Rebalancing Long-Term Care in New Jersey:
From Institutional toward Home and Community Care

by Susan C. Reinhard and Charles J. Fahey

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Reforming States Group

Milbank Memorial Fund

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FOREWORD

This report describes efforts in one state to reduce reliance on nursing homes for care that seniors could receive, and that most would prefer to receive, in their own homes or in homelike settings. The authors assess the experience of "rebalancing long-term care" in New Jersey since 1996, when that state consolidated all services for seniors in one department.

This is a story of steady progress, not dramatic reform. "A few states," the authors write, "have led the way for decades. Other states, like New Jersey, demonstrate that it is possible to change the direction of long-term care—step by step, year by year." The authors derive lessons from New Jersey's experience for policymakers in other states.

This report began, as most projects of the Milbank Memorial Fund do, with a question from a policymaker. Christine Grant, then Commissioner of Health and Senior Services of New Jersey, asked in mid-2001 if the Fund would convene persons experienced in making and implementing policy for long-term care from New Jersey and other states to assess the results of the first six years of the consolidation of health and senior services in that state. The meeting occurred in January 2002; participants in that meeting as well as persons who reviewed the report in draft are listed in the Acknowledgments.

The report goes considerably beyond the discussion at the meeting because of the expertise of its authors. Susan Reinhard served as the first Deputy Commissioner for Senior Services after the reorganization in 1996. She is now co-director of the Rutgers Center for State Health Policy. Charles Fahey, currently a Program Officer of the Fund, has held many distinguished positions in the fields of aging and long-term care at local, state, national, and international levels. More information about each of the authors is available at the end of the report.

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EXECUTIVE SUMMARY

Older adults in New Jersey are like their counterparts around the country: If they need long-term care, they would rather get it at home. But like their peers in most states, they get public financial support more readily if they go to a nursing home. In 1996, New Jersey ranked "average to well below average" regarding its use of public dollars for home- and community-based systems of long-term care. That year, New Jersey launched a multipronged strategy to change this situation.

The state consolidated all services for seniors into one department, with the mission to promote independence, dignity, and choice for older adults. This new department developed more home- and community-based services, and spearheaded a county-based system of information and assistance to help seniors find the services they prefer. With these changes in place, New Jersey has more than doubled the percent of long-term care funds spent on home- and community-based care, rather than nursing home care, for older adults—from 7.3 percent in state fiscal year 1997 to 15.3 percent in fiscal year 2002. For state fiscal year 2003, the percent is expected to rise to 17.2. From FY 1997 to FY 2002, the number of people on Medicaid in nursing homes dropped by more than 3,000, a 10 percent reduction.

This report chronicles New Jersey's recent experience in order to assist policymakers in other states who face similar challenges to meet elders' preferences for long-term care and to develop sustainable services and systems at the same time. It explains why New Jersey wanted to reform its long-term care system and how it went about making the changes. The report also includes recommendations for current New Jersey officials and policymakers and for their counterparts in other states.

Through a 1996 Governor's Executive Reorganization Plan, more than 20 programs and 600 staff members from four different state departments were brought together into a single division of senior services within the "new" New Jersey Department of Health and Senior Services (NJDHSS). This cabinet-level department was granted full policy and budgetary authority to:

- Create new long-term care alternatives and oversee their quality through licensing and certification.
- Inform older adults and the people who care for them about their options.
- Pay for senior services through all state funding dedicated to that purpose and through Medicaid and Older Americans Act funding.

Senior services were consolidated into one department to promote independence, dignity, and choice for New Jersey's 1.4 million older adults and to coordinate policies, budgets, and programs toward that end. The state sought to change its long-term care system from one devoted almost exclusively to institutional care in nursing homes to one that would help seniors live in their homes and communities for as long as possible. In 1996 (FY 1997) almost all of New Jersey's public funding for long-term care of older adults went to nursing homes. The New Jersey Department of Health and Senior Services stimulated the development of new long-term services and more support for family caregivers. It also created new ways to find out about these home- and community-based options. NJEASE, a county-based information and assistance program, was designed as a "one-stop shopping" point of entry into senior services. Community Choice Counseling helped people in nursing homes learn about their other long-term care options.

The consolidation of senior services into one department led to a concerted effort to develop polices and programs to help more seniors remain in their homes and communities. NJDHSS data indicate that these efforts have contributed to a steady shift of public resources from institutional to home- and community-based long-term care. New Jersey reduced its reliance on nursing homes from 92.7 percent of its funding to 84.7 percent over the five years from state fiscal year 1997 to 2002. During the same period, home- and community-based care rose from 7.3 to 15.3 percent of the budget for senior services.

Six years after consolidation, however, the state still plans to spend more than 80 percent of the funds for long-term care of older adults on institutions. If New Jersey wants to join Oregon, Washington, Colorado, and other states that have are "above average" in the percent of public funding going to noninstitutional care, much work remains. The authors of this report offer recommendations about that work for the state.

While each state is unique in its history, economy, and social commitments, the aging of America is a universal reality that affects every state's public policies. Certain aspects of New Jersey's experience have national relevance. In any state that wants a fundamental shift in its delivery of long-term care, policymakers must:

- Encourage a civic process that engages people and lets them express their preferences. This discourse helps create a groundswell for change—although focused, sustained leadership by a few champions of change is essential. In some states, like Oregon, senior advocates who pushed a bill through the legislature were the driving force for change. In New Jersey, leaders in the executive branch galvanized change and sought advocates and legislators who would endorse the necessary programs and financing.
- Identify the champions. Many forces can create the impetus for change. But talented, committed leaders must make sure that vision and energy are channeled into substantive results. A few visible champions are needed to keep the issues in the limelight. The most effective champion is a governor who will embrace the change.
- Develop and support staff members. Regardless of the driving force for change, knowledgeable, creative staff in the executive branch must devise and coordinate policies and programs. It takes time to develop a policy or program from a concept to a reality. Sustained leadership and staff efforts are vital.
- Develop a clear statement of underlying values to help focus the policy process. New Jersey uses independence, dignity, and choice.
- Recognize that these values mean little without actual services and access to them. Nursing home care will continue to be needed, although it may be scaled down. However, some of the most impaired older adults are now living in their own homes. These people need services there, otherwise they will be forced into institutions.
- Leverage consumers' desire to remain at home and the state's desire to minimize expensive institutional programs as complementary, formidable forces for change.

- Understand that long-term care reform is multifaceted. It includes health promotion, disease prevention, and regulatory reform—as well as expansion of home- and community-based services.
- Use federal and state dollars creatively to expand home- and community-based services to help older adults at all income levels. Develop "seamless" programs with consistent eligibility criteria and uniform consumer-contribution requirements.
- Develop user-friendly structures, close to the consumer. They are an important factor in making choices real, regardless of the person's income. Even people who are not poor should know that they have a place to call for "one-stop shopping"—help in finding affordable services.
- Develop a universal preadmission screening form and process to assess the needs of people seeking long-term care.
- Acknowledge that state activities are constrained or allowed by federal statutes, regulations, and interpretations. The Older Americans Act, Medicare, and Medicaid provide the bulk of public funding for long-term care and have a major impact on its structure. Differing eligibility standards as well as regulatory idiosyncrasies make it hard for consumers, providers, and state policymakers to develop or access complementary kinds of care. However, much can be done even within these limits.
- Examine the issues in integrating services for older adults, younger people with disabilities, and people with developmental disabilities. The Supreme Court's Olmstead decision, and the state's responses to it, tend to focus on younger persons with disabilities.

States that want to shape policies and programs to help older adults live as independently as possible in their preferred environments can make significant progress toward that goal. A few states, like Oregon and Washington, have led the way for decades. Other states, like New Jersey, demonstrate that it is possible to change the direction of long-term care—step by step, year by year.

The economic constraints that states currently face make it more important than ever to examine how long-term care dollars are spent. Some of the most progressive states made their most significant progress during economic downturns because policymakers were willing to listen to new ideas. Leadership is critical, and dialogue with the public is important to shape long-term care to meet the needs of those who may use it.

INTRODUCTION

Historically the State of New Jersey has shown its concern for older adults in both the public and private sectors. But New Jersey's public spending for long-term care, like that of most states, contrasts sharply with consumer preferences. While consumers prefer supportive care in their homes and communities, their choices are often restricted to institutional settings, especially if the consumers have limited funds. In 1996, the state launched a three-pronged strategy to lessen its overreliance on long-term care in institutional settings and increase community-based care. First, the state consolidated all senior services into one department charged with promoting independence, dignity, and choice for older adults. Second, this new department developed more home- and community-based services. Finally, the state spearheaded a county-based system of information and assistance to make it easier for seniors to find their preferred services.

This report chronicles New Jersey's experience in order to assist policymakers in other states who need to meet their older adults' preferences for long-term care and, at the same time, to develop sustainable services and systems. It explains why New Jersey wanted to reform its long-term care system, how the state made its changes, which key stakeholders were involved, what early successes arose, and what challenges remain. The report also makes recommendations for current New Jersey officials and policymakers and for their counterparts in other states.

BACKGROUND AND GOALS

New Jersey is home to 8.4 million people, including 1.4 million persons aged 60 or older. The 1.4 million includes more than 1.1 million who are more than 65 years old, and 136,000 of them are over 85. The population is slightly older than that of most states; 13.2 percent of all New Jerseyans are over 65, compared to the national percentage of 12.4 (Census 2000 Summary File 1, available at http://factfinder.census.gov). Many of these older adults need long-term care. As in the rest of the country, about one in five older New Jerseyans (19.8 percent) have difficulty with mobility or with caring for themselves (AARP 2000).

Like their counterparts around the country, older adults in New Jersey who need long-term care prefer to get it at home. However, like their peers in most states, they get public support more readily if they go to a nursing home. Based on 1992 data, New Jersey was ranked "average" in its efforts to change that situation by creating strong home- and community-based systems of long-term care (Ladd et al. 1995). During the next four years, New Jersey's nursing home caseloads and expenditures grew, and no programs permitted older adults to direct their own care at home. Before the state launched its redesign of senior services in 1996, New Jersey ranked "well below average" for its commitment to home- and community-based care when compared with other states (Ladd, Kane, and Kane 1999).

Two forces for change converged to propel the state in a new direction. First, public discussion helped lay a foundation of support for change and introduce some new concepts in long-term care. Second, leaders in long-term care entered public service and championed changes.

PUBLIC DISCUSSION

Two sets of statewide public forums held in the early 1990s highlighted consumer dissatisfaction with the state's long-term care. Compared to Indiana, Oregon, Wisconsin, and many other states, New Jersey was not known for its strong senior advocacy groups (Ladd 1997). The forums brought senior advocates, policymakers, and providers together in discussion groups—atypical events in New Jersey. The gatherings sparked the development of important relationships and new ideas that would later influence the state's policy and program development.

The first set of public forums began in 1990 as the state was preparing its State Health Plan regulations. This State Health Plan included a chapter on long-term care that decried the fragmentation of services for older adults among three major state departments and agencies; services were organized around funding sources rather than peoples' needs (NJDOH 1991). Although the State Health Plan was never formally adopted in regulation, public discussion of long-term care helped create a groundswell for change. This consensus document called for consolidation of state agencies to focus on alternatives for long-term care, including assisted living and adult foster care. It had the support of consumer groups, such as AARP, and provider associations, including nursing home and home health care leaders who believed their members could play a part in diversifying long-term care services. Two nursing home leaders even went to Oregon to learn more about assisted living, adult foster care, and the state and local infrastructures that supported service delivery.

The 1993 work groups leading up to the 1994 Governor's Conference on Aging provided a second set of forums for discussion of broad issues in senior services. These groups called for streamlining long-term care and making the system more consumer-friendly (NJDCA 1994). They also advocated more long-term care choices.

LEADERSHIP

These public discussions helped document the desire for change in New Jersey. However, public discourse alone would probably not have led to action. It took concerted effort by a few champions to bring the message to the highest levels of government and begin the process of rebalancing long-term care.

Shortly after the two public forums, New Jersey elected a new governor, Christine Todd Whitman. Her 1993 transition team included strong advocates for changing long-term care policy, financing, and services. Several of these advocates then joined the Whitman administration to advance change from within the government.

To increase the momentum for change, the state applied for a grant from the Robert Wood Johnson Foundation (RWJF) for new, locally based pilot programs to give older adults the information they needed to find services. Susan Reinhard was the project director of this RWJF grant and coordinated efforts with the governor's office and four state departments. The state added $400,592 in matching funds to RWJF's planning grant of $238,251. The 1995 RWJF grant required the governor's office to convene an interdepartmental planning group that would report progress, issues, and barriers to the governor's Office of Planning. This project helped make the case to county and state stakeholders that the best way to help older adults and their families was to consolidate access to a full range of information about health and long-term care, and other pertinent services, at the county level. After examining similar initiatives in Oregon, Connecticut, Illinois, and Indiana, the interdepartmental group launched the New Jersey Easy Access, Single Entry (NJEASE) initiative to help seniors and their families find information and assistance at the county level (Reinhard and Scala 2001). Thirteen out of 21 counties immediately volunteered to participate in NJEASE; later, all adopted it.

This interdepartmental investigation into streamlining services for seniors at the local level kept the issue before the governor and the commissioners in the departments that provided such services. As momentum for consolidating information and access at the local level grew, the need for a parallel consolidation of long-term care services and financing at the state level became more apparent to leaders of the executive branch. Many other questions emerged about the mix of services that New Jersey was offering—questions that policymakers in all states should ask about their own long-term care systems. (See Box 1.)

BOX 1. PRIORITIES IN REBUILDING

Some policy options based on New Jersey's experience include:

- Designing a local system of information and assistance to make sure older adults at all income levels can find affordable services to help them stay in their homes when possible.
- Helping people use their personal resources wisely. Seniors can usually stay at home longer by "spending down" their own resources than by "spending down" in a nursing home.
- Designing a universal assessment and screening tool to help document the person's activities of daily living and other factors that will determine service needs and eligibility for public assistance. The state may allocate resources based on impairment levels, changing these levels according to state budget capacity to assure that the most impaired persons get preference for services.
- Developing programs that help people who are not eligible for Medicaid get services to help them stay at home. Sliding-scale programs can help older adults stretch their dollars for these services.
- Instituting a transition program to identify people in nursing homes who want to return to their own homes and communities and are able to do so, given adequate aid.
- Designing Medicaid home- and community-based programs that help people to avoid nursing homes, or to leave them when possible. State and Medicaid funds should help pay the one-time costs of returning home (e.g., help with the first month's rent, security deposits, furniture, and the like).
- Examining ways for nursing homes to downsize in accordance with changing market demand.

By the fall of 1995, the commissioners of those departments housing the major components of senior services agreed that consolidating those services at the state level was good public policy. They wrote to Governor Whitman to say so, but stopped short of saying how consolidation should occur. The governor asked her staff to appoint an internal consultant to propose methods for consolidation, which could have included changing existing departments or establishing a new department.

Governor Whitman chose the Department of Health to lead the consolidation in a "new" New Jersey Department of Health and Senior Services (NJDHSS). NJDHSS became effective in July 1996. Its new Division of Senior Services combined services, financing, and staff from four departments:

- Health: licensing and certification of all long-term care facilities
- Human Services: the Medicaid budget and policy responsibility for nursing homes and home- and

community-based waivers that primarily serve older adults, as well as pharmaceutical assistance for the aged and disabled

- Insurance: Medicare and supplemental insurance counseling
- Community Affairs: services supported by the Older Americans Act

GOALS

The primary goal of consolidating senior services into one department in 1996 was to promote independence, dignity, and choice for New Jersey's 1.4 million older adults and to coordinate policies, budgets, and programs to that end. The state sought to shift its long-term care system from one focused almost exclusively on institutional care in nursing homes to one that would help older adults live in their homes and communities for as long as possible. Almost all of New Jersey's public funding for long-term care for older adults (92.7 percent) was going to nursing homes. It was far easier for older adults and their families, physicians, and other providers to find information about nursing homes than about alternatives. And alternatives to nursing homes were scarce.

To promote independence, dignity, and choice, the new department established several objectives (NJDHSS 1998). The department would work with consumers, providers, and local and state policymakers to:

- Promote health and wellness so that older adults can maintain their highest level of independence.
- Provide more choices for care, particularly in people's homes and communities.
- Use public and private resources carefully—including the individual's private resources—so that these choices are more accessible and affordable.
- Ensure that the care provided is high quality.
- Help people find these options quickly and easily.

AGENCY RESTRUCTURING

By the end of 1996, the largest reengineering effort in the history of the New Jersey Department of Health was completed. Through the Executive Reorganization Plan (no. 001-1996), more than 20 programs and 600 staff members from four different state departments were consolidated into a single Division of Senior Services in the "new" New Jersey Department of Health and Senior Services (see Box 2). This new department was granted policy and budgetary authority to:

- Create new long-term care alternatives and oversee their quality through licensing and certification.
- Inform older adults and the people who care for them about their choices for care.
- Pay for senior services through Medicaid, the Older Americans Act, and all state funding dedicated to senior services.

By consolidating authority for policies, programs, and financing for long-term care for older adults, New Jersey joined a handful of states that concentrated on rebalancing such care. No state, New Jersey included, has combined all long-term care funding and functions for all populations into a single agency (Kane, Kane, and Ladd 1998). Oregon, Washington, Kansas, and Michigan have tried to integrate long-term care (Braunstein 2002; Kane, Kane, and Ladd 1998), using different methods. Unlike the other states, New Jersey now divides Medicaid financing responsibility between two cabinet-level departments, rather than creating one large "umbrella" agency.

BOX 2. PROGRAMS CONSOLIDATED INTO THE NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES IN 1996

From the Department of Health

- Development of regulatory standards and licensing of all facilities—nursing homes, assisted living, adult foster care, home health agencies, adult day care, etc.
- Planning for nursing homes—certificates of need
- Alzheimer's Day Care Program

From the Department of Community Affairs

- State Unit on Aging—the Division on Aging, with oversight of all area agencies on aging, Older Americans Act programs, Social Security block grant, etc.
- Office of the Ombudsman
- Office of the Public Guardian
- Adult Protective Services
- Congregate Housing Services Program

(continued)

From the Department of Insurance

- Senior Health Insurance Unit

From the Department of Human Services

- Nursing Facility Rate Policy and Reimbursement—rate setting, rate policy, claims, and provider support
- Nursing Facility Level Services—long-term care field offices, nursing facility preadmission screening, clinical audits
- Home- and Community-Based Services for Older Adults
- Statewide Respite Care Program
- Adult (Medical) Day Care
- Adult Social Day Care
- Home Care Expansion Program
- Community Care Program for the Elderly and Disabled (CCPED, which is a 1915(c) Medicaid waiver program)
- Pharmaceutical Assistance to the Aged and Disabled
- Lifeline Credit Program
- Tenants' Lifeline Assistance Program
- Hearing Aid Assistance to the Aged and Disabled
- Enrollment into the Medicare Savings Programs

ORGANIZATIONAL COMPLEXITIES

Consolidating authority for senior services was a complex process. In order to divide Medicaid budget and policy authority between NJDHSS and the New Jersey Department of Human Services (NJDHS), the two departments negotiated an interagency agreement, which was approved by the federal Centers for Medicare & Medicaid Services (formerly known as the Health Care Financing Administration). The federal government permits states to treat Medicaid more as a funding stream than as a functional program. States can divide responsibility for Medicaid between two or more agencies through several mechanisms. New Jersey chose to make NJDHS the "single state Medicaid agency" to coordinate the paperwork flow between the state and the federal government. Through an interagency agreement, NJDHS assures that all documents are completed in the form and process required by federal law. But NJDHSS has "the authority to establish the State's policy regarding care for its seniors," including budget authority over all Medicaid funds for senior services. In addition, the U.S. Administration on

Aging designated the new department as the single state agency for services provided under the Older Americans Act (NJDHSS 1997). Federal officials agreed to these changes after several high-level meetings.

Two aspects of this decision to split Medicaid policy and budget responsibility between two cabinet-level departments were particularly problematic. First, from an administrative perspective, the two departments needed to determine the most efficient way for NJDHSS to "subcontract" certain services that would be inefficient if split—services like information systems, claims processing, and fraud and abuse investigations. Second, from a policy perspective, the split between services for seniors and people with disabilities was sensitive. Which programs were primarily serving which group of people? The goals of policy and program consolidation might have been better served by consolidating both the Medicaid and state-only services for seniors and people with disabilities. But the governor's office had focused only on older adults. Without consulting people with disabilities, the governor's office determined that consolidation should be confined to senior services and programs. Since Oregon had first consolidated senior services and later included services for people with disabilities, the governor's office felt it would be prudent to begin with senior services and reevaluate the decision later. Several years later, Governor Whitman established an Office of Disability in the New Jersey Department of Human Services.

Although limited only to senior services, New Jersey policymakers agreed this consolidation was a good starting point to help many people who need long-term care find the information and services they need to make reasonable personal choices. The state legislature passed a resolution approving consolidation of senior services. The public concurred during regional meetings convened by area agencies on aging and their citizen advisory committees. The meetings stressed the need to help older adults and their families find information and assistance early enough to use their personal resources wisely and to find public support that would let them stay in their homes and communities whenever possible.

Reorganization of all senior services into one cabinet-level department appeared to raise the level of the policy debate about home- and community-based care for older adults and caregiver support for their families. The governor could now hold one department accountable for developing new programs and announce those programs county by county. She held roundtable discussions with older adults and their family caregivers and included their issues in her annual State of the State addresses to the legislature and the general public.

Organizational Cultures

Another major difficulty in consolidation was integrating staff from the Medicaid, Older Americans Act, public health, and survey-certification departments. Each group had its own perspective or organizational culture:

- The philosophy of the staff that administered the Older Americans Act was in many ways the strongest call to action. This staff believed that all older adults, regardless of income or frailty,

should have access to services that promote independence. They wanted to focus on older adults' ability to contribute to society as a whole. They wanted information and assistance for long-term care. But they also wanted information about employment, educational opportunities, and volunteer activities like reading to children.

- The staff from the Medicaid culture understood the public investment in long-term care and was vigilant about budget and accountability mechanisms to safeguard the public's trust.
- The public health staff members were "upstream" oriented. They wanted to promote self care, prevent disability, and restore function to all older adults, whatever the setting.
- The survey and certification staff continually spoke of quality. With the staff of the Ombudsman and the Public Guardian, they concentrated on the most vulnerable citizens who required protection by the state.

All these goals are noble. They also embody conflict. For example, it is not always possible to promote independence and protect people from the harm that can come from their own choices. It is very stimulating and important to hear discussions among survey staff and Ombudsman staff—who are mandated to protect public safety—and State Unit on Aging staff, who fiercely defend the older adult's right to make decisions, even when the decisions are rejected by families and neighbors. As staff members reflecting these varied perspectives came together, there were many debates and months of intense discussions. Those discussions shaped subsequent policies about adult foster care, assisted living, consumer-directed home care, health promotion, caregiver support, respite services, and adult protective services. The overriding mission—to promote independence, dignity, and choice for all older adults—helped to forge consensus. It was also helpful that the governor's office expected the staff to iron out differences internally and offer coherent policies and programs that would be embraced by the public and the legislature.

The best measure of this merger of philosophies and programs is the actual shift of long-term care from an almost exclusive investment in nursing homes to more home- and community-based options. The major question is whether reorganization helps achieve this goal. At a minimum, a rebalanced system helps people who would otherwise have entered an institution to receive care in the community instead; ideally, the system also supports people who are unlikely to need a nursing home but who do need services in order to remain at home.

Authority and Accountability

The policy rationale for consolidation is that it lets a governor hold one commissioner or secretary accountable for rebalancing. In most states, the authority and accountability for programs and budgets are diffused among three or more government agencies. Even states that have created a separate cabinet-level department of aging, like Pennsylvania and Maryland, do not grant these cabinet officials policy and budget authority for long-term care for seniors. The officials do not have authority over the nursing home budget. They do have administrative responsibility for "waiver"

programs that provide home care services to people who are eligible for nursing home care under Medicaid. But it is the Medicaid agency that has the final authority. This is very different from Oregon or New Jersey. In Oregon and New Jersey, the officially designated single state Medicaid agency processes the paperwork for the Centers for Medicare & Medicaid Services because other state agencies have the policy and budget authority over programs for older people and people with disabilities, not just "delegation" authority to administer programs on behalf of the single state agency.

It is difficult to shift funding among departments without clarifying the policy and budget authority vested in each department. Typically, the single state Medicaid agency feels that the aging agency does not respect its fiscal responsibilities and that the experts on aging will "give it all away." Conversely, the aging agency's experts think their Medicaid colleagues do not spend money creatively so that more people can live in their homes and communities. These competing voices make it difficult to advance a single, consistent, convincing argument for rebalancing long-term care. One goal of developing a consolidated department for senior services is to align the "creativity" of the aging community with the "accountability" of the Medicaid community. The governor finds both perspectives in one place. Those who advocate change have to deliver on the budget for change.

NEW LONG-TERM CARE OPTIONS

Bringing both the Medicaid and aging-agency perspectives to the licensing staff in New Jersey stimulated new thinking about services. The consolidated senior services division invested much of its energy in developing an infrastructure for long-term care that included new options for older adults regardless of income.

Assisted Living

Regulations for Assisted Living led to a major growth of this new option in 1996. The regulations for it developed from a consensus among consumer advocates, state regulators, and providers, including nursing home providers. (New Jersey's assisted living regulations are available at http://www.state.nj.us/health/ltc/regnjac836.pdf.) They support a nursing home substitute framework for consumers who want to age in place in residences that offer increasing levels of care as the consumer's needs change. This long-term care option has grown dramatically—from 1,082 beds in 1996 to 14,956 beds in 2002.

As in most states, most older adults in assisted living residences are paying privately. However, in 1996 New Jersey obtained federal approval of a 1915(c) Medicaid waiver to pay for care in a licensed assisted living facility. This waiver gave NJDHSS a new way to help people leave nursing homes for other settings or to avoid nursing home placement altogether. Senior state officials visited reluctant assisted living providers to encourage them to become Medicaid providers. Recent legislation mandates that all new assisted living facilities make at least 10 percent of their beds available for

Medicaid beneficiaries, assuming there are enough waiver "slots" to meet this demand. Currently, 1,741 New Jerseyans receive support from Medicaid to live in assisted living facilities.

Adult Family Care

Adult Family Care regulations created another new option. This alternative has grown slowly because state law required adult family care providers to register as boarding homes if they cared for more than one unrelated adult. The state found that people who might otherwise be interested in providing care to two or three people did not want to be boarding home operators. Based on the example of adult family care in Oregon and other states, New Jersey officials worked with the legislature and stakeholders to enact legislation in January 2002 that removed the barriers to growth for this program. State law now permits adult family care providers to obtain a license to care for up to three people without becoming boarding home operators. Older adults who choose adult family care can pay privately or receive this service through a 1996 Medicaid waiver or state funding.

Senior Initiatives: CAP and JACC

For two years (1996–98), NJDHSS leaders met with consumers, providers, county officials, state legislators, and members of the governor's planning and budget offices to develop a set of new or expanded programs that would help rebalance long-term care. The Senior Initiatives announced in 1999 introduced new home care programs—the Caregiver Assistance Program (CAP) and Jersey Assistance for Community Caregiving (JACC)—to help older adults remain at home, even if they are not eligible for Medicaid. The Senior Initiatives also provided family caregivers with more respite care and training to manage their responsibilities. State staff would counsel nursing home residents about all of their options through the new Community Choice Counseling program described below. Because nursing homes will continue to be necessary, perhaps on a smaller scale, the state seeks innovation that will improve the quality of care and the quality of life in nursing homes. That is why the state launched a pilot program to promote the Eden Alternative, which supports nursing homes that want to improve residents' quality of life.

Created by NJDHSS leaders, these Senior Initiatives were embraced by Governor Whitman, who included funding for them in her 1999 budget address to the legislature and public. The Governor's Advisory Council on Elder Care, chaired by Assemblywoman Carol Murphy, also endorsed the initiatives.

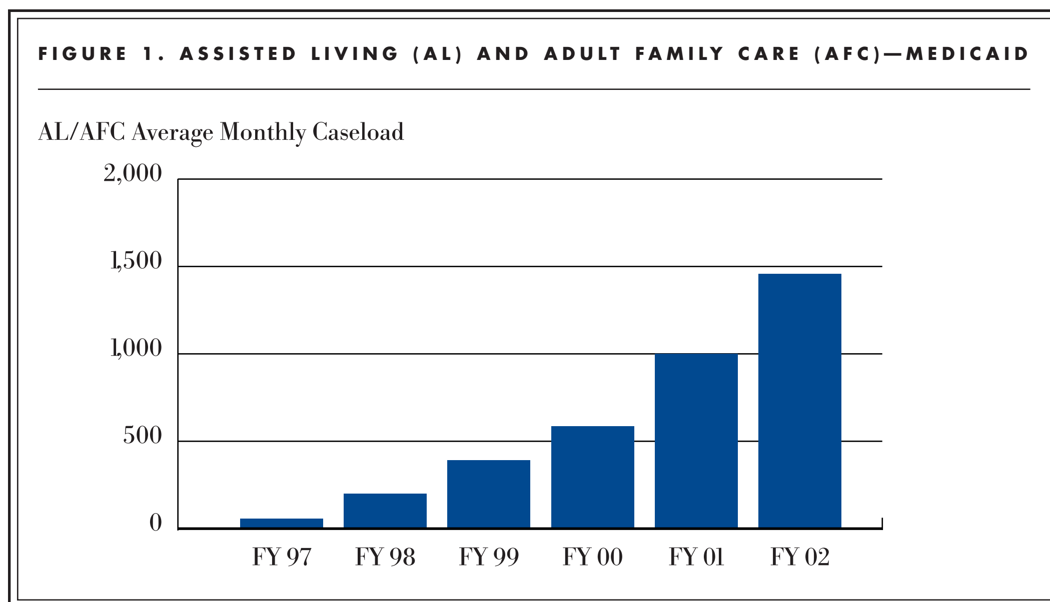
In 1999 the legislature approved the Senior Initiatives plan for $60 million in new state and matching federal dollars to be used over three years. These new funds were not taken from the annual nursing home budget, which remains a separate budget category. Unlike Oregon, which has a "global budget" for long-term care, the NJDHSS cannot move money from the nursing home account to fund home- and community-based programs without permission from the legislature.

The Medicaid, Older Americans Act, and state-funded programs were designed to allow people of all incomes to get the help they need, according to their ability to pay for that care. The programs in the Senior Initiatives "fit together" using different funding streams—creating "seamless" support for everyone.

The Senior Initiatives included two new home care programs that offer more flexible services, including consumer-direction policies that let older adults hire family members, neighbors, and friends to provide paid care at home. The first new home care program is the Caregiver Assistance Program (CAP). CAP, a Medicaid waiver service, is meant to help older adults—and younger adults with disabilities—remain at home and direct their "client-employed providers," including family members and friends. To qualify for CAP, participants must require a "nursing home level of care." Registered nurses employed by the state assess the person's health needs and functional impairments to determine whether she or he is entitled to receive a nursing home level of care, at home, through Medicaid. Available services include environmental accessibility adaptations, home-delivered meals, personal emergency response systems, and caregiver training, in addition to more traditional services like attendant care and case management.

This new home care program, CAP, was blended with the Medicaid waiver program for Assisted Living and Adult Family Care, a program funded under a Medicaid waiver that had been approved in 1996. NJDHSS considered the in-home component (CAP) and the residential component (Assisted Living and Adult Family Care) a single "Enhanced Community Options" waiver program. Beneficiaries can therefore move easily from home care to residential care without leaving one program to enter the other (see Figure 1).

FIGURE 1. ASSISTED LIVING (AL) AND ADULT FAMILY CARE (AFC)—MEDICAID



The second new home care program in the Senior Initiatives package is Jersey Assistance for Community Caregiving (JACC). JACC is a state-financed, sliding-scale program designed to mirror the

Medicaid-financed CAP for persons 60 years of age or older. That is, CAP and JACC have the same "nursing home level of need" eligibility requirements and offer the same set of services, including the consumer's ability to direct "client-employed providers" like family members, neighbors, friends, and others. As noted earlier, JACC is meant to provide seamless service to older adults who may at first be able to pay for some services privately, but may later require more public support through Medicaid. The goal is to ensure that no older adults are told they are ineligible for services. The message is, "We can help you get the services you need, and we can help you pay for them if you cannot afford them." Older adults can purchase care on a reasonable "cost-share basis."

These two new programs, CAP and JACC, were added to the existing programs, which had been transferred to NJDHSS in the 1996 consolidation. Blending the new in-home programs with the Community Care Program for the Elderly and Disabled (CCPED), a Medicaid waiver program that began in the early 1980s, has been problematic (see Figure 2). In half of New Jersey's counties, home care agencies are case managers for CCPED beneficiaries, having subcontracted with the state; in the other half, county agencies serve this role. These agencies had long ago successfully lobbied against the original cost-sharing requirement for CCPED. Therefore, CCPED participants pay no part of the cost of their care but are eligible for fewer services and cannot hire and direct nonagency providers like family and friends. State staff members report that consumers are confused by differences between the old and new programs. Local and government staff also encounter administrative complications; there is anecdotal information that people switch between programs to save money even though they may want the newer services. The state has not yet analyzed such information.

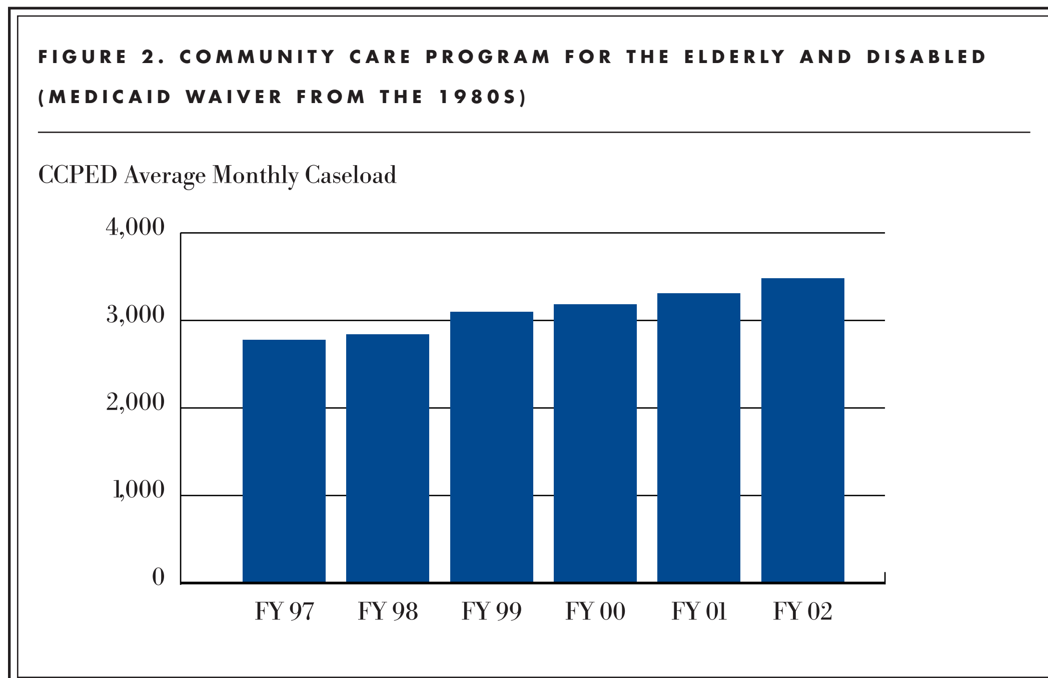


FIGURE 2. COMMUNITY CARE PROGRAM FOR THE ELDERLY AND DISABLED (MEDICAID WAIVER FROM THE 1980S)

NEW WAYS TO INFORM OLDER ADULTS ABOUT LONG-TERM CARE CHOICES

In addition to the new home- and community-based services, NJDHSS created two new programs to help older adults and their families understand and choose among the long-term care options it was creating. As mentioned above, New Jersey Easy Access, Single Entry (NJEASE), planned with a grant from the Robert Wood Johnson Foundation, helps people find information by phoning a single number that leads them to aid at the local level. The Community Choice Counseling Program helps people in nursing homes to get information about other options and to return to their homes and communities when possible.

NJEASE

NJEASE was developed in two phases. In Phase I, protocols and arrangements were established at the local level to make sure that older adults and their families could call one number and get a trained professional who would ask consistent questions and know how and where to direct that caller for more help. These tasks are consistent with the responsibilities of the area agencies on aging. However, the counties needed more training, more protocols, and better information systems in order to provide consistent information and referrals. Phase I focused on these tasks.

In 1996, Phase I of NJEASE was launched in four counties—Ocean, Union, Morris, and Atlantic. By 2000, all 21 counties had started Phase I, and the state had set up a national toll-free number (Reinhard and Scala 2001). There was no state legislation to create NJEASE, no mandate to choose a particular county agency to serve as the NJEASE office, and little money for this phase. Each county selected its county office on aging (also the designated federal area agency on aging) to serve as the lead NJEASE agency. There were some other early contenders, such as home health care agencies and county boards of social services, but the area agencies on aging succeeded in gathering support at the local level.

Phase II of NJEASE involves more complex organizational capacity and development. Phase II tasks move from information referral to more sophisticated forms of assistance and case management, including the responsibility to manage budgets for home- and community-based services using all funding streams from Medicaid, the Older Americans Act, the Social Security Block Grant, state casino revenues, and elsewhere.

New Jersey's 21 counties have a long history of local control. Their agencies differ in their infrastructure and their capacity to provide case management. Developing a sophisticated "single point of entry" system in Phase II has therefore proved challenging. The NJEASE mission is to ensure that older adults and their families can get the full range of services they need by calling the toll-free number that is directed to the local NJEASE office. Some callers merely need information. Others may need a thorough assessment of their needs and resources. Each county's NJEASE office should have

care or case managers with authority to enroll consumers in home- and community-based programs, including Medicaid waiver programs, and the managers should be well-trained and accountable. Accomplishing this requires major shifts in policy and budgeting, a process that is continuing.

Community Choice Counseling

Because many older adults enter nursing homes directly from hospitals, without understanding their other options, NJDHSS created a Community Choice Counseling pilot program in March 1998 (Reinhard, Howell-White, and Quinn 2001). Now a statewide program, Community Choice Counseling helps nursing home residents explore community-based alternatives. It provides information about in-home services, housing alternatives, and community programs. At first the state tried to assign counselors to hospitals for the purpose but found that there was not enough time to counsel older adults and their families in an acute care setting. After a hospital-based pilot program in 2000, the Community Choice Counseling staff recommended that they concentrate on nursing home residents, including those who are newly admitted on Medicare but are likely to remain for longer stays unless they receive the information and support they need to return to their homes and communities. Most counseling now occurs in nursing homes.

Since its inception, Community Choice counselors have helped more than 4,000 people move from nursing homes to private homes, senior housing, or assisted living residences. Although the counselors devote most of their attention to people who have lived in a nursing home for less than a year, they have also helped transfer people who have lived in one for as long as nine years (Reinhard, Howell-White, and Quinn 2001). The state now employs 29 primary nurses to provide this counseling. However, hiring freezes in 2002 may reduce this workforce.

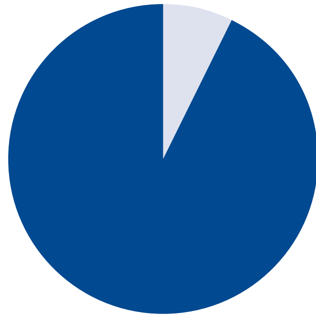
An evaluation of the Community Choice Counseling program found that the counselors see themselves as educators and advocates, helping older adults and their families understand and act upon their long-term care choices (Palmer and Howell-White 2001). Most people who made these choices left nursing homes and returned to a home or apartment with no unmet needs (Howell-White, Palmer, and Bjerklie 2001).

Analyses by the New Jersey Department of Health and Senior Services show that the consolidation of senior services in one department led to a concerted effort to develop polices and programs that allow more older adults to choose to live at home and in communities instead of in nursing homes. This effort has contributed to a steady rebalancing of public resources from institutional to home- and community-based long-term care.

The department selected its "rebalancing" measures in 1996 and began tracking them in July 1996, during state fiscal year 1997. In that fiscal year, 92.7 percent of public funds for older adults' long-term care was spent on nursing homes and 7.3 percent for home- and community-based options. In fiscal year 2002, funding shifted to 84.7 percent for nursing homes and 15.3 percent for home and community care (see Figure 3). The FY 2003 budget allocates 82.8 percent of the long-term care dollars for nursing homes and 17.2 percent for home- and community-based care.

The measures (or indicators) that New Jersey selected to track include the state share of the Medicaid budget for all nursing home care, medical day care (adult day health services), the state-funded home care program (JACC), and the largest home- and community-based Medicaid waivers for which NJDHSS has policy and budget responsibility (including home care and assisted living). These waiver programs primarily serve older adults but include services for people with disabilities; waivers that primarily serve younger persons with physical or developmental disabilities are not included here. The measures also include Older Americans Act funding, and these state-funded programs: the Alzheimer's program for adult day health care, the Safe Housing and Transportation program, the Congregate Housing program, the Home Care Expansion program, and the Statewide Respite Care program for the informal caregivers of persons who might otherwise be placed in nursing homes.

FIGURE 3. NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES LONG-TERM CARE FUNDING ALLOCATION (STATE SHARE)



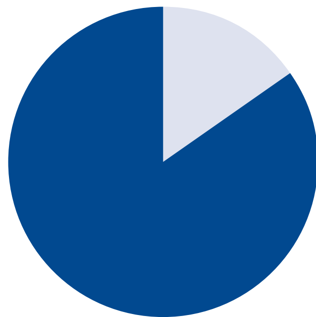
FY 1997

■	Home and Community	7.3%
■	Nursing Homes	92.7%

Total LTC allocation was $591.7 million

Home and Community Programs

- CCPED
- Respite Care
- Home Care Expansion Program
- Medical Day Care
- Older Americans Act
- Alzheimer's
- Safe Housing and Transportation
- Congregate Housing



FY 2002

■	Home and Community	15.3%
■	Nursing Homes	84.7%

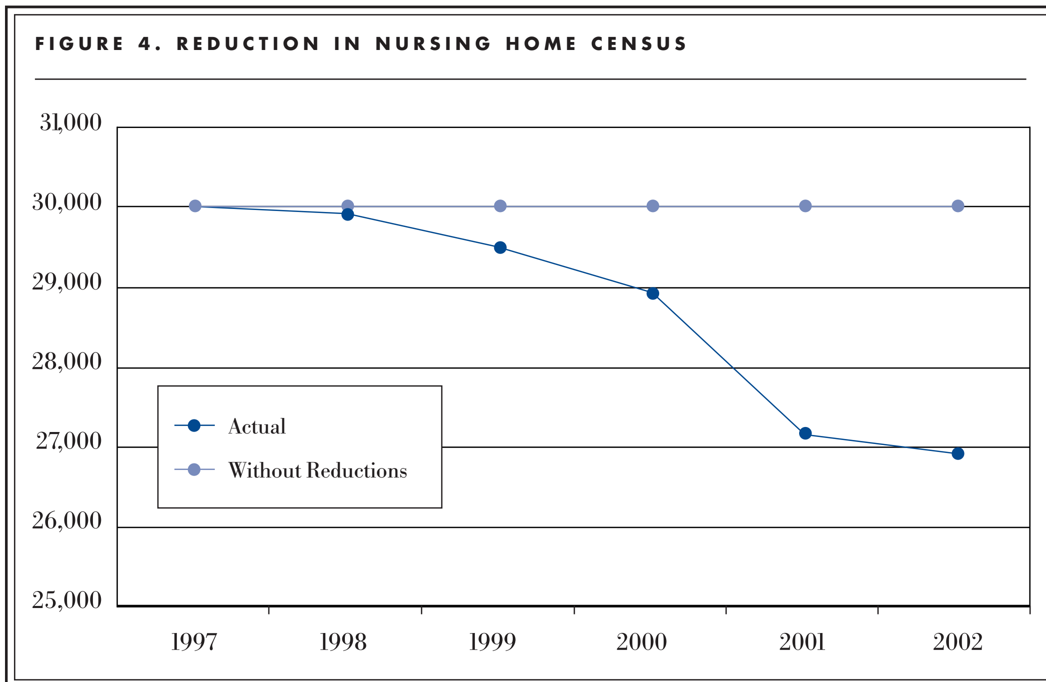
Total LTC allocation was $747.5 million

Home and Community Programs

- CCPED
- Respite Care
- Home Care Expansion Program
- Medical Day Care
- Older Americans Act
- Alzheimer's
- Safe Housing and Transportation
- Congregate Housing
- AL/AFC
- CAP
- JACC
- Community Choice Counseling

Figure 4 shows that the number of Medicaid beneficiaries in nursing homes was reduced by more than 3,000 people from FY 1997 to FY 2002, a 10 percent reduction. Note that nursing homes did not receive less money during this period, even though their census declined and state spending on home- and community-based care rose. Specifically, $549 million of state funds were allocated to nursing homes in FY 1997 and $632 million in FY 2002, due in part to cost-of-living increases built into the nursing home rate-setting system. That means an $83 million increase in state funds for nursing homes over five years, despite the lower census (a $166 million increase in state plus federal funds despite 3,000 fewer residents). The nursing home budget would have grown at an even steeper rate had the census not consistently declined: at approximately $50,000 per year for a nursing home placement, New Jersey would be spending $75 million more in state funds ($150 million total funds). In addition, the declining census indicates that "backfill" (nursing homes fill the empty beds) did not occur in New Jersey.

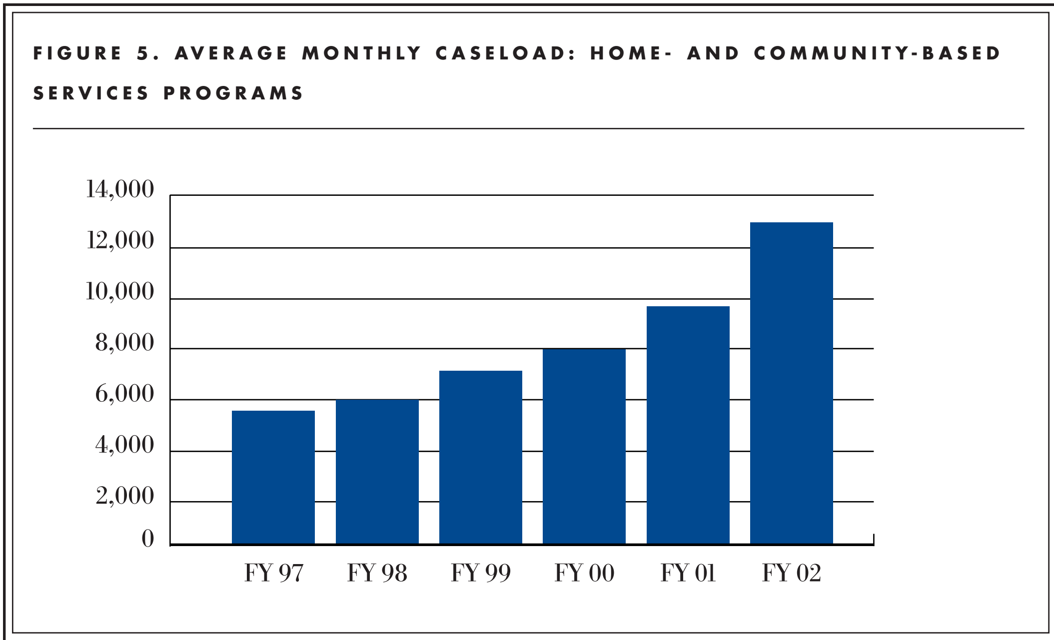
FIGURE 4. REDUCTION IN NURSING HOME CENSUS



As the nursing home census of Medicaid beneficiaries has decreased, the number of people in Medicaid- and state-funded home- and community-based programs has steadily increased. Figure 5 summarizes caseload growth for all the home- and community-based programs that NJDHSS tracks.

New Jersey's officials are pleased with this rebalancing trend, although they acknowledge that the state lags behind others that consolidated senior services years ago—like Oregon and Washington (O'Connor 2002). The state tracks its progress by using selected measures, making it difficult to compare New Jersey to other states. Recent analyses of states' Medicaid expenditures for 1915(c) home-

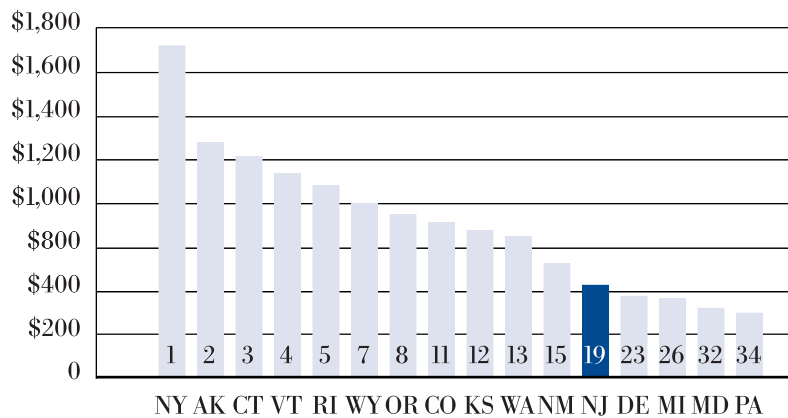
FIGURE 5. AVERAGE MONTHLY CASELOAD: HOME- AND COMMUNITY-BASED SERVICES PROGRAMS



and community-based waivers from federal fiscal year 1995 through federal fiscal year 2000 show that New Jersey ranks 37th in the country in the percentage of its Medicaid long-term care funds spent on home services. New Jersey spends 19 percent of its Medicaid long-term care budget on home services. Oregon spends 61.9 percent, Washington 44.9 percent, Kansas 42.3 percent, and Michigan 23.4 percent (Eiken and Burwell 2001). However, almost three-fourths of these expenditures go to support people with mental retardation and other developmental disabilities.

Looking only at home- and community-based expenditures per person aged 65 or older, New Jersey ranked 19th in the country in 1999. However, even these data are not always helpful in comparing states to one another. For example, New York ranked number one, spending $1,710 per person aged 65 or older. But because New York also spends the most on nursing homes, its percentage spent on home- and community-based care—34 percent—is less impressive than the percentages found in Oregon (62%), Vermont (54%), or Kansas (42%) (Eiken and Burwell 2001). Alaska has a different situation. It ranks second to New York, spending $1,221 per person aged 65 or older, but it uses state funds for "Pioneer" nursing homes that are licensed as assisted living facilities because they do not meet Medicaid's nursing home requirements. Despite the limitations of available national data, New Jersey ranks in the upper half of states in its spending on home- and community-based care per older adult when it is compared to states that devote at least 40 percent of their long-term funds to home- and community-based care, states that have consolidated senior services into one agency, and states that are located nearby. New Jersey spends more than Michigan, but less than Oregon, Washington, and Kansas (see Figure 6).

FIGURE 6. HOME- AND COMMUNITY-BASED SERVICES EXPENDITURES PER PERSON AGED 65 AND OLDER (1999): SELECTED STATES WITH RANKINGS



Another “rebalancing” measure that invites national comparisons is nursing home occupancy. As older adults get more long-term care options and states provide more funds for them, nursing home occupancy tends to decline. New Jersey’s occupancy declined from 94 percent of all beds in 1996 to 89.7 percent in 1999. However, declining occupancy is a national trend, and New Jersey still exceeds the 1999 national occupancy level of 82.7 percent. New Jersey currently uses a target occupancy of 85 percent in computing nursing home rates, to encourage facilities to control costs and to use their licensed beds. Nursing home care remains the most expensive option (see Box 3).

BOX 3. COMPARATIVE COSTS OF LONG-TERM CARE FOR OLDER ADULTS IN NEW JERSEY

Average monthly cost per person: nursing home, state-federal funds	
FY 1998	$3,245
FY 2001	3,821
Average monthly cost per person: assisted living residence	1,551
Average monthly cost per person: adult foster care	1,283
Average monthly cost per person: new home care programs	
CAP (Medicaid), 50% state/50% federal funds	1,106
JACC, state funds	492

REMAINING CHALLENGES

New Jersey's long-term care rebalancing efforts are steadily proceeding, having already more than doubled the percent of long-term care spent on older adults in home- and community-based, rather than nursing home, care—from 7.3 percent in state fiscal year 1997 to 15.3 percent in state fiscal year 2002. The projection for state fiscal year 2003 is 17.2 percent. The number of persons on Medicaid in nursing homes dropped by more than 3,000 people, a 10 percent reduction.

The data point to two important policy concerns. First, New Jersey still expects to spend more than 80 percent of the dollars earmarked for long-term care of older adults on institutional care. If it wants to join states like Oregon, Washington, Colorado, and others that are above average in the percent of public funding for home- and community-based care, New Jersey still has a long way to go. The most progressive states spend more than 40 percent of their long-term care funds on home- and community-based care (Eiken and Burwell 2001). Second, New Jersey needs to develop measures that help track progress in a national context. It is important to distinguish between change that results from state policies designed to advance home- and community-based long-term care and nationwide trends that are occurring even in states that are not dedicated to rebalancing. Declining nursing home occupancy rates are one example.

New Jersey faces a number of challenges in accelerating change. They include: (1) the implementation of NJEASE; (2) the inconsistent policies among Medicaid waivers and services and caps on some of these services; (3) the economic constraints that states are facing; and (4) the fragmentation of some home care programs between NJDHS and NJDHSS. Stronger tracking and accountability systems are also necessary.

NJEASE IMPLEMENTATION

The state sought to develop a locally based infrastructure to serve as a single point of entry for information and services for older adults. Two major problems in implementation have arisen. First, too few consumers and providers know how to get help through NJEASE, despite a six-month statewide advertising campaign promoting the service and the national toll-free number. A single ad campaign is unlikely to educate the public as a whole or to change its habitual ways of seeking help overnight, but getting money for more advertising is difficult in the current economic climate. Reliance on nursing homes remains strong, in part because physicians and hospital discharge planners are already familiar with institutional options and find home- and community-based options more complicated to arrange.

The second problem is that counties' implementation of NJEASE is uneven in scope and quality. Phase II of NJEASE, providing care management and access to newer and older home- and community-based programs, required more infrastructure development than just providing uniform information as in Phase I. Many county offices on aging had to hire staff and train care managers in the intricacies of Medicaid waiver eligibility policies and procedures. In addition, half of the counties had no responsibility for one of the oldest Medicaid waiver programs, CCPED, the Community Care Program for the Elderly and Disabled. For many years, the negotiations between the NJEASE agencies

and home care agencies regarding care management for CCPED have varied from county to county. The goal is to ensure that every NJEASE agency can provide care management for older adults under Medicaid programs, the Older Americans Act, state-funded programs, and private-pay options. Such local arrangements are crucial in developing an infrastructure that works well for consumers while being accountable to the state for its use of funds.

This Phase II NJEASE infrastructure development is complex. Counties that were able to work with the state and local stakeholders to organize a stable structure moved most quickly in offering the new home care programs. Counties that had difficulty hiring and training new case managers and learning how to manage the data required for the Medicaid home care programs were slower to implement Phase II. Some of the Senior Initiatives programs began more slowly than anticipated, partly because of this uneven infrastructure development. The two new home care programs, CAP and JACC, were developed by NJDHSS leaders in the fall of 1998, announced by Governor Whitman in an address in January 1999, authorized through the budget approved by the legislature in June 1999, and actually implemented in 2000. Enrollment was slow until 2001, as state officials oriented the various NJEASE offices, which had to develop their care management capacities to carry out the new programs.

INCONSISTENT POLICIES AMONG SERVICES

Inconsistent policies among the Medicaid waivers and services are another important problem. For example, New Jersey's new in-home programs require a copayment, but older ones do not. This inconsistency undermines the goal of seamlessness between programs. Consumers seem to switch from the new program (CAP) to the older program (CCPED), whenever a slot becomes available, even though CCPED is less flexible and does not let consumers hire nonagency people like family and friends. Consolidating these waiver programs may resolve the issue, so that older adults have as much flexibility as possible. To do this, the state will need to decide whether or not to continue requiring the consumer to share the costs of home care programs.

Another contradictory policy is the "nursing home level of care" threshold. It is not clear in the state Medicaid regulations and is inconsistently interpreted in the home care programs at the local level. Other Medicaid long-term care "state plan" services—like personal care or medical day care (adult day health services)—do not fit smoothly into the state's vision for long-term care choices. For instance, it is not clear whether Medicaid-financed medical day care should be authorized as an "early intervention" program for seniors who are independent in most or all activities of daily living, to prevent the need for residential long-term care. The recent caseload growth in medical day care has New Jersey officials asking fundamental questions that should be discussed with consumers and other stakeholders. Should older adults who need social activities more than health-related services be entitled to a Medicaid program? Or do state and local officials and providers need to develop other options for social programs?

ECONOMIC CONSTRAINTS

Like most states, New Jersey faces falling state revenues and rising budget pressures, particularly in health and long-term care (Coleman et al. 2002). It will be difficult to add new dollars for program development. However, long-term care innovators in states like Oregon and Maine recall that they made the greatest progress toward more home- and community-based care during economic downturns. That is because downturns may overcome traditional resistance to change. When governors and legislators have to question everything in the budget, everything is on the table (Ladd 2001; Gianopoulos 2002). Those who have a reasonable plan to use long-term care dollars more efficiently can be heard.

CONTINUED FRAGMENTATION AND LIMITS OF SOME SERVICES

Consolidation itself has caused some discontinuity in policies. While most services for older adults—including adult day health services—were consolidated in NJDHSS, the responsibility for most state plan services (e.g., home care, personal care, and hospitalization, as opposed to waiver services in lieu of nursing home care) remained in NJDHS. During the administrative consolidation of services in 1996, NJDHS cited internal statistics showing that most beneficiaries of home care and personal care were younger than 60 years old. Since consolidation did not include services for younger people with disabilities, NJDHS retained jurisdiction over these services. Home care industry representatives note that some confusion and conflicting policies appear to have resulted. They also cite a lack of communication between the industry and the state, particularly NJDHSS, and the need for higher reimbursement rates for home care service providers. The workforce shortage is another critical concern that both departments need to address, preferably in concert.

The enrollment cap in some waiver programs, particularly the assisted living and adult family care programs, limits the chance to rebalance long-term care. The state's fiscal 2003 and 2004 budgets do provide for an expansion of this program, but demand is high and the waiting list is growing. Community Choice counselors rely on assisted living as an important option for people who choose to move from a nursing home to their own homes or a more home-like setting. The success of Community Choice Counseling is threatened by caps on enrollments in home- and community-based waiver programs.

TRACKING AND ACCOUNTABILITY

Finally, data tracking and accountability mechanisms at the state and local levels are underdeveloped. The state designed a Comprehensive Assessment Tool (CAT) to collect uniform data on consumers' needs and resources (Reinhard and Scala 2001). This kind of universal preadmission screening instrument for people seeking long-term care is essential to transforming the delivery system. As

progressive states like Oregon, Washington, and Maine have found, it is important to assess the person's needs and ability to perform the activities of daily living in order to discuss all of the consumer's options.

In Maine, nurses working for the state conduct free online electronic assessment of care needs and eligibility for public payment for services for anyone who asks for it. They also use a universal screening tool to assess people in nursing homes regularly. By using an instrument with consistent criteria, Maine has been able to help people find services in and out of nursing homes. The state has reduced the nursing home population and used a significant portion of its savings to finance alternatives to nursing home placement. Today 39 percent of Maine's long-term care budget goes to home- and community-based care, up from 16 percent in 1995 (Gianopoulos 2002). Maine officials consider the universal screening instrument and good data systems essential to redesigning long-term care (Gianopoulos 2002; Concannon 2002).

New Jersey officials had consulted their colleagues in Maine, Oregon, and Washington to develop the Comprehensive Assessment Tool (CAT). They intended to use the CAT in all NJEASE and nursing home preadmission offices to learn more about older adults' long-term needs in order to design services to meet them. Officials also wanted to computerize the CAT data and link them to financial databases so that NJEASE officials and state program managers could follow individuals from one setting to another and funding could follow people. This data system is not yet in place.

New Jersey also needs to track service quality and consumer satisfaction from setting to setting. The state does have a survey team that conducts annual assisted-living inspections and investigates complaints, and this team is considering conducting and publishing consumer satisfaction surveys. The external Community Choice Counseling evaluation has also been a way to monitor results and satisfaction. Like all states, New Jersey needs to continue to monitor quality of care and quality of life and to develop new ways to bring the consumer's voice into that evaluation.

NEW JERSEY

New Jersey continues to seek a better balance of institutional and community care options for older adults who need long-term care. The State has invested six years in developing a state and local infrastructure and funding several new programs to improve that balance. NJDHSS data document progress, but both state and local officials report several remaining problems. To move closer to an "above average" nationwide rank, the state should reiterate its commitment to a more consumer-oriented system and evaluate its programs, policies, and structures. Although speaking only for ourselves, we offer these recommendations for that evaluation. Although they are specifically meant for New Jersey, they may be instructive to policymakers engaged in reforming long-term health care in their own states.

First, New Jersey should evaluate the current status of NJEASE and its implementation. The state should analyze the political nuances of attempting to change a county-based system in a state whose 21 counties are accustomed to strong local control. The evaluation should involve both the NJEASE directors and consumers to build a base for a change in direction, if change is needed.

One of the first steps in this evaluation is to choose one or two NJEASE offices that are implementing Phase II by providing substantial case management of the home care programs and then examine which policies are working for consumers and providers and which are not. In particular, the state should analyze the effects of inconsistencies among Medicaid waivers, such as copayments for some programs and not others. Critical policy and technical details must be identified and addressed to improve program implementation.

Second, New Jersey should encourage consumers and principal stakeholders to formulate statewide policy, with accompanying strategies, to emphasize the types of long-term services and residential settings that people need and prefer. There are two complementary reasons to renew this dialogue—a new administration and new ideas. Governor James E. McGreevey, who took office in January 2002, has a strong interest in health and senior services. New governors need fresh thinking to set the course for their terms, and there are fresh ideas in the long-term care field about how to bring more services into senior housing and how to give consumers greater control over them. The state can benefit from discussions about the future of nursing homes, assisted living, adult family care, home care programs, family caregiver support, and all other long-term care choices.

Third, the state should reexamine the structural and policy foundations for the consolidation of senior services. It should evaluate the interagency agreement between NJDHSS and NJDHS, and its implementation, so that New Jersey efficiently and effectively rebalances long-term care. In particular, the state should improve the coordination of policies, programs, and financing for home care and services for people with disabilities.

Finally, New Jersey should develop a comprehensive data tracking system to improve accountability and provide a consistent "scorecard" to measure progress. This scorecard can include New Jersey selected measures, which help NJDHSS staff and other state officials monitor and improve

their performance. However, the scorecard should also include measures that make it easier to compare New Jersey's progress to national trends.

NATIONAL IMPLICATIONS

While each state is unique in its history, economy, and social commitments, the aging of America is a universal reality that affects every state's public policies. Certain aspects of New Jersey's experience have national relevance. In any state that wants a fundamental shift in its delivery of long-term care, policymakers must:

- Encourage a civic process that engages people and lets them express their preferences. This discussion helps create a groundswell for change—although focused, sustained leadership by a few champions of change is essential. In some states, like Oregon, senior advocates who pushed a bill through the legislature were the driving force for change. In New Jersey, leaders in the executive branch galvanized change and sought advocates and legislators who would endorse the necessary programs and financing. In both states, engaging and retaining the support of advocacy groups like AARP, the Older Women's League, the Alzheimer's Association, and the local Advisory Councils on Aging helped overcome resistance to change.
- Identify the champions. Many forces can create the impetus for change. But talented, committed leaders must make sure that vision and energy are channeled into substantive results. A few visible champions are needed to keep the issues in the limelight. The most effective champion is a governor who will lead the change. Consolidation of services for older adults into one state department draws attention to the issues and increases accountability. Yet, regardless of the administrative structure, dedicated leaders are most critical.
- Develop and support staff members. Regardless of the driving force for change, knowledgeable, creative staff in the executive branch must devise and coordinate policies and programs. It takes time to develop a policy or program from a concept to a reality. Sustained leadership and staff efforts are vital. The recent nationwide trend toward early retirements by public officials and limited funds to recruit talented new leaders and to train new staff for senior services are major obstacles to change.
- Develop a clear statement of underlying values to help focus the policy process. New Jersey uses "independence, dignity, and choice."
- Recognize that these values mean little without actual services and access to them. Nursing home care will continue to be needed, although it may be scaled down. However, some of the most impaired older adults now live in their own homes (Borrayo et al. 2002). These people need services there, otherwise they will be forced into institutions.
- Leverage consumers' desire to remain at home and the state's desire to minimize expensive institutional programs as complementary, formidable forces for change.

- Understand that long-term care reform is multifaceted. It includes health promotion, disease prevention, and regulatory reform—as well as expansion of home- and community-based services. It also requires developing and retaining a qualified, committed workforce.
- Use Medicaid waivers and additional state dollars creatively to expand home- and community-based services to help older adults at all income levels. Develop "seamless" waiver programs with consistent eligibility criteria and uniform consumer-contribution requirements.
- Develop user-friendly local structures, close to the consumer. They are an important factor in making choices real, regardless of the person's income. Even people who are not poor should know that they have a place to call for "one-stop shopping"—help in finding affordable services. People should not be told dismissively, "You are not eligible for services." Instead they should hear, "Let me help you figure out what you need and where to go to get that help."
- Develop a universal preadmission screening tool to assess the needs of people seeking long-term care. Developing the tool, and the process for using it, may be complex, but other states' models can serve as guides.
- Acknowledge that state activities are constrained or allowed by federal statutes, regulations, and interpretations. The Older Americans Act, Medicare, and Medicaid provide the bulk of public funding for long-term care and have a major impact on its structure. Differing eligibility standards as well as regulatory idiosyncrasies make it hard for consumers, providers, and state policymakers to develop or access complementary kinds of care. However, much can be done even within these limits.
- Examine the issues in integrating services for older adults, younger people with disabilities, and people with developmental disabilities (Donlin 2002). The Supreme Court's 1999 Olmstead decision regarding community-based services for people with disabilities, and the states' responses to it, tend to focus on younger persons with disabilities. However, older adults are also seeking more control over their care, a trend that will grow as the "baby boomers" age.

SUMMARY

States that want to proactively shape policies and programs to help older adults live as independently as possible in their preferred environments can make significant progress toward that goal. A few states, like Oregon and Washington, have led the way for decades. Other states, like New Jersey, demonstrate that it is possible to change the direction of long-term care—step by step, year by year.

The economic constraints that states currently face make it more important than ever to examine how long-term care dollars are spent. Some of the most progressive states made their most significant progress during economic downturns because policymakers were willing to listen to new ideas. Leadership is critical, and dialogue with the public is important to shape long-term care to meet the needs of those who may use it.

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