery and quality of services received through care management provided by the NJ EASE project

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should be increased. For frail, elderly clients, an accountable person or agency should be assigned to each client. In addition, a quality monitoring process for care manager contracts under the NJ EASE project should be developed.

8. The Department of Health and Senior Services should explore the possibility of linking hospitals, outpatient clinics serving senior citizens and primary care physicians' offices to the NJ EASE care management services. For primary care physicians' offices, the county medical societies could possibly be the coordinating agencies to work with NJ EASE.

9. a. NJ EASE care managers and care managers in the private sector should work together in order to ensure greater access to programs and to ensure that, to the extent possible, finite State resources are targeted to those senior citizens in greatest social and economic need.

9. b. Both public and private sector care managers should be required to receive some form of accreditation of their skills and knowledge.

10. "Front-end" care management, in which anticipatory counseling and guidance are provided to senior citizen clients and their family members prior to a major hospitalization, nursing home placement or invasive medical procedure, should be encouraged.

11. Caregiver education and training should become an explicit mission of the Department of Health and Senior Services; and accordingly, funds should be appropriated to the department to develop a program, in collaboration with appropriate advocacy organizations, to provide education and training for caregivers on the aging process, home care techniques, cognitive decline and the specific in-home training needed to operate equipment, provide wound care and assist with pain management. This education and training should be presented in a variety of formats, such as printed materials and in-person seminars, and made accessible to the greatest number of caregivers.

12. The Department of Health and Senior Services should explore the possibility of providing financial support through tax incentives to unpaid caregivers for their caregiving responsibilities to frail, elderly family members who meet the eligibility criteria for placement in long-term care facilities.

13. Increased funding is necessary for Adult Protective Services, the Ombudsman for the Institutionalized Elderly, the Money Management program, the Office of the Public Guardian and other preventive and investigative programs, such as a telephone hotline for caregiver risk assessment and potential for abuse

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or neglect of family members, as well as referrals for mental health counseling.

14. For greater respite bed availability that is responsive to the needs of caregiving families, the Department of Health and Senior Services should promote flexibility in bed designations in long-term care facilities, sub-acute care and alternate family care settings and consider eliminating the use of a finite number of slots for programs.

15. The State should actively promote the development of affordable assisted living residences and comprehensive personal care homes for low and middle-income senior citizens.

16. The Department of Health and Senior Services should develop a plan that increases the utilization of the assisted living model among Medicaid-eligible senior citizens. The rate of Medicaid reimbursement should be determined based on the level of care that is administered to senior citizens, and the plan should avoid shifting expenses to those senior citizens who pay privately for assisted living.

17. The Department of Health and Senior Services should increase the flexibility of assisted living programs so that these programs can be established in non-publicly subsidized housing, if appropriate.

18. The Department of Health and Senior Services should prepare a consumer guide to facilities that are licensed as assisted living residences and comprehensive personal care homes.

Similarly, providers of assisted living residences and comprehensive personal care homes should be required to clearly and uniformly disclose information to consumers, such as: available care options, the business organization of the provider, the licensure status of the assisted living provider and other providers of health or home care services within the facility, a description of the term of the contract and the process for modifying, amending or terminating that contract, additional services that are available for additional fees, and any complaint resolution process available to residents. This information should be provided to consumers in materials that are written in plain language and legible print, either as part of the resident contract or supporting documents.

19. Funds should be appropriated to the Department of Health and Senior Services for expansion of the congregate housing services program and the promotion of innovative housing options such as shared living residences.

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20. The Department of Health and Senior Services should establish an educational campaign to inform senior citizens and their families about the possibility of using reverse mortgages and other creative financial options that would provide senior citizens with additional income to remodel their residences to accommodate their physical needs as they age in the community.

21. The Department of Health and Senior Services should work with municipal leaders to increase zoning variations in order to encourage a variety of housing options that would permit families or designated unrelated caregivers to care for elderly family members or senior citizens, respectively.

22. Municipal zoning laws should be adjusted to better accommodate the alternate family care program, in which an unrelated person who has been approved by a licensed sponsor agency and trained to provide caregiving, provides room and board, personal care and other health services to no more than three persons.

23. For better utilization of long-term care facilities, in the advent of increased community-based services and shorter hospital stays, nursing homes will need greater flexibility in bed designations so that they are able to readily accommodate respite care and rehabilitative needs.

24. Nursing homes should be given increased incentives to implement the Eden Alternative philosophy, in which a more independent, community-like setting is created by making companionship, variety, spontaneity and other opportunities to care for other living things a part of a nursing home resident's typical day.

25. In accordance with the Community Choice Counseling Program - Nursing Homes, the Department of Health and Senior Services should ensure that home care and community-based services are in place prior to the discharge from nursing homes of senior citizens who no longer need that higher level of care.

26. The State Medicaid reimbursement methodology should adequately reflect the population served by nursing homes, that is, the frailest and the sickest. This is particularly important as the more independent senior citizens seek out alternatives such as assisted living and adult day care.

27. Funds should be appropriated or obtained through grants to the Department of Health and Senior Services to develop a Statewide health promotion and disease prevention initiative for senior citizens.

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28. A continuing education support system and a recognition and promotion system for direct patient care providers, including nurse aides and homemaker-home health aides, should be established.

With regard to particular training requirements, nurse aides and homemaker-home health aides need dementia-specific training for patients with Alzheimer's Disease. This training should include specialty certification in dementia care.

29. In order to improve the delivery of services to senior citizens, health care professionals and agencies serving senior citizens should receive cross-disciplinary training. These geriatric training programs should be accessible through decentralized training tools, such as web-based training modules.

30. Geriatric training and research should receive enhanced support at the State's medical schools, colleges and universities, as appropriate. This expansion could include the creation and funding of a geriatric chair and student incentives, such as student loan forgiveness programs and geriatric medicine fellowships, to increase the number of health care professionals who choose to study elder care within the State.

31. Training for health care professionals should emphasize the need to inform families about palliative care, including the option of hospice care for end-of-life care and the importance of preparing advance directives. In addition, the Department of Health and Senior Services should establish an educational campaign to increase the public's awareness of the availability of palliative and hospice care and advance directives.

32. The Department of Banking and Insurance, in consultation with the Department of Health and Senior Services, should develop an educational campaign to inform middle-aged (ages 45-65) and young-old (ages 65-75) populations about the importance of planning for their long-term care needs, through the use of long-term care insurance, viatical settlements and other financial instruments that could provide necessary resources for senior citizens as they age. Also included in this educational campaign should be the importance of discussing and addressing these planning issues within families.

This campaign could be promoted through community education, collaboration with private employers, public service announcements, periodic State and local government mailings and other forms of advertisement.

33. The Department of Banking and Insurance, in consultation with the Department of Health and Senior Services, should explore the promotion of long-

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term care insurance as a voluntary option to public employees through the State Health Benefits Plan.

34. The State should consider implementing tax incentives for State residents who purchase long-term care insurance.

35. Funding needs to be made available for strengthening and developing local public transportation networks for senior citizens in urban and rural areas. Additional funding should be directed to meet the needs of the frail elderly, in particular, who need assisted transportation if they are to remain in the community.

36. There should be established an ongoing work group to continue to explore innovative ways to improve the care provided to the State's aging population and monitor and evaluate the implementation of the recommendations in this report. Members of the ongoing group should include some members of the Advisory Council as well as providers and consumer representatives.

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**FINDINGS AND RECOMMENDATIONS OF THE NEW
JERSEY ADVISORY COUNCIL ON ELDER CARE**

ACCESS TO COMMUNITY-BASED SERVICES

1. Home and community-based services, including medical and social adult day care, home health care, respite care and meals-on-wheels, need to be expanded and supported by increasing State funding and expanding the use of cost sharing for services based on a sliding-fee scale.

- In order to accommodate the growing needs of the increasing number of senior citizens in the State who require community-based services to remain in the community as they age, a full range of community-based services must be accessible and affordable.
- Testimony presented at public hearings indicated that middle and low-income families want their elderly family members to "age in place" as long as they can, but necessary home care services are not affordable and they find it difficult to continue their paid employment while providing care to their aging family members. In addition, persons in need of services often face waiting lists for entry into programs. By increasing funding and the use of cost sharing, the State would be able to reduce waiting lists and augment the availability of services, thereby serving a larger population.
- Social model adult day care programs, which provide services to a wide array of adults, including those with Alzheimer's Disease, serve a dual purpose. They provide a stimulating, safe environment for frail elders, and either respite for family caregivers or care for the frail, elderly person while the caregiver works. These cost-effective programs warrant a prominent place in the continuum of care.

2. The Departments of Health and Senior Services and Labor should develop a plan to attract people to the homemaker-home health aide profession and investigate ways to encourage the provision of health insurance benefits to these health care professionals who might otherwise rely on publicly funded health care benefits.

- In accordance with the increasing number of senior citizens in the State who want to rely on community-based services, there must be an effort to increase the labor force that will supply these services, in conjunction with the

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establishment of three new home care programs which will provide services based on a cost-sharing formula: (1) the Caregiver Assistance Program which will assist caregivers of Medicaid recipients in the purchase of in-home services and goods, which supplement family supports; (2) the Jersey Assistance for Community Caregivers program, in which non-Medicaid recipients will be eligible to receive services; and (3) the NJ EASE Home Care program, which will permit Medicaid-eligible senior citizens without family support to receive in-home services from home health and homemaker agencies.

3. The Department of Health and Senior Services should employ the concept of presumptive eligibility for community-based services, possibly on a pilot basis, in an effort to reduce stress on caregivers at the time that they need assistance.

- When waiting for services, caregivers can experience stress that adversely affects their ability to care for their family member as well as their own health, while the health of the elderly family member declines.

4. The Department of Health and Senior Services should prepare and distribute to State, county and local agency elder care staff, training materials and seminars that would ease cultural barriers and promote a customer-friendly atmosphere to senior citizens and their family members who are seeking elder care services.

- The State has a diverse population that encompasses many cultures. The staff members who work directly with the public need to be aware of cultural differences so that community-based services and information are tailored to meet the needs of the varying ethnic groups that comprise the State population and so that staff members are sensitive to cultural differences when arranging for and providing care to these various groups.
- Examples of training materials could include: translations of written elder care materials and program notices into languages relevant to the non-English speaking population in a geographic service area; culturally sensitive outreach to minority populations of senior citizens and their caregivers who are not currently being served; and ensuring inclusion of minority or non-English speaking populations when surveying for service needs.

5. a. The Department of Health and Senior Services should continue to expand to all counties the NJ Easy Access Single Entry (NJ EASE) project, which

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provides information and referral, assessment, care planning and care management to senior citizens and their family members.

5. b. The department should promote NJ EASE by increasing awareness through the advertisement of the project to potential caregivers and their family members and by targeting some of its marketing to needy caregivers and their family members.

- Presenters to the Advisory Council advised that counties which have coordinated their services through the NJ EASE project (Atlantic, Burlington, Camden, Cumberland, Essex, Middlesex, Monmouth, Morris, Ocean, Salem, Somerset, Sussex, Union and Warren counties) are able to help their senior citizens navigate the system to obtain the services that they need. NJ EASE needs to continue to expand to all counties in the State and the public needs more information about the NJ EASE project. Many caregivers and their family members are unsure how to access the services they need.

EXPANSION OF CARE MANAGEMENT

6. The NJ EASE project should receive increased funding for care management. As a means of outreach to the senior citizen community, care managers should be available periodically in senior centers and other places frequented by senior citizens.

- Care management is a consumer-focused collaborative process that assesses senior citizens' needs through the use of a standardized "comprehensive assessment tool" and plans, implements, coordinates, monitors and evaluates options and services to meet those needs.
- Care managers must be accessible to the community and must be available to continue to work with clients until their care plans are fully implemented.

7. The monitoring component that oversees the delivery and quality of services received through care management provided by the NJ EASE project should be increased. For frail, elderly clients, an accountable person or agency should be assigned to each client. In addition, a quality monitoring process for care manager contracts under the NJ EASE project should be developed.

- Care management is growing because of the success of the NJ EASE project, but more care managers are needed so that the ratio of clients to care manager does not spiral upward.

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- For those frail, elderly clients whose health conditions and service needs may change rapidly, closer monitoring is appropriate.
- The care manager contracts should be reviewed and evaluated periodically to ensure that the best possible services are being provided.

8. The Department of Health and Senior Services should explore the possibility of linking hospitals, outpatient clinics serving senior citizens and primary care physicians' offices to the NJ EASE care management services. For primary care physicians' offices, the county medical societies could possibly be the coordinating agencies to work with NJ EASE.

- Physician, hospital and outpatient clinic identification of senior citizens who are at risk for institutionalization and of caregivers who are suffering from excessive stress due to their caregiving responsibilities could permit the earliest and most efficient service intervention to help support the maintenance of senior citizens in the community.
- These additional linkages to NJ EASE would be complementary to other services and could serve as a safety net for those without resources for private care management or other services provided outside the hospital setting.
- Hospitals and outpatient clinics currently have very little contact with the NJ EASE project. Due to the large number of senior citizens who are served daily by these facilities, it would be appropriate to link them to NJ EASE.

9. a. NJ EASE care managers and care managers in the private sector should work together in order to ensure greater access to programs and to ensure that, to the extent possible, finite State resources are targeted to those senior citizens in greatest social and economic need.

9. b. Both public and private sector care managers should be required to receive some form of accreditation of their skills and knowledge.

- To the extent possible, State funds should be spent on those clients with the greatest social and economic need.
- The Advisory Council finds that the encouragement of a healthy public and private sector for care management services would benefit senior citizens and their family members, but there must be some assurance to these consumers that care managers are properly trained to serve their needs.

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10. "Front-end" care management, in which anticipatory counseling and guidance are provided to senior citizen clients and their family members prior to a major hospitalization, nursing home placement or invasive medical procedure, should be encouraged.

- Testimony presented to the Advisory Council revealed that often when patients and their family members are faced with a medical crisis, it is difficult for them to process the onslaught of information that is provided. Even with written instructions and reiterations, patients and family members find it difficult to cope. Anticipatory ongoing counseling would improve communication about the hospital stay and expected outcomes.
- Front-end care management can help patients and family members build positive relationships with health care professionals before a procedure or placement is to occur. Patients' and family members' expectations of longer hospital stays often are not met. Accordingly, it is difficult to build trusting relationships at a time when patients and family members perceive hospital discharges as premature.

CAREGIVING FAMILIES

11. Caregiver education and training should become an explicit mission of the Department of Health and Senior Services; and accordingly, funds should be appropriated to the department to develop a program, in collaboration with appropriate advocacy organizations, to provide education and training for caregivers on the aging process, home care techniques, cognitive decline and the specific in-home training needed to operate equipment, provide wound care and assist with pain management. This education and training should be presented in a variety of formats, such as printed materials and in-person seminars, and made accessible to the greatest number of caregivers.

- Testimony presented to the Advisory Council indicated that caregivers want to provide care for their family members at home but that they need training and preparation to do so. For those caregivers whose family members have specific chronic diseases, both the family members and their caregivers fare better if the caregivers are knowledgeable about the specific disease and how best to provide the necessary daily care for their family members.

12. The Department of Health and Senior Services should explore the possibility of providing financial support through tax incentives to unpaid caregivers for their caregiving responsibilities to frail, elderly family members who

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meet the eligibility criteria for placement in long-term care facilities.

- When balancing caregiving responsibilities with employment responsibilities, caregivers sometimes reduce their working hours and, as a result, receive less income. In those cases where frail, elderly family members might otherwise need to be placed in a long-term care facility, financial support through tax incentives might be appropriate.

13. Increased funding is necessary for Adult Protective Services, the Ombudsman for the Institutionalized Elderly, the Money Management program, the Office of the Public Guardian and other preventive and investigative programs, such as a telephone hotline for caregiver risk assessment and potential for abuse or neglect of family members, as well as referrals for mental health counseling.

- The daily stress of caregiving can sometimes lead to isolation, fatigue, anger, depression and thoughts of suicide. Caregiver stress can result in elder abuse or neglect. Mental health counseling for caregivers may be appropriate in some cases to alleviate caregiver stress.
- The incidence of elder abuse or neglect will most likely grow as the number of elderly persons increases. The agencies, offices and programs that serve these populations need to be expanded accordingly.
- Investments in Adult Protective Services, the Ombudsman for the Institutionalized Elderly and the Office of the Public Guardian would proactively address issues that otherwise might result in adverse health outcomes for the most frail and vulnerable elderly populations or premature nursing home placements at greater public expense.
- The Money Management program assists low-income senior citizens or disabled adults who have difficulty budgeting, paying routine bills or keeping track of financial matters. The program is based on a model designed by the American Association of Retired Persons (AARP) in 1981 and was developed by the Department of Health and Senior Services in partnership with AARP. The program promotes independent living and needs to be expanded to accommodate the growing number of senior citizens who want to remain in the community.

14. For greater respite bed availability that is responsive to the needs of caregiving families, the Department of Health and Senior Services should promote flexibility in bed designations in long-term care facilities, sub-acute care and

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alternate family care settings and consider eliminating the use of a finite number of slots for programs.

- A greater use of community-based care alternatives might occur if caregivers could be assured that short-term nursing home, sub-acute care or alternate family care placements would be available at the time that they need respite beds for their family members.
- A system that could respond rapidly to the varying needs of caregivers, who, for example, might become ill and need same-day short-term placement for their family members, would reduce the burden on caregivers and on acute care facilities that otherwise might receive those family members as patients.

INCREASED OPTIONS FOR AFFORDABLE HOUSING

15. The State should actively promote the development of affordable assisted living residences and comprehensive personal care homes for low and middle-income senior citizens.

- The independent residential environment of assisted living appeals to many, but the price makes it inaccessible to low and middle-income families who are ineligible for the Medicaid program but still cannot afford to utilize this housing option.
- Assisted living residences are new construction that is designed and built to provide assisted living services, whereas comprehensive personal care homes are based on a model that permits providers to convert existing buildings to the assisted living lifestyle and provide assisted living services within their buildings without undergoing extensive renovation or reconstruction that would be prohibitive in cost. Both models should be available to low and middle-income families.

16. The Department of Health and Senior Services should develop a plan that increases the utilization of the assisted living model among Medicaid-eligible senior citizens. The rate of Medicaid reimbursement should be determined based on the level of care that is administered to senior citizens, and the plan should avoid shifting expenses to those senior citizens who pay privately for assisted living.

- As of July 1999, there were a total of 93 licensed assisted living residences and comprehensive personal care home providers in the State, with about

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7,398 beds. Of the 93 licensed providers, 67 were providers of assisted living residences; and 26 were providers of comprehensive personal care homes, with 5,848 and 1,550 beds, respectively.

- Included in these amounts are 19 assisted living residence providers and 19 comprehensive personal care home providers who accept Medicaid reimbursement, with 161 Medicaid recipients utilizing the comprehensive personal care home option and 141 Medicaid recipients utilizing the assisted living residence option.

17. The Department of Health and Senior Services should increase the flexibility of assisted living programs so that these programs can be established in non-publicly subsidized housing, if appropriate.

- The assisted living program is a package of assisted living services, such as nursing and personal care, that is provided by a licensed sponsor to residents in publicly subsidized housing. There are currently 13 assisted living programs in the State. In order to make it worthwhile for a sponsor to provide the package of assisted living services to a particular housing complex, a high percentage of the population in that publicly subsidized housing must need and be eligible for these services.
- If other housing settings, in addition to publicly subsidized housing, could appropriately accommodate the assisted living program, it would be beneficial to permit the program to be administered in those settings as well.

18. The Department of Health and Senior Services should prepare a consumer guide to facilities that are licensed as assisted living residences and comprehensive personal care homes.

Similarly, providers of assisted living residences and comprehensive personal care homes should be required to clearly and uniformly disclose information to consumers, such as: available care options, the business organization of the provider, the licensure status of the assisted living provider and other providers of health or home care services within the facility, a description of the term of the contract and the process for modifying, amending or terminating that contract, additional services that are available for additional fees, and any complaint resolution process available to residents. This information should be provided to consumers in materials that are written in plain language and legible print, either as part of the resident contract or supporting documents.

- The assisted living industry is young and it has grown rapidly. Senior citizens

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are faced with many choices when they plan to choose this housing option. As consumers they should be able to access information that allows them to compare different residences, both assisted living residences and comprehensive personal care homes, based on uniform criteria presented by the Department of Health and Senior Services and by the providers.

19. Funds should be appropriated to the Department of Health and Senior Services for expansion of the congregate housing services program and the promotion of innovative housing options such as shared living residences.

- The congregate housing services program, which provides supportive services such as housekeeping, personal assistance, case management and meals provided in a group setting to low-income frail, elderly persons residing in subsidized housing facilities, is an economical way for senior citizens to remain in the community. The program combines shelter and services so that senior citizens who need assistance as they age in place are able to avoid premature or unnecessary relocation to a long-term care facility.
- Shared living residences, in which each resident has his or her own private bedroom and bath, while sharing common areas such as a kitchen, living room and dining room within the comfort of a traditional home that is situated in a family neighborhood, provide another economical option for senior citizens who want to remain in the community.

20. The Department of Health and Senior Services should establish an educational campaign to inform senior citizens and their families about the possibility of using reverse mortgages and other creative financial options that would provide senior citizens with additional income to remodel their residences to accommodate their physical needs as they age in the community.

- Many senior citizens have amassed a substantial amount of equity in their homes due to the length of time that they have resided in those homes. These assets, however, are not available income. A reverse mortgage or a home equity loan could provide the needed cash to permit senior citizens to remain in their homes by enabling them to remodel their homes to accommodate their needs.

21. The Department of Health and Senior Services should work with municipal leaders to increase zoning variations in order to encourage a variety of housing options that would permit families or designated unrelated caregivers to care for elderly family members or senior citizens, respectively.

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- Increased zoning flexibility would enable families or unrelated caregivers to create their own style of extended family living arrangements. These arrangements could provide independent, protected living environments for senior citizens within close proximity to younger family members or unrelated caregivers.

22. Municipal zoning laws should be adjusted to better accommodate the alternate family care program, in which an unrelated person who has been approved by a licensed sponsor agency and trained to provide caregiving, provides room and board, personal care and other health services to no more than three persons.

- The alternate family care program provides an opportunity for Medicaid-eligible senior citizens to age in a home in the community rather than in a facility. This option sometimes faces challenges by local zoning boards. A broadening of zoning laws would permit the trained caregivers of the alternate family care program to increase availability of this community housing option to the aging senior citizens in the State.

NURSING HOMES - A NECESSARY OPTION FOR THE MOST VULNERABLE POPULATIONS

23. For better utilization of long-term care facilities, in the advent of increased community-based services and shorter hospital stays, nursing homes will need greater flexibility in bed designations so that they are able to readily accommodate respite care and rehabilitative needs.

- As an increasing number of senior citizens shift from nursing homes to community-based care services and as the lengths of hospital stays decrease, nursing homes must be allowed to adapt their facilities to meet the demand for increased respite care and rehabilitative services.

24. Nursing homes should be given increased incentives to implement the Eden Alternative philosophy, in which a more independent, community-like setting is created by making companionship, variety, spontaneity and other opportunities to care for other living things a part of a nursing home resident's typical day.

- Eden-style homes strive to combat loneliness, helplessness and boredom by giving residents the opportunity to make as many choices as possible in their daily lives. This humane, positive approach to helping senior citizens live out

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their lives in a nursing home setting would enhance the quality of life of nursing home residents.

25. In accordance with the Community Choice Counseling Program - Nursing Homes, the Department of Health and Senior Services should ensure that home care and community-based services are in place prior to the discharge from nursing homes of senior citizens who no longer need that higher level of care.

- The Community Choice Counseling Program - Nursing Homes began on a limited basis in 1998. As the program expands, it is important for counselors to be certain that there are services available in the community to meet the current needs of the patients being discharged from nursing homes.

26. The State Medicaid reimbursement methodology should adequately reflect the population served by nursing homes, that is, the frailest and the sickest. This is particularly important as the more independent senior citizens seek out alternatives such as assisted living and adult day care.

- With the increased use of assisted living and community-based services, nursing homes will be caring for the most service-intensive population.

PREVENTIVE HEALTH SERVICES IN THE COMMUNITY

27. Funds should be appropriated or obtained through grants to the Department of Health and Senior Services to develop a Statewide health promotion and disease prevention initiative for senior citizens.

- Although the risk of disease and disability increases with age, health promotion interventions can postpone or prevent disease and disability, maintain and improve health status, contain costs and enhance independence and quality of life.
- A possible model for this initiative was developed by the New York City Department of Aging. The components of the program are health education and exercise.
- Education sessions would be presented by professionals on a variety of topics, including the value of exercise, nutrition, home safety, medication and substance abuse and smoking cessation. Exercise programs would be conducted at several locations throughout a county on a regular basis. Physical therapists would provide training for leaders of the exercise

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programs.

EDUCATION OF HEALTH CARE PROVIDERS

28. A continuing education support system and a recognition and promotion system for direct patient care providers, including nurse aides and homemaker-home health aides, should be established.

With regard to particular training requirements, nurse aides and homemaker-home health aides need dementia-specific training for patients with Alzheimer's Disease. This training should include specialty certification in dementia care.

- The quality and effectiveness of direct patient care are highly dependent upon the attitudes and training of the professionals providing that care.
- Appropriate training and recognition for those workers who provide the majority of direct care, but generally receive the least amount of training and education, would improve the outcomes of patients and show support for direct care workers.

29. In order to improve the delivery of services to senior citizens, health care professionals and agencies serving senior citizens should receive cross-disciplinary training. These geriatric training programs should be accessible through decentralized training tools, such as web-based training modules.

- Cross-disciplinary training of health care providers would facilitate the sharing of information between agencies and institutions that provide different services to senior citizens.
- This coordinated effort could be the source for identifying underutilized resources and for measuring the effectiveness and impact of support services on caregivers and their family members.

30. Geriatric training and research should receive enhanced support at the State's medical schools, colleges and universities, as appropriate. This expansion could include the creation and funding of a geriatric chair and student incentives, such as student loan forgiveness programs and geriatric medicine fellowships, to increase the number of health care professionals who choose to study elder care within the State.

- The demographics of the increasing senior citizen population warrant the

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increase of geriatric training and research at the State's medical schools, colleges and universities, as well as the offering of professional opportunities and incentives to attract health care professionals to the field of geriatrics.

31. Training for health care professionals should emphasize the need to inform families about palliative care, including the option of hospice care for end-of-life care and the importance of preparing advance directives. In addition, the Department of Health and Senior Services should establish an educational campaign to increase the public's awareness of the availability of palliative and hospice care and advance directives.

- Palliative care is the active, total care of a patient whose disease does not respond to curative treatment. The goal of palliative care is achievement of the best quality of life for patients, and the care includes control of pain and can include treatment of the condition and other symptoms, including psychological, social and spiritual problems. Palliative care can be provided to patients who have chronic and terminal illnesses at all stages of their illnesses.
- Hospice care is a part of palliative care and provides comfort care during a particular phase of end-of-life care, the final six months.
- Patients and their families can assume the responsibility for their care if they are aware of the options that are available to them. Increased education of health care professionals and the public about palliative and hospice care and the role of advance directives would assist patients and their families in selecting the type of care that is right for them.

PLANNING FOR LONG-TERM CARE NEEDS

32. The Department of Banking and Insurance, in consultation with the Department of Health and Senior Services, should develop an educational campaign to inform middle-aged (ages 45-65) and young-old (ages 65-75) populations about the importance of planning for their long-term care needs, through the use of long-term care insurance, viatical settlements and other financial instruments that could provide necessary resources for senior citizens as they age. Also included in this educational campaign should be the importance of discussing and addressing these planning issues within families.

This campaign could be promoted through community education, collaboration with private employers, public service announcements, periodic State and local government mailings and other forms of advertisement.

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- According to a study conducted in 1998 by the American Council of Life Insurance, the success of private insurance to finance long-term care needs depends on, among other factors, the extent to which the current middle-aged population understands the risk of needing long-term care services.
- Testimony presented to the Advisory Council confirmed that the public needs increased awareness about the importance of planning for their own long-term care needs, and in particular, the affordability of long-term care insurance for those who begin purchasing this insurance at a relatively young age.
- Unfortunately, the younger population ignores the need for purchasing this coverage when they are young and the premiums are affordable. The problem occurs when people age and want to purchase long-term care insurance, but the premiums are too expensive.

33. The Department of Banking and Insurance, in consultation with the Department of Health and Senior Services, should explore the promotion of long-term care insurance as a voluntary option to public employees through the State Health Benefits Plan.

- If the State were to lead by example in offering long-term care insurance to its employees as a voluntary option through the State Health Benefits Plan, private employers, in an attempt to be competitive in their benefits packages, might follow by offering long-term care insurance to their employees.
- By offering the benefit on a voluntary basis, the benefit does not become a burden to the employer.

34. The State should consider implementing tax incentives for State residents who purchase long-term care insurance.

- The growing number of State residents who will be 65 years or older in 2030 no doubt will have an impact on the State's resources and ability to meet long-term care needs.
- Private long-term care insurance can help ease the burden if the current middle-aged population purchases this coverage. The study conducted by the American Council of Life Insurance determined that one of the keys to realizing the potential of private insurance to provide for long-term care needs was to encourage the current middle-aged population to purchase long-term care insurance.

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TRANSPORTATION ISSUES

35. Funding needs to be made available for strengthening and developing local public transportation networks for senior citizens in urban and rural areas. Additional funding should be directed to meet the needs of the frail elderly, in particular, who need assisted transportation if they are to remain in the community.

- Lack of availability of public transportation is an enormous problem for senior citizens and their families in accessing health and social services in the community. The frail elderly have great difficulty getting in and out of their homes and need assisted transportation.
- As consumers who want to age in place, senior citizens provide a strong economic base and often can meet their shopping needs independently, but their spending power will not benefit the State's economy and they will not be able to remain in the community if they cannot find transportation to their shopping destinations.
- Legislation recently enacted by the Legislature and signed by Governor Whitman on August 5, 1999, P.L. 1999, c.179, which permits reduced fares for certain senior citizens at peak times of travel, rather than only during offpeak hours, exemplifies the accommodations that are being made, and that need to continue to be developed, to promote the independence and self-sufficiency of senior citizens.

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CONCLUSION

Further Study of Elder Care Policy

36. There should be established an ongoing work group to continue to explore innovative ways to improve the care provided to the State's aging population and monitor and evaluate the implementation of the recommendations in this report. Members of the ongoing group should include some members of the Advisory Council as well as providers and consumer representatives.

- The issue of improved elder care does not conclude with this report. The importance of continuing to search for innovative ways to improve the care of the State's aging population warrants a continued effort to evaluate and monitor the success of the Advisory Council's recommendations and to develop further policy recommendations for the future.
- As an ongoing work group, the Advisory Council could undertake some of the recommendations of the report, such as: exploring the possibility of presumptive eligibility; examining the feasibility of linking NJ EASE care managers with hospitals, outpatient clinics and physicians' offices; and studying the ramifications of providing tax incentives to certain unpaid caregivers.
- In addition, the ongoing group could address some long-range issues that were raised by members of the Advisory Council, such as:
 - promoting partnerships among providers of acute care, long-term care, assisted living and other senior housing options, who could collaborate so that the existing capacity of beds and housing space is used in the most appropriate way;
 - attempting to ensure that Medicaid funding for nursing homes, assisted living and residential health care facilities addresses the needs of the population served as functional and cognitive impairment increase;
 - examining the anticipated labor shortages for all levels of nursing care and other health care providers;
 - reviewing regulations for program entry;

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- contributing toward the evaluation of the effectiveness of State-funded programs for senior citizens, which could include working in cooperation with the Center for State Health Policy to evaluate the full set of senior initiatives.
- working toward integration of funding streams to provide further flexibility;
- encouraging the counties to assess their effectiveness in meeting the transportation needs of their senior citizens;
- reviewing the opportunity to include hospice care in advance directives;
- studying the degree to which different ethnic or cultural factors may affect a person's decision to save or plan for retirement;
- studying the needs of the aging population in the next three to five years so that the State will be able to meet the increasingly complex needs of the aging population; and
- ensuring that the Department of Health and Senior Services has an adequate capacity to collect and analyze data regarding the State's senior citizen population and its increasing need for services.