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THE CAPITOL FORUMS
On Health and Medical Care

Medicaid Funding of Chronic and Long Term Care

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background information for the discussion at the

CAPITOL FORUM
on Wednesday, May 4, 1994
Masonic Temple Library
Trenton, New Jersey

Sponsored by
The League of Women Voters of New Jersey Education Fund

Underwritten by a grant from
THE ROBERT WOOD JOHNSON FOUNDATION

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Vignettes

At-risk Elderly

Your aunt, Mary G., is 78 years old and has been widowed for four years. She still lives where she and your uncle lived all of their lives, in a row house in Belleville, New Jersey. Their one daughter is married and lives in Indianapolis, where the family was transferred for her husband's job. Aunt Mary was doing well until complications from her cataract surgery left her legally blind in one eye and an untreated diabetic condition has led to retinal problems with her "good" eye. She has been able to live on her husband's pension and Social Security check, which totaled approximately $1,400 a month. Aunt Mary fell last week and broke her hip; after surgery, she will need to have 6 to 8 weeks rehabilitative care and physical therapy. Once home, Aunt Mary will need continued physical therapy and assistance with bathing, toileting, cleaning, cooking and other daily living activities. Because of her vision problems, she needs more intensive help than someone not visually disabled. Coordination and management of her care is critical to avoid institutionalization. She just found out that Medicare rejected her home care treatment as "unreasonable" and her Medigap insurance denial for coverage is under appeal. Where does Aunt Mary turn for help?

Disabled elderly are more likely to be widowed females. Three out of four elderly residents in nursing homes are widowed females with chronic health problems ("Familiar Faces," 1992).

Disabled and Poverty

Just one accident, as in the case of your neighbor Joe T. (44), who was left a paraplegic after being caught in the cross-fire of a robbery in a down-town store, can lead to loss of work, home and dependence on cash assistance programs, as well as Medicare (after a two-year waiting period), even though Joe is under age 65. Because his disability is total and permanent, Joe will most likely be an Social Security Disabled Insurance (SSDI) recipient and Medicare beneficiary throughout his life. Joe must first qualify for SSDI medically and then the amount of his benefit, or Primary Insurance Amount (PIA), is determined based on a formula using his work history and salary. There is a five-month waiting period before he can receive payment from SSDI. The amount of his PIA is based on his most recent earnings before he became disabled. His wife, Elaine, and two children, are eligible for benefits as well; however, their monthly maximum family benefit can only be 150 percent of Joe's set PIA. In Joe's case, his PIA is $900. Together, his wife and children may receive benefits of $250 per month, since their maximum family benefit is $1,350 (or 150 percent of $900). Annual benefits amount to $16,200. Since Medicare coverage requires a two-year waiting period, Elaine had to leave her part-time job to do the home care tasks that Joe requires, such as bathing, dressing and cooking. How will this family negotiate the risks of poverty and the downward social and economic spiral to which Joe's accident left them vulnerable?

The Center for Vulnerable Populations reports that the poverty rate for individuals between the ages of 18 and 64 with a reported work disability is three times the rate reported for those individuals not disabled. Because of the poverty that results from their being disabled, this population becomes dependent on public programs for care ("Familiar Faces," 1992).

Medicaid Funding of Chronic and Long Term Care

An issue brief prepared by Joanne T. Fuccello, MSW
for discussion at the May 4, 1994, Capitol Forum

The Issue:

Both nationally and in New Jersey, Medicaid is the single largest payer for long term care services. Currently in New Jersey, approximately 68 percent of all nursing home patients are Medicaid recipients. **In light of the growing numbers of elderly and disabled living in New Jersey, how can we best organize funding mechanisms and delivery of services to meet the long term care needs of these groups (both community-based and institutional), without bankrupting the Medicaid system?**

This issue brief looks at: the factors that brought us here, the current plans with New Jersey Medicaid to resolve the problem, future trends in Medicaid spending for long term care, and the Supplemental Security Income (SSI) population (which has been identified as accounting for a disproportionate share of Medicaid expenditures, primarily for institutional services, such as nursing homes and Intermediate Care Facilities for the Mentally Retarded), as well as those financially independent individuals who convert to Medicaid as a result of nursing home placement.

Introduction

In fiscal year 1992, Federal and state spending for the Medicaid program nationally was $119 billion, and increase of 29 percent from 1991. 1993 outlays are approximated at $130 billion, covering an estimated 31 million Medicaid recipients. Who are these recipients and what types of services is Medicaid providing for them? A simple breakdown of Medicaid eligibles comprises two categories: Aid to Families with Dependent Children (AFDC) families (primarily women and children) and Supplemental Security Income (SSI) recipients, who are the elderly, blind and disabled. Specified income and asset standards are involved with eligibility. When the two groups are compared along the lines of eligibles and expenditures, the SSI recipients emerge as receiving a disproportionate share of expenditures for their actual numbers, in contrast to the AFDC population. While AFDC-related groups represent 74 percent of program eligibles, they account for 27 percent of program expenditures, compared to SSI-related groups, who represent 26 percent of the program eligibles, yet account for 73 percent of Medicaid program expenditures. This "73 percent" is primarily used for services rendered in institutional facilities, such as nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICF-MR).

In its effort to control costs and improve access and quality of services, New Jersey Medicaid is joining other states in implementing mandatory enrollment of its AFDC population in Health Maintenance Organizations (HMOs) and other managed care systems (see Capitol Forums Issue Brief for March 2, 1994). The goal is to coordinate and provide the type of care needed by this young population of AFDC eligibles, in appropriate settings, with an emphasis on preventive care. What is New Jersey's status in providing services for its SSI eligible population with its chronic and long term health care needs? Is managed care appropriate for the SSI population? In its most recent overview of New Jersey's Medicaid program, the Division of Medical and Health Services notes that eligibility for the aged, blind and disabled populations is growing significantly. The elderly and disabled represent a population that is a frequent and consistently high utilizer of health care services. The delivery of appropriate services to these populations is a complex task, which involves targeting the individual recipient's needs for medical, psychological and social services.

When we are confronted with the issues of resolving long term care policy issues, we are faced with forming an "value system" as a collective group. We are forced to question how we as a society feel about our most vulnerable populations, at both ends of the age spectrum, from the newborn baby with multiple congenital disabilities who will have a lifetime of chronic care needs, to the frail elderly widow living alone with chronic health problems in need of long term care services, such as help with cooking and bathing. How do we provide access to quality health care to these groups in an environment of limited resources?

This issue brief will focus on the Medicaid program's Supplemental Security Income (SSI) population, its chronic and long term care needs, New Jersey's current initiatives to provide accessible home and community-based care settings as alternatives to nursing home placements and the corollary issues that arise when long term care is raised. This brief includes a Data Book (Section I) with national and state data, a summary of New Jersey's Medicaid Wavier Programs and other community care programs (Section II) and a Glossary of Terms (Section III).

The National Medicaid Program

Evolution from 1965 to the Present

From the enactment of the 1965 Federal legislation which amended the 1935 Social Security Act and created Title XVIII (Medicare, Parts A & B) and Title XIX (Medicaid) to the present day, the Medicaid program has evolved into not one but over 50 different Medicaid programs. While the Federal government determines broadly who is eligible and the standard benefits to be provided, the states have leeway in such significant areas as expanding eligibility to "optional" groups, offering optional services and establishing

fees, so that fees and benefits vary greatly across the states. The Health Care Financing Administration (HCFA) administers the Medicaid program on the Federal level. The percentage of Federal funding to the states varies from 50 percent to 80 percent, and it is determined through a formula based on annual per capita income. New Jersey has a 50-50 match with the Federal government. The national average has states paying approximately 43 percent of the overall Medicaid budget.

At the beginning of the 1980s, Medicaid covered the two primary categories of recipients receiving payments from the cash assistance programs: those families receiving Aid to Families with Dependent Children (AFDC) and the elderly, blind and disabled receiving Supplemental Security Income (SSI) (*The Washington Post,* January 30, 1994). Qualification for both AFDC and SSI constitutes eligibility for Medicaid. The individual states have discretion in determining monthly income levels for AFDC cash assistance. The Social Security Administration oversees the SSI program for low-income elderly, blind and disabled individuals who must meet medical and income criteria for eligibility (Ibid). The general medical criteria is the finding by a physician that the individual is permanently disabled. A finding of disability related to Acquired Immunodeficiency Syndrome (AIDS) is included as a criteria for disability under SSI and Medicaid. While the Social Security Administration designates income standards for SSI eligibility determinations, the states also provide state supplemental funds.

(See Section I, Data Book, for income and resource levels for AFDC and SSI; for example, in New Jersey, the 1994 monthly payment standard and resource level for an AFDC family of four is $507.00 per month, and $1,000 of resources; the 1994 SSI income standard and resource level for a single individual is $477.25, and $2,000. In comparison, the 1994 monthly Federal poverty level for a family of four is $1,234 per month.) .

Even with just these two categories of Medicaid eligibles, there is great complexity establishing eligibility. One is that eligibility depends on a mix of Federal mandates and state options. As well, because Medicaid eligibility is attached to the AFDC and SSI cash assistance programs, it becomes dependent on Federal and state level decisions on funding these cash assistance programs.

Expansion of Medicaid Eligibles and Expenditures

During the 1980s, Federal legislation allowed for program expansion in order to cover more individuals; this legislation included both mandatory program expansion and eligibility expansion at the option of the individual states. While the Omnibus Reconciliation Act of 1981 reduced Medicaid benefits to states for the years 1982 to 1984, the Deficit Reduction Act of 1984 did not continue this structure of Medicaid cost controls. In essence, during the 1980s the Medicaid system was expanded and reshaped to fill the major gaps in social services.

Eligibility expansion during the 1980s included the development of Medicaid "waiver" programs to extend home and community-based services to the elderly and disabled (1981 Omnibus Reconciliation Act (P.L. 97-35)). Between 1984 and 1990 through various budget reconciliation bills, the Medicaid eligibility expansion continued to include broad categories of individuals not receiving cash assistance such as: pregnant women and children with income up to 133 percent and 185 percent of the poverty level (a state option); payment of Medicare premiums, copayments, deductibles and some doctor premiums for poor elderly, and one year of Medicaid for those leaving the welfare system for work positions. (*The Washington Post*, January 30, 1994).

In 1987 a provision in the budget package required "disproportionate share" payments to hospitals treating large numbers of uninsured, which are vulnerable to financial pressures. The provision led states to make claims on these payments, resulting in the Federal government paying $10.8 billion to states in 1992 for the hospital subsidy, or one-sixth of the total Medicaid spending that year (Ibid) (Medicaid hospital services data for 1992 and 1993 is "skewed" based on the hospital subsidy payment.) In 1993, New Jersey received $412 million in disproportionate share Medicaid funds. The 1994 New Jersey Budget book indicates that $163.1 million ($81.6 million state share) is included in the Medicaid budget to provide subsidies for hospitals to "ensure the financial viability of potentially vulnerable hospitals during the transition from a highly regulated rate setting environment to one of deregulation and competition" (at p. 67).

The New Jersey Medicaid Program

Who is Covered?

Historically, New Jersey has been innovative in its applying for Medicaid waiver to design and establish home and community-based care programs for the elderly and disabled. New Jersey Medicaid services are available to New Jersey residents with incomes above AFDC or SSI eligibility limits, but at or near the Federal poverty level. New Jersey Medically Needy law (P.L. 1985 c. 371) extends coverage to pregnant women and children, the elderly, disabled and blind whose income is too high to qualify for the regular Medicaid program and have had excessive health care costs and medical bills. New Jersey also covers, through its "New Jersey Care" Medicaid expansion program, certain groups of pregnant women and children and aged, blind and disabled individuals within certain income levels related to the Federal poverty level.

Most states have Medicare buy-in provisions in their Medicaid programs, where-in they pay Medicare Part B premiums and deductibles to cover physician and related services under the Medicare program. By January 1, 1995, it will be mandatory to pay the Medicare Part B premiums for certain aged, blind and disabled individuals whose income does not exceed 120 percent of the Federal poverty level and whose assets do not exceed $4,000. The Data Book, Section I, contains the 1994 Monthly Income Standards and

Resource Levels for New Jersey Care recipients and describes each category of expanded eligibility. The Data Book also contains a complete listing of mandatory and optional eligibility groups, mandatory and optional services provided under Medicaid and an overview of the Division's operations.

In broad terms, New Jersey's optional eligibility groups include: poor, aged or disabled individuals whose income does not exceed 100 percent of the Federal poverty level and whose assets do not exceed $4,000; individuals not eligible in the community for Medicaid and who would be eligible if they were institutionalized; pregnant women and infants up to age one whose family income does not exceed 185 percent of the Federal poverty level, institutionalized individuals under a special income-eligibility level (much of the nursing home population gains eligibility under this option) and the individuals receiving home and community-based services under the Federal waivers.

What are the Services Provided?

The Federal government requires that the states provide 10 basic services under the Medicaid program: inpatient hospital; outpatient health services; rural health clinic services; other laboratory and x-ray services; skilled nursing facility services and home health services for individuals 21 and older; early periodic screening, diagnosis and treatment for individuals under 21; family planning; physician and psychiatric services; transportation for medical services and nurse-midwife services. States can provide, at their discretion, up to 30 optional services; New Jersey provides 30 optional services through its Medicaid program. Optional services include: podiatrist, optometrist and dental services, personal care services, coverage for Intermediate Care Facilities for the Mentally Retarded (ICF-MR) and hospice services. (See complete listing of services in Section I, Data Book). The Medicaid program is administered through its 16 Medicaid district offices, where medical eligibility is determined, and the county welfare agencies and the Federal SSI office, where financial eligibility is determined. A thumbnail sketch of Medicaid's operations presents that the regular Medicaid program is administered through the Federal-State-Casino-funded Medicaid program, along with the New Jersey Care and Medically Needy programs, the Statewide Respite Care Program, HealthStart (with the Department of Health), the Waiver programs (Community Care Program for the Elderly and Disabled, AIDS Community Care Alternatives Program and Model Waivers I, II and III.) Under the General State Fund and the Casino Revenue Fund, NJ Medicaid administers the Pharmaceutical Program for the Aged and Disabled and under Casino Revenue Funds are the Home Care Expansion Program, the Hearing Aid Assistance for the Aged and Disabled program and the Lifeline Programs for assistance in payment of utilities (See Section I, Data Book, "Overview of Division's Operations").

Reimbursement for Providers

As indicated earlier, just as states have broad discretion in establishing eligibility groups and service options, they also have leeway in establishing reimbursement and fees under their individual Medicaid programs. While cost-based retrospective reimbursement was employed in the initial stages of the Medicaid program, by the Omnibus Reconciliation Act of 1981, states were given new flexibility in establishing prospective reimbursement systems for hospitals and physicians, including prepaid service arrangements with HMOs (Beer and Lago, 1987). As a consequence, reimbursement methodology and rate-setting evolved for each of the service types. The Data Book (Section I), provides a chart of the New Jersey Reimbursement System in the major provider/service areas including nursing homes, hospital inpatient and outpatient services, physician services and home health care. The payment systems range from prospective per diem to "reasonable costs" (as with Medicare) and fee-for-service. The table indicates rate setting entities and the 1993 cost for the services.

Just as with eligibility, services and reimbursement methodology used, there is great variation in average Medicaid fees for each Medicaid service. When variation is looked at in average Medicaid fees, across all services, by state, New Jersey fees are approximately 33 percent of private fees and 47 percent of Medicare-allowable fees. Nationally, state Medicaid fees range from a high of 96 percent of private fees in New Hampshire to a low of 28 percent in New York. The lowest rates for Medicaid services are found in the Northeast and Southwest regions. Providers who participate in the Medicaid program must accept the Medicaid reimbursement levels as full payments for services rendered.

What Does It Cost? National and New Jersey Expenditures and Services

In fiscal year 1992, Federal and state outlays for the Medicaid program nationally were $119 billion, representing a 29 percent increase from 1991. 1993 outlays are approximately $130 billion, covering an estimated 31 million recipients. Nationally, expenditures for eligible groups were approximately: 33 percent for the elderly enrollees (aged 65 and over), 6 percent for blind enrollees, 36 percent for disabled enrollees and 29 percent for AFDC enrollees. Nationally, in 1991, the aged, blind and disabled represent approximately 26 percent of Medicaid enrollees; expenditures for this group were approximately 70 percent (See Section 1, Data Book, "Table on Medicaid Expenditures and Enrollment"). By comparison, in 1991, New Jersey enrolled 614,000 individuals with expenditures of $2,725,000. Massachusetts, with 651,000 enrollees, spent $2,828,000 in 1991. The entire Mid-Atlantic region (New Jersey, New York and Pennsylvania) had Medicaid enrollment of 4,353,000 and Medicaid expenditures of $19,889,000. New Jersey's spending represented approximately 14 percent of this total, Pennsylvania's represented 17 percent, with New York accounting for 69 percent of the total for Mid-Atlantic region Medicaid spending (See Section I, Data Book, Chart on "State-by-State Medicaid Enrollment and Expenditures").

The 1994 New Jersey Medicaid Budget

New Jersey's total 1994 Medicaid budget (state and Federal) is $4,000,846,000. Of the total appropriation, $1,132,070,000, or 28 percent, is for nursing homes; $1,084,077,000, or 27 percent is for other program services (which include the Medicaid eligibility expansion groups ($393,054,000), home health services, dental, transportation and other program services); $990,393,000, or 25 percent is for inpatient care; $417,821,000 or 10 percent is for outpatient care; $266,501,000, or 7 percent, is for prescription drugs and $109,984,000 or 3 percent, is for physician services (See Section 1, Data Book, Chart, "State Fiscal Year 1994 Medicaid Benefits").

A review of Medicaid eligibles (in New Jersey, the enrollment rate, or those who use services, compared to eligibles is 60 percent) indicates that in State fiscal year 1993, 442,138 enrollees were AFDC recipients and 164,760 were SSI recipients, out of a total figure of 659,997 eligibles. At the end of December 1993, eligibles increased to 672,826. Expenditures for AFDC enrollees were $916,908,338, while Medicaid expenditures for the SSI population were $2,122,873,813. Of total state fiscal year 1993 spending (approximately $3.6 billion), the largest expenditures were in the service areas of hospital care ($983,587,680) (approximately 25 percent), and nursing facility care ($929,931,331) (approximately 25 percent) (See Section 1, Data Book, "Expenditures by Service and County").

Long Term Care - The National Picture

How Did Medicaid Become the Primary Payer for Long Term Care?

Medicaid is currently the single largest payer of long term care services in the United States, accounting for approximately 46 percent of spending on nursing home services. In 1993, Medicaid spending for nursing home care alone was $46.9 billion, with projections for the year 2000 at $72.1 billion. (Health Care Financing Review, Fall 1992; see Section I, Data Book).

State Medicaid programs provide many services for the elderly and disabled that are not provided by the Medicare program. These services include skilled nursing facility care beyond the 100-day post-hospital benefit provided by Medicare (for acute and rehabilitative care), and long term care in intermediate care facilities. The Federal Medicaid law does not limit the length of stay of a recipient in a nursing home and states are allowed to cover intermediate care facilities, which are not covered under Medicare. The inclusion of long term care coverage in Medicaid was to move indigent persons out of expensive hospital care and into nursing homes as soon as possible (Federa and Oettinger, 1991). The legislative intent was never to provide broad cover-

age of these services beyond the most needy populations. Medicaid role as primary payer for long term care has evolved by default, not by any conscious plan or design.

Every state is struggling with how to control costs for the category of the Medicaid population that accounts for high hospital and nursing home expenditures in a disproportionate amount, as well as planning for the chronic care and long term care needs of the general population. For example, for hospital, nursing home and home long term care costs in New York, approximately 10 percent of the enrollees account for 50 percent of the spending.

Why Is Long Term Care Such A Problem?

In a July 1993 General Accounting Office (GAO) Forum on Long Term Care, Congress acknowledged the pervasive dissatisfaction with the current long term care system, which is expensive based on its institutional bias, supporting services in nursing homes and other institutions, rather than providing care in the home and community. The GAO Forum urged the states to continue to explore service flexibility in order to meet the chronic and long term care needs of the elderly and disabled. The answers to what went wrong with long term care system really lies in that it is not a system at all, not a planned- for, designed system of care. Rather, it is a mix of program services already existing to meet health and medical needs, but not specifically long term care needs. Medicaid is an example of this lack of planning for long term care needs, as it has inadvertently shifted to being the primary public funding source for long term care. Because Medicaid program design evolved from the medical model, Medicaid's primary long term care role has been to pay for nursing home care. Only a small percentage of Medicaid funding (5 to 6 percent) is available for home and community-based care and there continue to be strict regulations restricting the amount of non-medical services allowed under Medicaid; paradoxically, these are the very services which form the backbone of required long term care and chronic care services (GAO Forum on Long Term Care, 1993).

Long Term: Fragmentation in Funding and Services

Funding for long term care services comes from a fragmented mix of Federal sources, such as the Social Security Administration, the Health Care Financing Administration, the Older Americans Act, Social Services Block Grant, and various Federal housing and transportation programs as well as state and local programs which have been designed to fill in the service gaps (see Section I, Data Book, "List of Federal Programs for Elderly and Disabled"). Consequently, services are fragmented and not organized to best help the individual recipient. In addition, the organization, access to and delivery of long term care services poses many complex problems. One primary issue is that the system is biased in favor of institutional and medical approaches to care. Based on this bias, a significant number of the disabled and elderly receive

institutional care or intensive medical services, when the appropriate services may be non-institutional, less-intensive and lower cost.

A second significant issue concerns in the substantial gaps that exist in nonmedical home and community-based services. Service fragmentation is reflected in a complex array of public agencies, financing mechanisms and provider types and settings, from state-owned institutions to privately owned nursing homes, to locally administered community programs ("Familiar Faces," 1992). The conclusion of the July 1993 GAO Forum on Long Term Care, was to encourage states to continue their experiments with service flexibility in home and community-based programs, via the Medicaid waivers. Case management was seen as a vital link in providing appropriate services to the Medicaid eligibles and to serve as a central point of control to manage all services provided to persons at the lowest costs. The case management oversight role is imperative as many states fear the increased services and service flexibility may lead to a "coming out of the woodwork effect" with soaring demand for services and increased expenditures. The GAO also called upon states to aggressively work to shift that institutional bias of the Medicaid program for their elderly and disabled populations. A GAO 1993 Study of Long Term Care in the State of Massachusetts, found that most Medicaid long term care dollars were used for institutional care: 84 percent of Fiscal Year 1992 $2 billion spent by Massachusetts on long term care was for institutional care (nursing homes, intermediate care facilities for the mentally retarded and chronic hospitals); further, 80 percent of the state's spending on institutional care was provided by Medicaid funds. A significant fact is that while states have been successful in lowering the numbers of people in institutions, because the institutional operational costs remain high, the expansion of community-based programs remains limited.

An evaluation of Medicaid's shift to being the primary payer for long term care leads to a broader discussion regarding the economics and financing of long term care in general. Currently, the national debate focuses on the most appropriate direction for long term care financing and insurance: should it be through an expansion of a public program, such as Medicaid or Medicare (if so, what is the future of these two programs?); should private insurance coverage be more extensively developed, the responsibility for which falls on individual purchasing decisions; or should there be a mix of public-private insurance to cover long term care across socio-economic classes? Each of these options raises controversy among advocates and critics in the current environment of health care reform. For example, the repeal of the Medicare Catastrophic Coverage Act (passed in 1988 and repealed the next year) has sent an important message regarding the viability of expanding already-existent public programs to cover catastrophic care. The option of private insurance raises questions regarding quality and affordibility, as well as unknowns such as the intensity of consumer interest in purchasing such policies. In the area of public-private mix models, the Robert Wood Johnson Foundation is currently funding demonstration projects in four states — California, New York, Indiana and Connecticut — in which Partnership policies are sold to consumers. Individual policy holders are then entitled to keep assets "equal to the amount his or her

insurance paid out and still receive Medicaid benefits" (Meiners, 1992). Each of these options bears exploration and research.

Demographic Reality of Long Term Care

The issue of long term care is further complicated by the demographic reality that the population is aging. In 1992, nearly 31 million people in the US were 65 years or older, or 13 percent of the total population. The greatest growth in the elderly population will be in the age group aged 85 and older. This group, which is characterized by greater levels of disability and decreased functioning, will be dependent on a mix of medical and nonmedical assistance with activities of daily living, such as eating, dressing, toileting, etc, as well as the activities such as doing housework, preparing meals, driving and shopping. The disabled elderly are more likely to be widowed females, who are more likely to develop chronic disabilities before death. Census 1990 data indicates that New Jersey's over-65 population was 610,192, with a projected figure of 590,000 by the year 2000. In this population group, 95,547 individuals were aged 85 and over, with a year 2000 projection of 106,900 (See Section I, Data Book).

Vulnerable Populations: The Elderly, Disabled and Mentally Ill

At the National Academy for State Health Policy in Portland, Maine, a Center for Vulnerable Populations (working with the Institute for Health Policy, Brandeis University) has been created to address the complex problems of studying and planning for health and social policies to meet the needs of the elderly, disabled, and the chronically mentally ill. Their research points out that currently America's vulnerable populations total 11.3 million individuals: 1.2 million with developmental disabilities, 1.5 million with severe and persistent mental illness and 8.6 million with severe functional impairments without mental impairments. Sources of income for these groups are SSI, Social Security Disability Insurance (SSDI), which provides income to eligible disabled workers and state Supplementation to SSI. The Center for Vulnerable Population's 1992 Chartbook, "Familiar Faces, The Status of America's Vulnerable Populations," estimates that through Federal and state governments, close to $92 billion was spent in this country for adults with chronic disabilities. Public expenditures for these vulnerable populations in New Jersey in 1991 were approximately $3,016,600, or $386 per capita (see Section I, Data Book, "Public Expenditures for Vulnerable Populations"). By comparisons, national per capita expenditures were averaged at $367.

It is important to note that families, via "informal" care continue to provide care for these vulnerable populations; nationally, an estimated 20 to 25 percent of the elderly with disabilities receive formal paid care and approximately 15 to 20 percent receive community-based services such as adult day care and home-delivered meals through home care programs financed through multiple fund sources. ("Familiar Faces," 1992).

Long Term Care - The New Jersey Picture

New Jersey Medicaid Payments for Long Term Care and Home Care

New Jersey Medicaid payments for long term care and home care services can be approximated by looking at Medicaid payments in the following categories of services: nursing homes ($929,931,331); Community Care Program for the Elderly and Disabled ($31,934,064); medical day care ($16,451,334); home health ($91,510,540) and Model Waiver III ($14,223,239), totaling $1,084,050,508 in 1993 (See Section I, Data Book, "Medicaid Payments for Long Term Care Services"). A disproportionate share of this spending goes into institutional long term care; approximately 65 percent of all nursing home patients in New Jersey are Medicaid recipients (Interview with Medicaid staff, March 25, 1994).

New Jersey Medicaid Waiver Programs - Alternatives to Institutional Care

Since the early 1970s, the Federal government has funded several demonstration projects to develop community-based long term care delivery systems and services. Most of these projects involve two common elements: an expanded variety of community-based services and case management (1993 General Accounting Office Forum on Long Term Care). The Omnibus Reconciliation Act of 1981 (P.L. 97-35) authorized the issuance of waivers by the Health Care Financing Administration to allow states to use Medicaid funds to provide to Medicaid-eligible individuals who would otherwise require institutional care a variety a in-home and community-based services. Such services include: homemaker/chore services; personal care services; home health aide services; adult protective services; home-delivered meals; transportation services and respite care for caregivers.

New Jersey has been at the forefront in its waiver program development and design of home and community-based long term care programs. The states have led the way in formulating long term care policy, in the absence of any over-arching Federal directives. The financing options available under the Medicaid waiver programs facilitated the shaping of these long term care programs; consequently, long term care policies vary widely across the 50 states.

Currently, New Jersey has a mix of home and community-based waivers, which are five-year, renewable Federal waiver programs. The purpose of the programs is to help eligible individuals remain in the community, or return to the community, rather than be cared for in a nursing facility or hospital setting. Section II is a Summary describing the Community Care Program for the Elderly and Disabled: Model Waivers I, II and III; the AIDS Community Care Alternatives Program (AACAP); other new home and community-based waivers and other Medicaid community-based programs, such as the Home Care Expansion Program.

New Trends - Alternative Community Settings

In 1991, New Jersey's State Health Plan called for the development of such alterative care options as assisted living facilities and comprehensive personal care homes. While acknowledging that research over the past 10 to 15 years has failed to prove the effectiveness of home care services over institutional services for the long term care population, the plan reiterates the fact that individuals and families prefer to stay in home and community as long as possible rather than to choose institutionalization. The Department of Health has taken initiative regarding New Jersey's long term care system as it is introducing two new long term care options as "cost-effective home and community-based alternatives to nursing home care: assisted living residences and comprehensive personal care homes" (25 N.J.R. 3719; 25 N.J.R. 6037; December 20, 1993). While the assisted living residences will be newly constructed buildings offering apartment-style living for residents, the comprehensive personal care homes will be created through the conversion of existing residential health care facilities and Class C Boarding Homes. (Class C Boarding Homes are licensed by the Department of Health and offer shared-occupancy rooms and a "limited" amount of personal care assistance (Ibid)). Medicaid is planning a limited number of placements in these settings in 1994; it will reimburse for resident's personal care and health service costs, while the resident will be responsible for paying for his/her room and board payments (such as through SSI).

Another living alternative to institutionalization is being explored in the area of Adult Foster Care, as the pilot adult foster-care project in Bergen County. The program, operated by the Bergen County Visiting Homemaker and Home Health Aide Services, places elderly and frail elderly in a family home, along the lines of the foster care system for children. Oregon and Washington are two states which have been experimenting extensively with foster care for the elderly and have found that monthly costs are approximately $1,000, or one-third of nursing home costs (*The New York Times,* March 8, 1994).

Nursing Homes and Medicaid

In the U.S., $53.1 billion was spent on nursing services in 1990; 45 percent was Medicaid spending, 45 percent was out-of-pocket by individuals; 5 percent was Medicare; 3 percent was private insurance and 2 percent was from other government programs, such as the Veterans Administration program, which itself spent an estimated $1.2 billion for 75,000 veterans (GAO Report: VA Health Care. July 1993).

In 1993, New Jersey had 301 nursing facilities, with 42,018 beds. New Jersey requires approved Certificates of Need for any change in bed complement, any change in ownership or in services offered, or any construction costing more than $600,000 and equipment costing more than $400,000. Currently, an estimated 68

percent of nursing facility residents are Medicaid beneficiaries, and the average Medicaid rate for non-public facilities was $91.61 (as of July, 1992). Fiscal year 1993 Medicaid expenditures for nursing homes in New Jersey was approximately $930,000,000. The over age-85 group dominates the nursing home population, with about 45 percent of all elderly persons in nursing homes being over age 85 ("Familiar Faces," 1992).

To be eligible for nursing home care under Medicaid, persons must meet specified income and asset limits, which vary from state to state. The Medicaid program has shaped nursing home evolution in that it is the only program that covers nonacute long term care services. Medicare pays for only postoperative acute care in nursing homes and has strict length of stay limits. Medicaid is the primary long term care payment source for previously financially independent individuals in need of nursing home care. Most people who enter nursing homes as private pay patients quickly "spend-down" their financial resources and impoverish themselves. Approximately 25 to 30 percent of people entering nursing homes in New Jersey convert to Medicaid within the first six months of entry (Meeting with Medicaid Staff, March 25, 1994).

While historically, spousal impoverishment (in which the community spouse would be left impoverished in order to reach Medicaid eligibility through "spend-down" for a nursing home spouse), New Jersey Medicaid regulations now allow the community spouse's share of the couple's total resources to be equal to the greater of $14,532, or one-half of the resources, not to exceed $72,660. The community spouse is thus protected from being left impoverished and vulnerable as a result of the ill spouse's nursing home placement.

New Jersey is a state which has adopted an "income cap" for the provision of institutional services. With an income cap of $1,338, an aged, blind or disabled person may have income as high as $1,338 a month and still qualify for Medicaid-funded institutional care. There is a limit for liquid resources of $2,000 for a single individual. For couples, the monthly income cap is $2,676. and liquid resources are limited to $3,000.

Medicaid Preadmission Screening (PAS)

The New Jersey Medicaid program has developed a sophisticated Preadmission Screening (PAS) component to its program in order to assess appropriate placement for Medicaid recipients prior to admission to a nursing facility. A Medicaid District Office medical staff worker screens and assesses each client and evaluates whether he/she should be (1): sent directly to a long term nursing facility placement; or, (2): have a short-term nursing facility placement (usually six months) and be placed in the community after such time; or (3), be placed directly in alternative community care settings such as CCPED. For example, in calendar year 1993, of 18,522 PAS initial assessments, 12,359 (67 percent) were approved for nursing home placement; 2,461 (13 percent) were approved for short-term placement; and 2,266 (12 percent) were approved

for community care placement. The remaining 1,204 (8 percent) were either denied services or diverted. The total number of clients diverted or denied nursing home placement (5,931) represents an estimated savings of $216,481,500 for calendar year 1993. Of the approximately 18,000 referrals, 57 percent were from hospitals and 17 percent (3,075) were from nursing facilities where private pay clients were converting to Medicaid payments.

Nursing Homes: Medicaid Qualification and Divestiture of Assets

Because many elderly have no other option than to rely on Medicaid, which is a means-tested program, for nursing home payments, the middle-class elderly have become involved in exploring divestiture of assets as a means to become Medicaid eligible. Such strategies in which families aim to exclude a potential nursing home residents assets from being included in the estate continue to spark debate among opponents, who call it divestiture, and proponents, such as elder law attorneys, who call it estate planning (Federa and Oettinger, 1991). The seriousness of the problem is also debatable, as there is conflicting evidence being presented from both sides as to the extent of potential "abuse" of the Medicaid system. In response to concern about irregular practices regarding divestiture of assets, the Omnibus Reconciliation Act of 1993 has made considerable and complicated changes to the transferring of assets for Medicaid eligibility and Medicaid is waiting for final policy to be issued by the Health Care Financing Administration on these issues.

Conclusion

The issues for policy makers and decision makers regarding Medicaid spending and services for the elderly, blind and disabled, specifically, and for chronic care and long term care services in general are complex, over-lapping and cross cut along financing mechanisms, service delivery systems and population medical and health care needs. Solutions to these long term care issues fall directly on the states, which are taking the lead role in shaping long term care policy in the U.S. through the Medicaid waiver programs and alternative care settings. With improved medical technologies not only extending life for the elderly but also preserving life for babies and young children and maintaining life for those who survive accidents and chronic health problems — all needing varying degrees of health, medical and social service care, — the numbers of people in need of chronic and long term care services are projected to increase dramatically in the next decade. The following questions aim to focus participants on how New Jersey will continue to meet these challenges.

Questions for Discussion

System Design

The fragmentation of funding sources and services in chronic and long term care has created a system where services may be inappropriate, where access to services is compromised and quality of care is sometimes questionable. In New Jersey, services are provided through a myriad of state agencies, ranging from the Departments of Health, Human Services, Community Affairs, Labor and Insurance. What levels of coordination are in place to facilitate service integration for long term care and chronic care, both institutional and community-based?

A significant recurring issue in the current environment of long term care involves data analysis: because the long term care and home care services cut across such a complex mix of Federal, state and local governmental financing and administration, data comparison and evaluation, such as the comparison of service utilization and expenditures, have been spotty at best. What is New Jersey's commitment to coordinate and track —, via a state-wide standardized system that looks at data within and among state and local agencies — the utilization and expenditure data for all components of long term care?

In January 1994, the Washington Post series on Medicaid underscored that despite the expansion of Medicaid eligibles, 50 percent of the poor in this country, as defined by the Federal poverty level, do not have Medicaid coverage. How do we provide benefits for these individuals and families who "fall through the safety net" of publicly funded health programs? Tennessee's TennCare program is currently in the process of enrolling the state's Medicaid and uninsured populations into managed care settings. What is New Jersey's status with its uninsured population and health care coverage?

How will New Jersey continue its commitment to developing alternatives to institutional care with its home and community-based programs in a time of limited resources and growing expenditures for those remaining in institutional care? For example, HCFA data has indicated that while the number of elderly persons living in nursing homes has been decreasing on a national level over the past ten years, total dollars for institutional care has continued to increase.

Financing and Insurance

What approaches will New Jersey use for private long term care financing for its general population? Do New Jerseyans prefer the development of private long term care insurance or the expansion of public programs which are not means-tested? In 1987, recommendations from the New Jersey Task Force on Catastrophic and Long

Term Health Care called for the state's exploration in public and private arenas of issues such as long term care insurance, home equity conversion, risk-pooling arrangements, regulatory flexibility to experiment with insurance alternatives and long term care individual medical accounts for the financing of long term care. What is the status of such alternatives to long term care financing?

Between 1988 and 1992, more than 100 long term care proposals were introduced in Congress (Meiners, 1992). Where is New Jersey in its exploration of public-private partnerships with long term care insurance, such as the types of Partnership policies that allow policyholders to receive Medicaid benefits and been spared impoverishment? In the private sphere, are long term care insurance policies a viable option for New Jersey residents? A July 1992 GAO Report looked a significant problems with long term care insurance policies and the standards that govern them. The report found that consumers are vulnerable to unclear terminology, vague eligibility criteria and changes in premiums and called on states to adopt and enforce standards for the sale and distribution of these policies.

Where does New Jersey stand on the issue of the estate recovery following the death of a Medicaid beneficiary? Thirty states currently have laws to do so, but very few follow through. The GAO has found that estate recovery programs could be cost-effective. For example, Oregon, a state which has been quite aggressive in estate recovery, recovered almost $7 million between July 1, 1991 and June 30, 1992, about 13 times more than it cost Oregon to administer its estate recovery program (GAO Report on Estate Recovery for Veteran's Administration, July 1993).

Ethics and Long Term Care Policy

The burden of developing and implementing long term care policy has fallen on the states. It has been acknowledged that in reality there are over 50 Medicaid programs in operation in this country. Whether by default or design, the value system of the state forms the policies it develops, especially in relation to its most vulnerable populations. What are the values and ethics that form New Jersey's health and social policies for the elderly? the disabled? those with chronic physical or mental illness? What responsibility do the state's policymakers have to proactively work towards a collective agreement on such complex and difficult decisions as "rationing" care to the chronically ill, such as limiting who may receive kidney dialysis or organ transplants?

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