

March 4–5, 2002 / New York City

**NATIONAL  
HEALTH  
POLICY  
FORUM**

## Site Visit Report

Transitions along the  
Continuum of Care:  
Elderly and Disabled  
Persons in New York

The  
George  
Washington  
University  
WASHINGTON DC

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**Site Visit Managers**  
Lisa Sprague & Nora Super

**Research Assistant**  
Catherine Park

**Site Visit Coordinator**  
Dagny Wolf

**National Health Policy Forum**  
2131 K Street NW, Suite 500  
Washington DC 20037

202/872-1390  
202/862-9837 [fax]  
nhpf@gwu.edu [e-mail]  
www.nhpf.org [web site]

**Judith Miller Jones** – *Director*  
**Judith Moore** – *Co-Director*  
**Michele Black** – *Publications Director*

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The Forum is grateful to the dozens of people who shared their time and knowledge with staff in preparation for the visit and to those who agreed to do the same as part of the program itself. Bruce Vladeck, Mathy Mezey, and David Gould were especially helpful in providing contacts and counsel. Teresa Coughlin and Brian Bruen of the Urban Institute shared their statistical expertise. Site visitors benefitted from onsite meetings at the Visiting Nurse Service of New York and the Cabrini Center for Nursing and Rehabilitation; the Forum thanks Carol Raphael of VNSNY and Jeff Nichols of CCNR and their respective colleagues for being such gracious hosts.

Much of the success of this site visit was due to the caliber of the federal participants, whose interest and insight nourished dialogue with the New York cast.

March 4–5 , 2002 / New York City

# Transitions along the Continuum of Care: Elderly and Disabled Persons in New York

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## OVERVIEW

As people age and face medical problems or a disability, they may repeatedly move in and out of hospitals, private homes, and skilled nursing facilities (SNFs). Along the way, they encounter multiple payment systems and providers, each of which has varying incentives and standards of care. While, ideally, elderly and disabled persons have access to a continuum of services designed to meet their changing needs, experience usually proves otherwise. New York City provided a dynamic environment in which to study different levels of care, from acute hospital care to assistance with daily living. The sheer size and diversity of its population, coupled with significant public program spending, offered an opportunity for policymakers to better understand how payment streams affect the delivery of care.

With funding from the John A. Hartford Foundation, the National Health Policy Forum developed this site visit to explore continuum-of-care issues and the evolution of services provided to seniors during a period of rapid and fundamental systemic change. The site visit looked at efforts to integrate acute and long-term care as well as to provide higher-quality care to nursing home residents, individuals living at home, and those nearing the end of life.

The state of New York is home to some of the best medical care in the nation. It houses a large supply of medical specialists, academic medical centers, hospitals, and nursing homes. Yet despite its high level of sophistication and generous public programs, New York faces many challenges common to all states. The multiplicity of its programs, providers, and reimbursement sources results in a system that is comprehensive yet fragmented.

New York's population is large and diverse. New York is the third most populous state in the nation, with a total population of nearly 19 million. Of those, 2.4 million are over the age of 65 and more than 300,000 are over the age of 85. As of 2000, more than 8 million people lived in New York City. Nearly 1 million were over age 65 and 120,000 were over 85.<sup>1</sup> In many parts of the city, there are large numbers of

**Spending for the elderly, disabled, and blind population accounted for 72 percent of New York's total Medicaid spending in 1998.**

immigrant communities from countries spanning the globe. In New York City, 35 percent of residents are white nonhispanic; 27 percent are of hispanic origin; 24.5 percent are black/African American; and nearly 10 percent are of Asian or Pacific Island origin.<sup>2</sup>

New York State offers an extensive array of services to its residents, including nursing home care, home health care, personal care, community-based services, and other expanded programs. New York operates a comprehensive home- and community-based waiver program known as the Long-Term Home Health Care or Nursing Homes without Walls program, which was designed to provide care in the home for those eligible to receive nursing home care. In addition, New York approved one of the first PACE (Program of All-inclusive Care for the Elderly) sites providing health and long-term care services for people with both Medicaid and Medicare coverage.

New York has a long tradition of funding health care for its low-income residents. New York spends more than any other state on its Medicaid program. Medicaid spending in New York was \$27.5 billion in 1998. Total (federal and state) Medicaid spending per enrollee in New York was \$8,825, roughly double the national average.<sup>3</sup>

Spending is especially high for the elderly, disabled, and blind population, accounting for 72 percent of New York's total Medicaid spending in 1998. New York spent more than \$12 billion on Medicaid long-term care in 1998, representing nearly 45 percent of total spending. These high spending rates reflect a comprehensive benefit package, innovative programs, high nursing home expenditures, and extensive coverage of personal care services. High spending levels are also related to the high proportion of poor elderly who live in New York. In 1998, 14.5 percent of New York's seniors aged 65 and older were living in poverty, compared with 9.8 percent nationally.<sup>4</sup>

For institutional services, New York has among the highest nursing home expenditures in the nation. In 1998, half of New York's Medicaid long-term care spending was for nursing home care.<sup>5</sup> Nursing home spending increased at almost twice the national rate between 1995 and 1998, at about 8 percent per year on average.<sup>6</sup>

The Empire State also spends a great deal on home care services. In 2000, New York expenditures for home care—which includes home health services, home and community-based services, and personal care—represented 23 percent of national Medicaid spending for these services. The state's personal care program is one of the most generous in the country. New York's expenditures for Medicaid personal care services account for 39 percent of the national total for these services.<sup>7</sup>

Nearly 2.7 million Medicare beneficiaries live in the state of New York, accounting for 15 percent of the total state population. New

York represents 9 percent of total U.S. Medicare spending. Per beneficiary, Medicare spends \$6,924 on average in New York, compared with a national average of \$5,490.<sup>8</sup>

Contrary to conventional wisdom, enrollment in managed care plans by Medicare beneficiaries in New York State has long exceeded the national average, although the numbers have fallen in recent years, as they have elsewhere. While the state has controlled hospital bed supply with some effectiveness, the enormous medical education (undergraduate and graduate) presence and abundant supply of specialists have contributed to relatively high Medicare costs.

In terms of service use, Medicare SNF admissions in the state are lower than the national average, but covered days per beneficiary served in SNFs are higher. The number of Medicare home health users per 1,000 beneficiaries is close to the national average, but home health visits per person served are lower.<sup>9</sup>

## PROGRAM

The site visit began with an overview of the continuum of care for elderly and disabled persons in New York, with attention to the characteristics that make New York City unique. Federal, state, and city policies and their interactions were considered. A second panel examined how patients move among acute, subacute, and long-term care settings. Panelists explained how reimbursement policies, facility budgets, patient comorbidities, and technological and information-system deficiencies can all raise barriers to smooth transitions among care settings. Three participants in New York State's managed long-term care demonstration project outlined their approaches to providing care to a population with chronic care needs.

Later in the day, site visitors traveled to the Visiting Nurse Service of New York, the largest nonprofit home health care agency in the country, where they heard from officers, researchers, and home-health nurses about the challenges of providing care at 24,000 sites on a daily basis.

The second day began with an in-depth look at palliative and hospice care. Panelists made an eloquent case for federal policy changes to facilitate the delivery of humane care to fragile beneficiaries and struggling families. Nursing home quality was the focus of a second panel, composed of representatives of the state regulatory agency, the nursing home industry, and consumers, who collectively demonstrated that finding common ground is not the established pattern. Site visitors then toured a long-term care facility with a large Chinese population and—over a multi-ethnic array of luncheon dishes—discussed multicultural competency as well as staffing and reimbursement issues.

**While the state has somewhat effectively controlled hospital bed supply, the enormous medical education presence and abundant supply of specialists have contributed to relatively high Medicare costs.**

### IMPRESSIONS

#### New York as Leader

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*New York outpaces the nation in terms of health care spending and program development.*

New York's spending for elderly, blind, and disabled Medicaid beneficiaries is double the national average, on a per enrollee basis. With its extensive provider network and variety of delivery models, New York is also a leader in home- and community-based services program development and expenditure. The state spends significantly more than the national average on nursing homes and home care services. In sum, New York spends a great deal on everything, and its spending is paralleled by even greater demand.

*Graduate medical education is big business in New York.*

New York is recognized as a worldwide leader in medical education, having 14 medical schools and a graduate medical education system that trains 15,000 medical residents. New York has more than twice as many resident physicians-in-training per capita than the national average. With 6.8 percent of the nation's population, New York trains over 15 percent of its physicians, far exceeding the state's real needs for physicians.<sup>10</sup> A large supply of specialists and hospitals contributes to price inflation and greatly influences physician practice patterns.

#### Transitions among Care Settings

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*If the goal is to enable movement along the continuum of care in a rational, patient-centered fashion, we have not made much progress in 20 years.*

Despite attempts to bundle payments for services, providers seem to retain a fee-for-service mentality. Physicians seem to have acquired an attitude that says, "We'll provide what we get paid for." Or, they assume that if they do not get paid for providing a service, they are not "allowed" to do it. Providers seem inclined to divide care into incremental procedures that may or may not be reimbursed, rather than treating it as a patient-centered, seamless process. Lack of communication among providers in different care settings persists.

*Where patients receive services depends largely on payment and regulatory incentives.*

Medicare and Medicaid incentives are aligned to encourage transfer from nursing homes to the hospital for any medical condition that arises. For example, Medicare reimburses ambulance and emergency room services and provides higher reimbursements to physicians who provide care in hospitals. Also, nursing homes report that they never get cited by surveyors for transferring a patient, whereas they may for trying to manage that patient's condition themselves. Incentives within capitated systems, such as PACE, work to limit unnecessary or avoidable transfers to the hospital.

*While programs live in silos, patients do not.*

Moving patients in and out of institutional and home-based settings and sometimes back again often causes tremendous adjustment problems for patients. Case management that tracks individuals as they transition among health care facilities rarely occurs in New York. Even standard discharge planning seems to be a waning service. Physicians and other providers have neither the incentive nor (it appears) the interest to address nonmedical needs or make patients aware of other kinds of available services. A single point of entry for beneficiaries to receive information about the options available to them is clearly lacking, especially as compared with other state programs, such as Oregon's.

### Long-Term Care

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*While New York's long-term care services are extensive, the system is fragmented and complicated, with little momentum for change.*

The state offers a wide variety of long-term care services and delivery models, including nursing home care, home health care, personal care, managed long-term care, and PACE. Yet while the programs are generous, they are not well-coordinated or designed so that consumers can navigate the system to meet individual needs. Lack of coordination of personal care and home health care, in particular, can lead to unintended access problems; that is, a beneficiary receiving personal care might be better served by home health or vice versa, without knowing how to make a change. Legislative attempts to make the long-term care system more cohesive have been defeated in the past, largely due to opposition from the nursing home and home health care industries. The organizations that have historically administered service delivery in New York City bring in enough money that there seems to be no compelling interest in rationalizing care or improving consumer education and awareness.

*Paraprofessional workforce shortages seem less prevalent in New York City than in other parts of the state and the nation as a whole.*

Unionization has resulted in higher wages and benefits for personal care attendants and certified nurses' assistants (CNAs). The large influx of immigrants also assures a steady supply of paraprofessional workers in New York City. In addition, New York has maximized Medicaid funds by requiring counties to pay half of the state match and has used those funds to drive up wages. As a consequence, the shortages that characterize other segments of the health care workforce (especially nurses) are less prevalent in these categories.

### Managed Long-Term Care

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*Managed long-term care programs exhibit innovation within the confines of existing payment streams.*

Participants in the managed long-term care demonstration do their best to access whatever payment streams they can identify. While the funding fragmentation is

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frustrating, the provider organizations have in fact managed to put together a program that can provide new services to a population that needs them.

*No single approach to managed long-term care has emerged as optimal.*

Both full- and partial-capitation models have been developed, the former in PACE and the latter by the other programs comprising New York's managed long-term care demonstration. Partial capitation covers services such as case management, home health care, day care, transportation, and nursing home care; it does not cover acute-care services. There are trade-offs between the two models. Partially capitated programs cannot achieve the same efficiencies as the fully capitated, but they are more attractive to consumers and therefore serve a larger population. Perhaps the biggest selling point is that an enrollee in one of the partially capitated programs can keep his or her own physician.

*While not for everyone, PACE has proven an effective program design for some populations, particularly the very frail and very old.*

PACE is not a panacea. From a policy standpoint, it is expensive, insular, and serves a limited portion of the population. Beneficiaries who are comparatively healthy and mentally competent are unlikely to find so prescriptive a program attractive. Moreover, PACE's poster-child role deflects attention from broader-based long-term care reform. But for the very old and frail, its full complement of services and its small scale are advantages, given these individuals' need for extensive care and personal attention.

#### Home Health Care

*There is no brake on what a patient perceives as his/her need, particularly when it comes to home-based care.*

Demand for home care services seems insatiable. Capping hours and limiting services are met with great resistance from clients. Both status and companionship may be issues that influence perceived need. The prevailing attitude among care recipients seems to be, "I want a girl like Madge down the hall has"—in other words, a personal attendant to meet round-the-clock needs.

*Home health care in New York has shifted from a focus on postacute care to long-term care since the BBA.*

As profit margins shrank, hospitals exited the home health industry, resulting in fewer certified entities. Adapting to a prospective payment system, home health agencies say, has changed the emphasis from generating visits to actually managing care. The long-term care component of home health has increased in proportion to acute care. This shift could help move the public debate on long-term care forward.

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### *A decade of growth in home health care has leveled off.*

The number of Medicare beneficiaries served by home health care has declined recently. Because of the nursing shortage, agencies cannot keep up with demand. In addition, increased federal and state scrutiny has caused agencies to become more risk-averse and more selective about the types of patients they serve.

### *Although rewards are high, home health nursing also has drawbacks.*

Recruiting long-term care nurses, in general, and home health nurses, in particular, appears to be even more challenging than recruiting nurses in the hospital setting. While working independently and in a slower-paced home environment is a perk, lower compensation and an increased paperwork load have diminished the field's attractiveness. Within the fragmented system, visiting nurses are often put in the position of acting as caseworkers for their patients; job dissatisfaction and burnout have increased.

### *OASIS, while cumbersome, has utility and can be improved.*

Home health providers criticized OASIS (the home health patient assessment instrument required by the Centers for Medicare and Medicaid Services, or CMS) for its length and complexity and the frequency with which it must be completed. Front-line nurses like the support it offers in recording detailed data and patient histories but express concern about how much of a home care visit can be taken up filling out forms rather than providing direct care. Nonetheless, OASIS has shown promise as a standardized assessment tool for looking at resource use and determining critical predictors of outcomes. Getting timely feedback to front-line workers will be key to better acceptance and to gaining a sense of how it can improve service delivery.

### *Quality assurance in home-based settings is a significant challenge.*

Very little quality monitoring and measurement appear to take place within home- and community-based settings. Site visitors noted that, even with the high level of regulation and oversight from both state and federal governments, 30 percent of nursing homes have been cited for deficiencies involving actual harm or risk of harm. Out in the community, where there is far less direct supervision, quality assurance is effectively nonexistent.

## Nursing Home Care

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### *The survey and certification process remains sharply adversarial.*

Representatives of the nursing home industry and state regulators have differing views of what result the process ideally should produce: improvement guidance or sanctions for poor care. Both sides are entrenched in their positions, with consumer representatives taking perhaps the hardest line of all. Movement

### IMPRESSIONS

toward a more collaborative approach seems unlikely when there is disagreement on basics, such as the appropriate role of survey and certification agencies, and when such evident mistrust prevails.

*One thing that regulators, providers, and consumers agree on is that higher nurse staffing ratios do not guarantee improved quality.*

While adequate staffing is necessary to deliver quality care, it is not sufficient. Assigning a ratio deemed optimal does not address staff aptitude or training, both important elements in creating a culture of quality. Moreover, attempting to establish such ratios seems futile at a time when recruiting and retaining qualified nursing staff is a challenge to virtually all provider organizations.

#### **Palliative and Hospice Care**

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*Palliative care is good medical care, yet physicians seem reluctant or unwilling to provide it.*

Doctors are trained to save lives, not to approach dying as a natural process. Academic medicine still behaves as though disease and ultimately death can be conquered by research and technology. Attitudes toward end-of-life care are deeply influenced by personal and cultural values. Policymakers and providers alike are uncomfortable with value-laden discussions.

*The payment system reflects and reinforces a cultural unwillingness to deal with death.*

Good palliative care is labor-intensive. It often requires physicians to spend extensive time counseling patients and their families, sometimes about the futility of expensive procedures. Yet doctors get paid to do procedures, not talk to patients.

*Confusion and misunderstanding about payment for palliative care clearly exist among providers.*

CMS needs to do a better job of communicating with providers, sorting out which perceived barriers to effective care actually exist in statute and regulation, and highlighting what providers *can* do.

*Distinctions between palliative care and hospice are largely psychological from a patient's perspective, yet Medicare rules impose a rigid cure-care dichotomy.*

Because of Medicare's requirement that hospice patients give up all curative care, patients, families and physicians have been reluctant to "go over the wall" and enter hospice care. Yet palliative care and hospice share many goals: to relieve suffering and achieve the best quality of life as determined by patient and family.

*Death is not predictable.*

The Medicare hospice benefit is limited to those with a survival prognosis of six months or less, based primarily on the linear progression of a cancer model. Yet 75 percent of deaths follow an unpredictable pattern. Wide differences in disease progression and treatment make designing reimbursement systems for end-of-life care difficult.

**Multiculturalism**

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*New York's population is extremely diverse, making cultural competency an increasingly important component of medical practice.*

Multicultural competency represents a marketing and retention advantage to health care organizations, but this is not necessarily a financial advantage, as reimbursement levels do not keep pace with the breadth of service needs of an immigrant population. Efforts to accommodate cultural differences (for example, locating speakers of a particular language or dialect on the same floor of a residential facility) can also serve to further segregate ethnic populations.

*The demand for bilingual workers far exceeds supply.*

One public hospital in Queens recently reported that its 600+ beds held patients speaking 114 languages. Language translations between providers and patients often result in delays and miscommunication. Technology (for example, a remote simultaneous interpreter system) could help improve communication, but not without cost.

*Diversity issues are hugely complex just at a single site of care and multiply as attention moves into a broader population.*

Language is not the only obstacle to successful diagnosis and care delivery. Also important are other personal and cultural values, including family support patterns and religious beliefs. Particularly in a long-term care setting, even food preferences can be critical: if a resident does not recognize what she is being served as “real” food, she risks both grief and malnutrition. Around the city, same-culture enclaves or neighborhoods may resist (consciously or not) assimilation of language and behavior, particularly if they must face institutional care.

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**ENDNOTES**

1. U.S Census Bureau, Census 2000.
2. New York Department of City Planning; accessed February 15, 2002, at <http://www.nyc.gov/html/dep/html/html/popstart.htm>.
3. Teresa Coughlin and Amy Westpfahl Lutzky, “Recent Changes in Health Policy for Low-Income People in New York,” *Assessing the New Federalism*, State Update No. 22, Urban Institute, Washington, D.C., March 2002, 9.

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4. Coughlin and Lutzky, "Recent Changes," 17.
5. Henry J. Kaiser Family Foundation, "State Health Facts Online"; accessed February 14, 2002, at <http://www.statehealthfacts.kff.org>.
6. Coughlin and Lutzky, "Recent Changes," 18.
7. Urban Institute analysis of the Medicaid Financial Management Report for FY 2000 from the Centers for Medicare and Medicaid Services, Center for Medicaid and State Operations, unpublished.
8. Henry J. Kaiser Family Foundation, "State."
9. Henry J. Kaiser Family Foundation, "State."
10. Public Policy Institute of New York State, Inc., "The Tax New Yorkers Pay to Train Other States' Doctors,"; accessed March 13, 2002, at <http://www.ppiny.org/reports/hcra99rp.htm>.

## Sunday, March 3, 2002

7:00 pm Dinner at San Martin [143 East 49<sup>th</sup> Street]

## Monday, March 4, 2002

7:30 am Breakfast available [Sutton Suite, Roosevelt Hotel, 45 East 45th Street]

8:00 am Welcome

**Judith Miller Jones**, *Director*, National Health Policy Forum

THE CONTINUUM OF CARE IN NEW YORK:  
HISTORY AND CONTEXT

**Bruce Vladeck, Ph.D.**, *Acting Chair*, Department of Geriatrics and Adult Development, Mount Sinai School of Medicine

**Jane Gould**, *President and Chief Executive Officer*, Visiting Nurse Regional Health Care System

**Bridget M. Simone, Dr.P.H.**, *First Assistant Deputy Commissioner for Home Care Services*, Human Resources Administration, New York City

- How does the Medicare program operate in New York as compared with other parts of the country in terms of utilization of medical services, per capita spending per beneficiary, and the demographic characteristics of the population? Who are the dominant players in the market?
- What has been the history of New York's Medicaid program in serving elderly and disabled beneficiaries? How does it compare with other states in terms of spending per beneficiary as well as access to and variety of delivery settings?
- What are demographic characteristics of New York's long-term care population? How is the population distributed among the various care settings, and how has this changed over time?
- What features of New York's political and social character have influenced the state's approach to long-term care?
- What is the relationship between the state government and New York City government? How is regulatory responsibility divided? Do some services overlap?

9:45 am TRANSITIONS IN AND OUT OF ACUTE, SUBACUTE, AND LONG-TERM CARE SETTINGS

**Mathy Mezey, Ed.D., R.N., F.A.A.N.**, *Director*, John A. Hartford Foundation Institute for the Advancement of Geriatric Nursing

**Robin Kennedy, M.D.**, *Director*, Division of Geriatric Medicine, Maimonides Medical Center

## AGENDA

**AGENDA****Monday, March 4, 2002 (cont.)**

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**Tara Cortes, Ph.D., R.N.,** *Director, Primary Care and Medical Services Care Center, Mount Sinai Hospital*

- What types of challenges do patients face when moving from acute settings to subacute or long-term care settings and, often, back again?
- How do Medicare and Medicaid reimbursement rules affect site-of-care, discharge, and placement decisions? Have facilities changed their admissions practices in response to Medicare's new prospective payment systems for post-acute care? What are the major impediments in Medicare and Medicaid to smooth transitions of patients between institutions?
- What is the interface between hospitals, nursing homes, and subacute facilities? How do providers manage the flow of information about individual patients as they move among different levels of care?
- What innovations have hospitals or health systems put in place to help ease transitions?
- To what extent do workforce issues influence the transition of patients in and out of these settings?

11:00 am Break

11:15 am VARIATIONS IN MANAGED LONG-TERM CARE

**Holly Michaels Fisher,** *Vice President/Executive Director, VNS Choice*

**Rick Surpin,** *President, Independence Care System*

**Susan Aldrich,** *Senior Vice President, Comprehensive Care Management, Beth Abraham Family of Health Services*

- What was the genesis of the managed long-term care demonstration?
- What factors influence a managed long-term care contractor's ability to recruit members? To what extent are marketing efforts focused on eligible individuals, providers (such as physicians), and/or community organizations? Is the model compatible with consumer-directed care?
- What are the advantages and disadvantages of fully integrating finance and service delivery, as under PACE? How do other programs approach the idea of integration? Is expansion of this envisioned?
- How is case management/care coordination organized? Does this differ among managed long-term care contractors? Have certain elements emerged as critical? What activities does case management comprise? What role do consumer, family, and physician preferences play?

12:45 pm Lunch

Monday, March 4, 2002 (cont.)

AGENDA

1:30 pm Bus departure for Visiting Nurse Service of New York (VNSNY)

2:00 pm Briefing and discussion

HOME HEALTH CARE: MAKING HOUSE CALLS  
FOR MORE THAN A CENTURY

**Carol Raphael, M.P.A.**, *President and Chief Executive Officer*, Visiting Nurse Service of New York

**Joan Marren, M.Ed., R.N.**, *Chief Operating Officer*, Visiting Nurse Service of New York

**Penny Feldman, Ph.D.**, *Director, Home Care Policy and Research*, and *Vice President, Research and Evaluation*, Visiting Nurse Service of New York

- How has home health care delivery in New York changed over the past decade? Has the trend been toward more short-term or more long-term care? More or less skilled care? Are there fewer agencies competing in the New York market than before?
- How has VNSNY adapted to Medicare's new prospective payment system for home health care? How has delivery of services been affected? Have the types of patients covered by Medicare changed?
- How do Medicare-covered services compare with Medicaid-covered services? How is care coordinated for dually eligible beneficiaries? How do home care services differ from or complement outpatient services provided by hospitals, from that provided by skilled nursing and/or rehabilitation facilities?
- Has the nursing and paraprofessional shortage affected home health care more than other health care sectors? What factors contribute to difficulties in recruiting nurses and paraprofessionals in home health care?
- What has been VNSNY's experience in implementing OASIS (Outcome and Assessment Information Set)? What are the challenges of using an assessment tool for measuring functional status of patients and outcomes as well as determining level of payment?
- For nurses on the front line, what is a "typical day" in home health care? How do nurses communicate with physicians? What are the major challenges nurses experience? What are the critical factors during transition periods (for example, when a person is discharged from or needs to be admitted to the hospital)?

4:30 pm Bus departure for headquarters hotel

6:30 pm Dinner at Cité [120 West 51<sup>st</sup> Street]

### AGENDA

Tuesday, March 5, 2002

7:30 am Breakfast available [*Sutton Suite, Roosevelt Hotel*]

8:00 am Viewing of segment from "On Our Own Terms: Moyers on Dying," followed by discussion

#### FROM CURE TO COMFORT: THE ROLE OF PALLIATIVE CARE

**Diane Meier, M.D.**, *Director, Center to Advance Palliative Care, Mount Sinai School of Medicine*

**Donald Schumacher, Psy.D.**, *President and Chief Executive Officer, Center for Hospice and Palliative Care*

- What are the barriers to providing high-quality palliative care? Are they primarily financial or cultural?
- How do Medicare and Medicaid reimbursement rules affect the delivery of palliative care?
- How prevalent are palliative care programs in hospitals and nursing homes?
- What are the differences between palliative and hospice care?
- Should a designated DRG code for palliative care be created? If so, should hospice be treated separately or as part of palliative care?

10:00 am QUALITY ASSURANCE IN THE NURSING HOME:  
ROLES AND RELATIONSHIPS

**Anna Colello**, *Director, Division of Quality Assurance and Surveillance, New York State Department of Health*

**Carl Young**, *President, New York Association of Homes and Services for the Aging*

**Cynthia Rudder, Ph.D.**, *Director, Nursing Home Community Coalition of New York State*

- How and by whom is the quality of nursing home care regulated? Are skilled nursing, rehabilitation, and residential care components treated differently?
- What is entailed in a nursing home survey? To what extent is it focused on patient outcomes? How do surveyors determine whether a facility passes or fails the inspection? What might be lost or gained if survey frequency were determined by a facility's past performance record?
- To what extent are survey outcomes tied to reimbursement? Is this optimal?
- What impact has the inspection process had on facility performance?
- To what extent do regulators work with facilities to develop and implement improvements? Is this an appropriate role for them?

Tuesday, March 5, 2002 (cont.)

AGENDA

- To what extent is quality information available and used in nursing home selection by patients and families?
  - How do marketplace pressures reinforce or collide with regulatory objectives?
  - How helpful is MDS (Minimum Data Set) reporting to a nursing home administrator? What kind of feedback is received from the Centers for Medicare and Medicaid Services (CMS)?
  - How has the nursing home industry and how have consumers reacted to CMS's *Nursing Care Compare* Web site plans?
- 11:30 am Bus departure for Cabrini Center for Nursing and Rehabilitation (CCNR)
- Noon Tour and discussion, with lunch
- TOO MUCH GINGER IN THE CONGEE: ADJUSTING TO CULTURAL DIVERSITY IN LONG-TERM CARE FACILITIES
- Francesca Gany, M.D.**, *Director*, Center for Immigrant Health, New York University School of Medicine
- Jeffrey Nichols, M.D.**, *Medical Director*, Cabrini Center for Nursing and Rehabilitation
- What are the barriers to accessing health care for immigrant populations? How can the health care system more effectively support collaboration between care providers and community service organizations?
  - How have changing demographics on the Lower East Side affected CCNR's history? What is the demographic profile of today's residents? What about the staff? From what populations is staff recruited?
  - What is CCNR's case-mix profile (Medicare, Medicaid, other state programs, private pay) and how has this changed over time? How have the relative values of these payment streams to the institution changed?
  - How is multicultural competency built? How does it function as a marketing and retention tool?
  - How can surveys and other regulatory mechanisms better recognize the impact that responsiveness to diverse cultural needs has on quality of life? What are the cost implications?
- 2:00 pm Bus departure for Penn Station

## Federal Participants

**Kathryn Allen**

*Director*  
Medicaid and Private Health Insurance  
Programs  
General Accounting Office

**Jennifer Boulanger**

*Acting Deputy Director*  
Center for Beneficiary Choices  
Centers for Medicare and Medicaid Services  
Department of Health and Human Services

**Hope Cooper**

*Health Policy Advisor (R)*  
Committee on Finance  
U.S. Senate

**Ed Grossman**

*Assistant Counsel*  
Legislative Counsel  
U.S. House of Representatives

**Lisa Kidder**

*Senior Health Policy Advisor*  
Office of Senator Craig  
U.S. Senate

**Ryan McGinn**

*Researcher (D)*  
Special Committee on Aging  
U.S. Senate

**Michael McMullan**

*Acting Director*  
Center for Beneficiary Choices  
Centers for Medicare and Medicaid Services  
Department of Health and Human Services

**Carol O'Shaughnessy**

*Specialist in Social Legislation*  
Domestic Social Policy Division  
Congressional Research Service  
Library of Congress

**Richard Price**

*Section Head, Health Care and Medicine*  
Domestic Social Policy Division  
Congressional Research Service  
Library of Congress

**Richard Rimkunas**

*Section Head, Research Development*  
Domestic Social Policy Division  
Congressional Research Service  
Library of Congress

**Murray Ross**

*Executive Director*  
Medicare Payment Advisory Commission

**William Scanlon**

*Director*  
Health Care Issues  
General Accounting Office

**Andrew Scott**

*Deputy Branch Chief*  
Health Financing Branch  
Office of Management and Budget

**Terri Shaw**

*Legislative Assistant*  
Office of Representative Stark  
U.S. House of Representatives

**Julie Stone**

*Analyst in Social Legislation*  
Domestic Social Policy Division  
Congressional Research Service  
Library of Congress

**Chris Topoleski**

*Budget Analyst*  
Health Cost Estimates Unit  
Congressional Budget Office

**Sara Traigle**

*Legislative Assistant*  
Office of Senator Breaux  
U.S. Senate

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## Foundation Participants

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**Sarajane Brittis**

*Program Officer*

John A. Hartford Foundation

**Karen Davenport**

*Program Officer*

Robert Wood Johnson Foundation

**Christopher Langston**

*Program Officer*

John A. Hartford Foundation

**Corinne Rieder**

*Executive Director*

John A. Hartford Foundation

**Paul Verrett**

*Program Associate*

John A. Hartford Foundation

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## NHPF Staff

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**Judith Miller Jones**

*Director*

**Judith D. Moore**

*Co-Director*

**Lisa Sprague**

*Senior Research Associate*

**Nora Super**

*Senior Research Associate*

**Catherine Park**

*Research Assistant*

**Dagny Wolf**

*Program Coordinator*

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## Biographical Sketches — Speakers

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**Susan Aldrich** is senior vice president for managed care and for regulatory affairs at Beth Abraham Family of Health Services. She has been responsible for the development of the Comprehensive Care Management Program for the last 12 years. She is also responsible for the Long-Term Home Health Care Program, the Comprehensive Care Management Diagnostic and Treatment Center, and the Beth Abraham Naturally Occurring Retirement Community. Prior to joining Beth Abraham, Aldrich was senior program officer at the Commonwealth Fund, where she was responsible for grant programs involving aging and health. She has also worked in federal government policy offices reviewing health legislation and regulations focused on health maintenance organizations and Medicare. She received her B.A. degree from Swarthmore College and her M.A. from the University of California at San Diego.

**Anna Colello** is director of the Division of Quality Assurance and Surveillance for Nursing Homes and Intermediate Care Facilities for the Mentally Retarded in the New York State Department of Health. She is responsible for setting policy for surveillance in accordance with state and federal law for 670 nursing homes and 13 development centers. Colello implemented the Central Intake of Nursing Home Complaint system. She also works with the department's Division of Legal Affairs and the federal Centers for Medicare and Medicaid Services to enforce actions against noncompliant homes. She holds a B.A. degree from the University of Albany and a J.D. from New York Law School.

**Tara Cortes Ph.D., R.N.**, is director of primary care and medical services and associate hospital director at Mount Sinai Hospital. She holds professorships at New York University and Columbia University and is a visiting professor at the University of Kentucky. She is the project director of a Hartford Institute-funded program to enhance the transition of elderly people as they move between hospitals and nursing homes. Cortes recently implemented a program supported by the Robert Wood Johnson Foundation that educates lay people to help elderly asthmatics cope with their disease. She is a fellow in the Robert Wood Johnson Executive Nurse Fellowship Program.

**Penny Hollander Feldman, Ph.D.**, is vice president for research and evaluation at the Visiting Nurse Service of New York (VNSNY) and director of the Center for Home Care Policy and Research (CHCPR). At the center, she directs projects focused on improving the quality and outcomes of home health care, promoting equitable allocation of long-term care resources to vulnerable populations, developing supportive communities for a growing older population, and facilitating informed policymaking by federal, state, and local decision-makers. Before joining VNSNY, Feldman served on the faculty at Harvard University, in the Department of Health Policy and Management at the Harvard School of Public Health, and at the John F. Kennedy School of Government.

**Holly Michaels Fisher** is vice president and executive director of VNS Choice, a managed long-term care program currently serving 2,600 dually eligible nursing home-qualified seniors throughout New York City. She joined the Visiting Nurse Service of New York in 1994 as the director of long-term care program development. In 1997, she assumed the role of vice president for long-term care and was responsible for all VNS Home Care-sponsored long-term programs and services and in 1998 moved to her present

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**Biographical Sketches — Speakers**

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position. Before joining VNS, Fisher worked for the New York Academy of Medicine, the New York County Medical Society, the Greater New York Hospital Association, Empire Blue Cross and Blue Shield, and St. Luke's Roosevelt Hospital Center. She earned her B.S. degree in nursing and a master's degree in public health administration and urban planning from Columbia University.

**Francesca Gany, M.D.**, is founder and director of the Center for Immigrant Health and a member of the faculty of the New York University School of Medicine. The mission of the center is to improve access to and quality of health care for New York's large immigrant populations. Gany has served as the principal investigator on a number of pioneering immigrant health projects. As a Robert Wood Johnson faculty scholar, she conducted a study to elucidate barriers to the completion of tuberculosis screening and prophylaxis facing immigrants. She developed the National Cancer Institute/National Institutes of Health-funded Cancer Awareness Network for Immigrant and Minority Populations (CANIMP). CANIMP works with the Haitian, Latino, Chinese, Korean, and English-speaking Caribbean immigrant communities. Gany holds a B.S. degree from Yale University, an M.D. from Mt. Sinai School of Medicine, and an M.S. in health policy from the Wagner Graduate School of Public Service.

**Jane Gould** is president and chief executive officer of the Visiting Nurse Regional Health Care System, which includes the Visiting Nurse Association of Brooklyn, Empire State Home Care, At Home Health Services Agency, and the Brooklyn Visiting Nurse Foundation. These organizations provide an array of home care services to people of all ages, irrespective of their ability to pay. Gould is on the Board of Directors of the Home Care Association of New York State. Before coming to the Visiting Nurse Regional Health Care System, she was director of the New York State Office for the Aging and served in Gov. Mario M. Cuomo's cabinet. She has served as president of the National Association of State Units on Aging and on the Board of Directors of the National Council of Senior Citizens.

**Robin D. Kennedy, M.D.**, is vice chairman of the Department of Medicine-Geriatrics, director of the Division of Geriatric Medicine, and program director for geriatric fellowship training at Maimonides Medical Center in Brooklyn. He is a professor of clinical medicine at State University of New York Health Science Center at Brooklyn as well as an adjunct instructor in nursing at New York University. Kennedy is the author and editor of textbooks in geriatric medicine and nursing and is a co-director of the Consortium of New York Geriatric Education Centers. He received his undergraduate degree from the University of Glasgow, Scotland, and his M.D. from the State University of New York.

**Joan Marren, M.Ed., R.N.**, is chief operating officer of the Visiting Nurse Service of New York. In her 24 years with the agency, she has served as a field nurse, supervisor, educator, and administrator. Marren is responsible for overseeing the day-to-day operations of the agency, which in 2001 provided more than 6 million home care visits. She is also responsible for overseeing quality measurement and improvement programs and clinical education activities. Marren has helped to design and develop new models of long-term care for the elderly and chronically ill and was instrumental in launching the Medicaid managed long-term care program, VNS Choice. She also

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**Biographical Sketches — Speakers**

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led the development of an automated clinical system at VNS that enables field nurses to enter, transmit, and receive clinical data through pen-based notebook computers. She is a past president of the Home Care Association of New York State, and has served on many advisory and policymaking committees at both the state and national levels. Marren received her B.S. in nursing from Hunter College and master's degrees in nursing education and community health from Columbia University.

**Diane Meier, M.D.**, is director of the Center to Advance Palliative Care, a Robert Wood Johnson–Mount Sinai national program aimed at increasing the number of hospital- and nursing home–based palliative care programs in the United States. She is also director of the Lilian and Benjamin Hertzberg Palliative Care Institute as well as professor of geriatrics and internal medicine and Catherine Gaisman Professor of Medical Ethics at the Mount Sinai School of Medicine. She has been on the faculty of the Departments of Geriatrics and Medicine at Mount Sinai since 1983. She is also chief of the Division of Geriatrics for the Department of Medicine. Meier is the recipient of a National Institute on Aging Academic Career Leadership Award for her work on palliative care of the elderly and the mentoring and support of junior faculty in palliative medicine. She graduated from Northwestern University Medical School and completed residency and fellowship training at Oregon Health Sciences University in Portland.

**Mathy Mezey, Ed.D., R.N., F.A.A.N.**, is the director of the John A. Hartford Foundation Institute for the Advancement of Geriatric Nursing Practice, co-director of the certificate program in bioethics and the medical humanities at New York University Division of Nursing, and Independence Foundation Professor of Nursing Education at New York University. Previously, she was associate director of the Ralston-Penn Center: Care Education Research for the Older Adult at the University of Pennsylvania and a professor of gerontological nursing at the University of Pennsylvania. She holds B.S.N., M.Ed., and Ed.D. degrees from Columbia University.

**Jeffrey Nichols, M.D.**, is the chief of geriatrics and palliative care at Cabrini Medical Center and the medical director for the Cabrini Center for Nursing and Rehabilitation in Manhattan. He is also executive medical director for Cabrini's hospice program. Previously, he was director of professional affairs for Elderplan, the social health maintenance organization in Brooklyn, and medical director of Frances Schervier Home and Hospital in the Bronx. Nichols is board-certified in internal medicine and hospice and palliative care and has additional certification in geriatrics. He received his B.A. degree from Columbia and his M.D. from Cornell University Medical College.

**Carol Raphael** is president and chief executive officer of the Visiting Nurse Service of New York. Her responsibilities include managing its post-acute, long-term, maternal and child health, high-tech, rehabilitation, hospice, mental health, and public health programs, which provide care to 24,000 patients daily. Under her leadership, VNS created VNS Choice, a Medicaid Managed Long-Term Care Health Plan; the Medicare Community Nursing Organization, a community-based health care program for Medicare beneficiaries; and Centers of Excellence specializing in cardiopulmonary, diabetes, asthma, and cancer care. Raphael is a member of the Medicare Payment Advisory Commission and the New York State Hospital Review and Planning Council. Before joining VNS, Raphael was director of operations management at the Mount Sinai Medical Center

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**Biographical Sketches — Speakers**

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and, for ten years, worked at the New York City Human Resources Administration. She holds an M.P.A. degree from Harvard University.

**Cynthia Rudder, Ph.D.**, has been director of the Nursing Home Community Coalition of New York State (NHCC) for over 22 years. NHCC is a coalition of statewide consumer, civic, and professional organizations working to improve nursing home and assisted living care. She has published a number of reports and articles on nursing home issues, including reimbursement systems, profits and losses, subacute care, and quality issues as well as reports on how well the state is conducting its complaint and enforcement systems. She has just released the final report of an in-depth three-year study of assisted living in New York State. She has also been involved with a number of state and federal advisory committees, including the Health Care Financing Administration's (now CMS's) advisory committee for the Medicare Demonstration Project.

**Donald Schumacher, Psy.D.**, is president and chief executive officer of the Center for Hospice and Palliative Care outside Buffalo, New York. He is a member of the National Hospice and Palliative Care Organization (NHPCO) board of directors and chairs the Children's Hospice International Task Force on developing Medicaid 1115 waivers for pediatric hospice care. He serves on the NHPCO legislative subcommittee of the Medicare Benefits Implementation Task Force and is active in the National Hospice Workgroup. Additionally, he is director of public policy for Partnership for Caring. A clinical psychologist in both Massachusetts and New York, Schumacher graduated from the Massachusetts School of Professional Psychology.

**Bridget M. Simone, Dr.P.H.**, is first assistant deputy commissioner for the Home Care Services Program of the Human Resources Administration of the city of New York and is responsible for the largest Medicaid-funded personal care services program in the nation, with approximately 65,000 clients and an annual expenditure of over \$1.4 billion. She has also worked at the University of Chicago as proposal manager for the National Opinion Research Center and has an extensive consulting practice, working with, among others, Rosenberg and Associates, the Joint Commission on Accreditation of Healthcare Organizations, the American Academy of Pediatrics, and a number of community health centers in Chicago and California. She has also served as executive director/chief executive officer of a number of public institutions, including an emergency medical services agency responsible for one-quarter of the State of California and a 50-bed county hospital on the Colorado River. She received her M.P.H. and Dr.P.H. degrees from the University of Michigan.

**Rick Surpin** is the founder and president of Independence Care System (ICS), a non-profit Medicaid managed long-term care organization for adults with physical disabilities. ICS coordinates a wide range of health and social services to enable people with significant disabilities who are eligible for placement in a nursing home to remain at home. He is also founder and chairperson of Cooperative Home Care Associates, a worker-owned home care agency in the South Bronx and of the Paraprofessional Healthcare Institute, a national nonprofit health employment and advocacy organization for paraprofessional health care. He also chairs the board of the Home Care Association of New York State.

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**Biographical Sketches — Speakers**

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**Bruce C. Vladeck, Ph.D.**, is professor and acting chairman of the Brookdale Department of Aging and Human Development, professor of health policy, and director of the Institute for Medicare Practice at the Mount Sinai School of Medicine. He is also senior vice president for Policy of Mount Sinai NYU Health. From 1993 through 1997, he was administrator of the Health Care Financing Administration (HCFA), U.S. Department of Health and Human Services, and played a central role in the formulation and enactment of the Medicare, Medicaid, and child health provisions of the Balanced Budget Act of 1997. Subsequent to his service at HCFA, Vladeck was appointed by the president to the National Bipartisan Commission on the Future of Medicare. Earlier, he served ten years as president of the United Hospital Fund of New York and held positions on the faculty of Columbia University. He received his B.A. degree from Harvard College and M.A. and Ph.D. degrees from the University of Michigan.

**Carl Young** is president of the New York Association of Homes and Services for the Aging (NYAHSA), a group representing the continuum of not-for-profit, mission-driven and public long-term care organizations, including nursing homes, adult care facilities, senior housing, continuing care retirement communities, and community services providers. He is president of the Foundation for Long-Term Care and has chaired the state executives' forum of the American Association of Homes and Services for the Aging. Before joining NYAHSA, Young served as Broom County executive, implementing a nationally recognized alternative health care delivery system for the elderly. Young received his B.A. degree from Middlebury College and an M.A. from Syracuse University.

## Biographical Sketches — Federal Participants

**Kathryn Allen** is director for Medicaid and private health insurance programs in the U.S. General Accounting Office (GAO). She directs the agency's work on Medicaid, long-term care, and private health insurance. Her 23-year career with GAO also includes leadership positions in the Seattle and European field offices and, in the late 1980s, direct staff support to the National Commission to Prevent Infant Mortality.

**Jennifer Boulanger** is the acting deputy director for health plans in the Center for Beneficiary Choices at the Centers for Medicare and Medicaid Services (CMS, previously the Health Care Financing Administration), Department of Health and Human Services (DHHS). She works on issues relating to the Medicare+Choice program, including program policy and management, beneficiary education and enrollment, demonstrations, and quality improvement activities. Previously, she was director of the Medicare Part A Analysis Group in CMS's Office of Legislation. Other positions she has held at CMS include special assistant to the agency's administrator, director of the Bureau of Policy Development, and associate administrator for program development. Earlier, she worked on the staff of the Prospective Payment Assessment Commission, analyzing hospital payments under Medicare. She holds a master's degree from the University of Michigan and a B.A. from the University of Washington.

**Hope Hegstrom Cooper** serves as health policy advisor to the Senate Committee on Finance for the ranking member, Sen. Charles Grassley (R-Iowa). Her primary areas of responsibility are the Medicaid and Temporary Assistance for Needy Families (TANF) programs. During the 105<sup>th</sup> and 106<sup>th</sup> Congresses (1997 to 2001), she served under Grassley as professional staff member to the Senate Special Committee on Aging. From 1993 to 1997, she worked on Grassley's personal office staff as a legislative correspondent on a wide array of health care, education, and retirement issues.

**Edward G. Grossman** has been assistant counsel in the Office of the Legislative Counsel, U.S. House of Representatives, since 1975. He coordinated and drafted significant portions of the Norwood-Dingell bill and other patient protection proposals in 1999, as well as health care provisions in the Health Insurance Portability and Accountability Act of 1996, the Balanced Budget Act (BBA) of 1997, and the BBA refinement legislation passed at the end of the 1999 session.

**Lisa Kidder** is the senior health policy advisor to Sen. Larry Craig (R-Idaho), ranking minority member of the Senate Special Committee on Aging.

**Ryan McGinn** is a column writer and researcher for Sen. John Breaux (D-La.) and the Senate Special Committee on Aging. In addition to her research work, she assists in press relations and has helped design and draft content for the committee's Web site. Prior to joining the committee staff, she worked as an account executive for a Washington-based strategic communications firm and wrote for Washington arts and entertainment magazines. McGinn is a graduate of the George Washington University.

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**Biographical Sketches — Federal Participants**

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**Carol O’Shaughnessy** is a specialist in social legislation in the Division of Domestic Social Policy Division of the Congressional Research Service (CRS), Library of Congress. She focuses on issues related to long-term care, social services, and disability programs. In that capacity she works with committees of Congress having jurisdiction over the Older Americans Act, the Rehabilitation Act, Medicaid, and related programs. Prior to joining the CRS staff in 1981, she was an analyst with DHHS, the Department of Elder Affairs in the Commonwealth of Massachusetts, the Russell Sage Foundation, and the International Federation of Institutes for Social and Socio-Religious Research in Louvain, Belgium. O’Shaughnessy received a bachelor’s degree from Dunbarton College of the Holy Cross and a master’s degree from the Catholic University of America.

**Richard Price** heads the Health Care and Medicine Section of the Domestic Social Policy Division of CRS. In addition to his managerial duties, he serves as the section’s lead analyst on long-term care financing issues.

**Richard Rimkunas** is head of the Research Development Section in the Domestic Social Policy Division of CRS. The research development group prepares empirical analyses of prospective legislation for a wide array of policy issues in health and welfare. He has acted as project director for the Medicaid source book and has prepared analyses of Medicare managed care, Medicaid, and other issues related to long-term care.

**Murray N. Ross, Ph.D.**, is executive director of the Medicare Payment Advisory Commission. Previously, he was chief of the Health Cost Estimates Unit in the Congressional Budget Office’s (CBO’s) Budget Analysis Division, where he supervised preparation of baseline spending projections and cost estimates for Medicare, Medicaid, and other federal civilian health programs. His CBO service began with six years in the Health and Human Resources Division. Ross holds a doctorate in economics from the University of Maryland.

**William Scanlon** is director of health care issues at GAO. He has been engaged in health services research since 1975. Before joining GAO in 1993, he was the co-director of the Center for Health Policy Studies and an associate professor in the Department of Family Medicine at Georgetown University. He had also been a principal research associate in health policy at the Urban Institute. His research has focused in particular on the Medicare and Medicaid programs, especially provider payment policies, and the provision and financing of long-term care services. He has published extensively and has served as frequent consultant to federal agencies, state Medicaid programs, and private foundations. Scanlon has a Ph.D. in economics from the University of Wisconsin-Madison.

**Andrew Scott** is a senior analyst and deputy branch chief of the Health Financing Branch at the Office of Management and Budget. The Health Financing Branch is responsible for assisting in the formulation of the president’s legislative and regulatory agenda for the Medicare, Medicaid, and SCHIP programs, as well as for briefing OMB and White House policy officials on current health care issues and legislation. Policy issues include long-term care, disability, dual eligibles, prescription drug coverage and payment, and health-related taxes. Scott received his M.P.P. from the Georgetown Public Policy Institute.

### Biographical Sketches — Federal Participants

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**Terri Shaw** is a health policy analyst in the office of Rep. Pete Stark (D-Calif.), ranking member of the House Ways and Means Committee’s Subcommittee on Health. Issue areas include private health insurance and long-term care. Before joining Stark’s office, she worked for DHHS, the California Managed Health Care Improvement Task Force, and the Alameda County Social Services Agency. Shaw holds an M.P.H. degree from the University of California, Berkeley, and a B.S. from Stanford University.

**Julie Stone** is an analyst in social legislation in the Domestic Social Policy Division of CRS. Since coming to CRS in 2000, Stone has specialized in long-term care and in Medicaid, particularly as it pertains to the elderly and persons with disabilities. She also works on private health insurance issues. She received her M.P.A. degree from Cornell University in 2000 and her B.A. from the University of California at Berkeley in 1995.

**Chris Topoleski** is a budget analyst with CBO. His responsibilities include projecting baseline expenditures for Medicare post-acute and chronic services (skilled nursing facilities and home health), preventive screening, hospital outpatient services, laboratory services, end-stage renal disease, and most other nonphysician Part B services. In addition, Topoleski is responsible for analyzing proposals affecting these Medicare services as well as proposals affecting several federal health agencies. Before joining CBO, Topoleski was a senior associate with the health economics practice, Barents Group, LLC, of KPMG LLP from 1995 to 2000, providing health economics research to both public and private-sector clients.

**Sara Traigle** is a legislative assistant in the office of Sen. John Breaux (D-La.), where she concentrates on Medicare and Medicaid issues.



**National Health  
Policy Forum**

2131 K street, NW  
Suite 500  
Washington DC 20037

202/872-1390

202/862-9837 [fax]

[nhpf@gwu.edu](mailto:nhpf@gwu.edu) [e-mail]

[www.nhpf.org](http://www.nhpf.org) [web site]

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