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ACCESS TO HEALTH CARE

by Bob Griss

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STRATEGIES FOR ADAPTING THE PRIVATE AND PUBLIC HEALTH INSURANCE SYSTEMS TO THE HEALTH RELATED NEEDS OF PERSONS WITH DISABILITIES OR CHRONIC ILLNESS

INTRODUCTION

This policy bulletin focuses on the capacity of the private and public health insurance systems to respond to the health related needs of persons with disabilities and persons with chronic illness. Capacity is defined in terms of: (1) *access* to health insurance in spite of pre-existing conditions, (2) *adequacy* of health care coverage in relation to the range of health related needs, (3) *affordability* of health insurance in relation to a person's income, and (4) *availability* of competent providers who can deliver quality services.

What distinguishes people with chronic conditions from other groups is the presence of *predictable* needs and *higher levels of health care utilization* for both acute care and different types of non-acute care services¹. The health care needs consist of (A) primary care, (B) medical rehabilitation, (c) on-going maintenance services, and (D) preventive services. Even if their primary care needs are similar to those of nondisabled persons, many persons with chronic conditions have functional limitations which require **rehabilitation therapies** such as physical therapy, occupational therapy, and speech, hearing, or language therapies in order to function normally. They may also require **on-going maintenance services** such as durable medical equipment and assistive devices, personal assistance with self-care needs, drugs, disposable medical supplies, psychological services, and service coordination within the highly fragmented health delivery

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¹See *Access to Health Care*, Vol. 1, Nos. 1-2, September 1988.

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system in order to maximize their health and independence. In addition, although many persons with chronic conditions are not sick, they may have thinner margins of health which must be protected by **preventive services** which provide for early detection and treatment in order to avoid unnecessary complications.

Another critical aspect of the special needs of persons with chronic conditions is that their health related needs are not temporary. Unlike persons with acute care problems that will soon recover and resume their normal activities, persons with chronic conditions need health related services which do not interfere with their normal activities. In fact, they need services which empower them to manage their chronic needs so that they can live as independently as possible in their own homes, and function on their jobs, and participate as active members of their community. The problem is that the health care system is built on an acute care model. To receive health care services a person is expected to assume a "sick role" in which he or she passively conforms to the requirements of the health care provider. We are often tolerant of the indignities which this creates because most acute care needs are temporary and the patient is expected to recover from the sick role. For persons with chronic conditions, however, the health related services must be delivered in a way that minimizes interference with normal activities. That is why the health care financing policies which govern access to health care for persons with chronic conditions must be sensitive to issues of locus and control.

Both the predictability of their health related needs and their higher level of health care costs make people with chronic illness or disabilities very vulnerable in a voluntary private health insurance system. In the absence of an entitlement to health care, persons with disabilities or chronic illness are squeezed between a private health insurance system which is designed to charge according to the probability of risk, and a public health care system which subsidizes health care on the basis of age, poverty status, family structure, and an inability to work rather than on the basis of health care needs. People with chronic conditions are extremely vulnerable because the public system has not been designed to provide services to all persons with severe chronic conditions who cannot get their health care needs met through the private health insurance system.

This analysis of the limitations of the private and public health insurance systems is divided into four parts. **Part One** explores the historical evolution of the health insurance system in the U.S. This history reveals the

political and economic forces which have shaped public policy and framed the issues that health insurance reform has tried to address. The major historical actors which have influenced health care financing policy include organizations representing physicians, hospitals, insurers, employers, government at different levels, and finally, health care users. The historical section is followed by an overview of the current health care financing system which describes national health care expenditures by the sources of payment and types of health services.

Part Two examines the current limitations of different types of private and public health insurance plans for responding to the health related needs of persons with disabilities or chronic illness. The section on private insurance focuses on group and individual plans, self-insured employers, and prepaid capitated health care plans like HMOs. The section on public insurance concentrates on Medicare and Medicaid.

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Part Three assesses the strengths and limitations of various options for change at the federal and state levels. These options consist of (1) regulations of employers and insurers, (2) public incentives to the private sector such as high risk pools, public subsidies for private premiums, state health insurance plans for universal access, reinsurance mechanisms, uncompensated care pools, catastrophic insurance pools, and tax subsidies; (3) Medicare expansions; (4) Medicaid expansions; and other federal programs ranging from existing federal grant programs such as Maternal and Child Health, Education for Handicapped Children's Act, and Vocational Rehabilitation to new federal programs such as long term home care, Medicare, or National Health Insurance. The aim of this section is to consider the advantages and disadvantages of various options for addressing the health related needs of persons with chronic conditions. The aim is not to examine how these options affect the health care needs of other groups such as the uninsured in general.

Part Four addresses the role of the disability movement in health insurance reform. Because persons with disabilities represent less than ten percent of the uninsured population in the U.S. and less than ten percent of Medicare beneficiaries, they have played a minor role in the current debates on health insurance reform and long term care. Nevertheless, the World Institute on Disability believes that the disability movement has a unique contribution to make to the definition of health care benefits, the criteria for eligibility, and the equity of financing health care for everyone. Part Four will examine some of the dilemmas and some of the opportunities as the disability movement considers whether to view itself as a vanguard for equitable health care financing for everyone or as a tiny deserving minority whose needs cannot be expected to be dealt with through the generic health care financing system.

HISTORY OF HEALTH INSURANCE

Access to health care has been shaped by a continuous political and economic struggle over health care financing public policy². This section will briefly identify the historical actors which have shaped the evolution of health care financing policy in the private and public sectors and consider its implications for persons with chronic illness or disability.

The history of health care financing policy can be divided into the following stages: (1) origins of voluntary health care system, (2) movement for compulsory health insurance during the Progressive era (1906-1919), (3) rise of

third party payors during the Depression, (4) omission of health insurance in the Social Security Act, (5) expansion of employment-linked health insurance after World War II, (6) creation of Medicare and Medicaid in 1965, and (7) the challenge of health care cost-containment in the 1980s. This history will provide a context for considering the limitations of the private and public health insurance systems in the U.S. and analyzing the policy options for change.

Origins of voluntary health care:

Federal government intervention in health care actually occurred as early as 1798 when the U.S. government set up a Marine Hospital Service and required the owners of merchant ships to contribute twenty cents a month into a sickness fund for each seamen they employed³. Recognizing the strategic role of merchant marines in the young nation's economy, the federal government forced private employers to contribute to the health care of their employees. In 1902 and 1912, the Marine Hospital Service was expanded into the U.S. Public Health Service. The importance of this historical precedent is reflected in the Public Health Service emblem (see Figure 1).



Figure 1

The earliest private health insurance plans in the U.S. were sponsored through fraternal groups, unions, or employers. European immigrants established small benevolent societies in American cities offering sickness benefits to their members. The viability of these arrangements was limited by the size of the group and threatened

²This section has drawn extensively from Paul Starr, *The Social Transformation of American Medicine*, Basic Books, New York, 1982, especially pp. 235-334; and Peter A. Coming, *The Evolution of Medicare: From Idea to Law*, U.S. Department of Health, Education and Welfare, Social Security Administration, Office of Research and Statistics, Washington, D.C., Research Report No. 29, 1969.

³Coming, *op.cit.*, p. 3.

by the aging of its membership. Although trade unions were concerned with mutual aid as well as with jobs and wages, they faced a major dilemma which limited their capacity to provide protection against the cost of sickness. While the availability of benefits promoted solidarity, it also necessitated higher dues which could deter workers from membership.

The railroad, mining, textile, and lumber industries developed the first employee medical care programs whose employers deducted funds from the wages of workers and contracted with physicians who would treat work-related injuries. While physicians were eager to have patients, they resented contracts with employers or with unions which forced the physicians to compete with each other or to accept risk through prepayment.

As of 1900, the American government was highly decentralized with little direct regulation of the economy or social welfare. Except for creating a compulsory hospital insurance for merchant seamen, federal involvement in health issues was minor. Public health issues were largely left to the states and local governments which relied on private and voluntary action as much as possible. Physicians had not established a dominant role in the health care system and were competing with an abundance of different types of health care providers. While general hospitals in Europe became primarily governmental and tax-supported, in America they remained mainly private. In this context, health care evolved as a commodity available to those who could afford it, and charity care for the poor was organized at the local level.

Private health insurance companies tried selling health insurance around 1850 but quickly went bankrupt. Private insurers found it more profitable to sell disability insurance to the middle class that provided protection against losses from accidental injury and death. In the early 1900s, commercial insurance companies like Metropolitan Life and Prudential enjoyed enormous success selling "industrial" life insurance policies to working-class families to pay for the cost of a funeral and the expenses of a final illness. To collect premiums from working-class families while they were able to pay, an army of insurance agents would visit their clients after every pay day collecting 10, 15, and 25 cents a week from millions of American working-class households. Due to staggering administrative costs associated with collecting premiums weekly, the subscribers received in benefits only about 40 percent of what they paid in premiums. Nevertheless, the fear of a pauper burial was so great that Americans spent as much on

"industrial" life insurance policies in 1911 as Germany spent on its entire social insurance system⁴.

Idea of Compulsory Health Insurance during the Progressive Era:

Reformers in the Progressive era (1906-1919) sought to expand the role of government to regulate the abuses of unbridled competition and to safeguard the public interest. One of the first efforts to involve government in protecting the worker was the passage of industrial accident insurance at the state level. Spear-headed by the American Association for Labor Legislation (AALL), states adopted workers compensation laws in the early 1900s to protect workers injured on the job. Support for workers compensation laws came from unions, from insurance companies who would handle the claims (and the premiums), and from employers who would be absolved of financial responsibility for industrial accidents by workers compensation laws. By 1915, 30 states had adopted workers compensation laws⁵.

Advocates for workers compensation in the U.S. thought that compulsory health insurance would quickly follow the adoption of industrial accident insurance as it had in England. The AALL argued that compulsory health insurance would relieve poverty caused by sickness by distributing the uneven wage losses and medical costs that individual families experienced. Secondly, compulsory health insurance would reduce the total costs of illness by ensuring that all persons received effective medical care when they needed it. Instead of paying insurance agents to visit weekly to collect premiums for a funeral benefit, wage-earning families would be able to pay for doctors and nurses to visit them when they became sick. Thirdly, compulsory health insurance would create a monetary incentive for disease prevention among the payors for health insurance.

The AALL bill for compulsory health insurance called for four benefits for all manual workers and others earning less than \$1,200 a year. The benefits included: (1) physician, nurse, and hospital services, (2) sick pay to compensate for lost earnings due to sickness, (3) maternity benefits for the wives of insured men as well as insured

⁴Starr, *op.cit.*, pp. 242-243.

⁵*Ibid.*, p. 7.

women, and (4) a death benefit for funeral expenses in case the health care services were not successful. It was initially estimated that this compulsory health insurance would cost approximately 4 percent of wages, which would be divided equally among employers and workers, each paying two fifths, while the state contributed the remaining fifth. To reduce the burden of unaffordability among low-wage workers, the employers' share would be greater for the lowest income workers. The AALL claimed that this health insurance system had to be **compulsory** in order to make it universal among all low income wage earners and to secure contributions from employers and the public who shared responsibility for the conditions that caused sickness.

The AALL campaign for compulsory health insurance attempted to build on the experience in Europe with national health insurance. The move for government protection of the population was more advanced in Europe which had industrialized earlier, had a background of mutual aid societies, and had a class politics. National health insurance was first introduced in Germany in 1883 by Chancellor Bismarck, who sought to coopt a restive working class. England adopted national health insurance in 1911 to solidify support for the Liberal Party. In many

European countries, the national health insurance system started with health insurance coverage for low income workers and was then expanded throughout the population.

To raise the consciousness of Americans in 1919, the AALL circulated a political cartoon which contrasted the unprotected American worker with his British counterpart (see Figure 2). By 1919, the British worker had industrial accident insurance, health insurance, invalidity insurance (which is disability insurance to replace income lost because of a disability), old age pensions, and unemployment insurance. By contrast, the American worker only had some protection from industrial accident insurance and would have to wait until the Social Security Act of 1935 before securing the protection of old age pensions and unemployment insurance. Even today, at least 24 million American workers and their dependents do not have the protection of health insurance even though they are employed.

The failure of the U.S. to follow Europe's lead in national health insurance can be attributed to many factors. Many employers opposed compulsory health insurance because it was viewed as an increase in the workers' wages. In addition, employers did not want compulsory health

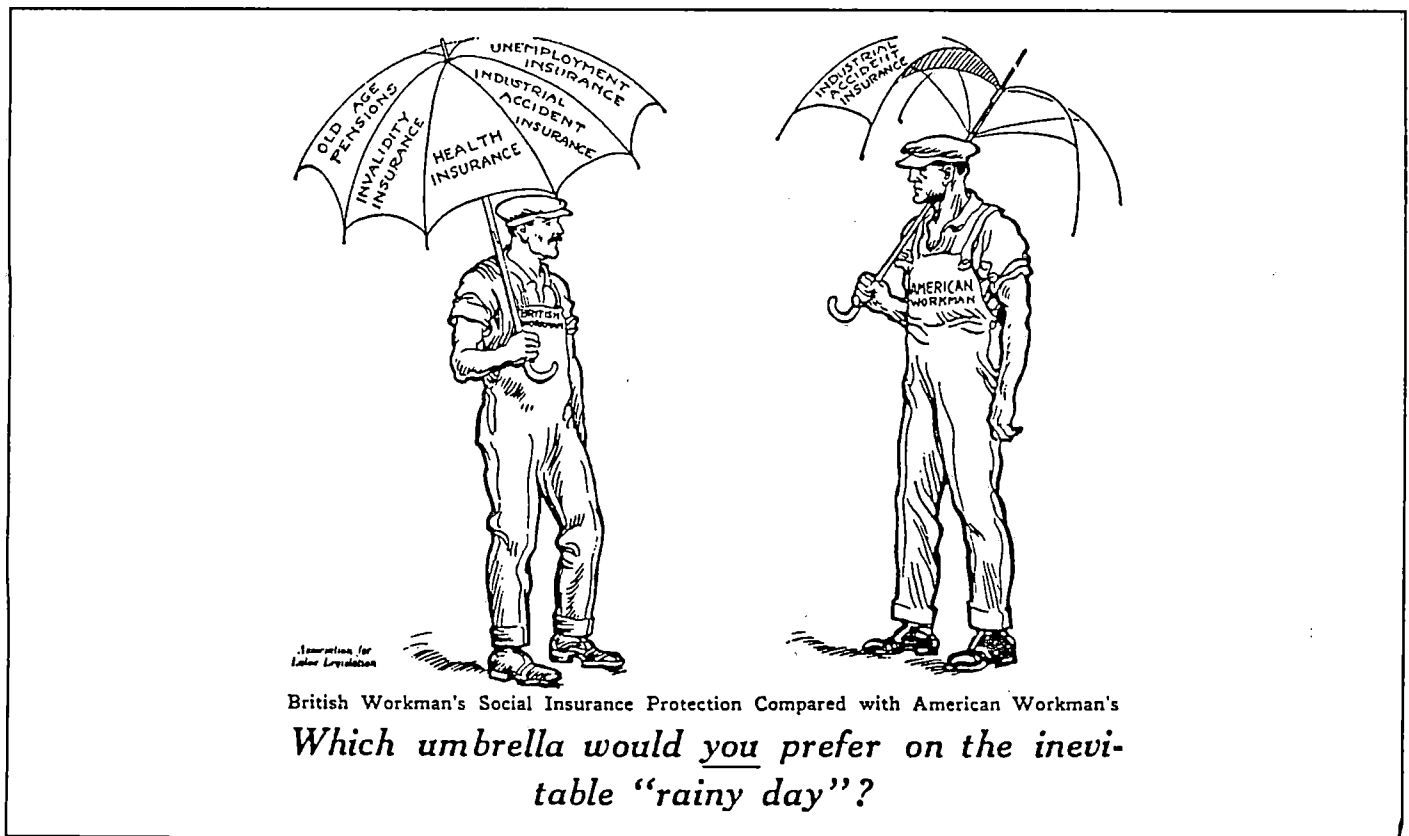


Figure 2: From American Labor Legislation Review, 1919, Vol. 9, p. 65.

insurance to interfere with the collective bargaining process. Moreover, while AALL leaders saw compulsory health insurance as a way to increase the productivity of labor, many employers were concerned that the availability of sick pay might encourage malingering rather than increase productive efficiency.

Besides employer opposition, the leadership in the American Federation of Labor (AFL) was divided over the role of compulsory health insurance. Samuel Gompers, president of the AFL opposed compulsory health insurance for removing an incentive for workers to join unions. Concerned that workers had to rely only on their own economic power, not the state, to obtain higher wages and benefits, Gompers also opposed legislation to establish a minimum wage, unemployment insurance, old-age pensions, and even the eight-hour day. Other member unions and state federations in the AFL favored compulsory health insurance which they did not view as a threat to labor solidarity.

Among all the groups who supported the concept of compulsory health insurance, it is perhaps most surprising that the leadership of the American Medical Association was initially favorably disposed to the concept of compulsory health insurance around 1916-1917. Many in the AMA saw compulsory health insurance as a way to consolidate their power in a crowded health care marketplace and to pay for the services which they wanted to provide. Nevertheless, the AMA resisted efforts by Progressive reformers to subordinate medical practice to public health, encourage the growth of group practice, or change the method of payment from fee-for-service to salary or capitation. Despite their initial support for the idea of compulsory health insurance, the AMA became one of the most outspoken opponents of any national health insurance program that would make physicians financially dependent on government.

Although private insurers were mostly selling life insurance rather than health insurance, they initially opposed compulsory health insurance because the funeral benefit threatened to eliminate an important source of profit for the insurance industry. Within national organizations of large employers like the National Civil Federation, private insurers used their role as an important source of investment capital for American business to mobilize opposition to compulsory health insurance.

Unlike the Progressive support for workers compensation which only required the state governments to verify that private employers would purchase workers

compensation insurance from private insurers, compulsory health insurance would have required the direct involvement of state government in the administration and financing of health care. Without the strong support from labor unions and a political movement in the U.S. and in the face of strong opposition by employers, insurers, and health care providers, the movement for compulsory health insurance was derailed right after World War I.

Rise of the Third Party Payor In the shadow of the Depression:

The evolution of the hospital in the 1920s created a need for stabilizing the income of health care providers. This need was intensified during the Depression when many people lacked income for health care. Recognizing that many people could not afford to pay for hospital care when they were sick, Baylor University Hospital in Dallas, Texas introduced the first effective hospital plan in 1929 collecting \$6 per year from local school teachers in exchange for providing up to 21 days of hospital care⁶. Single hospital prepayment plans soon evolved into multi-hospital plans which served as a model for Blue Cross. In 1932, the first Blue Cross plan was formed in Sacramento, California which negotiated rates with participating hospitals, charged a single community-wide premium rate to all subscribers, and guaranteed agreed upon payments to participating hospitals for specific services to subscribers.

The Blue Cross plan was limited to 21 days of hospital care in order to protect the hospital against large expenses for chronic or incurable diseases. C. Rufus Rorem, a leading theorist and organizer of the Blue Cross movement, argued that **payment for the treatment of chronic disease should be made the responsibility of the entire community and distributed among the largest group of taxpayers rather than being linked to a small group of insured persons**. This would require that financing be based on the principle of taxation throughout the population rather than on the principle of insurance among a specific group of insured persons.

Although physicians were wary of private insurance plans that would limit their incomes and discretion, physicians followed the example of Blue Cross and created Blue Shield in 1939 to cover physician services.

⁶Starr, *op.cit.*, pp. 295-296.

Omission of Health Insurance from the Social Security Act:

Meanwhile, the Depression created momentum for an expansion of the role of the federal government in order to promote economic growth and to preserve social stability. Beginning in 1933, federal relief money subsidized physician services for unemployed workers and their families which were paid for under contract between states and Medical Societies. In 1934, the Resettlement Administration (later Farm Security Administration) financed prepaid medical care in rural areas to reduce the number of farm foreclosures that occurred as a result of chronic illness and disability. But the need for old-age pensions and unemployment insurance overshadowed the urgency for health insurance during the Depression. Mindful of the vehement opposition of the AMA to compulsory health insurance, President Franklin D. Roosevelt was reluctant to follow the advice of many of his advisors to embrace national health insurance, for fear of jeopardizing tenuous support for other sections of the Social Security Act. Instead of financing health care benefits through social security taxes, the Social Security Act authorized federal grants to the states for assistance to crippled children and to needy mothers and infants through Title V for Maternal and Child Health.

In 1935-36, the first National Health Survey confirmed that the poor get sick much more than the rich, stay sick longer, and get less adequate health care. This survey also reported that 22 percent of the population had a "chronic disease, a permanent orthopedic impairment, or a serious defect of vision or hearing." Hospitals began to recognize that more than half of their costs were attributable to treating patients with chronic disease.

Growing out of the National Health Survey, supporters for compulsory health insurance developed a proposal for a National Health Plan in 1938. This plan involved Federal grants to States to subsidize compulsory health insurance for unemployed and low-paid workers. The National Health Plan called for (1) Expansion of the maternal and child health and public health programs included in the original Social Security Act; (2) Federal grants-in-aid for hospital construction; (3) grants to the states for direct medical care programs for citizens on public assistance and those who were "medically indigent"; (4) grants to the states to encourage statewide health insurance programs financed either through general revenues or through social insurance taxes; and (5) federal cash

payments through the old-age insurance system to persons who became disabled⁷.

Confronted with the prospects of a compulsory health insurance program, the AMA offered to support four of these recommendations if the plans for mandatory health insurance were dropped. The AMA and hospital leaders favored a system of voluntary insurance based on a national standard with the government paying for the health insurance costs of the non-working poor while the state and employers paid for low-income workers, the middle-income groups shared costs with employers, and the rich paid for themselves. But the advocates of the National Health Plan were unwilling to compromise on the principle of compulsory insurance although they were willing to exclude long term support from compulsory health insurance benefits in order to achieve compulsory coverage for acute health care. It was thought that this expedient decision to exclude long term support was necessary to protect the viability of relying on individual employers to finance health care. In the absence of an agreement to replace compulsory health insurance with a voluntary prepayment plan, the American Medical Association and the American Hospital Association opposed the entire program, and it died in Congress in 1939 and 1940.

Expansion of employment-linked health insurance:

The growth of private health insurance did not occur until after World War II, and only then as a direct response to public policies. As late as 1945, less than 25 percent of the U.S. population had any private health insurance. Various actions of the federal government stimulated the growth of private health insurance during the 1940s. In 1942 the War Labor Board decided that fringe benefits up to 5 percent of wages would not be considered inflationary. By exempting fringe benefits from wage freezes imposed during W.W. II, employers had an incentive to provide health insurance to attract and keep workers during this time of labor scarcity and economic growth. A 1943 ruling of the IRS allowed employers to use pre-tax dollars in purchasing health insurance for their employees. The McCarran-Ferguson Act of 1945 exempted private insurance from federal anti-trust laws and

⁷Coming, *op. cit.*, p. 47

reaffirmed the role of states as the primary regulator of insurance. And the Federal courts upheld the right of labor unions to bargain collectively for health and other benefits which culminated in the Supreme Court ruling in the *Inland Steel* case in 1949.

The percent of the population covered by private insurance jumped from 25 percent in 1945 to 50 percent in 1950, 61 percent in 1955, and 68 percent in 1960. But the expansion of health insurance coverage was largely organized in employer groups that excluded various segments of the population such as elderly and retired persons, disabled persons, unemployed persons, and low wage workers and their dependents. While public policy had medically enfranchised much of the population through employment-linked health insurance, those with the greatest health care needs were effectively disenfranchised. To encourage voluntary hospitals to serve people with chronic diseases, the federal government subsidized hospital construction through the Hill-Burton Act starting 1946.

The health insurance industry in the late 1940s consisted of non-profit Blue Cross/Blue Shield plans and a growing sector of commercial health insurers. Reflecting their ties to hospital providers, the Blues offered "service benefits" paying in full for covered services. The Blues also used "community rating" under which premium amounts were based on expected costs for all policyholders. Thirdly, most of the Blues practiced a policy of "open enrollment" permitting any individual or group to purchase coverage.

With government policy supporting the expansion of employment-linked health insurance, the commercial insurers saw an opportunity to develop a competitive advantage over the so-called non-profit health insurers. While the Blues offered "service benefits", the commercial insurers offered "indemnity" coverage, paying a fixed amount for each service and leaving the enrollee to pay any uncovered balance. With indemnity benefits, an insurer can reduce the premium by increasing the deductible and the copayments. Secondly, while the Blues used "community rating", the commercial insurers used "experience rating" under which the rate for each employer group was based on the costs for that specific group. This practice reduced the tendency of low cost individuals or groups to subsidize the cost of persons requiring more expensive health care. Thirdly, while the Blues offered "open enrollment" to justify their non-profit status, the commercial insurers adopted underwriting practices developed to assess risk for selling life insurance. As a result, applicants

for health insurance who were perceived to have higher risks could be charged higher premiums, provided an insurance policy that excluded certain coverage, or denied coverage altogether. By 1953, the commercial insurers provided hospital insurance to 29 percent of Americans compared to 27 percent provided by Blue Cross.

Eventually the competitive process diminished the differences between the Blues and the commercial insurers. Today most of the Blues utilize experience rating for large employer groups, medical underwriting practices to limit their risks, waiting periods for chronic conditions after enrollment, and employ deductibles and copayments even on service benefit plans.

Shaped largely by the needs of employers, providers of health care, and insurers, the cost of financing health care services in the private health insurance system has shifted from a risk pool composed initially of the community to a risk pool composed increasingly of employee groups. By concentrating on the employed population, group insurance targeted those young and healthy enough to work and created groups large enough to pay the cost of acute care for their members. But these employee groups were not uniformly capable of bearing the much greater costs of managing chronic illness and disability.

Creation of Medicare and Medicaid:

With large segments of the population excluded from employment-based health insurance, there was a resurgence of interest in national health insurance in the late 1950s and early 1960s, especially around the needs of the elderly. Elderly persons lacked adequate private insurance coverage at the time in their lives when their health care needs were greatest and their financial resources were lowest. The aging of the population created a growing demand for health care services which put a burden on the private health insurance system. Unable to collect payments from many elderly patients, hospitals increased the charges on paying patients which resulted in higher insurance premiums. Recognizing that a federal program of health insurance for the elderly would provide substantial new revenues, the American Hospital Association eventually broke with the American Medical Association over the desirability of relying on social security taxes to pay for health insurance for the elderly.

Support for Medicare was finally sufficient in 1965 to enact this first social insurance approach to health

care which had been resisted for so long. Despite voluntary efforts to expand private insurance coverage for the elderly, private health insurers recognized that elderly persons could not afford the premium level that insurers wanted to charge to cover their actuarial risks. Moreover, the insurers saw an opportunity to serve a lucrative market for supplemental health insurance to cover the cost of services beyond that which Medicare would cover. Meanwhile, employers wanted to reduce their liability to cover the health care needs of retirees, and wanted to avoid paying higher premiums to absorb the cost of uncompensated care. With a strong groundswell of grassroots support provided by elderly groups, there was sufficient organized pressure for the creation of Medicare.

The political debate over Medicare actually spawned the Medicaid program at the same time. As an alternative to the compulsory financing of Medicare through social security taxes, opponents to Medicare had proposed that the federal government finance the health care needs of persons with low incomes. The AMA claimed that this approach should cover both acute care and long term care needs for low income persons which would provide more benefits to the persons who needed it most at a lower cost. Faced with diametrically opposed ways of insuring health care, Wilbur Mills, Chairman of the House Committee on Ways and Means, suggested combining the three major proposals, which resulted in Medicare Part A and Part B, and Medicaid. Part A of Medicare provided hospital and related benefits financed through social security taxes (social insurance model), Part B provided supplementary benefits including physician services financed by a premium with subsidy for low income beneficiaries paid out of general revenues (subsidy of voluntary insurance model), and Medicaid provided for acute care and long term care for low income persons financed through federal and state revenues (welfare model).

Medicaid expanded on the federal government's grants to the states since 1950 which provided "vendor payments" to health care providers for persons receiving Old Age Assistance or payments to the Totally and Permanently Disabled. Under Medicaid, states are obligated to provide certain mandated services to persons who are recipients of various public assistance programs including SSI and AFDC and can provide medical assistance to the medically indigent whose incomes are below poverty because of health care expenses. But to encourage states to contribute a matching share to the Medicaid program, the federal government allows states to determine the eligibil-

ity criteria for poverty programs and the level of services which would be provided for.

Persons receiving Aid to the Permanently and Totally Disabled became eligible for the Medicaid program as soon as it was created in 1966, and continued to be eligible for Medicaid when the SSI program replaced the Aid to the Permanently and Totally Disabled program in 1972. In 1956, the Social Security Act finally created Social Security Disability Insurance (SSDI) for permanently disabled persons over 50 years of age who had contributed as workers to the Social Security Trust Fund before becoming disabled or who were dependents of workers who had contributed to the Social Security Trust fund and had subsequently died, retired, or become disabled themselves. In 1972, the Social Security Amendments extended eligibility to disabled persons 18-64 years old and made them eligible for Medicare after a two year waiting period. In addition, the Medicare program was extended to persons with End Stage Renal Disease regardless of age, creating the first entitlement for a specific disease in the U.S.

The Medicare and Medicaid programs greatly expanded health care services to elderly and disabled persons who were largely cut-off from employment-linked health insurance. In the absence of effective cost controls in the public or private sectors, the infusion of federal dollars greatly contributed to spiraling health care costs. Using its leverage over Medicare and Medicaid dollars, the federal government tried to control health care costs but this was extremely difficult in a fee for service market with multiple payors. Among the cost control mechanisms which the federal government has tried to control health care costs are: (1) utilization reviews, (2) Professional Standards Review Organization (PSRO) which determines whether a hospital admission, or a hospital stay, or an operation is "medically necessary, (3) Health Systems Agencies (HSAs) which were to develop plans for coordinating health services in a local area to control costs and improve access, (4) certificate of need (CON) programs to determine whether existing need is sufficient to justify an expansion in the capacity of the health care system, (5) rate setting, (6) prospective payment (DRGs) and (7) capitation⁸. Despite these efforts, health care costs have continued to rise out of control.

⁸Starr, *op.cit.*, pp. 379-419.

Challenge of cost containment:

The evolution of the health care financing system created a cost containment crisis in the 1980's (see Table 3, p. 15). Health care expenditures exceeded 11 percent of Gross National Product in 1987. Hospital charges and physician charges grew at 15% while inflation was only at 4-5%. The economic recession in the early 1980s forced many employers to reevaluate their continued support for the escalating health care costs of their employees and created a fiscal crisis at the federal and state levels.

In response to these economic pressures, the two largest payors in the private health care system imposed their own constraints on the health care marketplace. In 1983, the federal government began using Diagnostic-Related Groups (DRGs) to reimburse hospitals and created incentives for capitated payments for Medicare and Medicaid. Meanwhile, reeling from the economic recession in the early 1980s, employers resisted paying higher premiums which covered the costs of uncompensated care. Large employers also had a strong incentive to "self-insure" in order to reduce their contribution to the profits of commercial insurers and avoid state regulation of their health insurance plan. Self-insured plans are exempt from state mandates and state taxes (see pp. 22-23). With a restructuring of the economy away from manufacturing and toward smaller service industries, many employers refused to provide health insurance to their employees or to their dependents and those that provided health insurance began shifting the cost to their employees. As a result, health care providers became increasingly unwilling to provide care to the uninsured when they were unable to shift the cost of uncompensated care to other payors.

Between 1979 and 1986, the number of uninsured Americans increased from 28.4 million persons to 36.8 million persons under age 65⁹. In addition, persons with health insurance have to pay a larger share of their health care costs creating a crisis of under-insurance which especially hits persons with severe chronic conditions. Meanwhile, the fiscal crisis at the federal level accentuated by the combination of tax reductions and expansion of military spending have interfered with the federal government allocating more resources to the growing number of persons in need of Long Term Care. The

crisis of Long Term Care is a result of the aging of the population, the geographical dispersal of the extended family, the growing participation of women in the labor force, and the success of modern medicine in increasing the survivability of people with severe chronic conditions in early life and at the end of life.

Moreover, the AIDS epidemic since the early 1980s has revealed many of the existing cracks in the health care financing system and has created uneven burdens among health care providers. Private insurers have sought to prevent the enrollment of persons suspected of carrying HIV-antibodies through medical underwriting tests and to discourage their enrollment through limitations of the benefit package. When the City government of Washington, D.C. tried to prevent private insurers from testing insurance applicants for HIV antibodies in their blood, the private insurers chose to boycott the Washington, D.C. market and to bring pressure on the City government through an Act of Congress. Meanwhile, the federal government is concerned that an unwillingness of the private sector to cover persons with HIV antibodies will transfer their costs to the federal government.

Vulnerability of health care users in the era of cost containment:

The cumulative impact of these changes in the health care financing system has contributed to three distinct but interrelated crises: (1) a crisis of the uninsured, (2) a crisis of catastrophic costs among the insured, and (3) a crisis of long term support. In the following sections, we will identify the limitations of private health insurance and public health care programs to respond to these health related needs and then analyze the options for change.

Conclusion:

The significance of this section is that the evolution of health care services is driven by financing issues, and that financing is shaped not by market forces but by public policy. Compulsory health insurance was on the public agenda in the early 1900s and again during the New Deal, but it was diverted by the dominant interests of health care providers, employers, and insurers. Public policies expanded employment-linked private health insurance during the 1940's and 1950's, and public policies created Medicare and Medicaid in 1965 to cover certain groups excluded from employment-linked health insurance.

⁹Based upon March 1980 and 1987 Current Population Survey calculations.

The private health insurance plans which have emerged from Blue Cross Blue Shield and commercial insurers have tended to reflect the financing needs of hospitals and physicians who are the primary providers of acute care services, and the needs of employers who are the primary payors of private health insurance. Until the mid-1960's, most health insurance policies in the U.S. covered only hospitalization¹⁰. Now over sixty percent of Americans have major medical comprehensive policies which cover hospitalization, surgery, and outpatient physician services. But these health insurance policies continue to largely ignore preventive services and neglect the growing need for on-going maintenance services.

Through the public policy mechanism of state mandates, private health insurance has been broadened over the last twenty years to include services for alcohol and drug abuse and mental health services (see state mandates, pp. 45-50), but the definition of health care still focuses primarily on acute care needs. The growth of the population with disabilities and chronic illness among children, working-age persons, and elderly persons, however, is generating increasing pressure to redefine health care and to create an affordable financing mechanism to cover these health related needs. In the past chronic health care needs were generally excluded from private health insurance in order to protect the viability of an employer-funded health insurance system¹¹. If it is widely believed that employer groups cannot afford to finance the on-going maintenance needs of persons with chronic conditions, then this must become a priority of public policy.

One of the more incidious consequences of voluntary private health insurance is that most insured persons do not feel that they have a stake in improving the health care system for those who have been disenfranchised because of poverty or disability. Most insured persons are concerned about the features of their own group plans, not

about the need for minimum standards for health care coverage or the equity of health care financing in general. As the contradictions of the health care crisis continue to unfold, it is likely that various political actors will reassess their historical positions on health care financing.

History has revealed that many of the powerful forces have taken different positions depending on their assessment of their interests and the prospects for change. It is not insignificant that the AMA which opposed national health insurance for so long was actually supportive of it around 1916, and that the labor unions which initially favored the negotiation of health insurance benefits through the collective bargaining process are now supportive of national health insurance. It is also important to recognize that the AMA and the American Hospital Association chose to champion public support for health insurance for low income persons in the last 1930's in reaction to the proposal for compulsory health insurance, but then reversed their position when it became clear that there was not sufficient support for the compulsory health insurance proposal.

The growing crisis in health care financing has caused many groups to begin reevaluating the efficiency and effectiveness of the current health care financing system. In this context, it is not surprising that a recent policy statement printed in the Washington Post on April 13, 1989 called on Congress to expand Medicaid for Americans living below the poverty level which was signed by the American Medical Association, the American Hospital Association, the Health Insurance Association of America, and various labor, consumer, disability, poverty, and religious organizations. As the health care crisis deepens, there is growing awareness among health care providers, employers, and persons with insurance that the future of comprehensive health care coverage in the U.S. will depend on public policies for health care financing.

OVERVIEW OF HEALTH CARE FINANCING SYSTEM

To provide a context for examining the limitations of the private and public sectors for health care financing, it is useful to start with an overview of the health care financing system. This section will identify the size of the public and private sectors in health care financing and the types of services which various funding sources pay for.

¹⁰See Health Insurance Association of America, 1988 Update: Source Book of Health Insurance Data, Research and Statistics Department, Washington, D.C., Tables 1.1-1.4, pp. 3-6.

¹¹Daniel M. Fox, "Policy and Epidemiology: Financing Health Services for the Chronically Ill and Disabled, 1930-1990", The Milbank Quarterly, Supplement No. 1 on Disability Policy, 1989, in press.

WORLD INSTITUTE ON DISABILITY

The Health Care Financing Administration tracks national health expenditures each year by sources of funds and types of services¹². National health expenditures amounted to \$500.3 billion in 1987. This category consists largely of personal health care services (\$442.6 billion) and smaller amounts for program administration and net cost of private health insurance (\$25.9 billion), government public health activities (\$14.7 billion), and research and capital outlay (\$17.1 billion) (see Table 1).

These figures reveal that 93 percent of (non-commercial) research costs are borne by government and that the private sector provides 68.7 percent of construction costs. More surprisingly, private insurance accounts for three times higher administrative costs than the government to deliver almost 25 percent less personal health care services. While these comparisons provide

some insights into the dynamic of health care industry in the U.S., we are primarily interested in the sources of funds for personal health care services (see Table 2).

The first observation that can be made from Table 2 is that personal health care consists largely of hospital care (\$194.7 billion) and physician services (\$102.7 billion) which together account for more than two-thirds of all personal health care expenditures. The next largest expenditures are for nursing home care (\$40.6 billion), non-durable supplies including drugs (\$34.0 billion), and den-

¹²HCFA published a comprehensive projection of "National Health Expenditures, 1986-2000 in the Health Care Financing Review", Summer 1987, Vol. 8, No. 4 pp. 1-36. The most recent data for 1987 which is presented in this policy bulletin will be published in the forthcoming HCFA, Winter 1988.

**TABLE 1: NATIONAL HEALTH EXPENDITURES IN 1987
BY TYPE OF EXPENDITURE AND SOURCE OF FUNDS (in billions)**

Expenditure Category	PRIVATE						GOVERNMENT		
	Total	All	CONSUMER				Total	Federal	State and Local
	All Sources	Private Funds	Total	Out of Pocket	Private Insurance	Other			
National Health Expenditures	\$500.3	\$293.0	\$280.8	\$123.0	\$157.8	\$12.2	\$207.3	\$144.7	\$62.7
Personal Health Care	442.6	267.3	262.1	123.0	139.1	5.3	175.3	131.2	44.1
Program Administration and Net Cost of Private Health Insurance	25.9	19.4	18.7	—	18.7	0.7	6.6	3.5	3.1
Government Public Health Activities	14.7	—	—	—	—	—	14.7	1.6	13.1
Research	8.8	0.6	—	—	—	0.6	8.2	7.4	0.8
Construction	8.3	5.7	—	—	—	5.7	2.6	1.0	1.6

NOTES: Research and development expenditures of drug companies and other manufacturers and providers of medical equipment and supplies are excluded from noncommercial research, being implicitly included in the value of the good or service being produced. "Other Private Funds" include spending by philanthropy, industrial implant health services, and privately financed construction.

SOURCE: Health Care Financing Administration, Office of the Actuary: Data from the Office of National Cost Estimates. October, 1988.

Table 2: Sources of Funds for Personal Health Care in 1987.

Source of Funds	Total Health Personal Care	Components							
		Hospital care	Physicians services	Dentists' services	Other profes- sional services	Non- durable medical supplies	Durable medical equip- ment	Nursing home care	Other Personal Care
Amount In Billions									
Total Personal Health Care	\$442.6	\$194.7	\$102.7	\$32.8	\$16.2	\$34.0	\$9.5	\$40.6	\$12.0
Direct Patient Payments	123.0	18.5	26.3	20.0	6.4	25.5	6.3	20.0	—
Third Parties	319.6	176.2	76.4	12.8	9.8	8.6	3.2	20.6	12.0
Private Health Insurance	139.1	71.9	44.6	12.1	4.3	4.7	1.1	0.4	—
Other Private	5.3	2.2	0.1	—	0.1	—	—	0.3	2.6
Government	175.3	102.2	31.8	0.7	5.4	3.9	2.1	19.9	9.4
Federal	131.2	80.0	25.7	0.3	3.6	1.9	1.9	11.1	6.7
Medicare	81.2	53.3	22.3	—	2.0	—	1.8	0.6	1.3
Medicaid	26.8	9.7	2.4	0.3	1.5	1.8	—	9.6	1.4
Other Programs	23.2	17.0	1.0	0.0	0.1	0.1	0.1	0.9	4.0
State and local	44.1	22.2	6.1	0.3	1.8	2.0	0.2	8.9	2.7
Medicaid	22.6	8.1	2.0	0.3	1.5	1.6	—	8.2	1.0
Other Programs	21.5	14.1	4.1	0.1	0.3	0.4	0.2	0.6	1.7
EXHIBIT: Total Medicaid	49.4	17.8	4.4	0.6	3.0	3.4	—	17.8	2.4
Percentage Distribution									
Total Personal Health Care	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Direct Patient Payments	27.8	9.5	25.6	61.0	39.7	74.8	66.3	49.3	—
Third Parties	72.2	90.5	74.4	39.0	60.3	25.2	33.7	50.7	100.0
Private Health Insurance	31.4	36.9	43.4	37.0	26.5	13.8	11.3	0.9	—
Other Private	1.2	1.1	0.1	—	0.7	—	—	0.7	22.0
Government	39.6	52.5	30.9	2.0	33.1	11.4	22.3	49.1	78.0
Federal	29.6	41.1	25.1	1.1	22.2	5.6	20.3	27.3	55.6
Medicare	18.4	27.4	21.7	—	12.2	—	18.8	1.4	11.1
Medicaid	6.1	5.0	2.4	0.9	9.5	5.4	—	23.6	11.6
Other Programs	5.2	8.7	1.0	0.1	0.4	0.2	1.5	2.2	33.0
State and local	10.0	11.4	5.9	1.0	10.9	5.8	2.1	21.8	22.4
Medicaid	5.1	4.1	2.0	0.8	9.0	4.6	—	20.3	8.5
Other Programs	4.9	7.3	3.9	0.2	2.0	1.2	2.1	1.6	13.9
EXHIBIT: Total Medicaid	11.2	9.1	4.3	1.7	18.5	9.9	—	43.9	20.1

NOTE: 0.0 denotes less than \$50 million.

SOURCE: Health Care Financing Administration, Office of the Actuary, Office of National Cost Estimates.
October, 1988.

tists' services (\$32.8 billion). Other professional services [which include home health care, nurses, rehabilitation therapists, podiatrists, and chiropractors] account for \$16.2 billion, other personal care which is a miscellaneous category accounts for \$12.0 billion, and durable medical equipment [including eyeglasses and appliances] accounts for \$9.5 billion¹³.

A second observation is that the largest sources of funds for personal health care come from government (\$175.3 billion), private health insurance (\$139.1 billion), and direct patient payments (\$123.0 billion). Of the \$442.6 billion spent for personal health care in 1987, government contributed 39.6 percent and direct patient payments contributed 27.8 percent compared to only 31.4 percent paid by private health insurance. **Considering the importance attached to private health insurance in the U.S., it is interesting to recognize that it accounts for less than one-third of total personal health care expenditures.**

A third observation is that funding sources differ significantly in the types of personal health care services which they cover. Private health insurance accounts for 36.9 percent of hospital care and 43.4 percent of physician services while covering only 13.8 percent of non-durable medical supplies and drugs, 11.3 percent of durable medical equipment, and 0.9 percent of nursing home care.

Government is the largest payor of hospital care accounting for 52.5 percent of total hospital costs. Over half of this amount is provided by Medicare while Medicaid provides 9.1 percent of hospital costs. Other major federal government programs which contribute to total personal health care include the Department of Defense (\$9.7 billion), and the Veterans Administration (\$9.6 billion)¹⁴.

In spite of the historical opposition of physicians to financial dependency on government control, government is the second largest payor of physician services. It is estimated that 30.9 percent of physician services are paid for by government, over two-thirds through Medicare which accounts for 21.7 percent of physician services.

Direct patient payments account for 25.6 percent of physician services and 9.5 percent of hospital care. This reflects the large mandatory contribution of deductibles and co-payments characteristic of both private health insurance and Medicare. In addition, the greater percentage of physician services contributed by direct patient payment may reflect health insurance policies which cover only hospitalization and the large number of persons who are totally uninsured.

The differences between government sources of payment, private health insurance, and direct patient payment is particularly revealing for other personal health care services. Modeled after major medical private health insurance, Medicare does not cover dentists' services or non-durable medical supplies and drugs and accounts for only 18.8 percent of durable medical equipment, 12.2 percent of other professional services, 11.1 percent of other personal care, and 1.4 percent of nursing home care. Medicaid, on the other hand, covering both acute care and long term care, accounts for 43.9 percent of nursing home care, 20.1 percent of other personal care, 18.5 percent of other professional services including home health care and rehabilitation therapists, and 9.9 percent of non-durable medical supplies and drugs. (It is not clear why HCFA appears to have coded durable medical equipment for Medicaid as "other professional services" leaving the misleading impression that Medicaid does not cover durable medical equipment.)

While third party payors largely account for hospital care and physician services, direct patient payments account for 74.8 percent of non-durable medical supplies and drugs, 66.3 percent of durable medical equipment, 61.0 percent of dentists' services, 49.3 percent of nursing home care, and 39.7 percent of other professional services. Except for dental services which are clearly needed by everyone, these other health related services are disproportionately used by persons with chronic illness or disabilities. **In other words, the third party payers provide only limited protection for many of the health related serv-**

¹³The definitions and sources of data for these categories are described in "National Health Expenditures, 1985", Health Care Financing Notes, No. 6, September 1986, HCFA Pub. No. 03232, available from Division of National Cost Estimates, Health Care Financing Administration, L-1 1705 Equitable Building, 6325 Security Boulevard, Baltimore, Maryland 21207.

¹⁴Among the smaller federal programs which contribute to personal health care are: Hill-Burton (\$1.6 billion), ADAMHA (\$0.7 billion), Indian Health Service (\$0.7 billion), Maternal and Child Health (\$0.4 billion), Workers' Compensation (\$0.3 billion), and Vocational Rehabilitation (\$0.2 billion). State and local programs which contribute to personal health care include state and local hospital expenditures (\$8.6 billion), Workers compensation (\$8.6 billion), health care for persons on General Assistance (\$2.3 billion), and school health (\$1.0 billion).

ices which are most likely to be needed by persons with chronic illness or disabilities.

From aggregate statistics of the personal health care expenses of the U.S. population, it is difficult to identify the limitations of specific funding sources for persons with disabilities or chronic illness. One problem is the generality of the categories of specific health care services like "other professional services" which for persons with disabilities or chronic illness may refer to home health care or rehabilitation therapists while for other populations it may refer to podiatrists or chiropractors. The second problem is that persons with disabilities or chronic illness are a minority for each of the funding sources including private health insurance, Medicare, and Medicaid. For example, of the 22,405,000 persons receiving Medicaid in 1986 only 3,172,000 persons or 14.1 percent are eligible as disabled or blind persons under 65 years old. Likewise, of the 29,945,000 Medicare enrollees in 1985, only 2,801,000 or 9.3 percent are disabled under age 65. As a result, the percentage of personal health care services attributed to a specific funding source is likely to represent the health care needs of the general population more than the needs of persons with disabilities or chronic conditions.

Nevertheless, these aggregate statistics clearly reveal that: (1) private health insurance goes primarily for hospital care and physician services, (2) Medicare closely

resembles private health insurance in primarily covering acute hospital care and physician services, (3) Medicaid is spread between hospital care and nursing home care but also makes a significant contribution to non-durable medical supplies and drugs and other professional services, and (4) direct patient payments account for a majority of the costs for non-durable medical supplies and drugs, durable medical equipment, dentist services, and nursing home care.

Before examining the limitations of private and public health insurance for meeting the needs of persons with disabilities or chronic illness, it is important to consider the growth of national health care expenditures and personal health care expenditures by source of payment since 1965 (see Table 3).

Since 1965, national health care expenditures increased from \$41 billion to over \$500 billion in 1987. This represented an increase in national health care expenditures from 5.9 percent of the Gross National Product in 1965 to over 11 percent in 1987. The burden of these increases fell disproportionately on government and employers which became the major payors of health care expenditures. The rapid growth in health care costs has led to the current emphasis on cost containment by government and employers. The next section will examine the limitations of private and public health insurance for persons with disabilities or chronic conditions.

Table 3: National Health Care Expenditures and Personal Health Care Expenditures by Sources of Payment, 1965-1987 (in Billions)

	National Health Care Expenditures		Personal Health Care Expenditures			
	Total	% GNP	Gov't	Private health insur.	Direct patient payment	Other
1965	\$41.9	5.9%	\$7.9	\$8.7	\$18.5	\$0.8
1970	\$75.0	7.4%	\$22.4	\$15.3	\$26.5	\$1.1
1975	\$132.7	8.3%	\$46.3	\$31.2	\$38.1	\$1.6
1980	\$248.1	9.1%	\$86.5	\$67.5	\$63.0	\$2.7
1985	\$419.0	10.4%	\$147.5	\$113.5	\$105.6	\$4.9
1987	\$500.3	11.1%	\$175.3	\$139.1	\$123.0	\$5.3

Sources: Health Care Financing Administration, "National Health Expenditures, 1985" *Health Care Financing Notes*, No. 6, September 1986, HCFA Pub. No. 03232, Table 4, p. 12; and U.S. Department of Health and Human Services, "HHS News", November 18, 1988, Tables 1 and 3.

LIMITATIONS OF PRIVATE HEALTH INSURANCE

This section describes the limitations of private health insurance to respond to the health related needs of persons with disabilities or chronic illness. The analysis focuses on: (1) eligibility, (2) adequacy of benefits, (3) affordability, (4) financing, and (5) regulation. After comparing group and individual coverage, there is a brief examination of the experience of persons with disabilities in HMOs.

There are different types of health insurers. Among private insurers there are **commercial insurers** (stock ownership and mutual) and **non-profit insurers** (Blue Cross-Blue Shield). In addition, there are **self-insured plans** organized by employers who may or may not use private insurers for administrative services or for back-up stop-loss policies. There are also alternative health delivery systems like **health maintenance organizations (HMO's)** and **preferred provider organizations (PPO's)** which combine insurance and health care delivery through prepayment. Table 4 provides an overview of the relative size of the different types of private insurers in 1986.

Table 4: Total premiums earned by type of private health insurer in 1986 (Amount in billions)

Blue Cross and Blue Shield	\$44.6	(31.7%)
Commercial insurers	\$55.5	(39.4%)
Group policies	\$28.2	(20.0%)
Individual policies	\$ 6.3	(4.5%)
Stop-loss policies for self-insured plans	\$21.0	(14.9%)
Self-insured plans	\$30.3	(21.5%)
Prepaid health plans	\$10.3	(7.3%)
Total	\$140.7	(100%)

Source: Health Care Financing Review/Summer 1987/Vol. 8, No. 4, Table 21, p. 34

Despite differences in organizational structure, the process of competition has caused different types of

private insurers to operate similarly in the health insurance marketplace. The most significant difference is between group coverage and individual or family coverage, or more precisely between large group plans, and small group or individual plans.

Group coverage operates by spreading or pooling risk within the group. Insurers establish premiums based on an assessment of the potential losses that they expect to incur. For large groups organized for a purpose other than to buy insurance (e.g. employer groups), insurers assess risk not on the basis of individual health status but on the basis of the experience of the group in the preceding year. Employer groups generally consist of individuals with lower than average risks for insurance purposes because of the health standards required by employers for hiring and retaining workers. The risk to the insurer of attracting a disproportionate number of high risk individuals, which insurers regard as "adverse selection", is minimized by requiring participation of all group members in the insurance pool. As a result, an actual average group premium rate is charged for each employee which creates an affordable premium that does not increase with individual age and ensures that younger persons are available to cross-subsidize the older and higher risk group members.

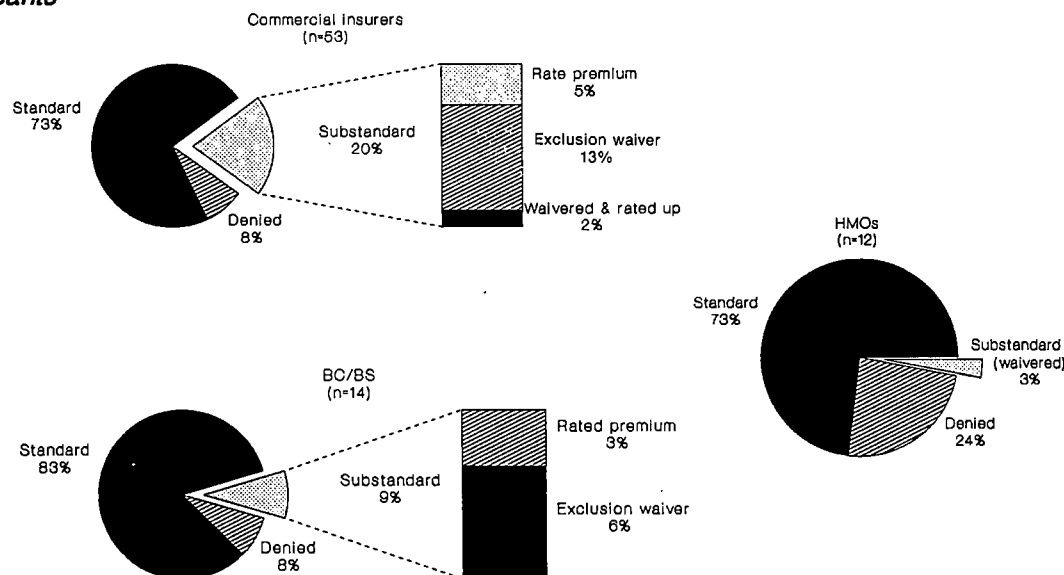
Smaller groups, on the other hand, have a lower capacity to spread risks. Without the participation of a large number of low risk individuals, the impact of one or more high risk individuals can greatly affect the total group costs and consequently the premiums which an insurer will require for each person. To protect themselves against the potential of "adverse selection" in small groups or individual or family plans, private insurers apply restrictive medical underwriting criteria based on the current and projected health status of individuals to ensure that the costs of the health insurance are proportional to the risks involved. Most health insurers deny any applicant whose probability of disease exceeds three times the average for his or her sex and age¹⁵.

Eligibility:

The barriers to eligibility differ in small group and individual plans compared to large group plans. In a small group or individual plan eligibility is determined through individual medical underwriting based on past, current, or predicted health status of individuals applying for health

¹⁵U.S. Congress, Office of Technology Assessment, *Medical Testing and Health Insurance*, OTA-H-384, Washington, D.C.: U.S. Government Printing Office, August 1988, p. 45.

Figure 3: Risk Classification in Individual Health Insurance: Estimated Proportions of Standard, Substandard, and Denied Applicants^{abc}



^aOnly those respondents reporting complete risk classification data were included.

^bProportions were estimated by dividing the respondents' total number of applicants in each risk class by their total number of applications.

^cPercentages may not total 100 due to rounding.

SOURCE: Office of Technology Assessment, 1988.

insurance. Applicants can be asked about: (1) their health history (including the severity of a past condition, degree of permanent impairment, possibilities of recurrence, and complications that may develop, etc.), (2) family health information relating to the health of parents, children, and spouses, and (3) the applicant's current health condition. If an applicant knowingly misrepresents his or her health condition, the insurer may have grounds for denying reimbursement for the pre-existing condition or rescinding coverage altogether. This creates a real dilemma for a person with pre-existing conditions who knows that acknowledgement of certain conditions may result in immediate denial of the application.

It is widely assumed that medical underwriting for individual and small group coverage is becoming more restrictive as competition increases among insurers under the pressure of cost containment. On the basis of the medical underwriting process, a private insurer assesses an individual's health risks in order to determine premium rates, impose coverage limitations, or reject the insurance application. Private insurers can require an applicant to report on medical history through an extensive questionnaire, request a statement from an attending physician, or require the applicant to undergo certain medical tests.

Insurers are permitted to determine their own medical underwriting procedures. Risk categories are generally established on the basis of underwriting manuals

without reference to actuarial data. There are no federal or state standards for the recency of the actuarial data. Many life and health insurers rely heavily on the Society of Actuaries' 1983 Medical Impairment Study based on statistical information on insured risks from 1952 to 1976 which do not take into account improved methods of classification, control, and treatment and recovery of persons with various chronic conditions¹⁶. Insurers generally lack sufficient information about the classification, treatment and risks associated with various chronic conditions, and what is more important, they lack an incentive in this risk averse industry to collect and update this information. To the extent that it is difficult to predict which persons with a specific chronic condition may become high health care users, it is often safer to exclude all persons with certain chronic conditions. A list of chronic conditions for which commercial health insurers commonly require a higher premium, exclusion waiver, or denial of individual coverage was identified in a recent Office of Technology Assessment survey¹⁷.

¹⁶A. Frank Thompson, "An Examination of Current Underwriting and Loss Experience Information Used by Insurers to Cover those with Epilepsy: Survey and Insurance Information Report", University of Cincinnati, Cincinnati, Ohio, prepared for Epilepsy Foundation of America, October 1988.

¹⁷See *Access to Health Care*, Nos. 1-2, September 1988, Table 11, p. 43.

Although there are rules prohibiting unfair discrimination in many states, there are no standards which specify the types of data or other justifications for underwriting actions that the state office of insurance commissioner will find acceptable in cases falling under the unfair discrimination laws. Anti-discrimination laws suffer from vague references to "sound actuarial principles" and "reasonably anticipated experience" as well as limited authority of the state insurance commissioner to compel insurers to provide health insurance under different terms.

The recent study of medical underwriting by the Office of Technology Assessment found that many applicants for individual private health insurance are charged higher premiums, subjected to preexisting condition exclusion waivers, or denied coverage altogether¹⁸. Based on a representative sample of each type of health insurer, OTA found that commercial insurers were more than twice as likely as Blue Cross-Blue Shield insurers to rate up a premium because of a pre-existing condition while both types of insurers rejected about 8 percent of individual applicants (see Figure 3). HMOs, on the other hand, appeared to reject as many as 24 percent of individual applicants but only raised the premiums of 3 percent of individual applicants¹⁹. While these data provide some indication of the extent of medical underwriting among private insurers they do not prove that one type of insurer is more restrictive than another. It is likely that HMO's receive a greater proportion of high risk applicants because of their comprehensive coverage and community rating practices and because federal qualification requirements and some state regulations restrict HMO use of pre-existing condition exclusions and rated premiums for high risk persons.

More significantly, OTA found that many private insurers were using information about sexual orientation and lifestyle to make risk assessments²⁰. It is not clear whether this information was used to select tests for medical underwriting or to get around prohibitions on the use of certain tests for HIV antibodies in the blood. When faced with a District of Columbia law prohibiting the use of blood tests for health and life insurance, private insurers threatened to abandon the health insurance marketplace in

the nation's Capitol and brought powerful political pressure in Congress to force the local government of Washington, D.C. to reverse its regulatory decision.

Many insurers will not cover a small group if it includes any persons whom the private insurer considers to have a high risk. Unable to afford the premium level that an insurer would require for a small group with a high risk employee, many employers choose not to contribute to the health insurance of any of their employees. In the absence of an employer mandate to provide health insurance to all their employees, the decision to not contribute to the health insurance of any employee is within the law while providing health insurance to only low risk individuals would constitute unwarranted discrimination. In this way, the fate of many standard risk individuals is intimately tied to the lack of adequate and affordable health insurance to so-called high risk individuals.

The dilemma facing small employers is more common than generally recognized. While a majority of employees do in fact work for large firms with over 500 employees which have a greater capacity to pool risks, 75 percent of all firms in the U.S. have fewer than ten employees²¹. What is most surprising is not the 54 percent of small employers with under 10 employees who do not offer any health insurance but the 46 percent of small employers who reported that they do provide health insurance²². A better study is needed not only on the percentage of small employers who provide health insurance but on the comprehensiveness of the health insurance that is provided.

While insurers of large groups do not rely on individual medical underwriting to assess risks, it is very

²¹Dun & Bradstreet, U.S. Enterprise and Establishment Microdata File (USEEM), December 1985 cited in ICF Incorporated, Health Care Coverage and Costs in Small and Large Businesses: Final Report, Washington, D.C., April 15, 1987, Table 1-2, p. I-11, prepared for U.S. Small Business Administration.

²²*Ibid.*, Table III-6, p. III-12. This estimate that 46 percent of small employers provide some form of health insurance may be unrealistically high because the SBA survey in 1986, which was analyzed by ICF, had a response rate of only 20 percent of employers. Although ICF found no differences between firms that responded to the SBA survey and those that did not, it is possible that firms in the SBA's Health Benefits Data Base were more likely to provide health insurance to their employees than firms which did not respond to the SBA survey.

¹⁸U.S. Congress, Office of Technology Assessment, Medical Testing and Health Insurance, OTA-H-384, Washington, D.C.: U.S. Government Printing Office, August 1988.

¹⁹*Ibid.*, pp. 55-92.

²⁰*Ibid.*, pp. 8-9.

misleading to conclude that only a small percentage of the American population is subjected to medical underwriting. The private health insurance system is rapidly being transformed by the trend toward self-insurance among large employers. The incentive to self-insure is not just to avoid state insurance mandates (see pp. 45-50), but to maintain the financial reserves which the company can invest to retain the earnings rather than to provide to an outside insurance company in exchange for taking the insurance risk. But self-insurance means that employers, in their capacity as insurers, have a financial incentive to screen their employees not only as potential workers but also as insurance applicants²³. With self-insurance accounting for a majority of persons covered by group insurance at the present time, a growing number of employees are subjected to medical criteria when seeking employment.

Employers are increasingly resorting to pre-employment screening, physical examinations, and drug tests of employees²⁴. The most prevalent type of medical screening required by employers is the general physical examination including routine medical tests. The National Institute for Occupational Safety and Health (NIOSH) has reported that the percentage of employers who require job applicants to pass medical screening examinations increased from 38.5 percent of employers in the early 1970s to 49 percent in the early 1980s. Moreover, a 1983 survey by the Department of Health and Human Services revealed that pre-employment medical exams are required for about 27 percent of employees in small firms (8 to 249 workers), about 56 percent of employees in medium sized firms (250 to 500 workers) and about 88 percent of employees in large firms (over 500 workers)²⁵. Since large firms are more likely to be self-insured, the use of pre-employment medical exams are especially increasing among self-insured employers.

The purposes of employment testing may vary from maintaining workplace safety and security, to promoting quality of products or service, increasing productivity, and minimizing health care costs. Under the pressure of cost containment, it is likely that employers will increasingly make use of diagnostic and predictive tests to screen for medical and health-related conditions among

prospective employees in order to hold down health care costs. The Foster Higgins Health Care Benefits Survey in 1987 found that 57 percent of employer plans used pre-existing conditions exclusions²⁶. Since the question on pre-existing condition exclusions has not been used before or since, it is difficult to determine what this response means or whether it represents a growing trend. Because group coverage does not generally utilize medical underwriting, it is not clear how pre-existing conditions would be determined other than by employer testing. Unfortunately, this type of critical information is not monitored by the U.S. Department of Labor's Bureau of Labor Statistics in its surveys of employee benefits in medium and large firms which leaves a major gap in our understanding of a significant barrier to access for persons with pre-existing conditions. While this information could be used to identify risk factors associated with disease so that the risk factors can be reduced through health education and preventive measures, there is also a danger that this information could be used to disqualify applicants who may increase the employer's premium level.

Legal restraints on the conditions under which employment-based screening can be legitimately used are being interpreted by the judicial system weighing the employee's right to privacy against the employer's control over factors affecting job performance and responsibility for protecting the property and safety of others. The federal Vocational Rehabilitation Act of 1973 which applies to federal employment and to employers receiving federal funds is supposed to ensure that handicapped persons must be hired or continue to be employed if they can be reasonably accommodated and can perform their work without endangering the health and safety of other workers (29 C.F.R. section 1613.702(f)). In addition, state laws in over 40 states prohibit discrimination against persons with handicaps in private sector employment.

While employers are increasingly using medical examinations and drug testing on both job applicants and employees, the use of genetic testing is still in its infancy. A 1982 study by the Office of Technology Assessment found that only 1.6 percent of large employers were currently conducting genetic testing although 15 percent stated that they would possibly use genetic tests in the next five

²³Deborah A. Stone, "Preventing Chronic Disease: The Dark Side of a Bright Idea", p. 15, forthcoming in Marion Ein Lewin, Editor, *Chronic Disease and Disability: Beyond the Acute Medical Model*, Washington, D.C., National Academy of Sciences, Institute of Medicine, 1989.

²⁴OTA, *Medical Testing and Health Insurance*, op.cit., pp. 95-118.

²⁵J. M. Ratcliffe, W.E. Halperin, T.M. Frazier, et.al., "The Prevalence of Screening in Industry", *Journal of Occupational Medicine*, Vol. 28, pp. 906-912, 1986, Tables 2, 3, and 6, cited in Stone, op.cit., p. 13.

²⁶Foster Higgins, *Health Care Benefits Survey, 1987*, Princeton, New Jersey, p. 11A.

years²⁷. Meanwhile, a 1986 survey of biotechnology companies developing or planning to develop genetic tests for commercial use found that almost half thought it likely by the year 2000 that insurance companies would be using genetic tests on applicants²⁸.

While improvements in diagnostic techniques could be a great boon for early intervention, the problem is that in a system of private health insurance, incentives exist for insurers and employers to use this information against persons who are predisposed to certain pre-existing conditions. Caught in the vise of cost containment, persons with chronic conditions are increasingly vulnerable to restrictive medical underwriting practices of insurers for small groups and individual plans on the one hand, and the use of medical testing by large employers on the other hand.

Adequacy of benefits:

While private health insurance plans differ widely in comprehensiveness of benefits, costs, and coverage limits, there are some generalizations that can be made. First, most group health insurance plans cover hospitalization and outpatient services for acute care needs. Coverage is more problematic for dental care, periodic physical exams, vision care, hearing care, prescription drugs, rehabilitation and assistive devices in a non-medical setting and is virtually non-existent for on-going maintenance therapies and personal assistance services in one's own home. The major gaps in private group coverage relate to well-being and preventive care including prenatal care and healthy infant care, diagnostic tests, etc. and long term support for chronic health conditions. Long term support includes a range of health and social services which may be needed in one's home, workplace, and community as well as long term care in a nursing home or protective residential setting.

While there is evidence that group plans are getting more comprehensive in the scope of benefits which can be provided, this information can be very misleading.

²⁷U.S. Congress, Office of Technology Assessment, The Role of Genetic Testing in the Prevention of Occupational Disease, OTA-BA-194, Washington, D.C., U.S. Government Printing Office, 1983.

²⁸U.S. Congress, Office of Technology Assessment, "The Commercial Development of Tests for Human Genetic Disorders," staff paper, Washington, D.C., in press.

For example, it is often pointed out that a growing number of group plans include home health care as a covered service. While this can be very important for persons who are recuperating from an acute condition, it should not be misinterpreted as a personal assistance service for on-going maintenance needs. Eligibility for the home health service may depend on prior hospitalization, and it may be available only for a limited number of visits, hours, or days, or only if the alternative would be more expensive hospitalization.

The growing use of various mechanisms for managed care can also be confused as a benefit. As insurers seek to reduce their costs, they are beginning to require pre-admission certification for hospitalization and mandatory second opinions for surgery, etc. Some private insurers are also experimenting with some form of individual case management program for persons with catastrophic health care needs as an alternative to hospitalization. Under certain conditions, private insurers may be willing to extend insurance coverage to otherwise uncovered services which are needed to maintain the insured person in a less costly alternative care setting. For example, home care coverage may be expanded to provide home health services and equipment to allow an enrollee to live at home or even to provide occasional respite services for the parents as primary caretakers. Flexible benefits provided under individual case management programs are proving to be a more cost effective way to control costs than utilization review. Through individualized case management, an insurer may be willing to pay for certain services, under the supervision of a case manager accountable to the insurance company, beyond what is covered in the health insurance contract.

While this practice of individualized case management can provide for much needed greater flexibility, this practice is generally limited only to persons who would cost an insurance company much more for treatment in a hospital. In the absence of long term care insurance for institutional care, there is no incentive for an insurance company to provide for home care on a maintenance basis. Moreover, for persons who receive individualized case management benefits, it remains to be seen whether these people will have trouble renewing their health insurance policy on favorable terms at the end of the year. Insurers can increase the premiums and reduce the benefits when an insured person converts from a group policy to an individual policy if enrollment in the group policy is terminated due to disability or chronic illness. In addition, the protection of group coverage can be jeopardized if an employer switches group insurance carriers and the new insurer

chooses to use medical underwriting against high cost individuals.

Affordability:

The predominant response of employers to the rising cost of health care is to shift the costs to their own employees through higher deductibles and higher employee contributions to premiums. Some employers have also created separate deductibles for each insured member of the family and even required separate deductibles for specific services. These measures to avoid first dollar coverage which are suppose to create incentives for reducing unnecessary health care utilization actually impose severe financial burdens on persons who need high levels of health care services. Employers are also imposing annual and lifetime benefit maximums to limit the insurance company's obligation to covering persons who exceed a certain dollar limit.

The use of "cafeteria plans" which permit employees to decide which services they want to purchase with their employer's contribution to their fringe benefits is another development which can adversely affect persons with high health care needs. Although appealing to employees with different types of needs not ordinarily cov-

ered by health insurance and to dual wage earner families with duplicate coverage from more than one group plan, the "cafeteria plan" can further reduce the capacity of the insurance system to spread risks throughout the group, thus penalizing persons who have higher health care expenses. By limiting the employer's contribution up to a specified limit, the "cafeteria plan" may reverse the previous trend among group insurance toward comprehensive coverage which had the potential of permitting low health care users to subsidize the costs of higher health care users within the group.

The major reason for the growing number of uninsured persons between 1979 and 1986 has not been a decline in employment-based coverage for employees but a decline in the contribution of employers to dependency coverage. Based on an analysis of Current Population Survey data for 1979 through 1986 by the Congressional Research Service, Table 5 reveals that the percentage of persons covered through someone else's insurance (i.e. family dependents) declined from 34.3 percent to 31.4 percent while those covered on one's own job increased slightly from 33.1 percent to 33.4 percent (see Table 5)²⁹.

²⁹Congressional Research Service, *Health Insurance and the Uninsured: Background Data and Analysis*, U.S. Library of Congress, Washington, D.C., June 9, 1988, Publication No. 88-537 EPW, pp. 179-192.

TABLE 5: Sources of Health Insurance Coverage by Year for Nonaged Population, 1979 - 1986

	Percent of Nonelderly Population				
	1979	1983	1984	1985	1986
Employment-based plans					
Covered on own job	33.1	32.5	32.6	33.1	33.4
Covered through someone else	34.3	32.1	31.4	31.2	31.4
Total employment based	67.4	64.6	64.0	64.3	64.8
Other plans ^{a/}	17.9	18.5	18.3	18.1	17.7
Uninsured	14.6	16.9	17.7	17.6	17.5
Total	100.0%	100.0%	100.0%	100.0%	100.0%

^{a/} Excludes persons covered by employment-based plans.

SOURCE: Table prepared by Congressional Research Service based on data from the March 1980, March 1984, March 1985, March 1986, and March 1987 Current Population Survey. Information from 1980 to 1982 is not presented due to errors on the CPS computer tapes for those years.

Unable to afford the high out-of-pocket costs of dependency coverage, an increasing number of low income workers who are covered by group insurance have spouses and children without health insurance.

Furthermore, the emphasis on cost containment of the major payors of health care has reduced the capacity of health care providers to shift costs to the paying clients for subsidizing the costs of serving the uninsured and underinsured. This increases the cost of those least able to pay creating a growing barrier to access.

Financing:

Besides the unmistakable trend of cost-shifting from the employer to the employee in group plans, there is an important underrecognized public subsidy in employer provided group insurance. Because Internal Revenue Service (IRS) laws allow an employer to deduct contributions to employee health insurance from taxable income, the Federal government is in effect subsidizing the cost of private health insurance for employers who provide group plans. The Joint Committee on Taxation estimates that the Federal Government will forego \$27.6 billion in tax revenues in 1989 because contributions for employer-sponsored health plans are excludable from individual income calculations³⁰. This \$27.6 billion represents almost 20 percent of the \$140.7 billion which private insurers collected in total premiums in 1986 (see Table 2, p.13). It is important to recognize that this substantial public subsidy is not targeted to the employers who are least able to contribute to their employees' health care, but is rather provided disproportionately to the employers who have the most generous health plans. Secondly, it is significant that the Federal Government does not define the minimum essential features of a health insurance plan which must be met to qualify for the federal subsidy.

Thirdly, as long as the premiums for private health insurance are allowed to be based on actuarial ratings, the potential for health insurance to redistribute health care costs between high and low users is greatly reduced³¹.

Actuarial rating means that people pay into an insurance program according to their expected risk of incurring harm for which the insurance will pay out. To the extent that the actuarial rating can be precisely predicted and the individual charged for the costs that he or she will incur, the risk-pooling nature of insurance would be entirely eliminated. This would create greater barriers to access and affordability for persons with high risk and require government intervention to subsidize costs to an affordable level for the individual. If the growing knowledge about risk factors for chronic illness and disability is allowed to be used by private health insurers, the population will increasingly be segmented into self-paying homogeneous risk groups. In the context of pressures for cost-containment in the health care delivery system and greater use of pro-competitive strategies health insurers and providers will increasingly be looking for ways to seek out the healthy and shun those with higher health care needs.

Regulation:

The private health insurance system is regulated at the state level rather than at the federal level. Regulation is primarily aimed at ensuring the financial viability of the private insurance companies which sell insurance rather than ensuring that health insurance is accessible to all persons, affordable to health care users, or adequate to health care needs. In many states there are certain mandates that private insurers must meet with regard to certain coverage and eligibility requirements. For example, the definition of health care was significantly broadened through state mandates to require health insurers to provide for reimbursement of mental health benefits including treatment for alcohol and drug abuse as part of certain health insurance policies. State mandates have also been used in most states to require health insurance companies to cover newborn children from the moment of birth in a family health insurance plan rather than to allow the insurance company to decide over a one month period whether the newborn was an "insurable risk". Although some states have adopted anti-discrimination clauses in their health insurance statutes, serious loopholes continue to exist because states have not specified the standards which must be met in medical underwriting.

In some states, mandates apply only to individual policies where it is assumed that the consumer is least likely to be knowledgeable about the health insurance marketplace, while in other states the mandates are applied to group plans which cover the most people. Ironically, the

³⁰U.S. House of Representatives, Committee on Ways and Means, Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means, 1988 Edition, March 1988, Table 1, p. 596.

³¹Stone, *op.cit.*, pp. 2-4.

fastest growing sector of private insurance, the self-insured employers who are estimated to account for the majority of persons with group plans, are exempt from state mandates because of the federal Employee Retirement Income and Security Act. ERISA was developed to provide for federal regulation of the pension plans of self-insured employers to reduce the danger of racketeering, but has come to be interpreted by the courts as preempting self-insured employers from state health insurance mandates. This is particularly ironic because ERISA contains no minimum standards for the health insurance plans of self-insured employers, and therefore undermines the states' capacity to regulate the fastest growing segment of private health insurance.

Besides these ineffective regulations of private insurers, employers are regulated by Internal Revenue Service (IRS) laws and the Fair Labor Standards Act at the federal and state levels to avoid discrimination against employees in hiring and the conditions of employment and in the provision of fringe benefits. While these laws determine how employers provide health insurance if they choose to do so, they do not require employers to provide health insurance to their employees as they require employers to contribute to workers compensation, unemployment insurance, and Social Security for their employees.

Experience of persons with chronic conditions in HMOs:

The capacity of HMOs to respond to the special health care needs of persons with chronic illness or disability is a critical issue in the private and public health insurance programs. By combining the insurance function and the service delivery function, HMOs are being promoted by both employers and by Medicare and Medicaid to replace the incentive structure of fee-for-service medicine with a delivery mechanism in which the provider has an incentive to avoid performing unnecessary or expensive procedures. As a system of prepaid managed care, HMOs reveal many of the problems of balancing cost containment and quality of services. These problems are accentuated when providing health care to persons with thinner "margins of health" due to chronic conditions. Although many persons with chronic conditions are not sick, their physical impairments may make them more vulnerable to certain health problems³².

While the performance of HMOs in responding to the special health care needs of enrollees with chronic

illness or disability has not been systematically evaluated, there is a growing literature on the problems which persons with chronic health care needs encounter in HMOs³³. Among the most important problems are: (1) limited benefits for extensive hospitalization or rehabilitation, (2) primary care gatekeepers who are neither knowledgeable about special health care needs nor empowered to authorize access to specialists who are not affiliated with the HMO, and (3) administrative control mechanisms that are designed for acute care and which disrupt the continuous treatment needed for certain chronic conditions.

Eligibility:

The strong incentives which HMOs have to control costs may lead to strategies for selecting low cost enrollees and disenrolling persons with chronic needs. To the extent that prepayment is based on the average cost of persons, HMOs have a financial incentive to screen out those whose care will be more costly than average. Data from the OTA survey on medical testing cited above indicates that HMOs reject 24 percent of their applicants for individual coverage. Critics of HMOs claim that HMOs are health care delivery systems for healthy persons only and that not only do they not want enrollees with chronic illness or disability but they are unwilling to offer care that such enrollees must have. HMOs can discourage the enrollment of persons with chronic illness or disability through medical underwriting and through the structure of benefits.

Adequacy of benefits:

HMOs have an incentive to provide preventive services and coordinated care for acute conditions in order to reduce the need for costly hospitalization. Unlike

³²Andrew I. Batavia, Gerben DeJong, Lauro S. Halstead, and Quentin W. Smith, "Primary Medical Services for People with Disabilities", *American Rehabilitation*, Winter 1988, forthcoming.

³³Kathy Gaylord and Nina Camic, "An Agenda for Change: Position Paper of Group on HMOs and Children with Special Health Care Needs", Center for Public Representation, Madison, Wisconsin, unpublished draft, October 1988; Mark Schlesinger, "On the Limits of Expanding Health Care Reform: Chronic Care in Prepaid Settings", *The Milbank Quarterly*, Vol. 64, No. 2, 1986, pp. 189-215.

traditional health insurance policies, most HMOs cover routine office visits, annual physicals, well baby care and immunizations. But for those who need extensive hospitalization or continuous care coordination, the HMO benefits may be too limited to cover their needs.

HMOs have often been criticized for providing inadequate rehabilitation services in a hospital as well as inadequate psychiatric care. It is not uncommon for an HMO to limit coverage for rehabilitation to 60 days per year. This level of treatment is often inadequate for persons with chronic illness or disabilities. HMOs have also been found to impose severe limits on home health care and various therapies and sometimes to refuse to pay for services that will not rehabilitate or cure a condition. In addition, HMOs have sometimes used very restrictive definitions of what is "medically necessary" or a "treatable illness" to justify not providing covered benefits.

For persons with special health care needs who require a more frequent and intense use of specialty care, primary care and allied health professionals, it is important to consider how a specific HMO provides for various therapies, durable medical equipment and medical supplies, prescription drugs, nutritional services, home health care, mental health services, case management/service coordination, and respite care or day care.

Secondly, HMOs limit an enrollee's choice of health care providers. This can create significant problems for persons who may need special services or treatment. The limited number of specialists on an HMO's closed provider panel may result in longer waits for an appointment. In addition, the administrative control mechanisms designed to control costs may delay or frustrate efforts to obtain timely health care services. While this can be inconvenient for persons without chronic conditions, a delay in appropriate treatment can have devastating consequences for persons with chronic conditions who may be more susceptible to medical complications³⁴. Moreover, the HMO may not provide services which are not authorized by a primary care physician who is acting as the gatekeeper. This single physician gatekeeper model may be overly restrictive for chronic conditions which require the expertise of a multidisciplinary team to assess needs and authorize access to specialists. The single physician gatekeeper is usually not in a good position to perform case coordination for a person with chronic conditions. Where appropriate specialists are not affiliated with the HMO, problems may also arise for the care coordination and financing of care provided by outside specialists. HMOs can refuse to pay for specialty care provided by providers who are not affiliated with the HMO.

Thirdly, HMOs have an incentive to provide lower cost alternatives to hospitalization. But the incentive to provide support services in the community is reduced if the person with a chronic condition depends on unpaid assistance from family members or friends, or if the person may be eligible for a publicly financed system of care. For example, some HMOs have been found to deny coverage to children with special health care needs for "covered services" on the mistaken assumption that a disabled child may be eligible for certain services provided through the public school system.

Fourthly, the logic of prepayment creates a direct tension between quality and cost. HMOs may limit access to outside specialists to avoid expenses which exceed the amount of capitation received. Or the HMO may provide inferior durable medical equipment or prosthetics because the HMO contracted with a low-bid supplier. While these decisions may be rational for promoting cost containment in general, they may have disastrous consequences for persons with disabilities or chronic illness. Without standards of health care delivery enforceable by a governmental agency like the Office of Commissioner of Insurance or the Department of Health and Social Services, the pressures for cost containment may overwhelm the demands for quality, especially for persons with special health care needs.

By limiting the adequacy of certain chronic care benefits, HMOs may be able to discourage the enrollment of persons with chronic conditions with above average care needs.

Affordability:

One of the most popular features of HMOs is the lack of paperwork associated with claims. With first dollar coverage, HMOs generally reduce out-of-pocket costs to most enrollees. Some HMOs charge minimal copayments for services or prescriptions but these are typically much lower than coinsurance or deductibles in a traditional health insurance plan.

The problem of affordability for persons with special health care needs depends largely on the out-of-pocket costs for **uncovered services** and the out-of-pocket

³⁴Gerben DeJong, Andrew Batavia, and Bob Griss, "America's Neglected Health Minority: Working-age Persons with Disabilities", *Milbank Quarterly, Supplement on Disability Policy*, No. 1, 1989, in press.

costs for covered services when the HMO may not be willing to authorize a referral to an outside specialist.

Financing:

Whether HMOs can save employers money is still a matter of some controversy. To the extent that HMOs draw healthier persons out of traditional health insurance plans, they may be raising the cost of traditional health insurance premiums. As long as persons have an option of joining an HMO or obtaining health insurance through a traditional insurance plan, they can decide which coverage offers the benefits which they are most likely to need. A special problem arises, however, if Medicaid or Medicare recipients are required to enroll in an HMO. When HMOs contract with state Medicaid programs which increasingly are requiring Medicaid clients to enroll in HMOs, the HMO may require the state government to act as a public reinsurer to protect the HMO from individual expenses which exceed a certain level. In this situation, the public subsidy may actually be required to take the form of the premium as well as a subsidy for outlier costs.

HMO Summary:

This critique of HMOs should not be interpreted as implying that HMOs are less capable of serving persons with chronic illness or disabilities than are traditional health insurance plans. Both of these models create problems for persons with disabilities. But as a system of managed care, HMOs reveal many of the service delivery problems associated with serving high risk persons in any system. Since the HMO represents an effort to promote cost containment without sacrificing quality, the real issue is not whether HMOs are better or worse than traditional health insurance plans, but how can the special health care needs of persons with disabilities best be met cost-effectively. It may be that neither HMOs nor private health insurance can do this within the constraints imposed by private health insurance.

In the absence of empirical surveys of the experience of persons with disabilities in HMOs, there are many reasons to question whether HMOs have been able to reduce hospitalization, promote the continuity of care, and prevent secondary illness for persons with chronic conditions. While there are some examples of Social/Health Maintenance Organizations like On-Loc which has successfully served a frail elderly population in San Francisco's Chinatown³⁵, there are other examples like the Urban Medical Group in Boston which have not been able

to reduce health care utilization with extensive care management efforts for a working-age population with severe physical conditions³⁶. Greater attention is needed for adapting the prepaid model to the health care needs of persons with chronic conditions. This may require more accurate assessments of the benefits of care for persons with specific chronic conditions, more appropriate standards of care for persons with chronic conditions, impartial and timely grievance procedures which a consumer can use to challenge the judgment of an HMO gatekeeper, and perhaps financing mechanisms which provide the HMO a differential capitation payment to compensate the HMO for providing a higher level of services for enrollees with certain pre-existing conditions.

Conclusion:

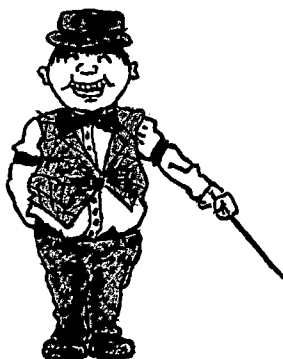
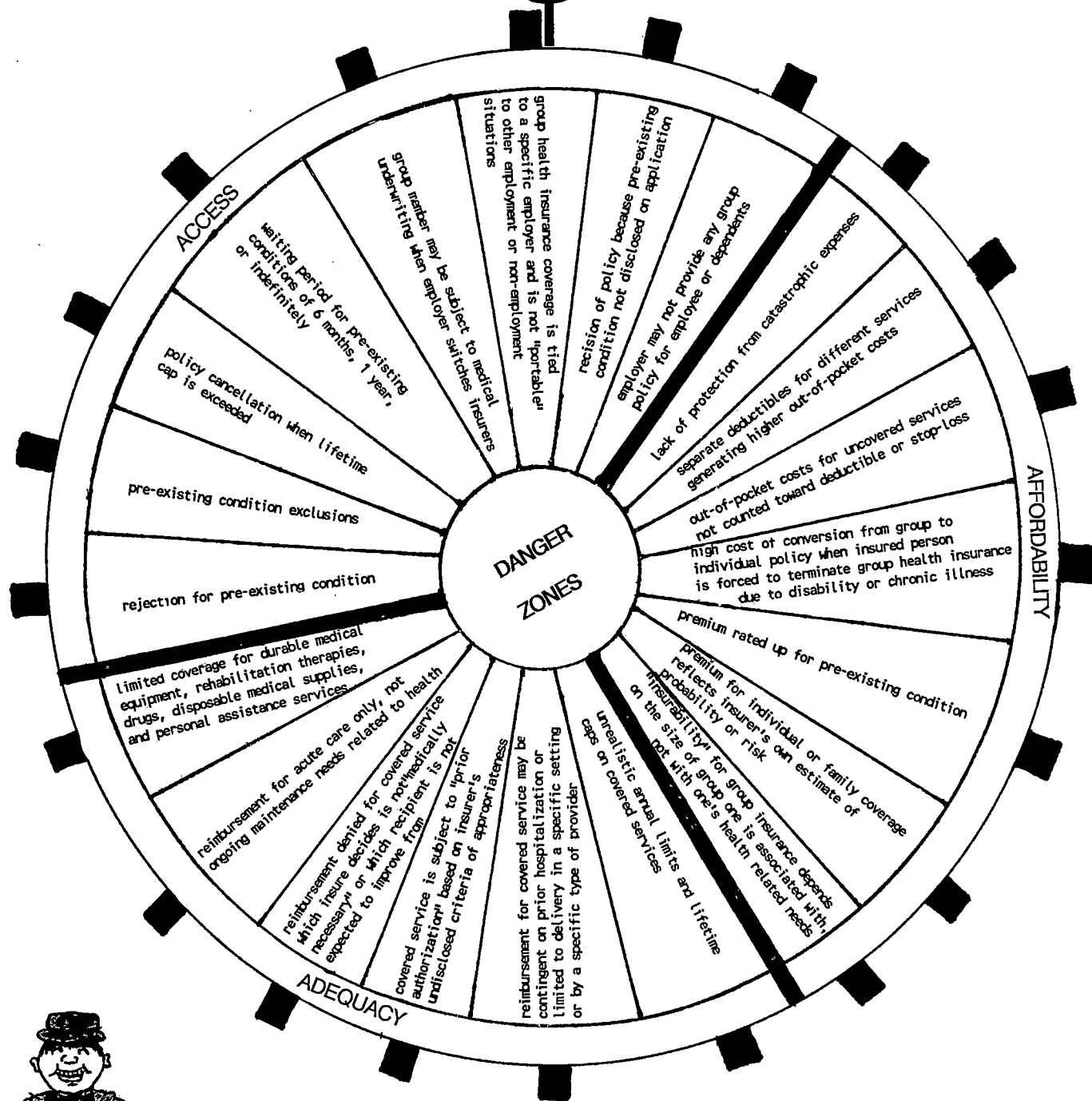
The danger zones of private health insurance for persons with chronic conditions can be illustrated by the "Health Insurance Roulette" wheel depicted in Figure 4.

The roulette wheel is divided into twenty-one danger zones corresponding to the need for Access, Adequacy, and Affordability. As the health insurance roulette wheel turns, finances often determine which danger zones an individual with chronic conditions lands on. If this is the finest protection that voluntary private health insurance can offer, many people with chronic conditions will not be smiling.

³⁵Zawadski, R., J. Shen, C. Yordi, and J.C. Hansen, "On Lok's Community Care Organization for Dependent Adults: Research and Development Project - Final Report (1978-1983)", 1985.

³⁶Alan R. Meyers, et.al., "A Prospective Evaluation of the Effect Managed Care Utilization Among Severely Disabled Independently Living Adults", *Medical Care*, 1987, 25(11), pp. 1057-68; and "The Epidemiology of Medical Care Utilization by Severely Disabled Independently Living Adults", *Journal of Clinical Epidemiology*, 1988, 41(2), pp. 163-172.

HEALTH IN \$URANCE ROULETTE



Drawing by Laura Wallace

"Step right up to the finest protection that voluntary private health insurance can offer!"

Figure 4:

LIMITATIONS OF PUBLIC HEALTH INSURANCE

This section will examine the limitations of the two primary public health insurance programs, Medicare and Medicaid, for meeting the health care needs of persons with disabilities or chronic illness.

MEDICARE:

Medicare is a federally administered social insurance approach to health insurance established under Title XVIII of the Social Security Act in 1965. Over 95 percent of persons over age 65 are covered by Medicare along with 3 million disabled persons under 65. Unlike private health insurance, the benefits in Medicare are available to all Medicare beneficiaries on the basis of need rather than on the basis of differential premium contributions. Although Medicare covers only a segment of the population, it is financed through a compulsory payroll tax on the earned income of all wage earners, half contributed by the employer and half by the employee. Self-employed persons are responsible for contributing both the employer and the employee share. In 1987, Medicare payments amounted to \$81.2 billion which represented approximately 18.4 percent of the total national personal health care expenditures. As a result, Medicare is the largest single purchaser of hospital care and physician services, accounting for 29 percent of all hospital revenue and for 21 percent of physician services (see Table 2; p. 13).

Some disabled persons under 65 became eligible for Medicare in 1972. They constitute approximately 10 percent of Medicare beneficiaries including disabled workers, disabled adult children, disabled widows and widowers; in addition, approximately 2.2 percent of disabled Medicare beneficiaries (47,216 persons in 1987) are eligible for Medicare because they need End Stage Renal Dialysis (ESRD)³⁷. This is the only disease-specific entitlement in Medicare and covers all age groups, including children.

Eligibility:

The Medicare program imposes eligibility limitations based on age and an inability to work which denies access to many people with chronic illness or disabilities.

³⁷Social Security Bulletin: Annual Statistical Supplement, 1988, Table 7.B5, p. 287.

At age 65 persons are automatically eligible for Medicare if they have previously contributed to the Social Security system through the payroll tax. The small number (less than 5 percent) of persons over 65 who have not contributed to the Social Security system are permitted to buy into Medicare. Children under 18 years old are not eligible for Medicare even when their parents have contributed to Social Security. Adults between 18-64 years old can be eligible for Medicare if they become disabled after they have contributed for a certain period³⁸ to the Social Security system or if they are dependents of Social Security beneficiaries who are retired, disabled, or deceased.

The legal definition for disability used by the Social Security Administration for both the SSDI and SSI programs is that the person is unable to engage in any "substantial gainful activity (SGA) by reason of a medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months." The Social Security Administration has used the SGA level of \$300 per month since 1980 to determine whether one is capable of employment even though this arbitrary amount (two-thirds of the poverty level) is unrelated to the capacity for self-sufficiency, especially for a person with a disability. This criterion of disability disqualifies people with what might be regarded as partial disabilities.

The Social Security Administration determines the severity of an impairment for different medical conditions by symptoms, signs, and laboratory findings described in "Medical Listings"³⁹. The criteria included in the "Medical Listings" are often problematic for certain disabilities. If a person does not meet the conditions in the "Medical Listings", the Social Security Administration is supposed to evaluate the individual's residual functional capacity. These eligibility criteria for disability ignore the extent of one's impairments or the cost of their health related needs if the person can earn over \$300 per month. This excludes persons with partial disabilities who have difficulty getting private health insurance even if they are

³⁸According to Section 223(c) of the Social Security Act workers who are 31 years old or over must have 20 quarters of coverage during the preceding 40 quarters, and workers under the age of 31 must have been covered for at least one half of the quarters since they reached age 21 (but no fewer than 6 quarters).

³⁹U.S. Department of Health and Human Services, Social Security Administration, Disability Evaluation Under Social Security, SSA Publication No. 05-10089, February 1986.

GRIN & BEAR IT WAGNER



"I see that you were born 65 years ago, but with a heart transplant and a new kidney your net age makes you ineligible for Medicare."

Figure 5: Reprinted and adapted with special permission of NAS, Inc.

able to work and creates a disincentive to work for persons with severe impairments.

Another barrier to eligibility for Medicare is the two year waiting period from the time of eligibility for SSDI. While five months is required to prove one is permanently disabled to become eligible for SSDI, the SSDI beneficiary must wait an additional 24 months to become eligible for Medicare. At the time that the health care costs are likely to be highest, the disabled worker is expected to wait 29 months from the onset of the disability to be eligible for Medicare services. This two year waiting period excludes from eligibility many disabled workers who die during the two year waiting period. For example, the Social Security Administration has reported that as many as 55 percent of SSDI beneficiaries with cancer do not survive the two year waiting period⁴⁰. The importance of this issue of survivability has recently been raised with regard to persons who develop AIDS. In addition, this researcher has estimated that as many as one-third of SSDI beneficiaries are uninsured at some point during the two year waiting period for Medicare⁴¹.

⁴⁰James Lubitz and Penelope Pine, "Health Care Use by Medicare's Disabled Enrollees," *Health Care Financing Review*, Vol. 7, No. 4, Summer 1986, Table 9, p. 29.

⁴¹See *Access to Health Care*, Nos. 1-2, pp. 28-29.

Ironically, these barriers to eligibility are imposed during the very time that the disabled worker's health care costs are likely to be highest and when access to appropriate care can most affect his or her rehabilitation potential. While it has been assumed that many disabled workers are covered by the group insurance policy of their previous employer, it is increasingly being recognized that many persons are uninsured while they are employed and that many insured workers have inadequate rehabilitation benefits. Although Medicare functions as a "secondary payor" if a disabled person is eligible for employer group benefits, the rigid eligibility criteria for Medicare do not take into account whether a disabled worker has private health insurance or adequate rehabilitation benefits in determining the starting/waiting period for Medicare.

The Social Security cartoon (see Figure 5) mocks a hypothetical concept of "net age" which is posed as a possible cost containment strategy. The significance of this cartoon, however, is not to give the Social Security Administration or the Health Care Financing Administration any ideas they haven't already thought of, but to highlight limitations in the public system which compromise the health care needs of people with disabilities. In many ways, the concept of "net age" is no more arbitrary than the concept of a two year waiting period for Medicare or the legal definition of disability based on a substantial

gainful activity (SGA) level of \$300 per month, which is hardly enough for a non-disabled person to be self-sufficient much less a person with disabilities.

Benefits:

Patterned originally after the **acute care orientation** of private health insurance, Medicare benefits are designed to cover acute care needs rather than the range of on-going maintenance needs that many elderly and disabled persons experience. First, Medicare does not cover **preventive or wellness care** such as routine physical exams and tests, eye or ear care to prescribe or fit eyeglasses or hearing aids, routine foot care, or immunizations.

Secondly, Medicare will often not pay for **on-going maintenance services**. While many persons with permanent functional limitations need personal assistance with self-care and household chores, Medicare generally identifies these activities as "custodial" and excludes them from coverage. Before 1980, home health care used to be covered by Medicare only if it was needed for convalescence after at least three days of hospitalization. Now, home health care can be covered if it is part of a physician prescribed plan of care, and the person is confined to his or her home (without the assistance of another person or the aid of a supportive device), and needs or needed skilled nursing care, or physical therapy or speech therapy on a part-time or intermittent basis. However, Medicare will reimburse for home health care only if it is delivered by, or under arrangements with, a Medicare certified home health agency. Given the large number of Medicare beneficiaries who need "intermittent" home health care for acute medical conditions, Medicare is, in fact, a major payor for home health care.

Another service which Medicare covers inadequately is outpatient mental health services. Limited to a maximum of \$450 per year, the mental health services which Medicare will pay for are not likely to be adequate for persons coping with adjustments to physical or mental impairments in a society largely designed for persons without disabilities.

Persons with chronic illness or disabilities often require drugs or biologicals to maintain their health. Nevertheless, Medicare has not paid for prescription drugs or biologicals that could be self-administered including insu-

lin. As a result of the Medicare Catastrophic Coverage Act of 1988, beginning in 1991, Medicare will pay 50 percent of the cost of prescription drugs after out-of-pocket expenses of \$600. This will gradually be expanded to 80 percent of the cost of prescription drugs in the future.

Medicare will pay for certain durable medical equipment and certain disposable medical supplies needed by persons with chronic illnesses or disabilities. For example, Medicare will pay for prosthetic devices including heart pacemakers, colostomy or ileostomy bags and certain related supplies, artificial limbs and eyes, and braces for an arm, leg, back or neck. Medicare will also help pay for durable medical equipment such as a wheelchair that is prescribed by a doctor for use in one's home. While some assistive devices are considered durable medical equipment, others which have come into use after Medicare was established in 1965 are not covered. For example, a wheelchair for a person with a mobility impairment can be covered by Medicare while an augmentative communication device for a person with a speech impairment is not. These arbitrary distinctions, which reflect the historical legacy of the Medicare program, reduce the utility of Medicare to persons with disabilities. Medicare will also not cover services or items which are considered to be "personal comforts" or "conveniences" even though they can significantly improve the quality of a person's life.

These major gaps in Medicare benefits must not hide the fact that Medicare plays a major role in financing acute care in hospitals and on an outpatient basis, as well as home health care and medical rehabilitation. Medicare is the single largest payor of medical rehabilitation which covers certain inpatient and outpatient rehabilitation services provided at a rehabilitation hospital or unit, an acute care hospital, skilled nursing facility (SNF), Comprehensive Outpatient Rehabilitation Facility (CORF), rehabilitation agency, therapist's office, or in the patient's home. The most common diagnosis for medical rehabilitation is recovery from a stroke.

Nevertheless, Medicare will pay for health related services only when they are considered "medically necessary" and only when skilled care is "reasonable and necessary to the treatment of the beneficiary's illness or injury or to the restoration of maintenance of function affected by the beneficiary's illness." This has permitted Medicare fiscal intermediaries to deny coverage to persons with chronic or stable conditions who are judged to lack "restorative potential". In 1988, the Center for Medicare Ad-

vocacy in South Windom, Connecticut brought a federal class action lawsuit against a Medicare fiscal intermediary for denying Medicare home health coverage to patients deemed to be "chronic" or "stable"⁴².

Partly in response to the Rizzi class action suit, the Health Care Financing Administration has recently published new guidelines (effective July 1, 1989) for Medicare fiscal intermediaries and Medicare certified home health care agencies which clarify that: "The determination of whether a beneficiary needs skilled nursing care should be based solely upon the beneficiary's unique condition and individual needs, without regard to whether the illness or injury is acute, chronic, terminal or expected to extend over a long period of time. In addition, skilled care may, dependent upon the unique condition of the beneficiary, continue to be necessary for beneficiaries whose condition is stable."⁴³ Deciding whether skilled therapy services such as physical therapy, speech therapy, and occupational therapy are "reasonable and necessary" for persons with permanent disabilities whose potential for continuing to make functional progress may be difficult to predict remains a serious problem.

Under a grant from the Connecticut Department on Aging, the Center for Medicare Advocacy has also prepared a series of self-help advocacy kits to assist Medicare beneficiaries in appealing unfair Medicare denials for home health care, hospital care, skilled nursing home care and Part B services⁴⁴.

Affordability:

Medicare consists of two programs, Part A and Part B, which pay for different services and are financed differently. Part A refers to the Medicare Hospital Insur-

ance program which covers inpatient hospital care, hospice care, inpatient care in a Medicare-certified skilled nursing facility (SNF), and home health care services. It is funded through the mandatory contributions of employers and employees which each pay 1.45 percent of earned income to the Social Security Hospital Insurance (HI) Trust Fund. In addition to the combined HI tax of 2.9 percent on earned income up to \$48,000 in 1989, Medicare recipients must pay a deductible of \$560 once each calendar year and copayments for some Part A services. Part B refers to Medicare's Supplemental Medical Insurance which primarily covers physician and outpatient services including durable medical equipment. Part B of Medicare is funded through the premium contributions of Medicare beneficiaries who enroll in Part B which included 98.5 percent of elderly Medicare beneficiaries and 92 percent of disabled Medicare beneficiaries in 1987. In addition to the Part B premiums, Medicare beneficiaries must pay a \$75 Part B deductible and 20 percent copayments depending on the covered services utilized.

There are four types of affordability problems with Medicare. One problem is that many low income Medicare beneficiaries cannot afford the premium, deductible, and copayment requirements for Medicare. This problem is accentuated by the second problem that Medicare has not contained a stop-loss provision limiting the out-of-pocket expenses for deductibles and copayments. States have had the option of using Medicaid dollars to subsidize the Part B premium and Medicare deductibles and copayments for SSI-eligible persons and those below the federal poverty level. In fact, 72.2 percent of Part B receipts in 1986 came from government contributions while only 23.2 percent came from premiums from participants⁴⁵. Nevertheless, it has been estimated that only one-third of poor elderly people have Medicaid coverage to fill in Medicare's cost-sharing, pay the Medicare part B premium, and provide additional benefits⁴⁶.

A third problem relates to the coverage limitations of Medicare which require beneficiaries to pay out-of-pocket for uncovered services. This burden falls disproportionately on persons with disabilities who have costly long term care needs. The fourth problem relates to the fact that Medicare will only pay 80 percent of approved

⁴²Center for Medicare Advocacy, Center News, Vol. II, No. 2, Autumn 1988, p. 1. The Federal class action lawsuit is Jack Rizzi, et.al. vs. Otis R. Bowen, Secretary, U.S. Department of Health and Human Services, U.S. District Court in Bridgeport, Connecticut, Civil Action No. B-88-360.

⁴³Health Care Financing Administration, Medicare Intermediary Manual, Part 3 - Claims Process, Sections 3118.1A4; this section is equivalent to chapter 2 of Health Insurance Manual (HIM-11) for Medicare providers, Transmittal 222.

⁴⁴These four self-advocacy kits are available from the Center for Medicare Advocacy, Inc., P.O. Box 171, South Windham, Connecticut 06226; telephone: (203) 456-7790 for \$10 each.

⁴⁵Social Security Bulletin, Annual Statistical Supplement, 1987, Table 151, p. 235.

⁴⁶Diane Rowland and Barbara Lyons, Medicare's Poor: Filling the Gaps in Medical Coverage for Low-Income Elderly Americans, Commonwealth Fund Commission on Elderly People Living Alone, Baltimore, Maryland, November 20, 1987.

charges for covered services. This means that Medicare beneficiaries may be responsible for the difference between the actual charge and the maximum allowable charge which Medicare approves. Although the allowable maximum for Medicare is likely to be much higher than the Medicaid reimbursement rate, it is often less than the prevailing rate of customary charges which providers demand.

Although failing to address the major long term care limitations of Medicare, the Medicare Catastrophic Coverage Act of 1988 reduced some of these affordability problems by: (1) requiring states to pay the Medicare Part B premium and Medicare deductibles and copayments for elderly and Medicare-eligible disabled persons under 100 percent of the Federal poverty level, (2) extending Medicare acute care benefits for hospitalization and physician services, and (3) limiting the out-of-pocket costs for Medicare deductibles and copayments (see Table 11, p.66).

Reimbursement:

Unlike Medicaid which often provides reimbursement levels far below the prevailing rate, Medicare pays "reasonable" charges based on previous average charges for specific services. While allowable costs may be adequate for many generic health care services, it is often below the market price for specialty care that many persons with disabilities may require. In most cases, health care providers are free to collect from Medicare beneficiaries the difference between the approved Medicare rate and the actual charge. This ensures that there are more providers who are willing to take Medicare beneficiaries than Medicaid recipients.

Medicare reimbursement policy can also influence the types of services which are provided to Medicare beneficiaries. For example, Medicare requires that providers meet certain standards to be eligible for reimbursement, and patients can be covered up to different payment levels for different types of providers. Although it is appropriate that Medicare limit reimbursement to providers who meet certain standards, there is a danger that the standards may reflect the historical emphasis on acute care hospitalization or may be used to limit certain types of providers. For example, when the "comprehensive outpatient rehabilitation facilities" (CORFs) were created in 1980 to expand non-hospital based outpatient rehabilitation services, the Health Care Financing Administration limited the development of this new type of Medicare provider by adding

the regulation that all CORF services must be provided at a single location. Congress finally removed this restriction on the delivery of off-site physical therapy, occupational therapy, and speech-language pathology services in December, 1987⁴⁷.

Another Medicare reimbursement issue affecting the quality of health care delivery involves the development of payment methodologies for physicians and the creation of a prospective payment system for medical rehabilitation hospitals. When HCFA implemented a prospective system for inpatient hospital care based on diagnostic related groups in 1983, rehabilitation hospitals, children's hospitals, long term hospitals, and psychiatric hospitals were exempted. Although this topic is somewhat beyond the focus of this current policy bulletin on access to health care, there is a growing literature on the implications of different payment models for rehabilitation care⁴⁸.

The administration of Medicare payments is another reimbursement issue which deserves to be examined. Some believe that the Health Care Financing Administration evaluates the performance of its fiscal intermediaries for Medicare by using such criteria as the rate of claims denials. This has given some the impression that delays or difficulties in the processing of claims may be part of a deliberate strategy to control costs.

Financing:

The Medicare program is the best example of a social insurance model in the U.S. for spreading health care costs throughout the population. Although the health care costs of Medicare beneficiaries are spread throughout the working population, the financing of Medicare is highly regressive in two respects. First, the Medicare Hospital Insurance tax is a flat rate regardless of a person's income level. Secondly, only the first \$48,000 of earned income was subject to the Medicare tax in 1989. This ensures that persons with higher incomes actually pay a lower percentage of their earned income than persons with lower incomes. Rectifying this inequity can generate additional funds that could be used to finance various options for

⁴⁷Andrew I. Batavia, The Payors of Medical Rehabilitation: Eligibility, Coverage and Payment Policies, National Association of Rehabilitation Facilities, Washington, D.C., January 1989, pp. 17.

⁴⁸See Andrew I. Batavia, The Payment of Medical Rehabilitation Services: Current Mechanisms and Potential Models, American Hospital Association, Chicago, Illinois, 1988.

change (see Pepper bill, pp. 64-65). While some advocates for social insurance favor higher income persons paying a larger amount than lower income persons, others argue that progressivity may actually undermine support for social insurance.

MEDICAID:

Title XIX of the Social Security Act established Medicaid in 1965 as a federal and state financed program administered by the state to reimburse for health care services provided low income individuals and families receiving Federally funded cash assistance programs for the poor⁴⁹. Medicaid is the primary public health care program for poor persons in the U.S., and is also the largest third-party financer of long-term care. In 1987, the Medicaid program provided services to 23.2 million eligible poor persons for a total cost of \$47.6 billion (\$26.6 billion Federal and \$21 billion state monies)⁵⁰. The Medicaid program is suppose to ensure that low income persons have access to the same health care providers as persons with higher incomes.

Eligibility:

Medicaid represents a welfare approach to health care in contrast to the social insurance approach of Medicare. Within federal guidelines, states have broad discretion in determining which groups their Medicaid programs will cover and their financial criteria for Medicaid eligibility. There are basically two distinct problems related to Medicaid eligibility. One problem involves the eligibility criteria for Supplemental Security Income (SSI) and Aid to Families with Dependent Children (AFDC) upon which Medicaid eligibility depends in most states. The second problem involves the state's discretion to extend Medicaid eligibility to various "optional" groups.

Although thirty-five states and the District of Columbia automatically provide Medicaid eligibility to all

SSI recipients, fourteen states have elected to use the so-called 209(b) option in the Social Security Act which permits them to use more restrictive eligibility criteria that were in effect in the state's Medicaid plan in January 1972 when the SSI program was created. The primary problem related to Medicaid eligibility, however, reflects the eligibility criteria for SSI or AFDC where need is measured in terms of income, assets, and family structure (e.g. the presence of dependent children in a family where one parent is absent, incapacitated, or unemployed) rather than in terms of health related needs.

In the SSI program, eligibility is based on the same indicators of disability (i.e. "Medical Listings" and an inability to work above the "substantial gainful activity" level as the Social Security Administration uses for Medicare (see above). But in addition to these problematic factors, SSI eligibility requires that income and asset levels are below a federally determined level. As persons of all ages can be eligible for SSI, a problem arises in measuring the income and assets of disabled persons who live with non-disabled persons. For example, most disabled children under 18 years old live with their parents as do some disabled adults, and many disabled adults live with a non-disabled spouse.

The problem arises in how to count the income and assets of the non-disabled persons in determining the eligibility of the disabled person for Medicaid. According to SSA regulations, the income and assets of the parents of disabled children under 18 are to be counted or "deemed" when the eligibility of the disabled child is determined as long as the disabled child is living in the parents' household. This federal regulation has disqualified from Medicaid eligibility many disabled children who are living with their parents and created an incentive for families of disabled children to place them in institutions in order for their disabled child to become eligible for Medicaid⁵¹. The awful dilemma of forcing a family to institutionalize a disabled child in order to become eligible for Medicaid funded services received wide public attention by the Katie Beckett family. As a result of this controversy, Congress created what have come to be called "Katie Beckett waiv-

⁴⁹A major source of information about the Medicaid program is contained in U.S. House of Representatives, Subcommittee on Health and the Environment, Medicaid Source Book: Background Data and Analysis: A Report prepared by the Congressional Research Service, 100th Congress, 2nd Session, Committee Print 100-AA, November 1988. Another valuable source is American Hospital Association, Medicaid Options: State Opportunities and Strategies for Expanding Eligibility, Chicago, Illinois, 1987.

⁵⁰Social Security Bulletin, Annual Statistical Supplement, 1988, pp. 55-57.

⁵¹Foundation for Hospice and Homecare, The Crisis of Chronically Ill Children in America: Triumph of Technology - Failure of Public Policy, Washington, D.C., March 23, 1987; U.S. Congress, Office of Technology Assessment, Technology-Dependent Children: Hospital v. Home Care - A Technical Memorandum, OTA-TM-H-38, Washington, D.C., U.S. Government Printing Office, May 1987; Task Force on Technology-Dependent Children, Fostering Home and Community-Based Care for Technology-Dependent Children, Department of Health and Human Services, April 7, 1988.

ers" which allow states the option of not counting the parents' income if the child is at risk of institutionalization.

To avoid penalizing parents who support their disabled children in their households after age 18, the income of parents is not counted under SSA regulations. A problem which this age group faced, however, was having unearned income from SSDI raise their income level above the eligibility criterion for SSI which would disqualify them from Medicaid. Congress corrected this problem in 1987 by preserving the Medicaid eligibility of recipients who become ineligible for SSI payments because of entitlement to, or an increase in, Social Security disabled adult child benefits.

At the other end of the age spectrum, however, there is growing concern about the "spend down" requirements for Medicaid which can jeopardize the savings of elderly families when one member of the family has to enter a nursing home. Medicaid requires that persons must "spend down" to poverty in order to qualify for Medicaid funding for nursing home care. To avoid elderly persons having to divorce each other in order to protect the income and assets of the non-disabled spouse, Congress has recently passed a spousal impoverishment amendment to the Medicare Catastrophic Coverage Act of 1988 which will allow the non-disabled spouse to keep \$786 monthly income and one-half of the couples' assets (up to a maximum of \$60,000) when a disabled spouse in a nursing home spends down to poverty to become eligible for Medicaid.

The eligibility requirement that an SSI recipient not be able to earn over the SGA level of \$300 per month has also created a work disincentive for many of the 2 million working-age persons on SSI. Under strong pressure from the disability community, Congress created a permanent Section 1619 of the Social Security Act in 1986 to allow SSI recipients to earn a level of income up to the value of the cash assistance, Medicaid payments, and the publicly-funded attendant care benefits that they would have been eligible for through SSI and Medicaid by not working. Reflecting differences in cash assistance levels based on additional state supplements and differences in the services available in Medicaid programs in different states, a disabled person on SSI can earn up to \$19,965 in California, \$19,396 in New York, \$16,177 in Wisconsin, and \$19,092 in Massachusetts while still being eligible for Medicaid in 1989⁵². Persons requiring a higher level of

Medicaid services than the average in each state would be entitled to a higher individualized threshold level in determining eligibility for Medicaid under Section 1619(b).

While SSI became a federalized welfare program for elderly and disabled persons in 1974, the Aid to Families with Disabled Children (AFDC) program remains administered by the states which set their own income and asset levels for eligibility, significantly below the Federal poverty level and the eligibility level for SSI. Although state eligibility criteria for AFDC do not bear directly on the SSI program, they do provide an important reference point for comparison since both programs rely on state funding for Medicaid. A recent critique of state Medicaid programs by the Public Citizen Health Research Group reveals the disturbing inequities in income and asset levels required for Medicaid eligibility among the states, and indicates that less than half of the population with incomes below the federal poverty line are eligible for Medicaid⁵³. This exclusion of so many low income persons from eligibility for Medicaid reflects both federal regulations which exclude poor persons without children from the AFDC program and low state income and asset levels for AFDC eligibility. The size of this needy group which is largely uninsured competes with persons with disabilities or chronic illness for future Medicaid expansion.

Besides the SSI and AFDC recipients who are mandatory categorically needy recipients of Medicaid, states have the option of extending Medicaid coverage to "medically needy" persons whose high medical expenses cause their income to drop below a state determined threshold which does not exceed 133 percent of the state poverty standard for AFDC. In 1987, 36 states provided Medicaid to certain groups under a medically needy program.

To reduce the number of vulnerable individuals who continue to fall through the Medicaid safety net, Congress has taken several precedent-setting steps over the last few years to break the historic link between eligibility for cash assistance and eligibility for Medicaid. Through a series of Medicaid amendments, states have been given the option and then required to extend Medicaid to various vulnerable groups including pregnant women and infants, older children, elderly and disabled persons below the federal poverty level, and persons trying to work their way off AFDC or SSI (see pp.75-77) By substituting federal income criteria related to the federal poverty level

⁵²Social Security Administration, Program Operations Manual System, Part 05, Chapter 023, Subchapter 02; POMS is available at any Social Security office.

⁵³Karen Erdman and Sidney M. Wolfe, Poor Health Care for Poor Americans: A Ranking of State Medicaid Programs, Public Citizen Health Research Group, Washington, D.C., 1987.

for the varied state eligibility criteria, Congress has gradually expanded Medicaid coverage in small increments within budget constraints. Nevertheless, by federal statute, the Medicaid program does not provide health care services, even for very poor persons, unless they are aged, blind, disabled, pregnant, under 21, or eligible for AFDC.

Benefits:

The Medicaid program actually represents the most comprehensive set of health related benefits in the U.S. In contrast to the acute care bias of both private health insurance and Medicare, state Medicaid programs often cover on-going maintenance services, preventive services, and nursing home care in addition to hospitalization and physician services. States are mandated to provide certain services and have the option of providing others. Table 6 lists the optional Medicaid services and the numbers of states offering each service as of October 1, 1987 (see Table 6 on next column).

The problem with Medicaid benefits is that they are left to individual state discretion. States can pick among the wide range of federal optional services, set the "amount, duration, and scope" of federally mandated or optional services, and determine the rate of reimbursement for services. As a result, there are wide inequities among the states reflecting differences in fiscal capacity and philosophy toward serving poor people.

While many states choose to limit Medicaid expenditures for necessary health services, a new disturbing trend is on the horizon. In June 1987, the state of Oregon decided to ration health care services for the poor by choosing to stop using Medicaid funds to pay for heart, liver, bone-marrow and pancreas transplants. Reflecting both the high cost of transplant operations and the unreliability of their outcomes, the Oregon legislature decided to use the \$2.3 million that would be saved each year from organ transplants to expand prenatal care for needy pregnant women. Although it is commendable that Oregon is prepared to recognize that prenatal care is an essential health service that all pregnant women should receive, it is unfortunate that this precedent-setting action is portrayed as a "hard choice" necessitated by the soaring costs of health care. While there will be important trade-offs facing public policy decision-makers who are concerned about equitable access to health care for all citizens, this understandable trade-off is particularly disturbing because rationing is being applied only to people with low incomes

Table 6: Optional Medicaid Services and Numbers of States Offering Each Service as of October 1, 1987

<u>Health Related Service</u>	<u>No. of states and Washington, D.C.</u>
Prescribed drugs	51
Physical therapy	35
Occupational therapy	25
Speech, earing and language disorder	33
Prosthetic devices	49
Rehabilitative services	37
Personal care services	26
Case management services	15
Preventive services	21
Screening services	18
Diagnostic services	21
Clinic services	52
Dental services	49
Eyeglasses	47
Podiatrists' services	42
Optometrists services	51
Chiropractors' services	28
Other practitioners' services	35
Private duty nursing	20
Intermediate care facility services	50
ICF for mentally retarded	48
Inpatient psychiatric services for under age 22	37
SNF for under age 21	47
Services for age 65 or older in mental institution	
A. inpatient hospital services	42
B. SNF services	24
C. ICF services	29
Emergency hospital services	44
Transportation services	45
Hospice services	6
Christian science nurses	5
Christian science sanatoria	16

Source: U.S. House of Representatives, Subcommittee on Health and the Environment, Medicaid Source Book: Background Data and Analysis: A Report prepared by the Congressional Research Service, 100th Congress, 2nd Session, Committee Print 100-AA, November 1988, pp. 96-97.

who are dependent on limited public programs that are separate from the health care financing system that most other citizens rely on.

The federal government has continued to broaden the types of services which can be funded through Medicaid. These include developmental services through the ICF/MR program, case management for persons with

mental illness⁵⁴, and even supportive work for persons through the Vocational Rehabilitation program. In addition, the federal government has permitted states to apply for various time-limited federal waivers from Medicaid regulations which allow the use of federal Medicaid dollars for a totally flexible range of benefits (excluding only room and board) to enable disabled Medicaid eligible persons to live outside of institutions. The primary limitation on the Medicaid waivers is that the total cost of the services has to **cost less in the alternative to institutions** and that the State has to reduce its institutional capacity.

The use of Medicaid benefits for nursing home care has actually radically extended a public health care program originally designed for low income families and persons with disabilities into a middle class program for nursing home care. While 6.1 percent of Medicaid recipients received nursing home care (excluding ICF services for the mentally retarded), nursing home care accounted for 29.4 percent of Medicaid expenditures in 1987⁵⁵. These costs make it more difficult to extend Medicaid to other needs and populations.

Reimbursement:

Despite the potential comprehensiveness of Medicaid benefits, access to quality services is severely compromised by the low reimbursement rates established by many state Medicaid programs. A 1987 GAO study of Medicaid reimbursement rates revealed that the maximum allowable physician fees for a brief office visit to a general practitioner ranged from an average of \$6.00 in New Hampshire to \$28.41 in Alaska for 1986. New York paid \$7.00, Massachusetts paid \$8.00, California paid \$11.04, Wisconsin paid \$16.23, and the District of Columbia paid \$20.00 per office visit (see Table 7 on next page)⁵⁶.

Although the data apparently have not been collected, it is widely believed that the willingness of physicians to treat Medicaid clients varies with the reimbursement levels in each state. Low reimbursement levels to health care providers is one way that states have attempted to save state dollars.

While low Medicaid reimbursement levels have the effect of minimizing Medicaid expenditures for services provided, it also has the effect of discouraging health care providers to receive Medicaid patients. This is so because providers are obligated to accept the Medicaid reimbursement level as payment in full. In some situations, states are required to use other programs such as Title V

Maternal and Child Health Block Grant funds (see pp.82-83) to pay health care providers to treat Medicaid eligible clients with scarce federal dollars that could have been used more flexibly for support services, when those same providers are unwilling to accept the Medicaid rate of reimbursement. The low reimbursement for Medicaid also creates a stigma around services provided as "welfare medicine" and perpetuates a two-tier system of services that the Medicaid program was suppose to avoid.

Financing:

To increase the willingness of poorer states to expand their Medicaid programs, the federal government provides a different matching rate depending on the state's average per capita income level. The federal matching rate varies from 50 percent for wealthier states to a maximum of 83 percent for the poorest states although the highest rate in FY 1989 is 79.8 percent⁵⁷. Despite this differential rate of federal participation, the wealthier states continue to spend more Medicaid dollars per capita than the poorer states. It appears that the fiscal constraints at the state level often limit a state's Medicaid expenditures even though a poor state would be responsible for paying less than one-quarter of the Medicaid expenditures. Clearly, the differential matching rate does not increase the capacity of the poorer states to generate their own revenues which would be required to expand the Medicaid program.

Affordability:

Since persons have to be poor to be eligible for Medicaid, the use of premiums and deductibles would perpetuate the very barriers to access that the Medicaid program is suppose to remove. However, states have been permitted to introduce small co-payments on certain services to discourage unnecessary utilization.

⁵⁴An important examination of the limitations of the Medicaid program for persons with mental illnesses and discussion of strategies to change state Medicaid plans has been written by Chris Koyanagi, Operation Help: A Mental Health Advocates's Guide to Medicaid, National Mental Health Association, Alexandria, Virginia, 1988.

⁵⁵Social Security Bulletin, Annual Statistical Supplement, 1988, pp. 299-301.

⁵⁶U.S. General Accounting Office, Medicaid Interstate Variations in Benefits and Expenditures, Washington, D.C., Publication No. GAO/HRD-87-67BR, May 1987, p. 35.

⁵⁷Medicaid Source Book: Background Data and Analysis, op. cit. pp. 197-198.

**Table 7: Maximum Allowable Physician Fees for
Brief Office Exam by General Practitioner^a, 1986^b**

State	Fee	State	Fee
Alabama	\$11.70	Nebraska	\$12.40
Alaska	28.41	Nevada	15.82
Arkansas	12.00	New Hampshire	6.00
California	11.04	New Jersey	7.00
Colorado	11.75	New Mexico	10.40
Connecticut	8.80	New York	7.00
Delaware	12.66	North Carolina	11.40
District of Columbia	20.00	North Dakota	8.20
Florida	10.00	Ohio	12.00
Georgia	15.60	Oklahoma	11.00
Hawaii	11.58	Oregon	11.07
Idaho	10.50	Pennsylvania	13.00
Illinois	11.50	Rhode Island	14.00
Indiana	17.30	South Carolina	9.50
Iowa	*	Rhode Island	14.00
Kansas	15.00	Tennessee	18.00
Kentucky	12.00	Texas	*
Louisiana	10.69	Utah	9.92
Maine	8.00	Vermont	8.00
Maryland	10.50	Virginia	6.30
Massachusetts	8.00	Washington	13.92
Michigan	7.75	West Virginia	10.00
Minnesota	15.75	Wisconsin	16.23
Mississippi	11.55	Wyoming	16.30
Missouri	10.00		
Montana	11.30	SIMPLE AVERAGE	11.93

* Brief office visit for evaluation and treatment of an established patient.

^b For states not reporting 1986 rates, HCFA used rates as reported in a previous year.

* Not indicated on source document.

Source: HCFA, unpublished data (Baltimore, Md.) taken from U.S. General Accounting Office, Medicaid Interstate Variations in Benefits and Expenditures, GAO/HRD-87-67 BR, Washington, D.C., May 1987, p. 35.

The real barriers to the affordability of health care are determined by the eligibility and service coverage limits established in the state Medicaid programs. One of the most meaningful comparisons of the impact of Medicaid eligibility and coverage policies is provided in the study of Medicaid and Poor Children: State Variations in Eligibility and Service Coverage for National Association of Children's Hospitals and Related Institutions⁵⁸. Four children either uninsured or underinsured were selected to illustrate some of the real life experiences of very sick children typically treated in a children's hospital. Among the children the first had cystic fibrosis, the second had a

traumatic brain injury, the third was a ventilator dependent infant, and the fourth was a catastrophically ill infant. The study compared how each of these four children with different health needs, family situations, and medical expenses would be affected by the Medicaid programs in four states (i.e. Alabama, California, Ohio, and Texas) which were selected to reflect the diversity in Medicaid programs throughout the U.S. In some of the states, the child would be denied certain critically needed services, in other states the child would have to remain in the hospital to receive the service, and in other states the child would be cared for in the most appropriate setting without driving the family into poverty. These real life profiles revealed more starkly than any listing of eligibility criteria or mandated and optional services how the structure of the Medicaid program, in conjunction with other public programs (e.g.

⁵⁸Susan S. Laucina and Debra J. Lipson, Medicaid and Poor Children: State Variations in Eligibility and Service Coverage, The National Association of Children's Hospital and Related Institutions, Alexandria, Virginia, September 1988, pp. 71-89.

Crippled Children's Service) and private health insurance benefits and regulations affect access to adequate and affordable health care.

Conclusion:

This section has focused on the limitations of Medicare and Medicaid for responding to the health care needs of persons with disabilities or chronic illnesses. The cartoon in Figure 6 lampoons the hospital bed of the future operating in a capitated reimbursement system based on Medicare DRGs (diagnostic-related groups). (See Fig. 6).

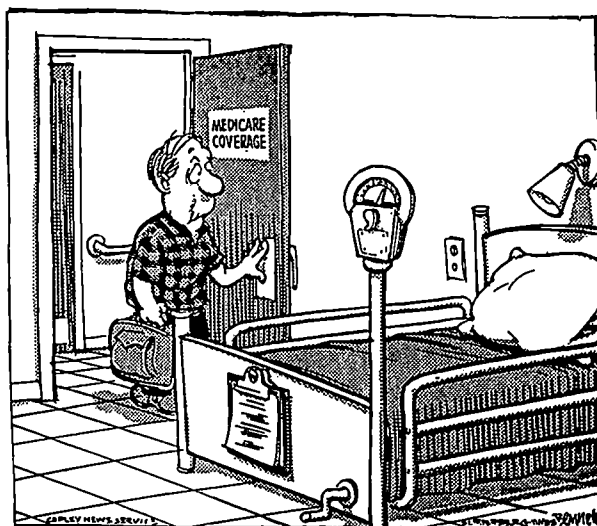


Figure 6: Drawing by Bennett, Copley News Services, St. Petersburg Times (Reprinted with special permission)

While the cartoon could pertain to private health insurance as well as to Medicare, this section has raised important questions about the functioning of a public health insurance system. For persons who are frustrated with the way the federal government operates Medicare or the states administer Medicaid, there may be some trepidation in contemplating how a National Health Insurance program could incorporate the worst elements of both Medicare and Medicaid. This question must be addressed both historically and comparatively.

The section on history attempted to show how the operation of the Medicare and Medicaid programs represented compromises with various interest groups in the private and public sectors. While these compromises may have been necessary to gain the needed political support at the time, the operation of these public programs do not represent the only model under which a national health insurance program would have to function. Much of the arbitrariness in the Medicare and Medicaid programs stems from the fact that the funding for public health programs is

highly limited, and there is no clearly defined entitlement to comprehensive health care and long term care. This is in sharp contrast to most other industrialized countries which have national health insurance programs which appear to provide better health care to more people with less money than the U.S. system⁵⁹.

A recent Harris Poll of public attitudes in the U.S., Canada, and Britain about their health care systems revealed that Americans favored their own system over Britain's by 68% to 29%, but only 37% of Americans favored the U.S. system compared to 61% who favored the Canadian system. Public opinion in both Canada and Britain preferred their own systems, and the American system was least favored among both Canadians and Britons⁶⁰.

While many advocates are working to expand or extend the Medicaid and Medicare programs, it should be recognized that neither of these programs was designed to ensure access to adequate and affordable health care for all persons. Some observers think that the compromises represented in the Medicaid and Medicare programs would necessarily have to be repeated in a new National Health Insurance program. In fact, these two public insurance programs have been experimenting with new ways to reimburse services through capitation and managed care. Other observers of the health care system think that existing crises in the health care system require that the health care financing policies be radically restructured. Thomas S. Bodenheimer argues for the advantages of a single payor system⁶¹, and David Himmelstein and Steffi Woolhandler show that at least 10 percent of national health care expenditures represent "administrative waste" without benefit in the U.S. health care system⁶². Building on these critiques, a 1,200 member group called Physicians for a National Health Program developed a proposal for universal health

⁵⁹National Health Care Campaign, *Paying More, Getting Less: How U.S. Health Care Measures Up*, Washington, D.C., December 1988.

⁶⁰Robert J. Blendon, "Three Systems: A Comparative Survey", *Health Management Quarterly*, Vol. XI, No. 1, First Quarter 1989, pp. 2-10.

⁶¹Thomas S. Bodenheimer, "Payment Mechanisms Under a National Health Program", paper prepared for the American Public Health Association, Boston, Massachusetts, November 1988.

⁶²David U. Himmelstein and Steffi Woolhandler, "Cost without Benefit: Administrative Waste in U.S. Health Care," *New England Journal of Medicine*, February 13, 1986, pp. 441-445.

insurance which was printed in the New England Journal of Medicine⁶³. While many of these issues take us far beyond the health care needs of persons with disabilities and chronic illness, they are extremely relevant to the way that different interest groups are beginning to reassess their interests in health insurance reform. The next section will explore various policy options for increasing the capacity of the private and public sectors to respond to the health care needs of persons with disabilities or chronic illness.

⁶³"A National Health Program for the United States: A Physicians' Proposal", New England Journal of Medicine, 1989, Vol. 320, No. 2, pp. 102-108.

OPTIONS FOR CHANGE AT FEDERAL AND STATE LEVELS

Various policy options have been proposed to address the health care needs of different sub-groups who are not adequately served by group health insurance linked to employment or by existing public programs. Among the major policy options are: (1) regulations on employers and or insurers, (2) public incentives to employers, insurers or providers to provide health care to certain groups (3) Medicaid expansions, (4) Medicare expansions, and (5) other federal programs ranging from National Health Insurance for all age groups or Medicare for children, to the expansion of various health grant programs (see Figure 7).

While many of these options can be combined, they will be considered here as separate conceptual models to clarify their differences. The critical issue represented by these different approaches is what is the most appropriate base for organizing the financing of health care for persons with chronic illness or disability.

The feasibility of any of the proposed health insurance reforms depends on political support from various

interest groups with a stake in change or maintenance of the status quo, and the political jurisdiction of the level of government. Public decision-makers are often limited by the resources which they have control over and the political and legal structures to which they are accountable. These constraints have a way of perpetuating the status quo or allowing it to change incrementally while making basic restructuring appear infeasible. This gives rise to what one astute political actor in the health care field has called "baking bread one slice at a time" or another has described as "moving to National Health Insurance organ by organ". But while incrementalism is often viewed as the only feasible approach to restructure an entrenched system, the noted academic on health care financing policy, Rashi Fein, borrowing a quotation from Winston Churchill, reminds us: "one does not leap over a chasm in two steps."

Whether the chasm is visible may depend on whether one is among the 37 million uninsured persons, or hospitals facing over \$9.5 billion dollars in uncompensated care, or employers who have increased health insurance payments over 200 percent between 1965 and 1985. Some incremental proposals deliberately focus on one aspect of

FIGURE 7: FEDERAL AND STATE HEALTH CARE FINANCING OPTIONS FOR PERSONS WITH DISABILITY OR CHRONIC ILLNESS

REGULATIONS OF EMPLOYERS AND INSURERS	PUBLIC INCENTIVES TO THE PRIVATE SECTOR	MEDICAID EXPANSION	MEDICARE EXPANSION	OTHER FEDERAL PROGRAMS
A. Employer mandates	A. High risk pool	A. Medicaid reforms	A. Longterm home care	A. National Health Insurance
B. Insurer mandates	B. Public subsidy of premium for private insurance	B. Medicaid Buy-in	B. Elimination of two year waiting period	1. Medicare
	C. State health insurance plan		C. Medicare buy-in	B. Federal grant programs
	D. Reinsurance mechanism			1. Maternal & Child Health
	E. Uncompensated care pool			2. Education of the Handicapped Act
	F. Catastrophic insurance pool			3. Vocational Rehabilitation
	G. Tax subsidies			

one problem in order avoid resistance from interests which have a stake in the status quo. Other proposals envision a more broad-based solution in order to increase the number of groups who will perceive that they have a common interest in the success of the proposal.

Although many of the policy options are developed to address the needs of the uninsured population, the primary purpose of this section is to consider how these policy options are likely to affect the access to adequate and affordable health care for persons with chronic illness or disability. To assess the impact of various options for change on persons with chronic illness or disability, it is necessary to consider:

(A) the strengths and limitations of each approach in terms of meeting the health related needs of persons with chronic conditions;

(B) how each approach might affect the private health insurance system, the public health care programs, and the willingness of employers to hire persons with chronic conditions, and

(C) whether the same objectives for each option can be better promoted through other means.

REGULATIONS OF EMPLOYERS AND INSURERS

The first set of options involve regulations to ensure that employers and insurers act in ways that accommodate the needs of uninsured and underinsured persons. These regulations may occur at the federal or state levels.

Employer mandates:

The Federal government has created incentives through the tax code for employers to offer health insurance to their employees. Employers are permitted to deduct contributions to their employees health insurance from the employer income before it is taxed. This constitutes a Federal subsidy estimated at \$27.6 billion in 1989⁶⁴. Interestingly, the subsidy goes to employers who have the most generous health insurance plans rather than to em-

ployers who have the least capacity to contribute to their employees' health insurance needs.

If an employer chooses to provide health insurance to some of the employees, the employer is required by anti-discrimination clauses in the Internal Revenue Service code to provide comparable health insurance to the other employees or else those with better health insurance coverage will have the monetary value of the difference treated as taxable income. However, unlike other employer mandates such as minimum wage laws or the employer obligation to collect and contribute to Social Security payments, Workers Compensation, and Unemployment Compensation, employers are not required to provide health insurance to their employees and their dependents. What is more, the Federal government does not specify any minimum standards which a health insurance package must meet before the employer can qualify for a tax deduction for health insurance expenses. As a result, the type of health insurance which an employee has access to varies widely in terms of benefits, costs, and whether dependents are covered. For persons with chronic conditions, this causes "insurability" to depend not on the nature of one's health condition, but on the size of the group with which one is associated.

For various reasons the insurance industry has managed to avoid Federal regulation and is regulated only at the State level. States have passed various laws governing the eligibility, benefits, and renewability of health insurance plans. Some of these mandates apply to group plans while others apply to individual plans. If an employer purchases group insurance for his or her employees, the group insurance plan is subject to the state mandates for group insurance. However, if an employer chooses to self-insure, the health insurance plan is not subject to state insurance laws. Instead, self-insured employers are subject to the Employee Retirement and Income Security Act (ERISA) at the Federal level which pre-exempts state mandates even though the Federal law does not contain Federal standards for health insurance. While we will return shortly to the subject of insurance mandates, the point here is to clarify the context in which employer mandates function.

Employer mandates have an obvious appeal to the Federal government, especially at this time of Federal budget deficits, because they can require employers to provide certain benefits to their employees at virtually no cost to the Federal government. The only Federal costs are the tax reductions based on the tax exempt status of employer contributions to the health insurance of their

⁶⁴U.S. House of Representatives, Committee on Ways and Means, Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means, 1988 Edition, March 1988, p. 596.

employees and their dependents. Opponents of employer mandates also argue that another Federal cost will be dealing with the social consequences of greater unemployment as the employer mandate drives some employers out of business. The actual impact of an employer mandate on health insurance must be considered in relation to other employer mandates such as proposed increases in the minimum wage (which has not been raised since 1981) and the cumulative impact of other proposed employer mandates such as parental leave, day care, etc. Nevertheless, in the long shadow of the Federal deficit, there is great pressure in Congress to rely on non-budgetary solutions to finance the health care of large segments of the population.

At the Federal level there are two types of employer mandate bills for health insurance. The first is the **Minimum Health Benefits For All Workers Act of 1988** (S. 1265) introduced by Senator Edward Kennedy (D-Mass.) as chairman of the Senate Labor and Human Resources Committee. [A revised bill called the **Basic Health Benefits for All Americans Act** (S. 768) has been introduced in April, 1989 which subsumes S. 1265.] The Minimum Health Benefits bill would require all employers to contribute to the health insurance of all employees working more than 17 and one half hours per week and their dependents. Employers will be required to pay at least 80 percent of the premium for most workers although the employer must pay the full premium for low wage workers earning less than 125 percent of the current minimum wage. Deductibles may not exceed \$250 per individual and \$500 per family and the coinsurance may not exceed 20 percent. The package must include catastrophic coverage limiting out-of-pocket family costs for covered services to \$3,000 per family.

The Minimum Health Benefits bill requires the employer provided health insurance package to include medically necessary hospital care, physician services, diagnostic tests, pre-natal and well-baby care, and a limited mental health benefit. Apparently, an employer may substitute alternative benefit packages, cost-sharing, and premium shares by offering a benefit package that is "actuarially equivalent" or better than the federally mandated minimum plan.

The Kennedy bill contains several features that could benefit people with chronic illness or disability. The Minimum Health Benefits bill would create regional health insurance pools for small employers and self-employed individuals to permit them to aggregate their small groups into larger insurance units to obtain the benefits of community rating, group purchasing power, and lower administra-

tive costs. Instead of charging a higher premium to a person with a pre-existing condition as a private health insurer would do, the regional pool will provide the minimum health benefits package to all enrollees at a single community-rated premium. Moreover, the Minimum Health Benefits bill eliminates exclusions from coverage based on health status within the regionalized pools which has penalized persons with disabilities or chronic illness in the health insurance marketplace. In addition, the Kennedy bill will limit out-of-pocket expenses for covered services to \$3,000 per family. Nevertheless, this level of catastrophic protection for family coverage will still impose a substantial burden on low income families with high health care needs.

While it is estimated that the Kennedy bill could promote health insurance coverage to approximately two-thirds of the uninsured population (e.g. 24 million persons) at practically no cost to the Federal government, it contains some serious drawbacks to persons with chronic illness or disability. The primary drawback is that the Minimum Health Benefits bill does not provide for comprehensive coverage of all the health related services needed by persons with disabilities. For example, the Minimum Health Benefits bill does not require coverage for prescription drugs nor does it ensure coverage of outpatient rehabilitation services provided in home and community settings. These limitations largely reflect the existing limitations in many private health insurance plans. While the Kennedy bill tries to improve private health insurance coverage for certain services, such as well-baby care for children up to age one, it consciously restrains itself from pushing employers further than most of them have already been willing to go in favor of extending existing health insurance benefits to employees and their dependents who are still uninsured.

One of the most controversial components of the Minimum Health Benefits bill is the preemption of state mandates. If employers are only required to meet the federal standards for Minimum Health benefits, states would be prevented from mandating additional health benefits. As a result, persons with disabilities or chronic illness whose access to certain types or levels of service in a particular state are protected by existing state requirements on health insurance policies, run the risk of losing those benefits as health insurance policies adjust to the federal minimum benefit standards. There is a real dilemma between designing a bill that all employers can afford and designing a bill that meets the special needs of various groups such as persons with chronic illness or disability. Defining the minimum health benefits in

terms of what is affordable to marginal employers would tend to reverse the trend toward comprehensive health insurance which many nondisabled and disabled employees have come to rely on.

Moreover, the linkage in the Kennedy bill of any future expansion of minimum benefits in employer mandates to Medicaid mandates for AFDC recipients make some observers very skeptical about the prospects of improving the nature of health insurance benefits once the Minimum Health Benefits bill is adopted. These drawbacks in the Minimum Health Benefits bill stem not from a lack of awareness of the health care needs of persons with disabilities but from the political and economic constraints of trying to design a benefit package which relies on private health insurers and at the same time is affordable to the smallest employers.

To further relieve pressure on small employers, the Minimum Health Benefits bill requires small employers with fewer than ten employees who have been in business for less than two years to offer only a low cost catastrophic plan to their workers, while the bill is phased in over a five year period for very small employers of five employees or less. The new version of the Kennedy bill is expected to create a small "hardship fund" which would provide a federal subsidy for small employers who would exceed five percent of gross revenues from complying with the employer mandate. The federal subsidy would provide 75 percent of the premium costs over 5 percent of gross revenues. This type of limited public subsidy for small employers already exists in Hawaii which has required almost all employers to provide health insurance to their employees since 1974 (see page 44).

Of course, it is possible to conceive of an employer mandate bill that requires adequate comprehensive health insurance coverage for all persons with chronic illness or disability. However, such a bill would impose severe financial burdens on certain employers and might create major disincentives for employers to hire persons with disabilities. The Kennedy bill attempts to get around these constraints by requiring all employers to provide minimum benefits or face civil penalties for non-compliance.

While the original version of the Minimum Health Benefits bill targeted only the employed population, the revised Kennedy bill called the **Basic Health Benefits for All Americans Act** will add a major public program component to extend health care coverage to all uninsured Americans not covered by employment-based health insurance or by other public insurance. Borrowing certain

concepts from the Med-America bill (see pp. 79-80), the revised Kennedy bill envisions phasing-in over the next ten years a public plan that will provide the identical benefits required under employment-based plans.

The first phase of the public program will cover all uninsured Americans who are below the poverty line and will be implemented simultaneously with the private program. These persons will not be expected to pay premiums, deductibles or copayments. Moreover, individuals under 100 percent of poverty who receive coverage from an employment-based plan will be able to apply to the public plan for payment of their deductibles and co-payments as well as the employee's share of the premium.

The second phase of the public program to be implemented by 1996 would provide coverage for uninsured persons between 100-185 percent of the poverty line. These persons could be charged a sliding scale premium, at state option, which would be limited to 3 percent of gross income, with deductibles set at maximum of \$125 per individual and \$250 per family, and an out-of-pocket cap set at a minimum of one-third of the requirement for private plans. States would have the option of imposing an income-related out-of-pocket cap equal to a maximum of ten percent of income.

The third phase of the public program would be implemented in 1999 to cover all remaining uninsured persons with incomes above 185 percent of poverty. Their premiums would be set at the actuarial cost of coverage for all enrollees in the public program (i.e. a community-rated premium) and their co-payments and deductibles would be set at the same levels as private, employment-based plans.

Although not explicitly identified as Medicaid, the public program would be financed by the Federal government matching eligible state expenditures at Medicaid matching rates, and the public program would be administered by the states under Federal guidelines. Among other things, these Federal guidelines would ensure that states provide payment rates at levels adequate to assure access to providers who would not be allowed to impose additional charges on program enrollees beyond allowed co-payments and deductibles.

An alternative employer mandate bill (H.R. 4951) which addresses the health insurance needs of all persons whether or not they are employed has been proposed by Congressman Pete Stark (D-CA), Chairman of the Ways and Means Subcommittee on Health in the House of Representatives. Stark's bill called the **Employee Health**

Benefit Improvement Act of 1988 would require all employers to provide health insurance to their employees and dependents or contribute to a state health insurance pool.

Employed persons and their dependents as well as individuals who are not employed could purchase health insurance through the state insurance pool. Premiums for the state insurance pool could vary by health status or pre-existing conditions but would be capped at 150 percent of standard group policies in the state. (The next version of this bill may drop this premium cap to 120 percent of standard group policies in the state.) Employers must contribute 80 percent of the premium cost for the employee and dependents and low-income employees would be eligible for a low income tax credit to subsidize the employee's share of the premium. Benefits in the Stark bill would be subject to an annual deductible of up to \$1000 per individual or \$1,500 per family. Once the deductible is reached, there would be no further copayments. After premiums are collected, the losses for the state health insurance pool would be paid by all employers in the state in proportion to each employer's wages paid in the state.

The primary contributions of the Stark bill are the concept of a state health insurance pool for all persons (regardless of health status) who are not enrolled in large group plans and the use of low-income tax credits to help subsidize the premium costs of low income persons. While the development of the Kennedy bill involved a lot of time defining the specific minimum health benefits that would be required by the employer mandate, the Stark bill proposes to use the Medicare benefit package as the standard for the mandated health insurance benefit in the state health insurance pool as well as in all employer provided health insurance plans. To the Medicare benefit package, the Stark bill will add maternal and child health services. While the Medicare benefit package is often more comprehensive than basic health insurance as opposed to major medical private health insurance, Medicare provides a much poorer mental health benefit than is proposed for Kennedy's Minimum Health Benefits bill. The Stark bill has used the Medicare benefit package largely as a "place-saver" which could be modified to accommodate budget constraints.

From a disability perspective, these two mandated health insurance bills each propose significant steps in increasing access to health care for many persons who are denied access because of an unwillingness of employers to contribute to their health care or because of pre-existing

condition exclusions. However, relying largely on employer contributions to avoid a major federal cost, neither bill guarantees access to the full range of health related services needed by many persons with disabilities or chronic illness. Nevertheless, the fate of these bills can be highly significant to persons with disabilities or chronic illness for three reasons.

The implementation of either bill will enable many persons with pre-existing conditions to purchase health insurance at a more affordable price than they can do now even if the benefit package is inadequate for their needs. Secondly, the passage of either bill will greatly reduce the total number of uninsured persons at minimal federal expense which reduces a major obstacle to targeting additional federal dollars to various groups who are not adequately served by the private and public health insurance systems. As long as 35-37 million persons remain uninsured in the U.S., including 11.2 million persons below poverty and 10.4 million persons between 100-200 percent of poverty⁶⁵, it is difficult to generate political support for allocating public funds to persons over 200 percent of poverty who cannot purchase adequate and affordable health insurance because of pre-existing conditions. Thirdly, if employers are unwilling to contribute adequately to the health care needs of their employees and dependents, this calls into question the effectiveness, efficiency, and equity of previous public policies which created incentives for publicly-subsidized employment-linked private health insurance. Without an employment-linked health insurance system, the U.S. can begin to consider various ways of restructuring health care financing policy along the lines of various national health insurance systems which exist in Canada, Europe, and all industrialized democratic societies.

On the other hand, if the final version of the Kennedy bill is modified to exempt small employers from providing the minimum level of benefits or provides a more restrictive definition of the eligible employee, then the number of uninsured persons who are likely to be covered by this employer mandate approach will be substantially lower. Not only will this defeat the purpose of substantially reducing the number of uninsured persons, but it will impose a federal mechanism that will preempt state mandates and could make it more difficult to create a more comprehensive health insurance system.

⁶⁵Employee Benefit Research Institute, *EBRI Issue Brief*, June 1987, No. 67, Table 2, p. 12.

Existing Federal Mandates for Health Care:

Although private health insurance is regulated at the state level, there is some precedence for Federal mandates affecting health insurance. In the 1970s, Federal law required employers offering health insurance to meet specific requirements. For example, the **Health Maintenance Organization Act of 1973** required that certain employers with 25 or more employees offer an HMO option in their health plan if a qualified HMO existed in their area. In 1978, Congress amended the **Civil Rights Act** to extend the prohibition against sex discrimination in employment to include discrimination on the basis of pregnancy, child birth, or related medical conditions. This required employer health plans to include the services which women need. In 1974, the **Employee Retirement Income Security Act (ERISA)** was enacted at the Federal level to regulate employee welfare benefit plans. Employers who self-insure by assuming the risk for paying health insurance claims instead of paying premiums to an insurance company which takes the risk, are regulated by ERISA rather than by state insurance laws.

In 1986, Congress began to use its authority to determine the conditions under which employer contributions to their employees' health insurance would be tax deductible. According to Title X of the **Consolidated Omnibus Budget Reconciliation Act (COBRA)** employers with 20 or more employees who provide group health coverage are required to offer their employees and their families the option of continued health insurance at group rates for a limited time after the employee leaves the employment as long as the employee pays both the employer and the employees share of the premiums⁶⁶. This Federal mandate was adopted to prevent unemployment from leading to the loss of health insurance. Unfortunately, the COBRA continuation coverage mandate allows the group rate to continue for only 18 months for a worker after termination of employment while the Medicare entitlement for a disabled worker does not begin until 29 months after SSDI has been successfully applied for (see pp.27-28). In the eleven month gap between eligibility for COBRA continuation coverage and eligibility for Medicare, many workers with a disabling condition which has caused them to stop working are forced to become

uninsured⁶⁷. While previous legislative efforts have attempted to extend the COBRA continuation mandate beyond 18 months for workers and 36 months for dependents, these efforts have been staunchly resisted by employer groups. Nancy Pelosi (D-CA) has recently introduced H.R. 2308, 2309 and 2310 to extend the COBRA continuation mandate for 29 months only for workers who terminate employment because of a disability and become SSDI beneficiaries.

Meanwhile, Congress has already adopted a series of employer requirements to make Medicare benefits secondary to those payable under employer group plans for employed individuals 65 years and over. Medicare was also established as a "secondary" payor for disabled individuals who are covered by employer-based health plans with at least 100 employees in order to reduce Medicare expenditures. The General Accounting Office (GAO) is currently trying to determine whether these legislative efforts to treat Medicare as a secondary payor have adversely affected the employment of persons with disabilities.

State Employer Mandates:

Some states are attempting to build their health insurance strategies around employer mandates. As long ago as 1974, the state of **Hawaii** required almost all employers to provide health insurance coverage to employees who work a minimum of twenty hours a week⁶⁸. As a result, 98 percent of employed persons are insured in Hawaii. The state has a fund for subsidizing employers with fewer than eight employees who would have a "hardship" complying with the insurance requirement. Employers are required to pay at least half of the cost of the premium while employees are only obligated to contribute 1.5 percent of their monthly gross earnings towards the cost of the premium. Employees have the option of covering their dependents, but the employer is not required to contribute to their health insurance⁶⁹.

In April 1988, the state of **Massachusetts** passed a law which will require employers to pay a surcharge on their unemployment insurance contributions, beginning

⁶⁶Government employees, seasonal farm workers and workers in family-only businesses are exempted from the law.

⁶⁷American Hospital Association, Promoting Health Insurance in the Workplace: State and Local Initiatives to Increase Private Coverage, 1988, pp. 111-112; also T. Van Ellet, State Comprehensive and Catastrophic Health Insurance Programs: An Overview, Intergovernmental Health Policy Project, October 1, 1981 (out-of-print), pp. 52-58.

⁶⁶Beth C. Fuchs, "Private Health Insurance Continuation Coverage: CRS Issue Brief", Congressional Research Service, The Library of Congress, March 17, 1989, No. IB87182.

⁶⁷This problem has recently been documented among patients served at the Marshfield Clinic by Greg Nyez, Director of the Wisconsin Rural Health Research Center of the Marshfield Medical Research Foundation, Marshfield, Wisconsin, March 1, 1989.

January 1, 1992. The surcharge payment amounts to 12 percent of each full time worker's first \$14,000 in annual wages, a maximum of \$1,680 per employee, which will be used to help finance health insurance for eligible employees and their families. Employers that provide health insurance to their workers can deduct their premium expenses from the surcharge payment, while companies that don't provide coverage must pay the full amount. Unlike an employer mandate that requires all employers to provide health insurance, the Massachusetts law will create a system of incentives and penalties, referred to as the "pay or play option" to encourage employer-based coverage. There is no specific minimum benefit package although the state has mandates on all health insurance policies which require preventive and primary care services for children up to age 6 and certain mental health and alcoholism services.

To avoid resistance from the employers least able to pay, the Massachusetts law exempts employers with less than five employees and new employers from paying the surcharge. The state of Massachusetts will also assist small businesses by providing a small business income tax credit and a corporate excise tax credit amounting to 20 percent of premiums in the first year an employer pays at least 50 percent of its employees' premiums.

The Massachusetts approach was supported by a coalition of: (1) employers who provided health insurance and were subject to an additional tax for the uncompensated care pool which reimburses hospitals for providing health care to uninsured persons including many workers and their dependents who are not covered under employer-based plans, (2) hospitals who want relief from uncompensated care, and (3) consumers who want access to adequate and affordable health care⁷⁰. People with disabilities played a highly visible role in the state-wide coalition clarifying the limitations of private health insurance and demanding greater protection for special health care needs. To accommodate the special needs of persons with disabilities, Massachusetts was the first state to implement a state-funded Medicaid Buy-in program in July, 1988 for disabled children and employed disabled adults regardless of income who cannot get adequate coverage through employer-based plans (see "Medicaid Buy-in", pp. 79-83).

⁷⁰For a critical perspective on Massachusetts's new health insurance law, see Alan Sager, "Prices of Equitable Access: The New Massachusetts Health Insurance Law", *Hastings Center Report*, June/July 1988, pp. 21-25; and "Health Care for All And Not a Penny More: A Proposal", *Health/PAC Bulletin*, Spring 1988, pp.21-26.

The capacity of individual states to impose mandates on employers is limited by the competitive process of attracting private business. The willingness of Hawaii and Massachusetts to require employers to provide health insurance has been attributed to the geographical isolation of Hawaii and the robust economy of Massachusetts. A Federal mandate on all employers would probably be necessary in order to significantly extend health insurance to the working uninsured and their dependents throughout the U.S.

State mandates on insurers:

While employers have increasingly been subject to federal mandates, the powerful health insurance industry has managed to avoid regulation at the federal level and remain subject to laws only at the state level. State regulations are chiefly designed to ensure that insurance plans remain solvent safeguarding the interests of stockholders and enrollees. States have also passed various laws governing the eligibility, benefits, and renewability of health insurance plans. Some of these mandates apply to group plans only while other regulations apply only to individual plans.

Prior to 1965, there were only two state mandates compared to over 645 state mandates by 1986 according to the Blue Cross Blue Shield Association⁷¹. Using a schema based on "who, what, when, and where", Scandlen divides health insurance mandates into laws covering: (1) **providers** [payment for services by a type of practitioner]; (2) **benefits** [coverage for specific conditions or treatment methods]; (3) **beneficiaries** [coverage for particular categories of dependents under a plan]; and (4) **continuation** [conditions for the continuation or conversion of the health insurance plan]. These mandated benefits do not actually represent all of the regulations which affect how health insurance is sold but only those regulations which pertain directly to the health insurance contract. For example, although most states have laws which prohibit discrimination against persons with disabilities which are not based on relevant actuarial statistics, regulations of the medical underwriting process or even the premium setting process are not represented in the above typology.

The most common health insurance mandates (occurring in 30 or more states) are coverage for psycholo-

⁷¹Greg Scandlen, "The Changing Environment of Mandated Benefits" in *Government Mandating of Employee Benefits*, Employee Benefit Research Institute, Washington, D.C., 1987, pp. 177-183.

gists, optometrists, chiropractors, alcoholism treatment, newborn coverage, coverage for mentally and physically handicapped persons as dependents, and conversion privileges. Table 8 indicates the number of states mandating specific benefits or offerings⁷². (See Table 8 on next page)

In the absence of federal minimum benefit laws, state mandates have had an important role in broadening the definition of health care beyond the acute care services that have traditionally been provided in a hospital setting. By determining which services are to be covered through health insurance, state mandates can also influence the distribution of health care costs among those with health insurance. While one could review the state mandates to show how they protect different groups, this section will focus on state mandates that affect access to adequate and affordable health care for people with disabilities or chronic illness.

Provider mandates determine which providers are eligible to receive health insurance reimbursement for services provided outside of hospitals or physician offices. Since persons with chronic conditions may need access to services in their own homes or in community settings, provider mandates can influence which services a person has access to. While most insurance policies will reimburse for rehabilitation therapy provided in a hospital, a few states have adopted provider mandates requiring all insurance policies to reimburse for speech and hearing therapists, physical therapists, or occupational therapists providing services in home and community settings.

Benefit mandates determine whether health insurance will reimburse for such services as home health care, orthotic and prosthetic devices, prescription drugs, and long term care. While the majority of states require coverage for alcoholism and mental health services, orthotic and prosthetic devices are required in only five states, and prescription drugs and long term care are required in only three states⁷³. Some states mandate home health care only for persons who have been discharged from a hospital, while at least one state has mandated home health care as an alternative to hospitalization. No states have mandated home care on a maintenance basis.

A thorough review of state mandates is needed to identify precedents which can strategically increase access to health care for different populations. The range of mandates as well as their particularity is reflected in the following examples. Massachusetts requires group plans to comply with the guidelines adopted by the American Academy of Pediatrics in order to provide an adequate level of children's preventive care. To avoid discrimination against persons with AIDS, California has mandated that if drugs are covered by a health insurance plan that the drug AZT cannot be excluded. Missouri requires that speech language pathology and audiology services are covered in all group plans. Wisconsin mandates that a health insurance policy covering diabetes must provide coverage for installation and use of insulin infusion pump or other equipment or supplies in treatment of diabetes including coverage of diabetic self-management education and the cost of insulin. Minnesota has mandated that reconstructive surgery be provided to dependent children as a result of congenital disease or anomaly. Michigan mandates that Blue Cross Blue Shield maintain open enrollment for individual coverage during the entire year. And the State of Washington has mandated that a pre-existing condition exclusion or rider can be removed if no health care service has been received for the pre-existing condition during the previous five year period.

These examples illustrate different ways that state mandates can increase access to health care for persons with different needs. While very few persons may require surgery for a cleft palate, those persons in the six states which mandate coverage for cleft palate, can receive that service while adding minimally to the individual premium cost of other insured persons in the state. By spreading the risk and cost throughout a larger population, a mandate can enable those in need of care to obtain it while adding little to individual premium cost.

Mandates which define eligibility for health insurance plans can ensure that people with certain needs are not isolated from other insured persons who have the potential of cross-subsidizing their health care costs. For example, thirty-four states require insurance plans to include children above 18 years old with mental or physical impairments as dependents in their parents' health insurance plan if they live with and are financially dependent on their parents. By defining dependents, state mandates can determine who has access to private health insurance and who can be excluded on the basis of pre-existing conditions. Minnesota requires that handicapped dependents must be covered under all policies and that insurers are prohibited from using pre-existing condition limitations

⁷²Some mandate benefit laws require that a specific provision be included in certain categories of policies (e.g. group vs. individual) while others require only that a specific benefit be offered to groups requesting it for which a higher premium can be charged.

⁷³"State Mandated Health Insurance Benefit Laws (Enacted through December 1988)", Blue Cross and Blue Shield Association, Office of Government Relations, Washington, D.C., January 1989.

Table 8: Health Insurance Mandates by Number of States, through December 1988

PROVIDERS	Number of States	BENEFITS	Number of States
Psychologists	38	Alcoholism	40
Chiropractors	38	Mental Health	28
Optometrists	31	Drug Abuse	22
Dentists	28	Maternity	18
Podiatrists	26	Home Health	18
Nurse Midwives	24	Breast Reconstruction	11
Social Workers	14	Ambulatory Surgery	9
Nurse Practitioners	14	Public Institutions	9
Osteopaths	11	Pediatric/Preventive Care	8
Licensed Health Professionals	8	Antiabortion Provisions	7
Nurse Anesthetists	7	Health Centers	7
Nurses	7	Hospice	7
Physical Therapists	7	Cleft Palate	6
Psychiatric Nurses	6	Orthotic/Prosthetic Devices	5
Speech/Hearing Therapists	5	Ambulance for Newborns	4
Occupational Therapists	3	Diabetic Education	4
Oral Surgeons	3	Longterm Care	3
Naturopaths	2	Prescription Drugs	3
Denturists	2	Psychiatric Health Facility	3
Pharmacists	1	Second Opinion	3
School Psychologists	1	Accupuncture	2
Dietician	1	Cardiac Rehabilitation	2
Optician	1	Outpatient Dialysis	2
		Pap Smear	2
		Birthing Center	1
DEPENDENTS		Blood Products	1
		Chinese Medicine	1
Newborns	47	Diabetic Outpatient Care	1
Mentally/Physically Handicapped	34	Hairpieces for Alopecia Areata	1
Adopted Children	13	Home Health Aides	1
Dependent Students	6	Insulin Infusion Pumps	1
Noncustodial Children	2	Liver Transplants in HMO's	1
		Outpatient Psychiatric Center	1
		Prenatal Care	1
CONTINUATION		Pre-admission Testing	1
		OTHER	
Conversion Privilege	33		
Continuation for Dependents	27	Catastrophic Coverage	2
Continuation for Employees	24	Prepaid Health Care Plan	1

Source: Blue Cross and Blue Shield Association, "State Mandated Health Insurance Benefit Laws Enacted through December, 1988," Washington, D.C., January 1989, 8 pages.

for handicapped dependents. With only eight states requiring health insurers to include adopted children as dependents, a major obstacle existed for the adoption of disabled children. To remedy this problem, Congress passed the **Adoption Assistance and Child Welfare Act of 1980** (Public Law 96-272) which provided Medicaid coverage for adopted disabled children covered by the Act, regardless of the income levels of their adoptive families.

Another example of the important role of state mandates concerns newborn infants. Private health insurance companies used to require families to wait for a month before a newborn infant could be covered by the family health insurance plan. During that waiting period it was considered reasonable for the insurer to determine whether the newborn child was in good health and therefore constituted an "insurable risk". If the insurer determined that the infant was "uninsurable", the newborn would not be covered under the family insurance plan. Today, at least forty-seven states have outlawed this medical underwriting practice in both individual and group policies which greatly increases access to health insurance for newborn infants whose families are insured. The state of Montana has mandated coverage for a newborn child even if other dependent children are not covered.

The newborn mandate is an important precedent for considering other ways to regulate the medical underwriting process and the conditions under which people can become eligible for health insurance. With new developments in genetic screening and growing use of medical testing in the workplace, there is a greater opportunity for early intervention in latent health conditions to prevent or at least minimize disabling conditions. Unless the use of this information is carefully regulated, however, private insurers and employers may choose to use it to deny access to health insurance or to employment in order to minimize their own costs. This has important civil liberties implications for citizens and can create important fiscal implications for the Federal government if the private sector is allowed to exclude from private health insurance persons with certain alleged predispositions to chronic health conditions.

Another category of state mandates involves the continuation of health insurance benefits for employees and dependents. The continuation benefits may be critical if an insured employee terminates his or her employment with the employer providing the group plan. Building on a precedent set by a majority of states, in 1986 Congress authorized that group plans provide continuation benefits for employees and their dependents for a specified time

period following the termination of employment for an employee under 65 years old. Interestingly, this federal mandate pertains to all group plans whether self-insured or provided through a private health insurer, while state mandates pertain only to private health insurers. Another type of state mandate limits the power of insurers to terminate coverage for a member of a group because of high health care utilization without treating other members of the group in the same way. Some states require insurers who are taking over a group from a previous health insurer to accept all existing members of the group without medically underwriting persons with pre-existing conditions. Insurers are permitted, however, to medically underwrite late-entrants to a group of any size. With health insurance plans renewed on an annual basis, it is important to consider the conditions under which an insurer can terminate the policy or medically underwrite individuals who have become high health care users.

Besides these state mandates which pertain directly to the insurance contract, many states have adopted laws which prohibit discrimination in health insurance against persons with disabilities that is not based on "sound actuarial principles" or "reasonably anticipated experience". These laws were passed in response to the legal challenges of certain disability groups, like blind persons, who argued that insurers did not have credible actuarial data that blind persons are more prone to accidents than nondisabled persons. In 1979, the National Association of Insurance Commissioners (NAIC) adopted a model regulation on unfair discrimination in life and health insurance on the basis of physical or mental impairment⁷⁴. As of October 1987, 24 states have adopted the NAIC model or similar legislation⁷⁵. As a result, insurers will claim that their medical underwriting decisions are based on actuarial statistics rather than on their inability to predict which persons within a specific diagnostic category will become high health care users.

Unfortunately, the anti-discrimination laws and regulations do not ensure that the actuarial statistics are accurate, recent, or relevant to the needs of the individual who is applying the health insurance. As was pointed out in the section on "medical underwriting" (pp. 16-20), many health insurers rely heavily on the Society of Actuaries' 1983 Medical Impairment Study which utilizes data that is at least ten years old, and fails to recognize improved

⁷⁴1979 Proceedings of the NAIC, Vol. II, pp. 31, 34, 252, 258, 262-263.

⁷⁵NAIC Model Regulation Service, Kansas City, Missouri, 1987, pp. 895-1 through 895-4.

methods of classification, control, treatment, and recovery of persons with various chronic conditions⁷⁶. Nor do the anti-discrimination laws and regulations ensure that the insurance commissioner's office has the staff capacity to review all filings by insurers concerning justifications for different ratings, availability, and terms of coverage, to investigate complaints against insurers which violate the anti-discrimination provisions, or the legal authority to order the private insurer to provide the health insurance under different terms. Some consumer advocates have suggested that the administrative remedy provided by this incomplete mandate may actually interfere with a legal right to sue for a person with disabilities facing unfair discrimination. Regulations are needed to specify the types of data or other justifications for underwriting actions that the state office of insurance commissioner will find acceptable in cases falling under the unfair discrimination laws. Without these standards, major loopholes will continue to exist in laws prohibiting unfair discrimination.

Despite these limitations, without these state mandates, many people who are currently insured may become "uninsurable". This would create a huge financial burden that the government is not prepared to shoulder alone. The Department of Health and Human Services has already estimated that there are approximately 7 million persons who are "insured uninsurables"⁷⁷.

The strategy of relying on state mandates to ensure access to adequate and affordable health care, which was widely used during the mid-1970's, has largely been stalled at the state level in the era of cost-containment. In the last three years, there has been a decrease in the number of new health insurance mandates enacted by the states. Mandates are generally opposed by employers who are the major payors of health insurance because it is thought that mandates will increase their premium costs. Even when mandates can be demonstrated to be cost-effective for certain individuals needing certain types of services such as rehabilitation, it is feared that they will result in higher utilization levels which cause insurers to increase premiums. While employers resist mandates to avoid increasing premiums, insurers oppose mandates which cause employers

to switch from commercial insurance to self-insurance or to drop health insurance coverage altogether.

In a recent attack on state health insurance mandates, Goodman and Musgrave claim that state mandates raise premiums and reduce the number of persons who can afford to purchase private health insurance⁷⁸. On the basis of a statistical analysis correlating the number of state mandates and the number of uninsured persons, Goodman and Musgrave estimate that as many as one out of every four uninsured persons in the U.S. lack health insurance because of the impact of state mandates. Their statistical analysis fails to distinguish among different types of mandates at the state level and they do not consider the expected cost of health insurance without state mandates or the capacity of uninsured persons to purchase a no frills health insurance plan.

Goodman and Musgrave decry state mandates which prevent an insurer from excluding persons with physical or mental impairments, even though most state mandates against unfair discrimination require insurers to make medical underwriting decisions on the basis of actuarial data. To illustrate their point, Goodman and Musgrave emphasize how unfair it is for an insurer to provide insurance to a person who is blind when it is commonly known that blind persons are more prone to accidents and injury. These authors neglect to point out that blind persons won the legal protection of an anti-discrimination law in most states when the private insurance industry was unable to prove that blind persons generally have higher health care needs than non-disabled persons.

In the absence of state mandates, Goodman and Musgrave suggest that people would be able to purchase low cost "no frills" health insurance which would reflect their individual needs. If people are beyond the child-bearing age, there is no reason for them to contribute to the cost of newborn coverage or even well-baby care, and if they do not drink or abuse drugs, there is no reason for them to purchase health insurance coverage for alcoholism or drug therapy much less to contribute to the cost of those services through the requirements of state mandates. The logic of Goodman and Musgrave's position is that people should only pay for the services which they are likely to need and should not be expected to cross-subsidize the health care of others.

⁷⁶A. Frank Thompson, "An Examination of Current Underwriting and Loss Experience Information Used by Insurers to Cover those with Epilepsy: Survey and Insurance Information Report", prepared for the Epilepsy Foundation of America, Washington, D.C., October 15, 1988.

⁷⁷Department of Health and Human Services, Insuring Catastrophic Illness for the General Population, p. i, Office of Health Policy, 1986.

⁷⁸John C. Goodman and Gerald L. Musgrave, "Freedom of Choice in Health Insurance", National Center for Policy Analysis, Dallas, Texas, November 1988.

This view of the insurance principle maximizes "freedom of individual choice" and minimizes the spreading of risk among large groups of persons in order to reduce the costs for each individual. This ignores that people cannot predict what services they might need in the future even though 87.7 percent of working-age persons with a work disability acquired that pre-existing condition after age 18⁷⁹. Moreover, this perspective ignores what the premium cost would be if a service was only paid for by people who needed that service. Instead of estimating the number of uninsured persons in each state who might be able to purchase health insurance without state mandates, it would be interesting for Goodman and Musgrave to consider how many persons with a no-frills health insurance policy would still not be able to purchase the health care services they need because the cost is not cross-subsidized by other policyholders. Finally, their analysis makes no effort to estimate how many persons with health insurance would not have access to certain covered services if state mandates did not exist.

While the existence of specific state mandates illustrate how the regulatory process can reduce gaps in private health insurance, this state level process is at best uneven and reflects the political power of different interest groups at the state level rather than some overarching principles of comprehensiveness of benefits or equity in access or affordability. Persons with disabilities or chronic illness have certain rights of access to private health insurance under certain conditions in several states, but few state mandates address the need for on-going maintenance services. The greatest threat to state mandates, however, is not the arbitrariness of the political process or the general opposition by employers and insurers but the ERISA preemption. No matter how progressive state mandates might be, self-insured employers are not required to follow them. With the majority of group plans accounted for by self-insured employers, this is perhaps the major weakness of state mandates and underlines the necessity for federal regulation of health insurance.

PUBLIC INCENTIVES TO THE PRIVATE SECTOR

While mandates require employers or insurers to act in ways that the profit motive may not dictate, other strategies can create incentives for private health insurers to make private health insurance more accessible to persons with chronic conditions. These public incentive

strategies can be divided into the following seven approaches: (1) high risk pools, (2) public subsidies for the premiums of private health insurance plans, (3) state health insurance plans for the uninsured (and perhaps underinsured), (4) public reinsurance mechanisms, (5) uncompensated care pools to redistribute uncompensated care among health care providers, (6) catastrophic insurance pools, and (7) tax subsidies. All of these strategies, except federal tax policy, are likely to be administered at the state level, although federal legislation could increase the capacity and willingness of states to develop and utilize all of these strategies. This section will concentrate on high risk pools because this option has been presented as a substitute for private health insurance for persons with pre-existing conditions, and because there is extensive operating experience with high risk pools which have existed in various states since 1976. After a critical analysis of high risk pools, the section will conclude with a brief description of other public incentive options which are either designed to subsidize the cost of private health insurance as it currently operates or remains a conceptual approach which lacks a historical track record.

HIGH RISK POOL

Among the options for increasing access to health insurance for persons with chronic illness or disability, high risk pools represent one option that the state can create without any changes in federal law and with the appearance of no state administrative or funding obligations. This section examines how existing high risk pools affect the affordability and adequacy of health insurance benefits for persons with chronic conditions, how equitably they distribute costs, and how they legitimate the concept of "uninsurability". While high risk pools are often presented as an effective strategy to provide private health insurance to persons who have been rejected as "uninsurable" by private insurers, this analysis will consider to what extent existing high risk pools represent good public policy in addressing the problems of **uninsurance** and **under-insurance** among persons with disabilities or chronic illness. In exploring the dilemmas which high risk pools create for persons with pre-existing conditions, this section considers to what extent high risk pools provide a "stepping stone" for expanding the scope of health care services and broadening an entitlement to health care.

The high risk pool appears to benefit: (1) persons with chronic conditions who can afford the high premiums, deductibles, and co-payments but do not have access to private health insurance because of medical underwriting

⁷⁹Access to Health Care, Nos. 1-2, Table 3, p. 17).

practices, (2) private insurers who want to preserve their discretion to disqualify persons with pre-existing conditions but want to protect themselves from paying a disproportionate amount for the health care of high risk persons, (3) health care providers who want to reduce their liability for uncompensated care from uninsured persons with chronic conditions who cannot afford to pay out-of-pocket for their medical bills, and (4) employers who want to avoid paying more for high risk employees than for employees with standard risk.

The concept of high risk pools was originally promoted by the commercial health insurance industry in the mid- 1970s to deflect popular support from National Health Insurance. Recognizing that the public was concerned that many persons with pre-existing conditions were denied access to private health insurance, commercial insurers advocated the creation of a high risk pool at the state level that would sell a major medical health insurance plan to persons who had been rejected by private insurers. Blue Cross-Blue Shield insurers, with a tradition of open-enrollment which has justified their non-profit status, have been less enthusiastic about high risk pools which they have viewed as a strategy by commercial insurers to get them to subsidize the underwriting practices of their commercial competition. As the pressure of cost containment increases in the health care marketplace, the private health insurance industry is increasingly interested in high risk pools. The desirability of the high risk pool from the private insurers' perspective, is that it appears to provide a practical solution to most persons with disabilities or chronic illness but is actually available only to persons who can afford the high premiums, deductibles, and co-payments; the benefit package is limited to major medical acute care services; and the private insurers are protected from the high costs of high risk persons by distributing the deficit of the high risk pool among all insurers in the state in proportion to their market share.

Existing high risk pools:

A high risk pool is an organization of private health insurers which has been created by the state to share risks associated with a private health insurance plan targeted to persons who are unable to obtain health insurance at a standard rate. The high risk pool is typically governed by a board with a majority of representatives selected by private insurers and a few appointments by the Governor representing consumers with pre-existing conditions, health care providers, the public, and the state Commissioner of

Insurance. The private health insurers include the commercial health insurance companies and Blue Cross and Blue Shield Plan operating in a state as well as health maintenance organizations in twelve of fifteen states with high risk pools.

Fifteen states have passed legislation establishing a high risk pool, but only seven states have high risk pools which have been in operation for three or more years. Table 9 represents the salient characteristics of the fifteen states which have enacted legislation creating high risk pools (see Table 9 on next page).

Eligibility requirements:

In most states with high risk pools eligibility depends on being rejected by one or two private insurers, facing a premium which exceeds the premium level in the high risk pool, or receiving a notice of a benefit reduction or a restrictive rider which limits medically necessary treatment because of a pre-existing condition. These criteria ensure that the high risk pool isolates persons with pre-existing conditions from other uninsured persons and from persons with group coverage.

A few states have identified certain chronic conditions which automatically qualify for eligibility in the high risk pool, but other states have been reluctant to develop such a list for fear of legitimating the disqualification of many insured persons from private health insurance. High risk pools are supposedly for persons who are considered "uninsurable", but there is nothing inherently uninsurable about people with chronic illness or disabilities. While insurance actuaries may choose to reject persons with certain pre-existing conditions who apply for individual coverage or coverage in small groups, many people with comparable health status are in fact members of large groups and thus receive private health insurance through their group policies. The problem lies not in their health related needs but in the viability of the financing mechanisms for distributing costs. In a sense, **medical uninsurability has more to do with the size of the group with which one shares risk than with the nature of one's health care needs.**

There is only one high risk pool which does not exclude persons with low risks. This first high risk pool was created in Connecticut in April 1976 and actually functioned as an uninsured pool for low and high risk individuals, guided by the principle of open enrollment

Table 9: Characteristics of State High Risk Pools

State	Year Enacted	Premium Cap	Annual Premium (1986)*		Highest Deductible	Lowest Deductible	Highest Deductible	Lowest Deductible	Stop-loss for Deductible and Copayments	Risk pool enrollment (end of 1987)	Estimated Target Population** (1985)	Percent Target Population Enrolled (1985)	Total Assessment in Thousands (1987)	Change in pool deficit between 1983 and 1986
			Age 30 (female)	Age 60 (female)										
Connecticut	1976	125% min. 150% max.	\$856	\$1,521	\$2,335	\$3,684	\$1,500	\$400	\$2,000	2,209	27,610	8.0%	\$935	+74%
Minnesota	1976	125% max.	\$477	\$665	\$1,249	\$1,645	\$1,000	\$500	\$3,000	12,300	36,690	33.5%	\$11,280	+127%
Wisconsin	1981	150% max.	\$1,192	\$1,192	\$1,904	\$1,904	\$1,000	\$1,000	\$2,000	2,476	41,590	5.9%	\$1,200	-58%
N. Dakota	1981	135% max.	\$715	\$919	\$1,383	\$1,778	\$1,000	\$150	\$3,000	1,463	5,980	24.5%	\$1,510	+607%
Indiana	1981	150% max.	\$1,398	\$2,713	\$2,511	\$4,781	\$1,000	\$200	\$1,000 - \$2,000	2,610	48,560	5.4%	\$2,883	+2,805%
Florida	1982	150% min. 200% max.	\$1,164	\$1,552	\$2,956	\$3,941	\$2,000	\$1,000	\$2,500 - \$3,500	1,562	93,660	1.7%	\$1,827	NA
Montana	1985	150% min. 400% max.	NA	NA	NA	NA	\$1,000	?	\$5,000	32	7,290	0.4%	\$45	NA
Tennessee	1986	150% max.	\$746	\$1,271	\$1,273	\$1,775	\$2,000	\$500	\$1,500 - \$2,500	790	41,060	1.9%	\$0	NA
Nebraska	1986	135% min. 165% max.	\$987	\$1,364	\$1,832	\$2,386	\$1,000	\$250	\$5,000	390	13,890	2.8%	\$300	NA
Iowa	1987	150% max.	\$963	\$1,065	\$1,678	\$1,962	\$1,000	\$500	\$1,500 - \$2,000	276	24,720	1.1%	\$60	NA
New Mexico	1987	150% max.	NA	NA	NA	NA	\$1,000	\$500	\$1,500 - \$2,000	0	13,110	0%	\$0	NA
Illinois	1987	135% max.	NA	NA	NA	NA	\$1,000	\$250	\$1,500	0	101,510	0%	\$0	NA
Washington	1987	150% max.	NA	NA	NA	NA	\$1,000	\$500	\$1,500 - \$2,500	0	39,060	0%	\$0	NA
Maine	1987	150% max.	NA	NA	NA	NA	\$1,000	\$500	\$1,500	0	10,100	0%	\$0	NA
Oregon	1987	150% max.	NA	NA	NA	NA	?	?	?	0	23,320	0%	\$0	NA

* Premium data for Wisconsin is based on 1987 figures. Premium data for North Dakota is based on 1985 figures.

**Computed from the U.S. Department of Commerce, Bureau of the Census, 1986, based on Bovbjerg and Koller's (1986) assumption that about one percent of the under 65 population is "uninsurable."

Sources: Communicating for Agriculture, Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis, Minneapolis, Minn., Third Edition.

October 1988; Premium data from ibid., Second Edition, September 1987. Data on changes in pool deficits from U.S. General Accounting Office, Health Insurance: Risk Pools for the Medically Uninsurable, Washington, D.C., April 1988, GAO/HRD-88-66, Table 9, p. 19.

practiced in Connecticut's Blue Cross/Blue Shield group plan. Blue Cross/Blue Shield permitted open enrollment in its uninsured pool for individuals, while the commercial insurers operated a separate high risk pool for persons who they considered "uninsurable". By combining low and high risk persons in its uninsured pool, Blue Cross/Blue Shield attracted a larger enrollment which permitted it to keep its community-rated premium rates down, avoid deficits during several years, and minimize the pattern of adverse selection which is typical of all other high risk pools⁸⁰. Although applicants to Blue Cross/Blue Shield's uninsured pool after 1984 were referred to a merged high risk pool administered by commercial insurers when Blue Cross/Blue Shield changed its corporate status in Connecticut, low risk persons are still permitted to participate in Connecticut's single high risk pool. Nevertheless, the merged pool has tended to concentrate high risk persons, reducing the opportunities for cross-subsidization by low risk persons.

Affordability:

Concentrating high health care users in a high risk pool raises costs, creates pressure for higher premiums and limited benefits, and guarantees adverse selection which further reduces opportunities to spread risk. Excluding low risk persons from participating in a risk pool ensures that the average health care costs for persons with pre-existing conditions will be very high. To the extent that premiums are designed to reflect the actuarial experience of high risk pool enrollees, the premiums will necessarily be extremely high too. To guard against premiums being set at a totally unaffordable level, however, premium rates are capped in the state legislation establishing a high risk pool. In most high risk pools the maximum premium rate is currently set at 150 percent of the standard individual health insurance premium for comparable coverage. With individual premiums for comparable coverage likely to be significantly higher than standard group premiums, the actual cost of the premium to an enrollee in a typical high risk pool may be closer to 200 percent of a standard group premium. Connecticut is the only state which bases the premiums for its high risk pool on the average group premium rate offered by other insurers in the state. The lowest premium cap is 125 percent in Minnesota's high risk pool and the highest maximum premium is 400 percent of standard individual rates in Montana's high risk pool.

In addition to a high premium, enrollees in existing high risk pools are generally required to pay a high deductible of up to \$1000 before the high risk pool will pay on any claims. Florida and Tennessee have a maximum deductible of \$2000. While most low risk persons with standard health insurance can avoid paying the deductible because they do not use high levels of health care services, high risk persons are likely to have to pay the deductible as well as the premium in order to receive the health care services which they need. Many states offer a choice of different levels of deductibles with higher deductibles associated with lower premiums.

The third cost faced by enrollees in all existing high risk pools is a 20 percent co-payment on all covered services⁸¹. For health care expenses of \$5,000, a 20 percent co-payment would add an additional \$1000 plus the deductible to the enrollee's out-of-pocket costs. To protect the high risk pool enrollee from the cumulative impact of the deductible and the co-payment, states have established out-of-pocket cost-sharing limits ranging from \$1000 in Indiana to \$5000 in Nebraska and Montana. These cost-sharing limits do not include the cost of the premium which is also likely to be paid out-of-pocket.

The cumulative cost of the premium, deductible, and co-payment in most high risk pools can easily total between \$3,000-\$4,000 per person for covered services alone. This estimate does not even include the impact of the waiting period for pre-existing conditions during which covered services may not be covered. While persons without pre-existing conditions are not eligible to participate in a high risk pool, those with pre-existing conditions are subject to a waiting period of between 6-12 months during which treatment for pre-existing conditions may not be covered. In some high risk pools, however, the waiting period for pre-existing conditions may be waived if the enrollee has already complied with a similar waiting period under previous coverage which was involuntarily terminated. Insurers have created waiting periods in order to discourage high risk persons from enrolling just before they need expensive health care services. Since all of the high risk pools impose waiting periods for pre-existing conditions, the out-of-pocket costs can be even higher in the first year of enrollment. In light of the high turnover which occurs in high risk pools (e.g. over 25 percent per year in Minnesota's high risk pool), the limitation on coverage for pre-existing conditions adds substantially to the out-of-pocket costs. For all these reasons, existing high

⁸⁰Randall R. Bovbjerg and Christopher F. Koller, "State Health Insurance Pools: Current Performance, Future Prospects", *Inquiry*, 23, pp. 111-121, Summer 1986.

⁸¹Only Nebraska has a 10 percent co-payment for its high risk pool.

risk pools have largely been unaffordable to many persons with disabilities or chronic illness.

Wisconsin is the only state to have implemented a premium subsidy in order to reduce the cost to high risk pool enrollees. Since July 1985, approximately one-third of the participants in Wisconsin's high risk pool have received an income-adjusted premium subsidy ranging from 17-33 percent of the premium cost. Eligibility for the premium reduction is available to persons with incomes below \$16,500. Even with the maximum subsidy, however, the premium for the high risk pool is still higher than individual standard premium. Recognizing that the high deductible was also a major barrier to affordability, Wisconsin developed an income adjusted subsidy for its deductible in 1988 which can reduce the deductible from \$1000 down to \$500. These initiatives were taken in Wisconsin in response to surveys of its high risk pool enrollees which revealed that 59 percent of enrollees reported that the premiums were too high and 72 percent of enrollees reported that the deductibles were too high. Maine is about to become the second state to develop a premium subsidy for its recently formed high risk pool.

Adequacy of benefits:

High risk pools are often described as "comprehensive health insurance associations" in the legislation in which they are established. While the high risk pool benefits are more comprehensive than most individual health insurance plans, they generally cover a broad range of health services comparable to those covered through major medical catastrophic plans offered by large and medium-sized employers. Although high risk pools are targeted to persons with major health conditions, the benefit package does not generally cover any services that are not included in a standard major medical health insurance plan. Among the services likely to be covered in most high risk pools are: inpatient hospitalization, physician services, prescription drugs, diagnostic X-ray and laboratory tests, oxygen/anesthetics, skilled nursing facility care, home health care, limited mental health care, durable medical equipment (other than eyeglasses and hearing aids), and physical therapy⁸².

⁸²A summary of the program descriptions of each high risk pool (which curiously omits the benefit package of covered services) is provided in Aaron K. Tripler, Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis, Communicating for Agriculture, Minneapolis, Minnesota, Second Edition, September 1987, 386 pages. An updated description without premiums or enrollment forms is provided in the Third Edition, October 1988, 222 pages.

As with other private health insurance, these health care services are likely to be paid for on an acute care basis but not on an on-going maintenance basis. That is to say that the high risk pool is not likely to pay for home health care, durable medical equipment, or physical therapy on an on-going maintenance basis, nor will it generally pay for disposable medical supplies, non-prescription drugs, occupational therapy, or attendant services that might be needed on a maintenance basis. This is a significant limitation for a health insurance plan that is targeted to persons with chronic needs who may need access to health care on a maintenance basis in their own home or in a community setting in order to live as independently as possible. In the absence of these health related services, many persons with thin margins of health may have difficulty preventing deterioration of existing capacities or exacerbation of their chronic condition. Several high risk pools also impose a lifetime maximum benefit of \$250,000 which is often too low for many persons with high health care needs.

Maintaining that the purpose of high risk pools is to sell health insurance rather than to provide welfare, the Boards of Governors of high risk pools which are mostly dominated by the private health insurance industry have resisted efforts to expand coverage to health related needs that are not covered by standard health insurance. Aaron Tripler, a prominent advocate for high risk pools, has consistently argued that high risk pools should not be expected to cover any services that are not included in standard major medical insurance plans⁸³. Unwilling to provide coverage for on-going maintenance services, no high risk pool has been willing to offer a wrap-around plan to supplement the limitations of private health insurance even though most persons with disabilities or chronic illness are under-insured rather than uninsured.

Low enrollment:

The combination of high consumer costs and limited benefits has discouraged participation in existing high risk pools. While advocates for high risk pools estimate that there are 1-2 million "medically uninsurable" persons under age 65 (i.e. 1 percent of the non-elderly population), the total number of enrollees in high risk pools was only 23,000 persons at the end of 1987. Moreover, almost half of all these enrollees were in Minnesota's high

⁸³Debate on "Pros and Cons of High Risk Pools" at Michigan Coalition for Access to Health Care Conference, Lansing, Michigan, December 8, 1987.

risk pool. This is significant because Minnesota has the lowest premium (capped at 125%) suggesting the importance of affordability in providing access to health care. If the 1 percent estimate is used for defining the target population for high risk pools in each state, only a fraction of the target population is covered in the states with operational high risk pools. According to an update of the enrollment data presented by Bovbjerg and Koller⁸⁴ for 1986-87, high risk pools enrolled only 1.7 percent of the target population in Florida, 2.8% of the target population in Nebraska, 5.4% of the target population in Indiana, 5.9% of the target population in Wisconsin, 24.5% of the target population in North Dakota, and 33.5% of the target population in Minnesota (see Table 9). Many of those who are unable to obtain health insurance due to pre-existing conditions are not likely to be able to afford the high premiums and deductibles associated with high risk pools. Data from the Survey of Income and Program Participation (SIPP, 1984) analyzed in the previous policy bulletin revealed that 61.2% of working-age persons with a work disability who were uninsured had monthly incomes \$400 or less⁸⁵. Since this group is not eligible for group coverage, it is reasonable to assume that many of them are out of the labor force, unemployed, or self-employed, and not likely to afford the high out-of-pocket expenses of a high risk pool.

Despite the previous pattern of low enrollment in existing high risk pools, recent data from Wisconsin reveals a significant expansion in enrollment from 2589 persons to approximately 4000 persons between February 1988-February 1989⁸⁶. Explanations vary for this huge increase of 55 percent in enrollment in one year. One explanation is that the public subsidy for the premium and deductible in conjunction with a reduction in premium rates below 150 percent of standard rates has significantly increased the affordability of Wisconsin's high risk pool. Public awareness has also been raised by the state's new marketing strategy to publicize the availability of the high risk pool through drivers' license renewal notices. However, George Marvin, the Mutual of Omaha administrator of the high risk pool in Wisconsin and several other states,

attributes the increase in enrollment largely to more restrictive medical underwriting by private health insurers⁸⁷.

Besides the barriers of unaffordability, some observers have speculated that the low enrollment in high risk pools might reflect inadequate marketing strategies (e.g. insufficient use of radio, TV and brochures in drivers' license renewals publicizing the benefits of the high risk pool) and the low financial incentives (e.g. \$25-\$75) for insurance agents to help persons with pre-existing conditions to enroll in high risk pools. Perhaps a more important explanation is that the insurance industry has had very little incentive for high risk pools to grow under the present conditions.

Financing of high risk pools:

Although high risk pools were intended to be self-supporting through premium income, most high risk pools incur losses that must be financed through assessments on private insurers. These high risk pool deficits are distributed among all private insurers in proportion to the value of the insurance which they sell in the state. To reduce the burden of these high risk pool deficits, there is a tendency for private insurers to exert pressure through the Board of Governors of the high risk pool to raise the premiums or reduce the benefits. Under these conditions, increased enrollment of high risk persons would likely increase the size of the high risk pool deficit for which the private insurers would be financially responsible.

While the deficit of the high risk pool is distributed among all private insurers in the state (including health maintenance organizations), self-insured employers have managed to avoid contributing to the high risk pool. Self-insured employers have successfully challenged the states' authority to tax their health insurance plans because of the federal ERISA preemption of state regulations for employee benefit plans of self-insured firms. With self-insured employers accounting for almost half of all persons with group insurance in many areas, the burden of the high risk pool deficit falls exclusively on private insurers. To mitigate this burden on private insurers, many states have provided tax credits to private insurers reducing their state premium tax or state income tax obligations on a dollar for dollar basis for the amount of their assessment for the high risk pool. In this way, state revenues are indirectly sub-

⁸⁴Randall R. Bovbjerg and Christopher F. Koller, "State Health Insurance Pools: Current Performance, Future Prospects," *Inquiry*, 23: 111-121, Summer 1986.

⁸⁵Access to Health Care, Nos. 1-2, Table 16, p. 50.

⁸⁶Wisconsin Office of Commissioner of Insurance, Madison, Wisconsin.

⁸⁷Personal communication with George Marvin, Mutual of Omaha, Omaha, Nebraska.

dizing the high risk pool deficit even when private insurers are financially responsible.

To get around the ambiguity of state responsibility for the high risk pool deficit, the state of Illinois is planning to finance its high risk pool deficit directly out of state revenues, and the state of Maine is planning to finance its high risk pool deficit through a tax on hospitals' gross patient services revenues. Maine has resorted to a hospital tax as a way to capture contributions from self-insured employers along with private insurers. To discourage insurers from "dumping" many people with chronic conditions out of private health insurance plans, New Mexico will provide a 30 percent tax credit only on assessments which exceed \$75,000 per year. Meanwhile, Minnesota, which has the largest number of high risk pool enrollees and the greatest high risk pool deficit, has recently ended its premium tax credit to insurers under the pressure of budget constraints.

In order to spread the costs for high risk persons to the broadest possible segment of society, it is important that the high risk pool be subsidized not only by self-insured employers but also by employers who carry no health coverage at all. Private insurers would prefer to see states capture this subsidy by applying a payroll tax to all employers rather than assessing health insurance for pool losses.

Is a high risk pool good public policy?:

While existing high risk pools have made health insurance available to some persons who had been shut out of private health insurance because of pre-existing conditions, it is important to consider whether support for a high risk pool is good public policy. Some health care advocates view high risk pools as a strategic incremental step in expanding private health insurance to the uninsured while accommodating the needs of persons with pre-existing conditions who are rejected by private insurance. Confronted by the high consumer costs of high risk pools, some advocates of high risk pools seek legitimacy by explaining that high risk pools are appropriate only for higher income individuals who can afford them. Other proponents of high risk pools who are concerned about the health care needs of a broader group of persons with disabilities and chronic illness have considered what it would take to improve high risk pools from a consumer point of view⁸⁸. While it is easy to recommend expansion of public subsidies for premiums and deductibles and the addition of on-going maintenance

services, it is important to consider whether these changes are realistic given the structure and experience of existing high risk pools.

On the basis of the experience with existing high risk pools, it is important to consider: (1) the viability of a financing mechanism which is based on concentrating high risk people in one pool, (2) the inequity of making a quasi-public subsidy available only to people who can afford the high premium, deductible, and co-payment, (3) the inequity of requiring private insurers to absorb the deficit without contributions from self-insured employers, (4) the lack of managed care in high risk pools which could contain unnecessary costs and increase the coordination among fragmented services, and (5) the danger of creating incentives for private insurers to expand the definition of "uninsurables" in order to **dump** high cost users out of private insurance plans.

While a high risk pool can make a big difference in the life of a person who has been denied access to health insurance, the question which needs to be considered is whether the high risk pool is the most appropriate mechanism to provide health insurance to persons with pre-existing conditions. An examination of the characteristics of persons who enroll in high risk pools may provide some basis for judging whether high risk pools are more likely to be effective, cost efficient and equitable than other strategies. These alternative strategies which are examined in this policy bulletin include: **insurance regulations** which can affect medical underwriting, the definition of dependents, and the conditions under which eligibility for private coverage can be continued; **Medicaid buy-in** which permits an income-adjusted premium for a comprehensive health insurance plan that includes access to on-going maintenance services; and **other types of insurance pools** like Medicare or proposed state health insurance plans which could combine high risk and low risk persons and spread the risk over a much larger population.

Unfortunately, data on the participants in high risk pools is not readily available for most states. Only Wisconsin has conducted a detailed survey of the enrollees in its high risk pool. From this survey conducted in 1986, it appears that the majority of Wisconsin's high risk pool enrollees have heart conditions (22%), diabetes (14%),

⁸⁸Harriette Fox, "Final Project Report on the Feasibility of High-Risk Pools to Provide Health Insurance Protection for Children with Special Health Care Needs", Fox Health Policy Consultants, Washington, D.C., May 1988.

high blood pressure (11%), or cancer (9%)⁸⁹. Although many of the advocates for high risk pools expected them to provide a mechanism for persons with disabilities to purchase insurance if they could not get it through their employment, persons with chronic illness seem to be the primary consumers of high risk pools. Moreover, almost two-thirds of the participants in Wisconsin's high risk pool are over 50 years old with the largest single group being women 50-64 years old, reflecting the high vulnerability of displaced homemakers who became divorced or wives whose husbands retired or died. Finally, of the 39 percent of enrollees who are currently employed (26 percent of all enrollees are employed full time), 78 percent are employed in workplaces with fewer than 10 employees. Not surprisingly, health insurance is not offered as an employee benefit in 75 percent of their workplaces. Among all enrollees in Wisconsin's high risk pool, 70 percent were employed prior to participating in the high risk pool.

This profile of participants in one high risk pool reveals many of the gaps in our employment-linked health insurance system. Some of these gaps can probably be better filled by regulations governing continuation of benefits, definitions of dependents, and the medical underwriting practices than by creating a financing mechanism for persons who are pushed through the cracks. While the characteristics of Wisconsin's high risk pool enrollees may be different from other states without a subsidy for premiums or deductibles, the profile of Wisconsin's enrollees provide a basis for assessing the adequacy of the high risk pool model in the absence of data from other states.

While high risk pools enable some people to buy insurance that private insurers would not be willing to sell individually, only those who can afford individual coverage are eligible to have their costs subsidized through this mechanism. The effectiveness of the high risk pool model to subsidize costs is important to consider. Bovbjerg and Koller report that the pro rata assessment charges that pool insurers must pay to make up losses tend to run only about 10 percent of total pool spending each year⁹⁰. On the other hand, Laudicina⁹¹ cites some information from a few high risk pools which suggests that the deficit was as high as 43 percent of the total pool expenses in Indiana and 24 percent of the total pool expenses in Wisconsin in 1986. With a

deficit per enrollee of \$1710 in Indiana, \$768 in Minnesota, and \$368 in Wisconsin for 1986, different high risk pools appear to provide different levels of subsidization for the health care expenses of high risk pool enrollees. Perhaps even more important is whether the state subsidy for high risk pools should take the form of tax credits to private insurers to offset their assessment for the high risk pool deficit or whether the public subsidy should be used to reduce the cost of the premium and deductible for low income persons who are denied access to private health insurance.

The failure of high risk pools to require the contribution of self-insured employers has placed a disproportionate burden on private insurers. Ironically, the ERISA preemption has probably done more to inhibit the spread of high risk pools than any other factor.

Although many high risk persons utilize high levels of health care, high risk pools have made little effort to manage that care to contain unnecessary costs or to increase its effectiveness. In fact, some advocates favor the use of high risk pools for persons with chronic illness because it is assumed that the health care needs of high risk persons cannot be managed by the mechanisms which are likely to be utilized by generic health insurance pools for low risk uninsured persons. Other observers argue that managed care has the potential of generating even greater savings for high risk persons because of the high level of services which they utilize. Some states have recently attempted to promote cost containment in their high risk pools by requiring prior authorization from enrollees before admission to a hospital, administering concurrent review to determine whether medical services are still necessary, and requiring mandatory second opinions for surgical procedures, but no high risk pool administrator has a stake in the financial success of the high risk pool. Wisconsin is also making available on an optional basis (at no cost to the enrollee) care management services provided on a contract basis by rehabilitation consultants⁹².

The hidden danger of high risk pools is that they legitimate discrimination and may discourage private insurers from offering comprehensive plans through the private market (see Figure 8 on next page).

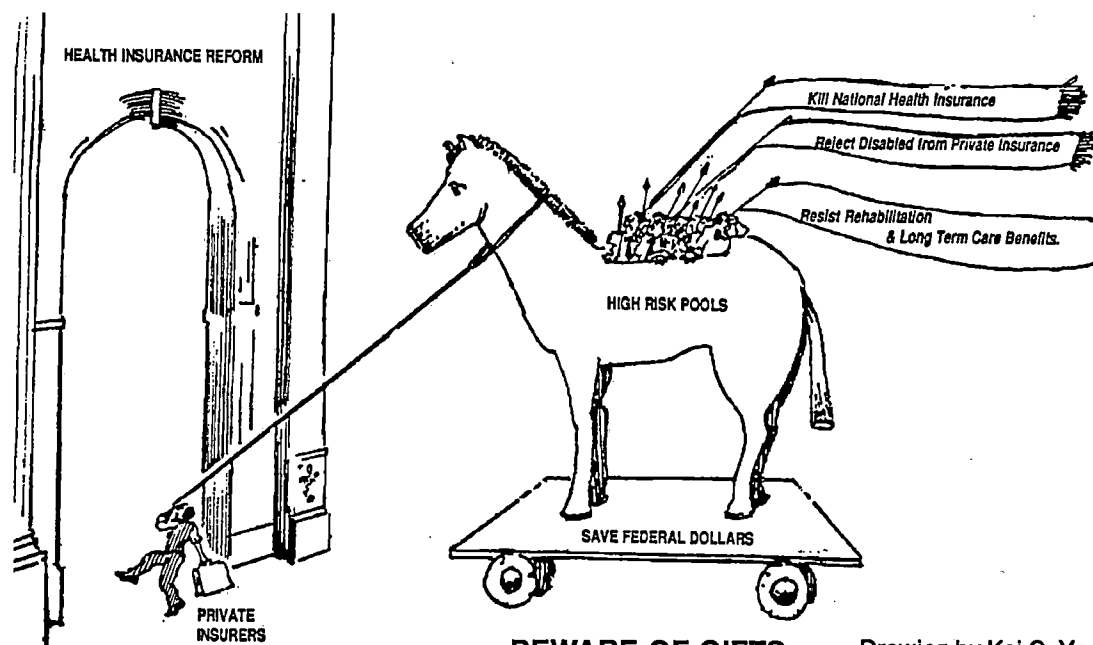
⁸⁹Eve Galanter, "The Wisconsin Health Insurance Risk-Sharing Plan", Office of the Commissioner of Insurance, Madison, Wisconsin, 1986.

⁹⁰Randall R. Bovbjerg and Christopher F. Koller, "State Health Insurance Pools: Current Performance, Future Prospects," *Inquiry*, 23, Summer 1986, p. 117.

⁹¹Susan S. Laudicina, "The Risk Pool Strategy: Comprehensive Health Insurance Associations", Intergovernmental Health Policy Project, Washington, D.C., February 1988, p. 14.

⁹²Personal communication with Rosemary Van Susteren, Wisconsin Office of Commissioner of Insurance, Madison, Wisconsin.

Figure 8



BEWARE OF GIFTS

Drawing by Kai C. Yee

Is this the best horse to ride? Should the disability movement support a high risk pool which offers only major medical benefits to individuals with chronic conditions who can afford \$3,000 to \$4,000 per year, or should we hold out for something harder to win which provides comprehensive coverage (including acute care, prevention, rehabilitation, and maintenance services) for everyone who needs it and distributes those costs among all citizens on an ability to pay basis."

As insurers become more restrictive, the need for high risk pools will increase. At the same time the existence of a high risk pool makes it easier for insurers to become more restrictive in this era of "cost containment". In this way, high risk pools may be thought of not as a pool for sharing risk but as a "trap"⁹³. By creating the illusion of a solution, high risk pools can be used to justify actuarial discrimination. In the absence of appropriate state or federal regulations of the medical underwriting process, private insurers can use their wide discretion to disqualify persons with pre-existing conditions. As long as the state does not have a direct responsibility for absorbing the deficit of high risk pools, the existence of a high risk pool could undermine efforts to develop regulatory strategies to end actuarial discrimination and to distribute health care costs in a more equitable way.

Dilemmas for persons with disabilities:

High risk pools present a real dilemma to persons with disabilities or chronic illness. On the one hand, high

risk pools represent a financing mechanism that can make health insurance available now to people who would otherwise be rejected by the private health insurance system. On the other hand, this solution to access is available only to people who can afford the high costs. Even with premium subsidies and deductible subsidies which exist in only one state (Wisconsin), the high risk pool is not an efficient mechanism to spread risk throughout the population. Concentrating high risk persons in one pool puts a disproportionate burden on persons with chronic health care needs, creates pressure on insurance companies to raise premiums and reduce benefits in the high risk pool in order to reduce their assessments, and invites adverse selection that further reduces opportunities to spread risk equitably throughout the population. Moreover, the benefit package is primarily oriented to acute care needs (reflecting the traditional bias of private health insurance) rather than the maintenance needs of the population which the high risk pool is supposedly designed for. Furthermore, there is the danger that an expansion of high risk pools will lead to dumping from the private health insurance system, although there has been little evidence of this so far.

⁹³Presentation by Bob Griss in *Proceedings of the National Conference on Health Insurance Risk Sharing Plans: What We Have Learned/Where We Are Going*, Wisconsin Office of the Commissioner of Insurance, Madison, Wisconsin, November 9-11, 1986, pp. 40-42; reprinted in *Word from Washington*, United Cerebral Palsy, Washington, D.C., March 1987 and April 1987.

These fears have been fueled by the recent proposal of the Insurance Commissioner in Minnesota, where the largest high risk pool already exists, that employers be encouraged to "carve out" disabled or ill employees from low risk employees as a strategy for reducing group premi-

ums paid by the employer⁹⁴. The Robert Wood Johnson Foundation has already funded a demonstration project in Wisconsin to subsidize the enrollment of high risk workers in Wisconsin's high risk pool as a strategy to expand group coverage among small employers. By encouraging employers to transfer high risk employees into the high risk pool and contributing to the premium an amount equal to that for a nondisabled employee, it is expected that the group premium for the employer should be substantially reduced. It is assumed that this will remove a major obstacle to small employers purchasing group insurance for their employees when one or more employees has a pre-existing condition. In addition, it is assumed that this will increase the willingness of all employers to contribute to the costs of a high risk pool. Recognizing the fiscal implications of an expanded high risk pool where the deficit was already \$15 million in 1988, the Insurance Commissioner in Minnesota is exploring the feasibility of a payroll tax directed to all employers, including those who are self-insured and those who provide no health insurance coverage, as a fairer way to finance the deficit for the high risk pool than an assessment on private insurers.

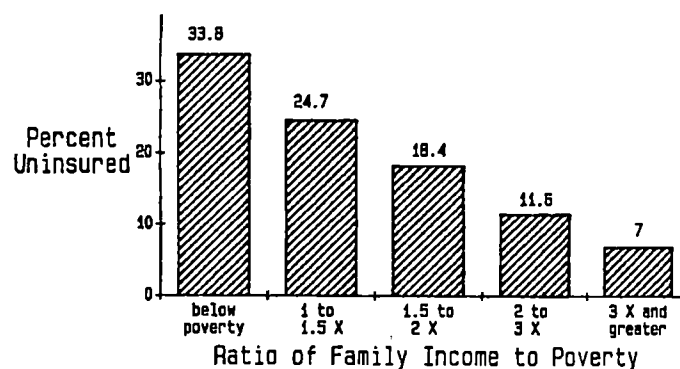
In assessing the strategic value of high risk pools, the disability movement should be concerned how high risk pools affect the federal and state government's interest in regulating medical underwriting practices and in developing mechanisms for spreading risks throughout the population. As states develop health insurance pools for the uninsured, there has been a disturbing trend to create a separate high risk pool to isolate persons with pre-existing conditions⁹⁵. To some extent this represents a response to the unwillingness of private insurers to insure persons in a state pool for the uninsured without the protection of medical underwriting. But there are other possible mechanisms which can be used to distribute costs in an equitable way such as the regional pool concept in the proposed Kennedy bill for Basic Health Benefits for All Americans Act (see pp.) or even some form of reinsurance for private insurers. Although persons with pre-existing conditions are probably less than 10 percent of the uninsured population, how states respond to the uninsured population has profound implications for the coverage of persons with pre-existing conditions as well as for "temporarily able-bodied persons" (i.e. TAPs) who will develop pre-existing conditions at some future time in their lives. The disability movement has to consider whether creating high risk pools is a meaningful step in the direction of closing health care

coverage gaps or whether high risk pools diffuse support and divert momentum from a more substantial restructuring of the health care financing system by appearing to make health care accessible to high risk persons.

Public subsidies for private health insurance premiums:

Among the other public incentives for expanding private health insurance to persons with disabilities or chronic illness are public subsidies for private health insurance premiums. This strategy is often considered as a solution for the uninsured population in general who disproportionately have low incomes. Table 10 indicates that 33.8 percent of persons with family incomes below poverty are uninsured as are 24.7 percent of persons with family incomes between 100-150 percent of poverty (see Table 10).

Table 10: Percent of Persons without Health Insurance by Ratio of Family Income to Poverty Level, 1984



SOURCE: Nat'l Health Policy Forum, "The Uninsured and Uncompensated Care," June 1986. Special tabulations from March 1985 CPS.

Recognizing that many low income persons cannot afford the premiums that private insurers want to charge (especially when the premiums are not subsidized by employer contributions), public subsidies for the premiums of low income persons would have some appeal to private insurers and to small employers. While this strategy might enable low income persons with standard health risks to obtain access to standard health insurance benefits, private insurers are less likely to be willing to insure persons with chronic illness or disability. Private insurers may persist in utilizing pre-existing condition exclusions and may demand a premium rate that far exceeds the average cost of Medicaid for SSI-disabled persons. Yet, even if persons with chronic illness or disability had access to standard health insurance, they still would not be covered for their on-going maintenance health related needs.

⁹⁴Letter from the Office of the Commissioner, Department of Commerce, St. Paul, Minnesota, dated August 1988.

⁹⁵This has recently occurred in the state of Washington and Maine.

State health insurance plans for the uninsured:

Several states are developing state insurance plans to provide health insurance to uninsured persons⁹⁶. Through a state health insurance plan, the state can have greater control over designing the benefit package, exercising leverage over health insurers and health care providers, and administering the program. Some states are targeting their state insurance pools to all uninsured persons below a certain income threshold which might range from 150%-200% of poverty while other states are targeting uninsured persons who are working for small employers, and other states are targeting different age groups of uninsured persons.

Massachusetts is planning to develop a state insurance plan to cover those who would not be eligible for employer mandated coverage or Medicaid. With funds from the state's free care/bad debt pool generated by a surcharge on hospital bills, the Massachusetts plan would subsidize the insurance premiums or purchase a plan for uninsured persons by contracting with private insurance plans.

Hawaii has also recently passed legislation to establish a publicly subsidized state health insurance program to provide basic health insurance to all "gap group individuals" who are not covered by mandated employer coverage or Medicaid⁹⁷.

The State of Washington has launched a demonstration project for its Basic Health Plan to subsidize the premiums with general revenue funds. The state plan will require enrollees to receive health care from prepaid, capitated managed care providers under contract with the state.

Maine is planning to establish a state-funded Medicaid Buy-in program which provides a sliding scale

premium for individuals up to 150 percent of poverty⁹⁸. For those who have private insurance, the Medicaid Buy-in would serve as a "wrap-around" providing coverage for benefits not in existing plans, covering dependents when employer-based insurance is only available to the employee, and subsidizing premiums which exceed 3 percent of gross income as well as copayments and deductibles when certain income criteria are met.

The Robert Wood Johnson Foundation is financing fifteen demonstration projects for the uninsured which are primarily targeted to extending private health insurance coverage to low income, uninsured workers employed by small firms⁹⁹. These demonstration projects exist in Denver, Colorado; Florida; Utah; Boston, Massachusetts; Maine; Michigan; Wisconsin; San Francisco, California; and West Virginia. West Virginia is attempting to use its Public Employees Insurance Board to provide health insurance to small private sector employers, the self-employed and the unemployed. The Public Employees Insurance Board is expected to contract with insurance carriers to offer plans to small businesses (with 50 or fewer employees) while keeping separate the employer-employee premiums from other funds appropriated to the public employees insurance fund. Other demonstration projects supported by the Robert Wood Johnson Foundation include state subsidies to assist low income people to obtain health insurance, a health insurance information and referral service in San Francisco to assist small businesses in obtaining insurance coverage for their employees, a state-wide Uncompensated Care Trust Fund to equitably distribute uncompensated care costs among hospitals in New Jersey, a managed care system for Basic Health Plan providers in Seattle, Washington, and a subsidy for high risk workers employed in small firms to use Wisconsin's high risk pool rather than raise the group insurance premiums to a level that discourages the employer from providing a group plan.

Many of these state health insurance plans are designed to "mainstream" individuals into existing private insurance arrangements rather than incorporating them into the Medicaid program. To achieve this, states recognize the need to create a fund to provide public subsidies for low income individuals to help cover the full premium costs of private insurance coverage. Families with incomes

⁹⁶Another source of information on highlights and trends in state health programs including Medicaid, indigent care programs, and programs for the uninsured is provided by the Intergovernmental Health Policy Project (IHPP) of the George Washington University in Washington, D.C. In addition to the newsletter State Health Notes, IHPP annually produces Major Changes in State Medicaid and Indigent Care Programs, under the direction of Debra J. Lipson, which summarizes the latest information about benefits, eligibility, reimbursement, and administration and management for each state.

⁹⁷State of Hawaii, H.B. No. 1906, C.D. 1.

⁹⁸Special Select Commission on Access to Health Care, "Assuring Access to Health Care", February 15, 1989.

⁹⁹The Robert Wood Johnson Foundation projects on health care for the Uninsured are described in Quarterly Reports and a Program Update newsletter of the Alpha Center, Washington, D.C.

below 150-200 percent of poverty are targeted for a public subsidy which allows them to pay premiums on a sliding fee scale. In the absence of employer mandates to provide health insurance in most states, one constraint on the development of these state health insurance plans is how to avoid encouraging "dumping" from private insurance plans.

Many of these state health insurance plans steer enrollees into managed prepaid health care systems. Besides providing a limited array of health care services, these managed care plans may create certain problems for persons with disabilities or chronic illness as was described in the section on HMOs (see pp. 23-25). To minimize these problems, Massachusetts has already implemented a Medicaid Buy-in plan to complement its state health insurance plan for persons with disabilities, while the state of Washington has instead created a separate high risk pool to divert people with disabilities and chronic illness from its Basic Health Plan. Maine has also recently created a high risk pool but is also developing a Medicaid Buy-in for persons with disabilities.

The American Public Health Association (APHA) which has long been committed to a national health program adopted nine principles for evaluating state health care access programs. Although there was some controversy at its Annual Meeting in November 1988 about whether state health insurance initiatives are an effective strategy for implementation of a national health program, the APHA adopted the recommendations of its Task Force on State Health Insurance, chaired by Patricia Butler. The APHA principles for a state health care access plan include¹⁰⁰.

1. Coverage should be universal and mandatory, regardless of income, age, and health status.
2. Benefits should include at least health screening and assessment, health education, care of acute and chronic illness and disability, rehabilitation, personal preventive health services, and case management of long-term health problems.
3. Financing for the system should be sufficient and equitably derived. If there are multiple sources of financing, beneficiaries should receive services through as uniform a system as possible.

¹⁰⁰State Health Insurance as Part of a National Health Program: A Report to the Executive Board, American Public Health Association, Washington, D.C., March 1988.

4. Premiums should be affordable. Public subsidies should be available for low-income persons.

5. Cost-sharing should not be imposed on certain services or low-income persons. Copayments and deductibles should not be used explicitly to control public or private budgets by shifting cost to beneficiaries.

6. Health care cost containment should be pursued through a variety of strategies. Managed health care system should be considered as a way to promote quality and cost efficiency.

7. State health care access plans should be administered by the state public health agencies with mechanisms assuring public accountability.

8. Administration must include consumer education and outreach, consumer protection, and consumer grievances, including a specified appeals process.

9. Quality assurance systems should be developed to assure that insurance plans provide quality services and access to care.

Reinsurance mechanisms:

To create an incentive for private insurers to charge affordable premiums regardless of the risks involved, it may be necessary to compensate insurers for losses which exceed some threshold level.

The Health Insurance Association of America (HIAA), trade association for commercial insurers, has proposed the creation of a reinsurance mechanism for "uninsurable" employer groups which represent high risks because of their small size or the presence of high risk employees or dependents. The reinsurance mechanism could function as a not-for-profit organization reimbursing insurers who incur a large loss in insuring a so-called uninsurable group. Losses incurred by the reinsurance mechanism could be financed entirely by the private sector sharing costs among all competitors including HMOs, self-insured groups, Blue Cross and Blue Shield associations, and commercial insurers.

Public reinsurance mechanisms have already been used by state governments in getting HMOs to insure Medicaid recipients. In addition, the Medicare Catastrophic Coverage Act of 1988 has required states to compensate

hospitals providing health care to a disproportionate share of Medicaid and low income patients for inpatient hospitalization for infants up to age 1 whose hospital expenses exceed the state's Medicaid limits. The hospitals would be compensated for high cost or exceptionally long lengths of stay with federal and state Medicaid dollars.

Reinsurance mechanisms could reduce the economic disincentives which private insurers have to cover persons with higher risks. A private reinsurance mechanism is more likely to reduce barriers to access for standard coverage, while a public reinsurance mechanism could remove many of the barriers to adequacy and affordability for persons with disabilities or chronic illness.

Uncompensated care pools among health care providers:

At least six states (Florida, Massachusetts, New Jersey, New York, Ohio, and South Carolina) have established uncompensated care pools to collect and redistribute funds to hospitals that have greater proportions of bad debt and charity care because they serve more people without health insurance¹⁰¹. Hospitals are assessed a certain percentage of total costs or gross inpatient revenues which are paid into an uncompensated care pool operated by the state. Hospitals collect this money through a surcharge on the hospital bills paid by all insurers.

Since persons with disabilities are more likely to lack health insurance coverage for health related services delivered outside of hospitals such as durable medical equipment, rehabilitation therapies, drugs, disposable medical supplies, and personal assistance services, this would be a definite limitation of an uncompensated care pool organized around hospital providers. Nevertheless, a surcharge on hospital bills is one way to capture the health care expenditures of self-insured employers and private health insurance, although it probably will not be allowed to increase the expenditures of Medicare or Medicaid.

Catastrophic insurance pools:

Some states have established catastrophic insurance mechanisms to protect persons against medical expenses which exceed a certain level of their income. Rhode

¹⁰¹Debra J. Lipson, *Major Changes in State Medicaid and Indigent Care Programs*, Intergovernmental Health Policy Project, George Washington University, Washington, D.C., p. 18.

Island established a Catastrophic Health Insurance Program (CHIP) in 1975 making the state the payor of last resort for comprehensive medical expenses for permanent state residents¹⁰². CHIP will pay for medical expenses once a CHIP deductible has been paid corresponding to the percentage of an applicant's income spent on eligible health services which are not reimbursable under a health insurance plan. The amount of the CHIP deductible varies inversely with the degree of health insurance coverage creating an incentive for the individual to have purchased a comprehensive health insurance plan. For example, the CHIP deductible is \$500 or 10 percent of allowable income for a fully qualified plan, \$1250 or 25 percent of allowable income for a semi-qualified plan, and \$5000 or 50 percent of allowable income for no health insurance plan.

Another type of catastrophic insurance pool has been created by New Jersey called the Catastrophic Illness in Children Relief Fund. This catastrophic coverage is targeted to children ages 18 or younger, whose medical expenses (not covered by another insurance policy or government program) exceed 30 percent of a family's income up to \$100,000 (or more than 40 percent of family income greater than \$100,000)¹⁰³. The state will raise revenues for this catastrophic program by levying a \$1.00 annual surcharge per employee for all employers subject to the state's Unemployment Compensation law.

While catastrophic insurance can protect against extraordinary medical expenses, it does not provide any payment until a specified level of out-of-pocket payments has been made by the recipient. Functioning as an invisible deductible, the level of out-of-pocket expenses can either be measured in terms of dollar amounts or percentages of a family's income. Persons with disabilities or chronic illness are vulnerable both to the definition of what constitutes an extraordinary financial burden and to the definition of what expenses to include in measuring out-of-pocket costs. To the extent that many relevant health related expenses fall outside the scope of acute care, persons with chronic conditions may fall through the cracks of catastrophic insurance.

Federal Tax Policy:

The Federal government helps finance the purchase of health insurance coverage and medical care through tax

¹⁰²T. Vann Ellet, *State Comprehensive and Catastrophic Health Insurance Programs: An Overview*, Intergovernmental Health Policy Project, Washington, D.C., October 1, 1981, pp. 86-96 (out-of-print).

¹⁰³Lipson, *op.cit.*, p.19.

exclusions, deductions, and credits. Federal "tax expenditures" for health care are expected to total over \$37 billion in 1989¹⁰⁴.

Federal tax law encourages employers to provide health benefits by permitting the costs to be deducted as an ordinary business expense and by allowing the exclusion of employer contributions from employees' taxable income. In addition, individuals who itemize deductions may deduct any qualified unreimbursed medical expenses which exceed 7.5 percent of their adjusted gross incomes.

There are many ways that federal tax policy can be used to encourage more employers to provide group health plans. One way would be to increase the business deduction for self-employed and unincorporated firms from the present 25 percent up to 100 percent of health insurance costs which larger employers can deduct. Tax incentives could also be created to subsidize the premium costs of employers who cannot afford them. On the other hand, the Federal government could disallow employer business expense deductions for health insurance plans which do not meet certain minimum benefit conditions. An important precedent for this type of federal leverage is the requirement that employer group health plans meet the health insurance continuation requirements that were established under title X of COBRA (see p. 44).

The exclusion of employer contributions from the employees' taxable income has recently been subject to a non-discrimination test applied by the Internal Revenue Service to ensure that the employer's health insurance plan does not discriminate in favor of highly compensated employees. Employers are beginning to complain about the cost of complying with these complex Section 89 non-discrimination rules and warn that these rules inhibit increased health benefit coverage for the employed and may cause some employers to drop coverage¹⁰⁵. It is surprising that the Federal government does not have any minimum standards for the nature of the health insurance plan that is subject to this large deduction for health care expenses.

Tax policy is also used to help individuals pay for unreimbursed medical expenses, including: (1) employee

contributions to health insurance; (2) diagnosis, treatment or prevention of disease or malfunction of the body; and (3) the costs of prescription medicines and insulin. By allowing a tax deduction for unreimbursed medical expenses, the government can reduce the cost of services to consumers while allowing them to select the services which they need.

Individuals who itemize deductions may deduct any qualified unreimbursed medical expenses which exceed 7.5 percent of their adjusted gross income (AGI). Between 1954-81, the floor for the medical expense deduction was only 3 percent of AGI. In the last few years, however, the medical expense deduction was raised to 5 percent of AGI between 1982-85, and was further raised to 7.5 percent in 1986. By raising the floor to 7.5 percent of AGI, the medical expense deduction has become more of a cushion against catastrophic expenses in relation to family income than a health care subsidy. Moreover, the medical expense deduction is not available to persons who do not have sufficient expenses (usually related to interest payments on home mortgages) to itemize their deductions. In addition, the medical expense deduction cannot provide immediate compensation for large medical expenses. For all these reasons, the present medical expense deduction is not an effective way to provide a tax subsidy to those most in need of financial assistance.

If the medical expense deduction was transformed into a refundable tax credit (i.e. health care tax credit), it would be much more useful to low income workers. The noted health care economist, Alain Enthoven, has recommended a refundable tax credit or direct subsidy to qualified health plans equal to 60 percent of premium payments up to a limit on subsidized premiums for an individual or family¹⁰⁶. It would be reasonable to adjust upward the tax credit to reflect the higher premiums, deductibles, and copayments for persons with high health care needs. In the Enthoven plan, the qualified health plans would have to meet certain minimum standards and provide community-rated premiums. In this way, tax incentives could be used to reshape the private health insurance system to make it more responsive to user needs, more cost-effective, and more equitably financed¹⁰⁷.

¹⁰⁴U.S. House of Representatives, Committee on Ways and Means, Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means, 1988 Edition, March 1988, p. 596.

¹⁰⁵See Washington Business Group on Health statement submitted for the record to the House Small Business Committee hearing on the impact of new employee benefit rules (Section 89) on small business, January 25, 1989.

¹⁰⁶Alain Enthoven, "Health Tax Policy Mismatch", Health Affairs, Spring 1984, pp. 5-13.

¹⁰⁷Alain Enthoven and Richard Kronick, "Universal Health Insurance in a System Designed to Promote Quality and Economy", New England Journal of Medicine, Vol. 320, No. 1, January 5, 1989, pp. 29-37; and Vol. 320, No. 2, January 12, 1989, pp. 94-101.

MEDICARE EXPANSION OPTIONS

The largest public health care financing program for persons over 65 years old and disabled adults is Medicare. Organized on a social insurance model, Medicare is financed by a payroll tax of 2.9 percent on earned income of people who are currently working and used to pay for the health care of persons who are no longer expected to work because of age or disability. Persons become eligible for Medicare as beneficiaries of the Social Security system to which they, or their family members on whom they are dependent, have contributed through previous employment subject to the Medicare payroll tax.

Modeled after major medical private health insurance for non-disabled persons, Medicare has failed to respond to the special health care needs of persons with disabilities in at least three ways. First, Medicare provides reimbursement for acute care needs but not for the ongoing maintenance health care needs that many disabled and elderly persons have. Secondly, the linkage of Medicare to eligibility for Social Security Disability Insurance (SSDI) has created two additional access problems. One is the two year waiting period for Medicare after eligibility for SSDI has been established, and the second is the work disincentive of losing SSDI and subsequently Medicare, once an SSDI beneficiary earns over \$300 per month.

This section will review various Medicare expansion options affecting eligibility and benefits which are being considered to improve the capacity of the federally administered Medicare program to respond to the health care needs of persons with disabilities or chronic illness. The primary options to expand Medicare include: (1) long term home care, (2) elimination of the Medicare waiting period for SSDI beneficiaries, and (3) the Medicare Buy-in.

Long term home care:

The failure of Medicare to cover long term care needs in one's home or in a nursing home has received much attention in the last few years. Unable to receive publicly subsidized home care services for which there are restrictive eligibility criteria and long waiting lists, many persons with disabilities have had to enter nursing homes where they rapidly spend-down to poverty and become eligible for Medicaid. To avoid the financial consequences of spending down to poverty and to preserve as much independence as possible, elderly and disabled persons

with functional limitations have looked to the creation of a Medicare Part C that could help pay for long term support services that would enable the individual to carry out the activities of daily living, maintain social integration and family supports, enhance consumer self direction, and prevent inappropriate institutionalization.

Congressman Claude Pepper (D-FL), chairman of the Subcommittee on Health and Long Term Care of the House Select Committee on Aging, introduced the **Medicare Long-Term Home Care Catastrophic Protection Act of 1987 (H.R. 3436)** in the last session of Congress to extend the social insurance approach of Medicare to long term home care needs. Widely known as the "Pepper bill", this Medicare expansion would have created an entitlement for home care benefits for persons with functional limitations in two or more activities of daily living (e.g. bathing, dressing, eating, toileting, and transferring). Besides covering elderly persons and SSDI beneficiaries who are already eligible for Medicare, Pepper proposed that the Medicare funded home care benefits would also be available to chronically ill or disabled children who meet the functional eligibility criteria and to technologically dependent children who need nursing services at home. Recognizing the inequity of excluding working-age persons from this home care benefit unless they are Medicare recipients, the Pepper bill proposed a demonstration pilot in the Medicare program to provide home care benefits to working-age persons who are not SSDI beneficiaries as long as they meet the functional disability criteria. The demonstration pilot would have tested the feasibility of providing long-term home care benefits through a **consumer-directed service model** under the Medicare program that would permit working-age persons with a disability, who are capable of directing their own long-term home care, to train, hire, and manage their own personal assistance providers rather than rely on home health agencies.

The demonstration pilot would have also studied "the size of the demand, cost, relative effectiveness, and impact on quality of life" of utilizing different models for providing personal assistance services to working-age persons with severe functional limitations "who (i) are at imminent risk of institutionalization ...without long-term home care, (ii) are institutionalized but who, if provided long-term home care, could be discharged from the institution, or (iii) need long-term home care to secure or continue employment, to increase independence, to enable present caregivers to secure or continue employment, or to stabilize families." These personal assistance services could be "made available away from an individual's pri-

mary residence, as well as at that residence," and "family members may be employed as caregivers if the family members would be employed if not providing such care or if the individual requires more than 20 hours a week of long-term home care." In addition, SSDI beneficiaries could purchase the home care benefits with a special premium during their two year waiting period for Medicare.

To finance this home care entitlement, Pepper proposed uncapping the income level subject to the Medicare Hospital Insurance (Part A) payroll tax. In 1989, the 2.9 percent Medicare tax is applied only to the first \$48,000 of earned income enabling high wage earners to pay a lower rate of their total earnings. According to the Congressional Budget Office, uncapping the income subject to the Medicare tax would generate an additional \$7.1 billion in 1990 which would rise to \$9 billion in 1993¹⁰⁸. This financing strategy would affect only 5 percent of wage earners and would reduce the regressive nature of the Medicare tax by requiring all wage earners to pay the same rate on all earned income. To ensure that the home care benefits would not exceed the bill's self-financing mechanism, the Pepper bill proposed that the maximum payment that an individual would be entitled to for home care services would be adjusted downwards from 62 percent of Medicare's cost for skilled nursing facilities to a level that assures that outlays do not exceed available revenues.

While breaking new ground in expanding the social insurance model in regard to eligibility criteria, benefits, and financing, the Pepper bill relied heavily on existing administrative and quality assurance mechanisms in the federally administered Medicare program. For example, the Pepper bill proposed to utilize Medicare certified home health agencies to deliver all of the home care services even though many consumers object that home health agencies reinforce a medical model. The Pepper bill also envisioned a federally certified home care management agency to assess needs and monitor the quality of services even though state governments have primary responsibility for long term care services. A revision of the Pepper bill which will be introduced this session transfers principal administrative responsibilities to the state for the federally financed home care entitlement. The revised Pepper bill will propose that a federally certified state agency will be responsible for establishing a needs assessment and service planning process that maximizes flexibility in defining covered services and expands the

range of eligible providers within federal guidelines. This will allow case managers to authorize services and supports to meet the unique needs of the individual and his or her family situation within established payment limits of the broadly defined home care benefit.

Although long term care needs are the major source of catastrophic expenses for the elderly population, the Reagan Administration proposed the "Bowen Plan" which only expanded Medicare coverage for acute care illnesses requiring hospitalization or nursing home care. The failure of this Medicare catastrophic approach to provide comprehensive coverage or protect against the catastrophic costs of long term care was highlighted by Congressman Pepper¹⁰⁹. The Congressional Budget Office estimated that the stop-loss or cost-sharing limits on Medicare created by the Medicare Catastrophic bills in Congress would protect only around 4.6 percent of Medicare beneficiaries whose out-of-pocket medical expenses for Medicare covered services exceeded \$2030 per year¹¹⁰. By the time the Medicare Catastrophic Coverage Act of 1988 was finally passed in June 1988, Congress added a prescription drug benefit that will be phased in starting 1991 in addition to certain Medicaid reforms that would increase access to health care for low income persons (see p.75-76). Table 11 provides an overview of the catastrophic illness protection in the Catastrophic Coverage Act of 1988 (see Table 11).

The most controversial aspect of the Medicare Catastrophic Coverage Act of 1988 is the way it has been financed. This controversy has triggered a recent backlash that threatens to color approaches to Medicare expansions. Unlike the social insurance model described above for Medicare Part A, the Catastrophic benefits are financed entirely by Medicare beneficiaries through a flat increase in Medicare Part B premiums and a supplemental premium that varies with income levels which approximately 40 percent of retirees will have to pay. The increase in Part B premiums shifts costs to the recipient population most of whom have fixed incomes, rather than spreading costs among all wage earners through the payroll tax. Meanwhile, many wealthier Medicare beneficiaries object to paying a sizeable income-adjusted premium (ranging up to \$800 per person) for catastrophic benefits that exceeds the

¹⁰⁸Congressional Budget Office Cost Estimate for H.R. 3436, June 6, 1988.

¹⁰⁹"Catastrophic Insurance: How the Bowen Plan Fails", Hearing before the Subcommittee on Health and Long-Term Care of the Select Committee on Aging, Committee Pub. No. 100-615, February 17, 1987.

¹¹⁰Congressional Budget Office, "Comparison of House and Senate Catastrophic Bills", December 16, 1987.

WORLD INSTITUTE ON DISABILITY

Table 11: Catastrophic Illness Protection Under Medicare Program

A. BENEFITS

<u>Old Law</u>	<u>New Law</u>
Costs to patient No limit	In 1990, out-of-pocket costs are held to \$2,146, including: - \$600 cap on hospital fees - \$1,370 cap on covered doctor and outpatient fees - \$176 cap on eligible nursing home stays
Hospitalization	
90 days a year 60-day lifetime reserve	Beginning Jan. 1, 1989: - Hospitalization covered for 365 days a year - \$564 annual cap on cost to patient
Prescription drugs No coverage	Phased-in coverage - 1991: 50% of costs above \$600 - 1993: 80% of costs above \$710
Nursing home care 100 days per illness Limited to care after 3 days hospitalization	150 days a year No prior hospitalization requirement
Home health care 3 weeks per illness/5 days a week	38 days per illness/7 days a week
Hospice care Up to 210 days a year	Indefinite care when terminally ill
Mammograms No coverage	Every other year

B. COSTS

<u>Old Law</u>	<u>New Law</u>
Premiums	
Part "B," for doctors' fees \$24.80 a month/no surcharges	Part "B," plus catastrophic coverage Beginning Jan. 1, 1989: - \$27.10 basic fee (\$31.10 total, expected to rise to \$42.60 a month by 1993) - \$4 a month surcharge (premiums to increase yearly due to inflation) - Medicaid pays premiums for poverty level pensioners
Income-related premium None	New supplemental premium: - Collected on tax returns for 1989 tax year - \$22.50 for each \$150 of tax liability (see chart below) - In 1993, rate rises to \$42 for each \$150 of tax liability

What some individuals will pay in 1990 for the catastrophic supplemental premium

Maximum per person fee: \$800 in 1989; \$1,050 in 1993

Adjusted Gross Income	Income Tax Liability	Supplemental Premium (1989)
\$11,100	\$ 90	\$ 0
12,000	225	33.75
16,500	900	135.00
25,500	2,250	337.50
31,500	3,150	472.50
38,375	4,181	627.30
44,500	5,652	800.00

SOURCES: House Democratic Study Group, Congressional Record

cost of the private "medigap" supplemental insurance policies which about two-thirds of elderly already had. In addition, this catastrophic protection does not help Medicare beneficiaries who are already covered by employer-financed retirement health plans. Aware that the Catastrophic coverage offers virtually no protection from long term care expenses other than a future prescription drug benefit, some organizations of elderly persons have advocated the repeal of the Catastrophic Coverage Act of 1988.

Meanwhile, several Medicare funded Long Term Care bills were introduced last session which propose various entitlements to a combination of home care services and nursing home care. Among these bills were: (1) Senator Kennedy's Lifecare Insurance Program (S. 2681 last year), (2) Senator Mitchell's Long Term Care Assistance Act (S. 2305 last year), (3) Congressman Stark's Chronic-Care Act (H.R. 5393 last year), and (4) Congressman Waxman's Elder-Care (H.R. 5320 last year)¹¹¹. Table 12 compares the major Medicare expansion Long Term Care bills in 1988 (see table 12 on the next page).

What is most notable about these Long Term Care bills is not their differences but their similarities. All rely largely on federal funding generated by some combination of payroll tax, income surtax, and estate and gift tax; all create incentives for private Long Term Care insurance to provide coverage of nursing home care at the front end or the back end for those who can afford it; all are open to all income groups among Medicare beneficiaries who meet the functional disability test; and all provide some protection for low income persons from cost-sharing requirements. One major difference is that only the Pepper and Kennedy bills propose to extend Medicare-financed home care services to non-Medicare beneficiaries (i.e. children under 19 years old).

Since our major concern is access to primary health care and on-going maintenance services in one's own home, we will not present a critical examination of each of these Long Term Care bills which are largely concerned with financing nursing home costs¹¹². Instead, we will confine our observations to the home care component of each of these Long Term Care bills. In each bill, eligibility is based on two or more functional limitations measured in terms of deficits in activities of daily living or

cognitive deficits accompanied by significant behavioral problems or or the need for constant supervision. In the Kennedy bill, however, a person who is unable to perform one ADL without personal assistance would be eligible for home care services.

In all of the Long Term Care bills, assessment of needs, certification of eligibility, development of plans of care, on-going case management, and monitoring of quality would be performed by a public or private agency that is federally funded and is independent of the provider. The home and community based services include a range of homemaker/chore aide services, personal care services, adult day care, and a small respite benefit in two of the bills. The payments for home care services are based on the degree of impairment and limited to a certain percentage of the annual cost of Medicare nursing facility services in the state. The payment levels range from 35 percent of Medicare nursing home costs for a "mild impairment" in the Waxman bill up to 100 percent of Medicare nursing home costs for persons in need of skilled nursing and rehabilitation care in the Stark bill. Each of the bills requires a 20 percent copayment for home health and adult day care, although the Kennedy bill requires a 10 percent copayment or 5 percent of the eligible individual's Social Security benefits, whichever is less. To further contain Medicare costs, the Mitchell bill also requires a \$500 deductible for home care services.

The emerging consensus that these bills represent are reflected in the legislative principles of the Long Term Care '88 Campaign coordinated by the American Association of Retired Persons (AARP) and the Villers Foundation. Supported by more than 100 national organizations representing senior citizens' and children's organizations, health and disability groups, labor unions, veterans, women's groups, racial and ethnic groups, and religious denominations, the legislative principles for Long Term Care include:

1. Long term care services should be **available to all who need them, regardless of age or income**. Eligibility should be based on functional, cognitive or behavioral limitations, or the need for supervision because of risk to safety or health, or the need for support or training.
2. A national long term care program should provide a **comprehensive range of facility-based and community-based health, social and support services**. Services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by beneficiary and family.

¹¹¹All of these bills are expected to be reintroduced this session with some modifications under different bill numbers.

¹¹²See Gail Shearer, Long-term Care: Analysis of Public Policy Options, Consumers Union, Washington, D.C., January 1989.

TABLE 12: COMPARISON OF LONG-TERM CARE BILLS IN 1988

ITEM	STARK	WAXMAN	PEPPER	MITCHELL	KENNEDY
1. Short title	Chronic-Care (HR 5393)	Elder-Care (HR 5320)	Medicare Long-Term Home Care Catastrophic Protection Act of 1987 (HR 3436)	Long-Term Care Assistance Act of 1988 (S. 2305)	Life-Care (S. 2681)
2. Eligibility	Medicare aged & disabled 3 activities of daily living (ADL) or cognitive impairment for nursing home benefit 2 ADLs or cognitive impairment for home and community benefits	Medicare aged & disabled 2 ADLs or cognitive impairment for all benefits	Chronically ill children, elderly and disabled who cannot perform at least 2 ADLs or similar cognitive impairment * 2 ADLs or cognitive impairment accompanied by	Medicare aged & disabled Completely dependent in 1 ADL significant behavioral problem for all benefits	65 or older, Medicare disabled or under 19 years or 2 ADLs, or cognitive impairment as to require constant supervision
3. Scope of nursing facility benefits	Skilled nursing facility or intermediate care facility after 3 months Deductible estimated at \$9,000 (in 1990)	Same except after 2None months Deductible estimated at \$6,000 (in 1990)		Any nursing home HHS approves after 2 years Deductible estimated at \$72,000 (in 1990)	Certified nursing homes for the first 6 months Coverage limited to estimated \$18,000 (in 1990)
4. Cost-sharing for nursing facility benefit	20% coinsurance after 3 month deductible Coinsurance estimated at \$7,200 per year after deductible	33% coinsurance after 2 month deductible for months 3-24 and 10% coinsurance for months over 24 Coinsurance estimated at \$12,000 per year after deductible up to 24 months; \$3,600 per year after 24 months	None	30% coinsurance after 24 month deductible Coinsurance estimated at \$10,000 per year after deductible	Premiums set at 45% of cost of stay and coinsurance of 35% First 6 months covered or up to a year if reasonable possibility of returning home Optional benefit for those age 45 and over to cover stays over six months Coinsurance estimated at \$6,000 during six months of coverage

ITEM	STARK	WAXMAN	PEPPER	MITCHELL	KENNEDY
5. Scope of home and community based services	All current Medicare home health services and homemaker-personal care services Adult day care Payments for home health and adult day care limited to service needs: 1)for those receiving skilled nursing and rehabilitation care -100% of the Medicare nursing facility limit on routine services in a wage area on a monthly basis; 2) for those home health and adult day care - 75%; and 3) for those receiving only home health care - 65% No separate respite benefit	Same Adult day care demonstration Payments for home health services limited to level of impairment: 1)for severe impairment - 65% of annual cost of Medicare nursing facility services in the state; 2)for moderate impairment -50%; and 3) mild impairment - 35% No separate respite benefit 20% coinsurance for home health & adult day care Made by federally funded nonprofit state-wide agencies Same but may be a state or local government Same	Same * 18 month adult day care benefit Payments for home health services limited to 62% of monthly state average of Medicare skilled nursing facility services or payments for technology dependent children limited to 100% of monthly state average of Medicaid skilled nursing facility services No separate respite care benefit None, unless Secretary determined shortfall in which case a beneficiary copayment would be established Made by state government agencies or if no government agency a private, non-profit agency or organization which does not provide long-term care services Same	Current home health services plus homemaker and chore aide services Adult day care only as respite Payments for home health and adult day services limited to 65% of annual national average of Medicare skilled nursing facility services Separate respite benefit up to \$2,000 annually with 50% coinsurance \$500 deductible for home health care per year and 20% coinsurance 50% coinsurance for respite care for a \$2,000 annual benefit Made by federally funded agency approved by the Secretary May be a public or private agency Same	Current home health services plus homemaker and heavy chores services Adult day care Payments for home health and adult day services limited to a maximum of 65% of annual cost of Medicare skilled nursing facility with individual payment limits corresponding to severity of need Up to 30 days of respite care a year 10% coinsurance or or 5% of eligible individual's monthly Social Security benefits whichever is less Made by federally funded state agency or if state declines private nonprofit approved by Secretary State or nonprofit agency must have separate screening and case management divisions
6. Cost-sharing for home & community based services	20% coinsurance for home health & adult day care	20% coinsurance for home health & adult day care	None, unless Secretary determined shortfall in which case a beneficiary copayment would be established	\$500 deductible for home health care per year and 20% coinsurance 50% coinsurance for respite care for a \$2,000 annual benefit	10% coinsurance or or 5% of eligible individual's monthly Social Security benefits whichever is less
7. Eligibility determination and patient management	Made by federally funded nonprofit state-wide agencies Must be a private nonprofit entity which does not provide long-term care services Assess eligibility, develop plan of care, make arrangement or referrals for services, on-going case management and quality review	Made by federally funded state-wide agencies Same but may be a state or local government Same	Made by state government agencies or if no government agency a private, non-profit agency or organization which does not provide long-term care services Same	Made by federally funded agency approved by the Secretary May be a public or private agency Same	Made by federally funded state agency or if state declines private nonprofit approved by Secretary State or nonprofit agency must have separate screening and case management divisions

ITEM	STARK	WAXMAN	PEPPER	MITCHELL	KENNEDY
8. Financing	Part A benefits: 1. Require all state and local employees to pay HI portion of FICA tax 2. Raise limit on amount of earnings subject to HI portion of FICA tax to \$100,000 3. Increase HI portion of FICA tax 0.7% on each employer and employee Part B benefits: 1. Increase Part B premium by \$5 a month 2. Reduce estate and gift tax exemption to \$300,000; change rate structure with a beginning rate of 15% for estates of at least \$300,000 rising to 70% for estates at least \$5 million; other estate & gift tax reforms	1. Eliminate cap on wages covered by entire FICA payroll tax 2. \$3.50 per \$100 surcharge on income tax liability for all taxpayers 3. 10% surcharge on taxable estates/gifts over \$100,000	Eliminate cap on wages covered by HI portion of FICA payroll tax	1. Eliminate cap on wages covered by HI portion of FICA payroll tax 2. Increase Part B premium by \$2 a month, and corresponding increase in supplemental premium to raise the same revenue as from the Part B premium 3. 5% surtax on gross estates in excess of \$200,000	1. Considering the elimination of cap on all wages covered by entire FICA payroll tax (15% of all earnings)
9. Medicaid requirements	State Medicaid programs required to use offsets from this legislation to: 1. Pay 100% of Medicare acute and long-term cost-sharing for beneficiaries whose income is up to 150% of the federal poverty level 2. Pay 50% of the cost-sharing for those with incomes up to 200% of poverty level	State Medicaid programs required to use offsets from this legislation to: 1. Pay Medicare cost-sharing for individuals with incomes below 200% of poverty 2. Provide coverage for all pregnant women and infants up to age 1 with incomes up to 200% of poverty	Permits disabled individuals to purchase Medicare coverage during the 24 month waiting before Medicare entitlement 1. Matching funds adjusted so that state continues to support long-term care at the same level as prior to the legislation 2. Medicaid spend-down requirement waived for beneficiaries who pay for the 2 year exclusionary period	State Medicaid programs: funds they would have spent on long-term care to fund part of the costs of this legislation	States required to spend the Medicaid

ITEM	STARK	WAXMAN	PEPPER	MITCHELL	KENNEDY
	3. Provide coverage for all pregnant women and infants up to age 1 with incomes up to 200% of poverty level	3. State option to establish home and community based services as a Medicaid benefit			
10. Estimated costs in 1993	\$46 billion	\$63 billion	\$9 billion	\$24 billion	\$22 billion
Nursing home		\$53 billion	_____	-\$16 billion	\$11.6 billion
Home care		\$10 billion	\$9 billion	\$ 8 billion	\$10.4 billion

* Also includes demonstration for working-age individuals who meet the same functional disability criteria and another demonstration for seriously mentally ill individuals.

Source: Data compiled by the House Ways and Means Subcommittee on Health and modified by staff of the bills' sponsors.

3. The financial risk for long term care should be spread as broadly as possible, through a social insurance program similar to Social Security or Medicare. The public program should provide a base of coverage for all.
4. The new public program should assist families and other informal caregivers. Families and friends should be an integral part of care coordination and should have access to supportive services and training to facilitate their caregiving. The program should ensure that the financial integrity and physical and emotional well-being of the family caregiver is maintained.
5. The new public program should be supported through sources of financing that are as progressive as possible.
6. Protection from out-of-pocket costs for low and moderate income persons should be provided.
7. The program should ensure high quality and access to care for all. A strong, independent care coordination component should be a central feature of the program. Paid caregivers should be carefully screened and well-trained, with wages and benefits commensurate with the substantial demands and responsibilities of caregiving. The payment system to providers should be structured to ensure quality of care and cost containment.
8. Cost containment should be built into the program. The public costs of the program should be minimized while meeting consumers' needs.
9. The program should allow for phasing-in to ensure orderly development of the new system and all of its services.
10. The states should be encouraged to be innovative and flexible in administering and delivering long term care services. Research should be conducted on the adequacy of services to meet family long term care needs and on more accurate measures of disability.

Whether it is feasible to create an entitlement for nursing home care before an entitlement to home care services is in place is an important strategic issue which has received too little attention. Many politicians are very sensitive to the organized pressure for relief from the high cost of nursing home care (which can average \$22,000 per year) and are wary about creating an entitlement to home care services which most persons currently receive through informal and non-paid relationships. On the other hand,

some observers are concerned that an entitlement to nursing home care before a reliable system of home care services is available will lead to a great expansion of nursing home utilization that will divert scarce resources from expanding the home care system which is needed to significantly reduce the demand for nursing home care. These issues, among others, will be examined by the recently established U.S. Bi-partisan Commission on Comprehensive Health Care which has been authorized to assess options for Long Term Care and comprehensive health care and report by November 1989.

Eliminating the Medicare Waiting Period for SSDI Beneficiaries:

The requirement that SSDI beneficiaries wait for two years before receiving Medicare was designed to contain Medicare costs but penalizes many disabled workers when they are most in need of adequate health insurance. Withholding Medicare benefits from persons who have been determined too disabled to work may reduce their chances of medical recovery, interfere with their return to work, and intensify their financial hardship. Estimates from 1984 Survey of Income and Program Participation data reveal that approximately one-third of new SSDI beneficiaries are uninsured at some time during their waiting period for Medicare¹¹³. A forthcoming study by researchers at the Health Care Financing Administration (HCFA) and the Social Security Administration (SSA) confirms that approximately 27 percent of new SSDI worker beneficiaries, who became entitled to SSDI between January-June 1981, report being without any health insurance during the last six months of their waiting period for Medicare¹¹⁴.

Another consequence of the two year waiting period for Medicare is that a certain number of new SSDI beneficiaries die before they become eligible for Medicare. The Social Security Administration reported that 11 percent of persons who became entitled to SSDI in 1975 died during the two year waiting period for Medicare benefits. This included as many as 55 percent of SSDI beneficiaries

¹¹³ Access to Health Care, Nos. 1-2, pp. 28-29.

¹¹⁴ Barry Bye and Gerald Riley, "Eliminating the Medicare Waiting Period for Social Security Disabled-Worker Beneficiaries," draft paper presented at the Annual Meeting of the American Public Health Association, Boston, Mass., November 15, 1988. (forthcoming in Social Security Bulletin)

with neoplasms (i.e. cancer)¹¹⁵. More recently, many persons with AIDS are denied access to Medicare because of the two year waiting period after they can no longer work.

Awareness that many persons with AIDS may not live beyond the waiting period has reinforced the urgency of reexamining the fairness of the two year waiting period for Medicare. Representative Ted Weiss (D-NY) and Senator Daniel Moynihan (D-NY) have introduced H.R. 416 and S. 224 respectively to waive for five years the two year waiting period for disabled persons with AIDS. It is possible that a precedent set for one highly visible group can shape the policy for other persons with disabilities. There is also discussion on Capitol Hill about shortening the waiting period for Medicare benefits, perhaps to 18 months, which would at least correspond to the COBRA continuation coverage mandate created in 1985. Alternatively, Congresswoman Nancy Pelosi (D-CA) has proposed in H.R. 2308, 2309, and 2310 that COBRA continuation coverage could be extended for 29 months for persons ending work as a result of disability which would carry SSDI beneficiaries to the end of their waiting periods. Under the current employer mandate for continuation coverage, employers with 20 or more employees who do provide health benefits are required to provide the option of continued coverage under the employer's health benefits plan for up to 18 months after termination of employment if the employee can pay both the employer and employee share of the premium¹¹⁶.

Meanwhile, Bye and Riley are conducting a study to estimate the cost of eliminating the two year waiting period for Medicare. According to a preliminary draft of their study, the cost to Medicare over a ten year period could rise approximately 44.7 percent for the expected health care utilization of SSDI recipients if the two year waiting period was eliminated¹¹⁷. Part of the reason for the increase in Medicare costs is that approximately 12.8 percent of new SSDI beneficiaries will die during the two year waiting period and 5.3 percent will leave the SSDI rolls because they will medically recover or return to work before becoming eligible for Medicare. By grouping the

waiting period costs by SSDI program status over the ten year period, Bye and Riley report that 58.3 percent of the waiting period costs would be distributed to SSDI beneficiaries who died within ten years, while 19.7 percent would go to those still on the SSDI rolls, 19 percent would go to those who achieved age 65, and 3 percent would go to those who recovered during the ten year period. This analysis, however, does not take into account to what extent the additional costs may be offset by improving access to health care during the first two years of SSDI status which may be critical for increasing chances of medical recovery or returning to work. More importantly, these estimates do not consider what it would cost for Medicare to act as a secondary payor which would eliminate the two year waiting period only for SSDI beneficiaries who are uninsured.

Medicare buy-in

To reduce disincentives to work for SSDI beneficiaries, there are two bills which are designed to permit SSDI beneficiaries to continue to have access to Medicare after they have returned to work and exhausted their eligibility for SSDI and Medicare. Under current law, disabled workers who return to work while still being severely impaired are eligible for Medicare benefits for two to three years after their SSDI cash benefits cease¹¹⁸.

The Social Security Work Incentive Act (formerly H.R. 4680, now H.R. 8) introduced by Congressman Steve Bartlett (R-TX) creates a new Medicare eligible category called "disabled and working" for SSDI beneficiaries who do return to work and earn above the SGA level of \$300 per month. For persons in the newly created "disabled and working" SSDI status, they will be able to purchase Medicare coverage as long as the impairment continues which originally qualified them for SSDI. If their earnings are below 150 percent of the federal poverty level, they would be able to continue to receive Medicare with their state Medicaid program paying the Medicare premiums. With earnings between 150-300 percent of the federal poverty level (approximately \$9,496-\$18,993 for a single individual in 1989), those in the "disabled and

¹¹⁵James Lubitz and Penelope Pine, "Health Care Use by Medicare's Disabled Enrollees," *Health Care Financing Review*, Vol. 7, No. 4, Summer 1986, Table 9, p. 29.

¹¹⁶Beth C. Fuchs, "Private Health Insurance Continuation Coverage: CRS Issue Brief", Congressional Research Service, March 17, 1989, No. IB87182.

¹¹⁷Bye and Riley, *op.cit.*

¹¹⁸Two years after a nine month "trial work" period (in which a disabled individual has earned over \$75 a month or worked at least 15 hours in self-employment), followed by a three month "grace period", SSDI beneficiaries lose their eligibility for health insurance under Medicare if they have earned over the substantial gainful activity level of \$300 per month. During the next 36 months of Extended Period of Eligibility (EPE), SSDI cash payments will be reinstated along with Medicare if the earnings drop below \$300 per month.

working" SSDI status can pay an income-adjusted premium to buy into the Medicare benefits. Individuals whose earnings are above 300 percent of the poverty line or whose countable assets are above the SSI eligibility level (\$2000 assets in 1989) would be expected to pay the entire Medicare Part A and B premiums to enable the Medicare buy-in to remain self-financing.

With Medicare Part A premiums at \$1,982 annually in 1989 (for voluntarily enrolled elderly beneficiaries) and Part B premiums at \$1,531 (if the federal subsidy is removed), the total Medicare premiums for an SSDI beneficiary in the "disabled and working" category would total \$3,403 for a person earning as little as \$18,993. In fact, earnings of \$18,993 would actually be reduced to approximately \$18,333 due to payroll and income taxes causing the Medicare premiums alone to exceed 18.5 percent of a person's income. While these steep costs could certainly act as a work disincentive for SSDI beneficiaries, H.R. 8 at least creates a precedent for buying into Medicare for persons who are "disabled and working". It does not, however, make SSDI beneficiaries who are "disabled and working" automatically eligible for Part A of Medicare based on their previous FICA contributions.

Although there appears to be a limited enrollment period for the Medicare buy-in when initially leaving the SSDI rolls, H.R. 8 would allow SSDI beneficiaries in the "disabled and working" category to subsequently buy-in to Medicare without penalty either to supplement a private health insurance plan or to substitute for the absence of an employment-linked health plan. This is important to ensure that SSDI beneficiaries who enter the labor force under the protection of group health insurance are not penalized if that private coverage is subsequently terminated in the future. In the proposed Medicare buy-in, Medicare would function as a secondary payor to an employer's health plan for persons in the "disabled but working" SSDI status.

In addition to ensuring access to Medicare, the Social Security Work Incentive Act would enable SSDI beneficiaries to gradually reduce their SSDI cash payments as their earned income increases. It is expected that SSDI beneficiaries will be more likely to enter the labor force when they do not have to worry about having their SSDI benefits abruptly terminated when they demonstrate the capacity to earn over \$300 per month (i.e. less than two-thirds of minimum wage) after the expiration of their nine month trial work period. While this provision is comparable to the 1619(a) work incentive in the SSI disabled

program, the higher cash payment levels in the SSDI program have the potential of generating significant new costs which were not associated with the introduction of section 1619 in the SSI program. The Social Security Administration claims that a major potential source of "induced demand" for the SSDI program is the large number of persons with severe impairments who are not currently eligible for SSDI benefits because they are earning over \$300 per month.

Various approaches are currently being considered to minimize the costs of "induced demand", such as restricting the gradual reduction in SSDI cash benefits to Disabled Adult Children (i.e. those adults with disabilities who are eligible for SSDI not because they are disabled workers but because they were disabled before age 22 and are financially dependent on parents who are retired-worker beneficiaries, disabled worker beneficiaries, or deceased Social Security beneficiaries. [The majority of Disabled Adult Children are persons with mental retardation.] These options for restructuring the SSDI program (Title II of the Social Security Act) to promote work incentives will not be examined here because they have more to do with structuring entitlement to cash payments for income replacement purposes than with ensuring access to health care.

An alternative Medicare buy-in bill is the **Disabled Americans Work Incentive Act** (S. 936 last year, now S. 320) which has been introduced by Senator Durenberger (R-MN) which permits a former SSDI beneficiary to purchase Medicare regardless of his or her income level. In the Durenberger bill there is no public subsidy for the Medicare premiums of former SSDI beneficiaries below 300 percent of poverty, but the premiums for Part A and Part B are capped at a maximum of 8 percent of the individual's adjusted gross income unlike the Bartlett bill.

Because of the limitation of Medicare benefits, neither the Bartlett bill nor the Durenberger bill provide for access to on-going maintenance services which can be covered by Medicaid. Unlike the Medicaid buy-in described below (which is designed to ensure access to adequate and affordable health insurance for all persons who do not have access to private health insurance because of pre-existing conditions), the Medicare buy-in is designed to provide an opportunity for the current SSDI beneficiaries to return to work. In neither the Bartlett bill nor the Durenberger bill will persons who are not current SSDI beneficiaries be eligible to buy into Medicare.

MEDICAID EXPANSION OPTIONS

Medicaid is the primary public health care financing program for low income people. As such, it is the largest provider of health care to poor persons under age 65 who are not covered by private health insurance. Because Medicaid is linked to eligibility for Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI), however, there are many low income people who are not eligible for Medicaid even though they are uninsured¹¹⁹. Since the federal government pays between 50-78 percent of the Medicaid expenditures depending on the level of poverty in each state, Medicaid is a logical vehicle for encouraging states to respond to the health care needs of persons who do not have access to private health insurance.

One major strategy is to expand Medicaid to serve uninsured people who cannot afford to purchase private health insurance. A recent report of The Health Policy Agenda for the American People revealed that 11 million persons below the federal poverty level (i.e. \$9,690 gross annual income for a family of three) are uninsured¹²⁰. Requiring states to set Medicaid eligibility at 100 percent of poverty would cost \$9 billion; standardizing benefits for current and newly added beneficiaries would add between \$6.5 billion (for the median state Medicaid benefit package provided by Washington State) and \$21.5 billion (for the most comprehensive state Medicaid benefit package provided by Minnesota); and raising the Medicaid provider payment levels to Medicare levels would add an additional \$5.2 billion¹²¹. Factoring in various cost offsets, The Health Policy Agenda estimates that the total costs for expanding Medicaid to all uninsured persons under 100 percent of poverty would be between \$13.2 to \$28.2 billion.

In addition to the 11 million uninsured persons below 100 percent of poverty, there are an additional 10.4 million persons who are uninsured with incomes between 100-200 percent of poverty¹²². Assuming that this near-

poor population can pay a premium equal to 5 percent of their gross family income, Medicaid would have to finance about 70 percent of the actuarially based premium if their Medicaid costs are comparable to the average Medicaid costs for AFDC families¹²³.

Because approximately two-thirds of the uninsured are poor or near-poor, a Medicaid solution to the problem of the currently uninsured population would be very expensive. Given the constraints of the budget deficit, two expedient federal strategies are actively being considered. One is to require all employers to provide health insurance to their employees and dependents which could reduce the number of uninsured persons from 37 million to 13 million (see employer mandate options, pp.40-45); the other is to target Medicaid expansion options to certain highly vulnerable populations. In this way, the public system can be gradually expanded within budget limits to cover all those who are not eligible for employer-provided health insurance.

Maternal and child health:

Two of the populations which are most vulnerable when they are uninsured are pregnant women and children. Congress has been interested in expanding Medicaid coverage to these populations because uninsured women often do not receive prenatal care and consequently have a higher risk of infant mortality or producing low birth weight infants who require high levels of intensive neonatal care that is much more expensive to provide than the preventive care would have been. In addition, the lack of well-baby care for uninsured infants and young children limits early detection of preventable health problems and reduces rates of immunizations that can prevent diseases. To expand Medicaid coverage to poor children who do not meet the state's eligibility criteria for AFDC, Congress passed the Deficit Reduction Act (DEFRA) of 1984 which required states to cover all children over age one and under age 5 with family incomes below the AFDC financial eligibility level regardless of whether they qualify for cash assistance¹²⁴. In 1986, Congress passed the Consolidated Omnibus Budget Reconciliation Act (COBRA '86) which permitted states to extend Medicaid coverage to pregnant

¹¹⁹See Limitations of Medicaid on pp. 32-37

¹²⁰Health Policy Agenda for the American People, Including the Poor: The Final Report of the Ad Hoc Committee on Medicaid, Chicago, Illinois, February 1989.

¹²¹Kenneth E. Thorpe, Joanna E. Siegel, and Theresa Dailey, "Including the Poor: The Fiscal Impacts of Medicaid Expansion," The Journal of the American Medical Association, February 17, 1989, Vol. 261, No. 7, pp. 1003-1007.

¹²²"Public Policy Options to Expand Health Insurance Coverage among the Non-elderly Population," Employee Benefit Research Institute (EBRI) Issue Brief, June 1987, No. 67, Table 2, p. 12.

¹²³Ibid. p. 13.

¹²⁴For a comprehensive summary of the Medicaid expansions to improve maternal and child health among low income families since 1984, see Kay Johnson, "Medicaid Coverage for Low Income Children and Pregnant Women: Five Years of Progress," Children's Legal Rights Journal, Vol. 9, No. 4, Fall 1988, pp. 5-13.

women and children under age 5 with family incomes between the state's AFDC financial level and 100 percent of the federal poverty level. In COBRA'87, Congress adopted the Medicaid Infant Mortality Amendments of 1987 which permitted states to cover pregnant women and infants up to age 1 whose family incomes are under 185 percent of the federal poverty level. At least eleven states have utilized this option so far. For pregnant women and infants with incomes between 150-185 percent of poverty, states have the option of charging a modest, income-related premium for this Medicaid coverage. Building on the above precedents, Senator Bill Bradley (D-NJ) has introduced in the current session S. 339 in conjunction with Representative Henry Waxman's (D-CA) H.R. 800 and Representative Mickey Leland's (D-TX) H.R. 883 to require states to expand Medicaid coverage to pregnant women and infants up to 185 percent of poverty by 1993 and to phase-in Medicaid coverage to all children below 100 percent of poverty up to age 7 by 1990 with a year-to-year extension up to age 18. Meanwhile, in his 1990 Budget, President Bush has proposed raising the mandatory Medicaid eligibility for pregnant women and infants from 100 percent to 130 percent of the federal poverty level and requiring states to extend coverage for children under 130 percent of poverty up to five years of age for immunization services only.

Medicaid buy-in of premiums and cost-sharing for poor Medicare beneficiaries:

Poor Medicare beneficiaries are another population which Congress has seen fit to use Medicaid for to expand their access to health care. Although more than 95 percent of persons over age 65 are eligible for Medicare, the premium requirements for Part B and the deductibles and copayments for Parts A and B make Medicare unaffordable to many low income elderly persons¹²⁵. States have had the option of using Medicaid dollars to pay the Part B Medicare premiums and Medicare cost-sharing for SSI eligible elderly persons through buy-in agreements between state Medicaid programs and Medicare. While this has enabled states to reduce their Medicaid expenditures for services provided by Medicare, only a third of poor elderly people have Medicaid coverage. In 1986, Congress gave the states the option of extending Medicaid coverage to elderly and disabled people with incomes below the

poverty level. The Medicare Catastrophic Protection Act of 1988 requires states to pay the Medicare premiums, deductibles, and coinsurance for all elderly and Medicare-eligible disabled persons with incomes below the Federal poverty level (\$5770 per year for an individual in 1988) and resources below twice the standard under the SSI program (\$3800 in 1988). This requirement is to be phased-in by 1992.

Technologically dependent children:

Another category of children targeted for mandatory Medicaid coverage are certain technologically dependent children living at home who need a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability. Representatives Henry Waxman (D-CA), Mickey Leland (D-TX), and George Miller (D-CA) have introduced Medicaid Technology-Dependent Children Amendments of 1989 (H.R. 832) to enable technology-dependent children to receive Medicaid while living at home regardless of their parents' income. Under current law, states have the option, under section 1902(e)(3) of the Social Security Act, to offer Medicaid coverage to children up through age 18 who are living at home if they meet the disability criteria for SSI and the state institutional income and resource eligibility criteria as long as they are at risk of institutionalization and the cost of caring for them outside the institution would not exceed the cost of caring for them in the institution. Previously, states had to obtain a "2176" Medicaid waiver to serve technologically children at home, and HCFA would only approve the waiver for certain individuals if the child was first institutionalized and the state could demonstrate that the home placement would generate savings or reduce the state's institutional capacity.

Work incentives for AFDC recipients:

In the area of welfare reform, Congress has been interested in extending Medicaid coverage to AFDC families who are trying to enter the labor force. Many parents on welfare are reluctant to take entry level jobs which often do not provide health insurance because they would lose the Medicaid coverage which their family depends on. Congress passed the Family Support Act of 1988 which requires states to extend Medicaid coverage for one year to families that have lost Medicaid coverage due to earnings from employment. States may charge a monthly

¹²⁵Diane Rowland and Barbara Lyons, Medicare's Poor: Filling the Gaps in Medical Coverage for Low-Income Elderly Americans, The Commonwealth Fund Commission on Elderly People Living Alone, Baltimore, Maryland, November 1987.

premium for the last six months of this extended Medicaid coverage to families whose earnings (less child care costs) are above 100 percent of poverty if the premium does not exceed 3 percent of the family's gross monthly earnings¹²⁶.

Work incentives for SSI-disabled recipients:

To create an incentive for SSI disabled persons to earn above the substantial gainful activity level of \$300 per month, Congress passed the **Employment Opportunities for Disabled Americans Act** which became effective on July 1, 1987. This Act makes Section 1619(a) and (b) a permanent part of the Social Security Act to enable working-age persons on SSI to maintain Medicaid coverage until their earnings are sufficient to replace the value of the cash assistance payments, the Medicaid payments, and the publicly-funded attendant care benefits that they would be eligible for by not working¹²⁷. For persons who require a higher level of Medicaid services than the state average, an individualized earnings threshold will be calculated for them to ensure that they do not lose Medicaid before their earnings exceed the value of the services to which they are entitled¹²⁸.

Reversing "institutional bias" in Medicaid for persons with developmental disabilities:

Another objective of Medicaid reform is reversing the "institutional bias" in the Medicaid program which has been used to support Long Term Care services for people with developmental disabilities. In 1971, the Intermediate Care Facility for the Mentally Retarded (ICF/MR) program was established allowing states to use Medicaid funds to serve people with developmental disabilities in public and private institutions which met certain federal regulations. Originally designed to upgrade conditions in

large institutions, these federal standards have encouraged the growth of institutional settings and inhibited the use of Medicaid funds for community and family supports in spite of a changing service philosophy which embraces such goals as deinstitutionalization, "least restrictive setting", independence, productivity, and community integration. The federal Medicaid home and community-based services waiver program (section "2176") has subsequently allowed states greater flexibility in using Medicaid for habilitation services in non-institutional settings, but only for a limited number of persons who are at risk of institutionalization, and only if the cost of the community services are less than the institutional services.

The **Medicaid Home and Community Quality Services Act of 1989** (S.384) has been introduced by Senator John Chafee (R-RI) to allow states to use federal Medicaid funds to provide a broad array of community and family support services to persons with developmental disabilities in non-institutional settings including their own homes, family homes, foster family homes and a variety of community living facilities. Extending the precedent of using Medicaid for long term support services, the Medicaid Home and Community Quality Services Act would permit states to use Medicaid for a wide range of services coordinated through an individual habilitation plan to promote individual development, independent functioning, productivity, and community integration.

States would be required to provide at least a minimum array of community and family supports including: independent case management; individual and family support services (including respite and attendant care); specialized vocational services (including pre-vocational services and supported employment services); and protective intervention services. Many of these services correspond to the needs of persons with mental retardation or developmental disabilities who are dependent on an underfunded community service system which has been isolated from sum-sufficient Medicaid funding. In addition, states would have the option of offering under their state Medicaid plans: habilitation services; case coordination services; educationally-related services; nonaversive behavior intervention therapy; crisis intervention; personal guidance, supervision, counseling, representation and advocacy; specialized training for families and caregivers; special transportation services; and maintenance of guide dogs and other similar trained animals; as well as occupational therapy, physical therapy, and speech therapy to improve or maintain functional capacities; periodic interdisciplinary diagnostic and assessment services; personal assistance and attendant care services; homemaker and

¹²⁶*Ibid.*, p. 13.

¹²⁷ An overview of the 1619 program and other work incentives for SSI and SSDI recipients is contained in "A Summary Guide to the Social Security and SSI Work Incentives for the Disabled and Blind," Social Security Administration, Baltimore, Md., SSA Publication No. 64-030, October 1988; and "Incentives to Work for SSI and SSDI Recipients," The National Association of Rehabilitation Facilities, P.O. Box 17675, Washington, D.C. 20041, October 1988, (\$5 for non-members).

¹²⁸ The maximum income thresholds for 1619 eligibility for each state are published in the Social Security Administration, Program Operations Manual System (POMS), Part 05, Chapter 023, Subchapter 02.020, "Evaluation of Sufficiency of Earnings".

chore services; prostheses, orthoses, supplies, appliances, adaptive equipment, communicative aids, and other functional assistive devices and technologies; design, adaptation, and modification of equipment, vehicles, and housing; home health services; preventive and therapeutic dental services; and any other services identified by the state and approved by the Secretary of Health and Social Services. Many of these services are needed by persons with physical, mental, or sensory disabilities at all ages in addition to persons with mental retardation or developmental disabilities.

The broad array of health and social services called for by the Medicaid Home and Community Quality Services Act would be initially limited to SSI eligible persons with a "severe disability" which originated prior to age 22. This appears to include persons with physical or mental disabilities which developed in their childhood even though they would not normally come within the category of "mental retardation or related conditions"¹²⁹. Moreover, to extend the coverage to persons with other disabilities at a later date, the bill calls for advancing the age of onset by one year for each year that the program is in operation until it ultimately reaches all persons with a "severe disability" which begins before age 50. Furthermore, states would be required to use the same income limits for Medicaid eligibility for persons living in the community as for persons living in an institution. This should allow children under 18 years old with severe disabilities who are living at home to be eligible for SSI regardless of the income of their families.

To reverse the "institutional bias" in the Medicaid program, the Medicaid Home and Community Quality Services Act would impose no limits on the availability of federal Medicaid matching funds for community and family support services, while large institutions (serving 16 or more persons) would be limited to the federal Medicaid payments the facility received for non-elderly, severely disabled persons during the previous fiscal year. Previous versions of the Community and Family Living Amendment bill created controversy by imposing a timetable for cutting off ICF/MR funding to institutions and requiring states to transfer individuals from large institutions to community-based settings. The current Chafee bill, which has 47 co-sponsors in the Senate, seeks instead to freeze the level of ICF/MR payments to institutions while expanding

the use of Medicaid funding for home and community services.

Under consideration on the House side is the **Medicaid Community and Facility Habilitation Amendments of 1989** (H.R. 854) which has been introduced by Representatives James Florio (D-NJ), Henry Waxman (D-CA), and John Dingell (D-MI). This bill would not impose any limitation on federal Medicaid payments for services to persons with developmental disabilities in large institutions and would only create the **option** of allowing states to use federal Medicaid dollars to provide new "community habilitation and supportive services". The Florio/Waxman/Dingell bill would also restrict eligibility for the new "community habilitation and supportive services" to persons with "mental retardation or related conditions" which is the current criterion for ICF/MR eligibility.

Community-based services for frail elderly:

The **Medicaid Frail Elderly Community Care Amendments of 1989** (H.R. 1453) introduced by Representatives Ron Wyden (D-OR) and Henry Waxman (D-CA) would allow states the **option** to cover "community care" services for SSI-eligible, functionally disabled elderly individuals under their Medicaid programs. Unlike the "section 2176" home and community-based services waiver, this option would not require the states to demonstrate budget neutrality or to limit participation to those at risk of institutional care.

Functional disability would be determined on the basis of a comprehensive assessment conducted by an interdisciplinary team designated by the state and used to evaluate an individual's ability to perform activities of daily living (ADLs). Those individuals who are unable to perform at least two (or at state option, 3 or 4) ADLs, or have a primary or secondary diagnosis of Alzheimer's disease would be eligible for services. Community care services would include homemaker/home health aide services, chore services, respite care, adult day health, and other services for which federal Medicaid matching funds are now available only under a limited waiver authority. To limit costs, the bill restricts eligibility to low income frail elderly persons who are eligible for SSI, constrains aggregate state expenditures for these Medicaid funded community care services to 50 percent of the cost for Medicare reimbursement for skilled nursing facility (SNF) services, and does not mandate that these services be provided.

¹²⁹ An overview of the age of onset for persons 18-64 who report a work disability by the health condition responsible for the disability is provided from the 1984 SIPP data in Access to Health Care, No. 1-2, Table 3, p. 17.

Preventing spousal impoverishment during Medicaid spend-down for nursing home care:

Another area of Medicaid reform that Congress has been concerned about is spousal impoverishment. The Medicaid spend-down requirements have tended to impoverish the spouse living in the community when an institutionalized individual has established eligibility for Medicaid. As part of the **Medicare Catastrophic Act of 1988**, Congress has recently protected a minimum of \$12,000 in resources or savings for the community spouse which states can raise as high as \$60,000 when requiring an individual in a nursing home to spend-down to poverty to become eligible for Medicaid. States are required to allow the community spouse to receive a sufficient amount of the institutionalized individual's income each month to raise the community spouse's income to at least 122 percent of the federal poverty level for a couple (currently \$786 per month) up to a maximum of \$1500 per month.

Medicaid Buy-in:

While some of the targeted Medicaid expansions described above can benefit certain persons with disabilities, the Medicaid option which will be examined in this policy bulletin is the **Medicaid Buy-in**. We are interested in this Medicaid expansion option not only at the federal level but also at the state level where various states are considering the option of allowing persons with disabilities to buy into the state Medicaid program. The term "Medicaid Buy-in" is a bit confusing because it has usually been used to describe the option by which states have been able to and now are required to pay the Part B premium and Medicare cost-sharing for low income elderly and disabled persons below 100 percent of poverty. In this analysis, the concept of Medicaid Buy-in refers to expanding eligibility for the Medicaid benefit package to persons who do not meet the financial eligibility criteria for Medicaid.

The concept of buying into Medicaid is not really new. While states are required to provide Medicaid to recipients of the AFDC and SSI programs (i.e. categorically eligible persons), states have always had the option of covering "medically needy" persons whose income and resources exceed the eligibility standards for categorically needy coverage but whose medical expenses reduce their resources and income below the medically needy standards established by the state. The original Medicaid statute in 1965 actually contained no upper limits on

protected income levels for the medically-needy. Therefore, states could have established "spenddown" thresholds which would have permitted Medicaid to act as a supplementary public insurer for middle class Americans¹³⁰. To prevent large budget costs, Congress passed a Medicaid amendment in 1967 limiting the income threshold for the medically-needy program to 133 percent of states' AFDC payment level. With state AFDC levels significantly below the federal poverty level, this ensured that federal dollars would have limited use in a Medicaid Buy-in¹³¹. For persons who are medically indigent because their medical expenses reduce their income below a state-determined income level, the spend-down level in the Medicaid program is functionally equivalent to a deductible in private health insurance. The difference is that a deductible in private health insurance is fixed and known ahead of time while the impact of the spend-down is highly variable and, more importantly, can leave a family with a level of poverty that is difficult to recover from.

Looking to the Medicaid program as an appropriate vehicle for financing the health care of all persons who cannot purchase private health insurance, Senator John Chafee (R-RI) proposed the **Med-America Act of 1987** (S. 1139) in the last session of Congress. This proposed major restructuring of the Medicaid program broke new ground in defining eligibility for this publicly subsidized health benefit, expanding the scope of services which could be reimbursed through Medicaid, and insuring that this comprehensive health care package would be affordable to persons with health care needs.

The Med-America bill targeted four groups who have difficulty getting access to private health insurance. These included: (1) people under 100 percent of poverty (including the current Medicaid recipients), (2) people between 100-200 percent of poverty, (3) small employers who cannot purchase affordable health insurance in the private market for their employees and their dependents, and (4) people with pre-existing conditions who are rejected by private insurers or exhaust their benefit levels for their private insurance. To ensure the affordability of this Medicaid buy-in, the Med-America bill proposed an income-adjusted premium: persons under 100 percent of poverty would pay no premium; those between 100-200

¹³⁰Sara Rosenbaum, "Children and Private Health Insurance", prepared for Recent Development in the Financing and Organization of Health Care: Implications for Children, forthcoming, footnote #139, October 1986 draft.

¹³¹In all but two states, the medically needy income level is below 100 percent of the federal poverty level.

percent of poverty would pay a sliding scale premium equal to 3 percent of their adjusted gross income; and those over 200 percent of poverty would pay the full premium. The full premium would be community-rated reflecting the collective experience of all persons covered by the Medicaid Buy-in program.

For persons with chronic illness or disability, the Med-America bill offered many advantages. First, access to health care would be guaranteed because persons with incomes above 200 percent of poverty would be eligible for the Medicaid Buy-in if they were rejected by private insurers or had exhausted their private health insurance benefits. Secondly, affordability would be ensured with premiums limited to 3 percent of their adjusted gross income if under 200 percent of poverty or community-rated premiums for persons with incomes above 200 percent of poverty. Thus, higher levels of health care utilization for persons with disabilities or chronic illness would not increase their premiums alone but would be shared equally among all participants in the Medicaid buy-in pool. Thirdly, adequacy would be promoted by allowing states to expand their Medicaid benefit package to include services provided through the home and community-based waiver program.

While these advantages to the Med-America bill are most apparent in states with well-developed Medicaid programs, the Medicaid buy-in approach also presents some major disadvantages. One major problem is the size of the target population which ensures that the total cost of the Med-America bill will be very great for the federal government as well as for the state governments. As has already been pointed out, the major contributor to the cost of a Medicaid Buy-in plan is the over 20 million uninsured mostly low risk persons with incomes below 200 percent of poverty, not the 2-3 million uninsured persons with high risk.

In addition to the large number of poor or near poor uninsured persons who would become eligible for a Medicaid Buy-in program, the high cost of the Med-America bill reflects essential maintenance of effort requirements that states not be allowed to diminish their commitments to existing Medicaid recipients. For reasons of equity, the Med-America bill also requires that each state fulfill its obligations to its lower income persons before responding to the health care needs of its higher income persons, and that benefits which are made available to newly eligible Medicaid Buy-in recipients also be made available to current Medicaid recipients.

A second disadvantage of the Medicaid Buy-in approach is that many states have very low provider reimbursement levels in their Medicaid programs. Unless these Medicaid payment rates are improved, a Medicaid Buy-in program may not increase the availability of health related services to Medicaid Buy-in recipients. Although this problem was recognized by the drafters of the Med-America bill, it was thought that making middle class persons eligible for the Medicaid Buy-in program would generate significant pressure for improving the Medicaid reimbursement levels.

A third disadvantage of this Medicaid Buy-in approach is that states could still determine the "amount, duration, and scope" of the benefits that would be provided through their state administered Medicaid Buy-in program. Rather than require all states to provide a uniform set of benefits, the Med-America bill enables states to utilize federal Medicaid dollars for a broadened array of health related services.

From a disability perspective, a fourth disadvantage of the Med-America bill is that it was envisioned for persons who are uninsured or who exhausted their private insurance, rather than for persons who are under-insured. Although many more persons with disabilities or chronic illness are under-insured than uninsured, the Med-America bill does not permit them to supplement their inadequate private insurance by using the Medicaid Buy-in as a wrap-around policy for on-going maintenance needs.

Despite these limitations, the Med-America bill has made a major contribution in forging an ambitious expansion of Medicaid options. Some of the concepts embodied in the Med-America bill have been incorporated into other health care bills. For example, former Senator Lowell Weicker (R-CN) proposed the **Medicaid Catastrophic Coverage for Children Act of 1987** (S. 1283) to require states to extend Medicaid coverage to certain children with extraordinary expenses for medical and remedial care. More recently, Senator Ted Kennedy is preparing to develop a public program component in his Minimum Health Benefits bill which would phase-in over a period of time health care benefits to persons who are not employed. In a significant revision of the Minimum Health Benefits bill this session, Senator Kennedy, who will be joined by Representative Waxman, chairman of the Energy and Commerce Subcommittee on Health and the Environment, will propose phasing-in health care coverage to persons under 100 percent of poverty at no charge, charging a sliding scale premium to persons between 100-

180 percent of poverty, and charging an actuarially equivalent (i.e. full community-rated premium) for persons above 180 percent of poverty.

While Congress considers various federal bills to expand the use of federal Medicaid dollars, states are developing their own state-funded Medicaid Buy-in plans for persons with disabilities. In July, 1988, Massachusetts became the first state to implement a Medicaid Buy-in plan for children and working-age persons with disabilities as part of the state's commitment to universal access. Persons who can meet the Social Security Administration's medical definition of disability may be eligible to buy into the state's Medicaid buy-in program called CommonHealth (Extra) regardless of their incomes. This Medicaid Buy-in program covers working disabled adults who are not eligible for disability benefits because of their employment and disabled children who have been denied SSI and Medicaid because of their parents' income and/or assets. The annual premiums are designed on a sliding fee scale based on gross incomes ranging from no premium for individuals with incomes under \$11,540, a premium of \$480 for incomes under \$20,000, a premium of \$1320 for incomes around \$30,000, a premium of \$1,956 for incomes around \$40,000, and a premium of \$3000 for incomes over \$50,000. Table 13 provides the current monthly premium schedule for Massachusetts' CommonHealth (Extra) benefit package (see Table 13).

Persons with private health insurance who only need supplemental coverage under CommonHealth (Extra) pay two-thirds of the premium amount. CommonHealth (Extra) covers a wide array of services including: inpatient acute hospital, lab and X-ray, physician services, home health, preventive services, family planning, skilled nursing facility, intermediate care facility services, nurse midwife, outpatient hospital, personal care, prescription drugs, ambulance, private duty nursing, durable medical equipment, physical therapy, occupational therapy, speech therapy, dental services, eyeglasses, and mental health services¹³².

Other states are in various stages of developing a Medicaid Buy-in program for persons with disabilities. Wisconsin is designing a pilot program that may be implemented in three counties to test the feasibility of a Medicaid buy-in for persons with disabilities. The concept of a Medicaid Buy-in was viewed in part as a way to accommo-

date persons who will be rejected by private insurers from the proposed state health insurance plan¹³³. Among the benefit packages which Wisconsin may experiment with for its Medicaid Buy-in is a wrap-around package which includes coverage for personal care, home health care, rehabilitation therapies, durable medical equipment, drugs and supplies. Maine is developing a Medicaid Buy-in for uninsured persons under 150 percent of poverty¹³⁴ and has already adopted legislation to create a Medicaid Buy-in for persons with disabilities¹³⁵. Other states such as Michigan have citizen task forces exploring the feasibility of a Medicaid Buy-in¹³⁶.

At the state level, the Medicaid Buy-in is often viewed as an alternative to a high risk pool. Even without federal Medicaid dollars, states can create Medicaid Buy-in plans targeted to persons who cannot purchase adequate or affordable private health insurance. An income adjusted premium allows persons to have access to the Medicaid Buy-in without creating the adverse selection which is typical of high risk pools. Secondly, the Medicaid program already covers many of the on-going maintenance services that are not covered by high risk pools unless a person is hospitalized. Thirdly, a Medicaid buy-in can be administered more efficiently than a high risk pool if the state uses its existing capacity for processing claims, negotiating with providers, and purchasing in quantity durable medical equipment, drugs, etc. Fourthly, the deficit for the Medicaid Buy-in (after premiums are paid) is financed out of general revenues rather than assessments on insurance companies which exclude the contributions of self-insured employers and employers who do not offer any health insurance. Fifthly, a Medicaid buy-in can build on existing approaches to managed care to promote cost containment and continuity of care. By contrast, a high risk pool has less incentive to reduce its costs by managed care because the costs are dispersed among all insurers and because it is easier to raise the premiums and limit the benefits which

¹³³Dan Johnson, Office for Persons with Disabilities, Wisconsin Department of Health and Social Services, One West Wilson Street, Madison, Wisconsin 53707; telephone: (608) 267-9582

¹³⁴Special Select Commission on Access to Health Care, "Assuring Access to Health Care," Augusta, Maine, February 15, 1989.

¹³⁵The author of this policy bulletin, Bob Griss, has a contract with Maine's Department of Human Services to develop the administrative mechanisms for the Medicaid Buy-in.

¹³⁶Kathy Peterson, coordinator of Coalition for Access to Health Care, 109 West Michigan Avenue, Suite 900, Lansing, Michigan 48933; (517) 487-1755.

¹³²Additional information about the operation of CommonHealth (Extra) can be obtained through a written request to Barbara Leadholm, Director of CommonHealth, 600 Washington Street, Second Floor, Boston, Mass. 02111.

Table 13: CommonHealth Employed Disabled Adults and Disabled Children Premium Schedule*

**CommonHealth Employed Disabled Adults
and Disabled Children
PREMIUM SCHEDULE ***

This schedule is used to determine the premium amount for an employed disabled adult or disabled child. The monthly premium amount for either full or supplemental coverage is based on the gross income for the appropriate family size and shall provide coverage for all eligible disabled family members.

FAMILY SIZE		MONTHLY PREMIUM	
1	2	Full	Supplemental
Gross Income			
Below \$ 11,540	Below \$ 15,460	\$ 0	\$ 0
11,540-14,424	15,460-19,324	5	3
14,425-17,309	19,325-23,189	23	15
17,310-20,194	23,190-27,054	40	27
20,195-23,079	27,055-30,919	58	39
23,080-25,964	30,920-34,784	75	50
25,965-28,849	34,785-38,649	93	62
28,850-31,734	38,650-42,514	110	74
31,735-34,619	42,515-46,379	128	86
34,620-37,504	46,380-50,244	145	97
37,505-40,389	50,245-54,109	163	109
40,390-43,274	54,110-57,974	180	121
43,275-46,159	57,975-61,839	198	133
46,160-49,045	61,840-65,705	215	144
Over 49,045	Over 65,705	250	167
3	4	Full	Supplemental
Gross Income			
Below \$ 19,380	Below \$ 23,300	\$ 0	\$ 0
19,380-24,224	23,300-29,124	5	3
24,225-29,069	29,125-34,949	23	15
29,070-33,914	34,950-40,774	40	27
33,915-38,759	40,775-46,599	58	39
38,760-43,604	46,600-52,424	75	50
43,605-48,449	52,425-58,249	93	62
48,450-53,294	58,250-64,074	110	74
53,295-58,139	64,075-69,899	128	86
58,140-62,984	69,900-75,724	145	97
62,985-67,829	75,725-81,549	163	109
67,830-72,674	81,550-87,374	180	121
72,675-77,519	87,375-93,199	198	133
77,520-82,365	93,200-99,025	215	144
Over 82,365	Over 99,025	250	167

FAMILY SIZE		MONTHLY PREMIUM	
5	6	Full	Supplemental
Gross Income			
Below \$ 27,220	Below \$ 31,140	\$ 0	\$ 0
27,220-34,024	31,140-38,924	5	3
34,025-40,829	38,925-46,709	23	15
40,830-47,634	46,710-54,494	40	27
47,635-54,439	54,495-62,279	58	39
54,440-61,244	62,280-70,064	75	50
61,245-68,049	70,065-77,849	93	62
68,050-74,854	77,850-85,634	110	74
74,855-81,659	85,635-93,419	128	86
81,660-88,464	93,420-101,204	145	97
88,465-95,269	101,205-108,989	163	109
95,270-102,074	108,990-116,774	180	121
102,075-108,879	116,775-124,559	198	133
108,880-115,685	124,560-132,345	215	144
Over 115,685	Over 132,345	250	167
7	8	Full	Supplemental
Gross Income			
Below \$ 35,060	Below \$ 38,980	\$ 0	\$ 0
35,060-43,824	38,980-48,724	5	3
43,825-52,589	48,725-58,469	23	15
52,590-61,354	58,470-68,214	40	27
61,355-70,119	68,215-77,959	58	39
70,120-78,884	77,960-87,704	75	50
78,885-87,649	87,705-97,449	93	62
87,650-96,414	97,450-107,194	110	74
96,415-105,179	107,195-116,939	128	86
105,180-113,944	116,940-126,684	145	97
113,945-122,709	126,685-136,429	163	109
122,710-131,474	136,430-146,174	180	121
131,475-140,239	146,175-155,919	198	133
140,240-149,005	155,920-165,665	215	144
Over 149,005	Over 165,665	250	167

* Chapter 514, Page 600

* Chapter 514, Page 600

has the added advantage, from the insurance industry's point of view, of reducing participation in the high risk pool. Sixthly, unlike the high risk pool, the Medicaid buy-in creates an incentive for the state to regulate insurers and employers more aggressively to maximize cross-subsidization, discourage dumping from private insurance, and to utilize managed care.

Despite these possible advantages to a Medicaid Buy-in, there is a danger that the state will opt to create a high risk pool within the Medicaid program. If the premiums are set at a high level, comparable to the high risk pool, then many persons (especially those with lower risk) will be discouraged from buying into the Medicaid Buy-in pool. This reduces opportunities for cross-subsidization and invites adverse selection which further ensures that only the highest cost individuals will enroll. If the Medicaid Buy-in was available to all uninsured persons on a sliding scale premium basis, however, as envisioned in the Med-America bill, it would be possible for the community rated premium to be lower, perhaps even than premiums for standard risk persons in individual plans, because of the greater economies of scale as long as a large percentage of low risk persons were included in the Medicaid buy-in plan. It would be necessary for the Medicaid buy-in to be accompanied by an employer mandate to provide health insurance to all employees and dependents in order to maximize employer contributions to the largest portion of the population.

Side-stepping the larger question of whether a Medicaid Buy-in should be used for all persons who are unable to purchase adequate or affordable private health insurance, we feel that a Medicaid buy-in targeted to persons with chronic illness or disabilities has many advantages over other options as an interim step toward both expanding the scope of health care and deepening our national commitment to access to health care on the basis of need rather than on the basis of income, age, employment status or family status.

OTHER FEDERAL PROGRAMS

This section briefly describes other federal programs that can be developed or modified to improve access to health care for persons with disabilities or chronic illness. As recently as the mid-1970s, there was great interest on Capitol Hill in proposals for National Health Insurance¹³⁷. Many of these proposals are waiting to be "rediscovered" along with the original 1915 proposal for

compulsory health insurance described in the history section (see p. 4-6). Rather than examine the specific proposals for National Health Insurance in this policy bulletin, we will simply note that some health care advocates have sought to build on the precedent of Medicare for elderly persons by proposing a similar federal entitlement for health care to children called Pedicare.

Short of a major restructuring of the health care financing system, it is possible to conceptualize a federal entitlement to certain types of health related services that are targeted to the special health care needs of persons with disabilities. For example, the failure of private health insurance and public programs to pay for personal assistance services (PAS) in one's own home has been emphasized throughout this report. At present, public programs provide limited amounts of PAS through Medicare, Medicaid, and Social Service Block Grant funds¹³⁸. There are actually important advantages and disadvantages to providing PAS through these different public programs.

Medicare provides a federal entitlement to the full range of Medicare benefits based on previous FICA contributions. Financing occurs primarily through the federal social insurance mechanism of a payroll tax on all earners, and the federally-administered benefits are uniformly available in all states. The major disadvantages are that Medicare provides for home health care only when it is medically necessary and only for Medicare eligible persons. Moreover, because Medicare is federally-administered, it relies exclusively on certified home health agencies to provide home care which often diminishes consumer control.

Medicaid, on the other hand, is a state entitlement for persons who meet certain low income and asset criteria set by the states. The financing for Medicaid is sum-sufficient in that the federal government will match state dollars allocated to Medicaid for all persons who meet the federal and state eligibility criteria. Because states are

¹³⁷Committee on Ways and Means, National Health Insurance Resource Book, U.S. Government Printing Office, Washington, D.C., April 11, 1974; "National Health Insurance: Major Proposals", Hearings before the Subcommittee on Health and the Environment, December 8-10, 1975, Serial No. 94-60, U.S. Government Printing Office, Washington, D.C., 1976; U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, National Health Insurance Working Papers, Vols. I and II, December 1980.

¹³⁸Simi Litvak, et al., Attending to America: Personal Assistance for Independent Living: A Survey of Attendant Service Programs in the United States For People of All Ages with Disabilities, World Institute on Disability, Berkeley, California, April 1987.

responsible for various Long Term Care programs, it is advantageous that Medicaid is state-administered allowing states greater flexibility in coordinating their various Long Term Care programs with Medicaid services. As a means-tested program, Medicaid can efficiently target those persons who are least able to purchase health-related services with their own incomes. In addition, Medicaid is available for on-going maintenance services in most states. The main disadvantages to Medicaid are that state-administration has led to uneven benefits, levels of service, and eligibility among the states. In addition, Medicaid pays health care providers directly, generally making the PAS consumer dependent on a home care provider agency. Some states have gotten around this Medicaid requirement by using Independent Living Centers as pass-through organizations which are prepared to assist consumers to manage their own PAS. Nevertheless, the Health Care Financing Administration has proposed tightening up the medical requirements for recipients of PAS discouraging states from using this federally-subsidized financing mechanism for this essential under-funded service¹³⁹.

The Social Service Block Grant (SSBG) is provided by the federal government to the states in a sum-certain amount for allocation to various social service programs. Many states use SSBG funds to provide cash grants to low income individuals with functional disabilities to help them purchase PAS. The consumer-directed service model is used in many states (especially California's In-Home Support Service program)¹⁴⁰ because it is the least expensive way to provide the most PAS and because it allows the consumer to manage their own PAS. The major disadvantages of SSBG funding are that it is limited by the funds available and that any expansion of PAS must rely exclusively on new state dollars. Moreover, PAS must compete every year with other social service programs at the state level for this limited federal SSBG funding.

A proposal is being developed by the Center for the Study of Social Policy to create a new federal entitlement to personal assistance services for all persons, regardless of age, who have a functional disability (physical, cognitive, or emotional/behavioral) that renders them consistently unable to perform two or more activities of daily living (ADLs)¹⁴¹. Instead of relying on age or current

Medicare status, as is proposed in current Long Term Care bills (see pp.) this new PAS entitlement could combine the best features of Medicare, Medicaid, and SSBG which would provide a cost-effective and equitable way to meet the PAS needs of approximately 2.5 million persons who need personal assistance with activities of daily living (or up to 7.5 million persons with functional limitations which interfere with housework, meal preparation, getting around or personal care)¹⁴². The new federal home care entitlement could provide:

(1) a broadly defined **flexible home care benefit** that would allow case managers to tailor services to meet the unique needs of the individual and his or her family situation **within established payment limits** based on the assessment of the functional disability and the availability of other supports; the proposal envisions coverage of a virtually unrestricted array of case manager-authorized services and supports, flexible enough to enable highly individualized case plans that reflect individual preferences and needs and broad enough to adapt to different informal support contexts; covered benefits would also include assessments for eligibility and service needs, case planning, and case management;

(2) a state-administered process within uniform federal standards resulting in a federally-approved state implementation plan which provides for a **uniform assessment and eligibility determination system**, design and implementation of case planning and case management procedures, designation and certification of case management entities, establishment of procedures for certifying or "approving" providers, development and implementation of internal and external quality assurance standards, proc-

¹⁴¹Doug Nelson, "Outline of Major Features: Federal Home Care Entitlement Act", Center for the Study of Social Policy, Washington, D.C., March 20, 1989.

¹⁴²The most comprehensive estimate of the under 65 population with assistance needs in basic life activities is based on the Health Interview Survey 1979-80 Home Care Supplement analyzed by Mitchell P. LaPlante, "Disability in Basic Life Activities Across the Life Span", Disability Statistics Report, No. 1, January 1989, Institute for Health and Aging, University of California, San Francisco, California. This survey provides estimates for all ages of the number of persons who need assistance with different types of activities (e.g. going outside, walking, bathing, dressing, using the toilet, getting in or out of bed or chair, continence, eating), the nature of assistance needed (e.g. completely unable, uses equipment only, needs help only, equipment and help), the frequency of need for help (e.g. all or most of the time, some of the time, once in a while), the need for assistance with IADLs (e.g. shopping, household chores, preparing meals, handling money), and the frequency that someone must be present at home (e.g. all or most of the time, once in a while, never). No survey provides accurate information about the number of hours of PAS needed.

¹³⁹"Medicaid Program; Coverage of Personal Care Services", Federal Register, Vol. 53, No. 123, June 27, 1988, pp. 24103-24106.

¹⁴⁰Hale Zukas, Kitty Cone, and Joan Leon, "Descriptive Analysis of the In-Home Supportive Services Program in California", World Institute on Disability, Berkeley, California, 1985.

esses, and policies, and fiscal administration of the program; the payment limits would be established as a certain percentage (e.g. 50%-65%) of Medicare SNF (skilled nursing facility) daily rates;

(3) the state would be responsible for determining eligibility, designating the case management entities independent of the provider, designing the assessment process of needs and the case planning process which ensures consumer participation and authorizes an individualized service plan, establishing quality assurance mechanisms, and determining training requirements and criteria for approved providers;

(4) the federal entitlement would be financed through a social insurance mechanism by uncapping the income subject to the Medicare payroll tax; the federal entitlement would cover a certain percentage (e.g. 50 percent) of the costs of all services, supports and assistance provided under an approved service plan up to a monthly maximum (e.g. \$1300 to be adjusted annually for inflation) while the remaining costs would be regarded as a "copayment". Medicaid funds would be available to subsidize the costs of the copayment that would reduce an eligible recipient's income below a certain level (e.g. 125 percent of poverty), while those with higher incomes would be expected to pay the copayment through private insurance or out-of-pocket payments. Assets of less than a certain amount (e.g. \$12,000 per individual or \$24,000 per family, excluding homesteads) would be excluded from calculating income.

These financing mechanisms would contain overall program costs, create a state and consumer stake in avoiding unnecessary or excessive utilization, introduce an ability to pay dimension into the entitlement, create an opportunity for private insurance, and hopefully remove unreasonable cost barriers to access for potential entitlements. This type of federal entitlement to PAS would enable persons to carry out activities of daily living in their own homes, maintain social integration and family supports, enhance consumer direction, and prevent inappropriate institutionalization.

While it is possible to conceive of other new federal programs to address the health care needs of persons with chronic conditions, the remainder of this section will review three existing federal grant programs which target the health care needs of different groups of persons with disabilities or chronic illness. The three federal grant programs include: (1) the Maternal and Child Health Block Grant which funds Services for Children with Special

Health Care Needs, (2) the Federal grant programs established by the Education for All Handicapped Children Act (P.L. 94-142) which fund the new Handicapped Infants and Toddlers program (Part H) and the Basic State Grant (Part B), and (3) the Vocational Rehabilitation Basic State Grant program¹⁴³. Although these federal grant programs do not have the capacity to become major vehicles for health care financing, they can be used to target certain health related needs of some persons with disabilities or chronic illness and perform such functions as capacity to become major vehicles for health care financing, they can be used to target certain health related needs of some persons with disabilities or chronic illness and perform such functions as capacity building in the health care system, especially in the area of care coordination, gap filling, public reinsurance, and service provision for persons who are not eligible for other private or public programs.

State Programs for Children with Special Health Care Needs:

The oldest federal grant-in-aid health program to states which is still in existence and permanently authorized was created by Title V of the Social Security Act in 1935. This program which is now the Maternal and Child Health Block Grant has included a program called the Crippled Children's Services (CCS) which funds health care for certain disabled children. In 1986, Congress changed its name to "Services for Children with Special Health Care Needs" to eliminate the longstanding restriction of the program to coverage of children with "organic diseases and defects."

The CCS program originally focused on treating and rehabilitating children with orthopedic impairments resulting from polio, which President Franklin Roosevelt was intimately familiar with. In the 1940s and 1950s the program began covering other chronic disabilities, particularly chronic heart and pulmonary ailments. Reflecting the wide discretion which states were historically permitted in administering state programs, states have been able to develop their own eligibility criteria for determining what constitutes a "covered" impairment. Many states ration their limited CCS dollars by favoring younger children over older disabled children and by excluding from coverage such major childhood disabilities as diabetes, cancer, asthma, sickle cell anemia, mental illness, and other prob-

¹⁴³The Older Americans Act authorizes another federal block grant which can be used to fund a wide range of social and health-related supports for elderly persons.

lems. Based on Section 504 of the Rehabilitation Act of 1973, advocates have challenged the right of states to impose age limitations on eligibility for CCS services among disabled children or to exclude children on the basis of certain diagnostic categories. States have also been criticized for making categorical coverage choices unrelated to an assessment of the prevalence of illnesses within a community. While the mandate of the CCS programs far exceeds the limited resources which it has available, the federal government has permitted the states wide latitude in deciding how to allocate these publicly funded resources for health care.

Some states use CCS to finance primary health care to uninsured disabled children while others use CCS to purchase rehabilitation therapies or to purchase case management services which the private health insurance system does not usually provide. Of the \$406.3 million Title V funds that were allocated to the states during FY 1986, about one-third or approximately \$135 million was allocated to the CCS program. State matches brought the total CCS expenditures in FY 1986 to over \$400 million.

The Federal statute prohibits states from imposing any charges on eligible children with family incomes below the federal poverty level, but states can charge families with incomes between 100 percent and 200 percent of poverty only in accordance with a "public fee schedule adjusted for family size and income."

An analysis of CCS variation among states came to the conclusion that CCS agencies which used fee-for-service reimbursement methods on an as-needed basis covered fewer disabling conditions and served fewer children than CCS agencies which contracted with a clinic, institution or other type of provider where payment was made on a per capita basis¹⁴⁴.

Although federal law treats Title V as "second dollar" to Medicaid, there is no federal requirement that providers who receive CCS payments are willing to accept Medicaid. As a result, some CCS programs have used

scarce CCS dollars to fund health care providers who refuse to participate in Medicaid¹⁴⁵.

States have been permitted wide latitude in administering the CCS program. Although states are expected to submit to the Secretary of Health and Human Services a "Description of Intended Expenditures" which should identify what services will be provided and who is eligible for care, there is no standardization in reporting requirements or in program administration. Many state Title V programs apparently operate without formal, public, written rules regarding who is eligible for the program, what benefits are covered, and under what conditions services will be furnished. According to some observers, many CCS agencies routinely deny, reduce or terminate benefits without even providing written notification, much less an appeals procedure¹⁴⁶. A recent legislative initiative in the Senate Finance Committee would require states to allocate at least 30 percent of the Maternal and Child Health Block Grant funds which they receive to Services for Children with Special Health Care Needs and would require states to prepare a statewide needs assessment which would identify unmet maternity and infant care needs and plan and develop a system of care coordination services for children with special health care needs.

Handicapped Infants and Toddlers Program (Part H):

As part of the Education of the Handicapped Amendments of 1986, a new state grant program was established under Part H of the Act to encourage states to develop early intervention services for infants and toddlers with disabilities¹⁴⁷. Public Law 99-457 provides federal funds to states for planning early intervention services to promote the "development" rather than the "education" of children from birth through age 2.

¹⁴⁵Sara Rosenbaum, "An Overview of the Title V Maternal and Child Health Block Grant's Crippled Children's Services Program", Children's Defense Fund, Washington, D.C., November 1986, pp. 19-20.

¹⁴⁶*Ibid.*, p. 21.

¹⁴⁷Penny Hauser-Cram, Carole C. Upshur, Marty Wyngaarden Krauss, and Jack P. Shonkoff, "Implications of Public Law 99-457 for Early Intervention Services for Infants and Toddlers with Disabilities", *Social Policy Report*, Volume III, Number 3, Autumn 1988, Society for Research in Child Development, Washington, D.C.

¹⁴⁴Henry Ireys, Robert Hauck, and James Perrin, "Variability among State Crippled Children's Service Programs: Pluralism Thrives", *American Journal of Public Health*, Vol. 75, No. 4, pp. 375-381; Henry Ireys and Richard Eichler, *Correlates of Variation among State Programs for Children with Special Health Care Needs: Report of a Survey and Six Case Studies*, MCH/CCS-MCJ-360479, National Technical Information Service, U.S. Department of Commerce, Springfield, Virginia, September 1988.

By October 1991, states must make available to eligible children and their families at least the following services, when appropriate: special instruction; family training, counseling and home visits; speech pathology and audiology; occupational therapy; physical therapy; psychological services; case management services; medical services for diagnostic and evaluation purposes; early identification, screening and assessment services; and health services necessary to enable the infant or toddler to benefit from the other early intervention services. These services, if "appropriate" for the child and family must be included in the family's individualized family services plan (IFSP). The IFSP constitutes a legally binding commitment by the state to an eligible child and his or her family that the state will provide the services in the plan.

Among the developmental needs which the early intervention program is suppose to address are: physical development; cognitive development; language and speech development; psycho-social development; and self-help skills. Health services are included only to the extent that they are "necessary for the infant or toddler to benefit from the other early intervention services". The intent of this legislation is for the federal funds to be used to establish a service system, and not to pay directly for individual services, except as a "payor of last resort."

To develop an early intervention system, states are expected to define developmental delay to be used to determine the eligibility of infants and toddlers for services, to develop methods of needs assessment, and to create a process for creating an individualized family service plan (IFSP) based on an assessment of the child's and family's needs. The IFSP will specify the services needed to meet the goals of the child and his or her family and will identify a case manager who is responsible for ensuring the implementation of the plan. By starting between birth and age 2, this approach to early intervention is expected to ease the transition into preschool programs which states are required to provide free by 1990 for public education and related services for all eligible children with disabilities from the age of 3 to 5 years. In 1975, Public Law 94-142 established the right to a public education for all school age children 5-17 years old¹⁴⁸.

¹⁴⁸S. See S. Behr and J.J. Gallagher, "Alternative administrative strategies for young handicapped children: A policy analysis", *Journal of the Division for Early Childhood*, Vol. 2, 1981, pp. 113-122; J. Singer and J.A. Butler, "The Education for All Handicapped Children Act: Schools as agents of social reform", *Harvard Educational Review*, Vol. 57, 1987, pp. 125-152.

The Part H program may create some important precedents by: (1) extending federal responsibility for the developmental needs of infants and toddlers regardless of family income, (2) developing a methodology for assessing the range of developmental needs associated with various chronic conditions, (3) providing a state level mechanism for coordinating services provided by different providers and funded by different sources, and (4) creating a public capacity to supplement the health related services provided by private insurance and public programs.

Education for All Handicapped Children Act (Part B):

Part B of the Education for All Handicapped Children Act requires that all handicapped children ages 3 through 21 years have access to a free appropriate public education in the least restrictive environment. The federal government provides a grant to each state, corresponding to the number of handicapped children in the state, to provide special education and related services. Today, over 4 million children receive special education and related services in elementary and secondary schools under P.L. 94-142's mandates.

The public school system is responsible for providing special educational services when a disability prevents a child from reaching his or her full potential in regular education. In 1984, the U.S. Supreme Court decided in the case of *Irving Independent School District v. Tatro* that a child with spina bifida was entitled to catheterization in the classroom as an educationally related service. Although though using a catheter to empty one's bladder is a health related process that doesn't teach very much, without it some children wouldn't be able to come to school at all, and so it is regarded as an "educationally related service". The *Tatro* decision affirmed the right to supportive services which enable the child to come to school or benefit from the programs in school.

Children with disabilities have a right to receive such educationally related services as: physical therapy, occupational therapy, speech therapy, and psychological and nursing help and assistance in the classroom by instructional or therapeutic aids to the teacher or the therapists. Among the special education personnel employed by public schools are nurses, psychiatrists, psychologists, school social workers, diagnostic staff, counselors, vocational education teachers, occupational therapists, physi-

cal therapists, audiologists, recreational therapists, bus drivers, etc.

Because the public school system is responsible for ensuring that public education is not diminished by the absence of these educationally related services, a problem has sometimes arisen between school systems and public and private insurers when they compete to be the insurer of last resort. As long as a service is needed by a child to obtain special education and the related service is identified in the child's Individual Education Plan (IEP), the public school system is required to provide the educationally related service at no cost to the family¹⁴⁹. In order to utilize other available funding sources, the public school system can request that a parent use private health insurance to pay for certain "educationally related services", but the school system would be obligated to pay for any increase in deductibles or premiums occasioned by the use of private insurance for this purpose. The public school's obligation to provide educationally related services extends to all handicapped children who need special education whether they are served in a public or private school, but the public school system can determine how those educationally related services are to be provided. The Medicare Catastrophic Act of 1988 also contained a clarification regarding Medicaid payments for covered services provided to children who are dually eligible for aid under both Medicaid and The Education for All Handicapped Children Act. According to the amendment, effective immediately, services that are covered under Medicaid will be reimbursed by Medicaid even if they are also educationally related and therefore reimbursable under the Education Act.

Vocational Rehabilitation Program:

The Federal government provided \$1.45 billion to states in FY 1989 to operate Vocational Rehabilitation (VR) programs for persons with mental or physical disabilities who need assistance to become gainfully employed and self-reliant. In order to be eligible to receive VR services, an individual must have a substantial handicap to employment and a reasonable expectation that he or she will become employable because of the VR services. On the basis of an assessment of the individual's needs for employment an Individualized Written Rehabilitation Plan (IWRP) is developed between the VR agency and the individual VR client. Among the services which VR will pay for in conjunction with an IWRP, are restorative

services including hospitalization, surgery, and medical treatment. In 1986, \$138.9 million dollars were spent on restorative services by state VR agencies which represents approximately twenty percent of the total VR service dollars¹⁵⁰.

When a person is placed in suitable employment, the case is closed and the individual is expected to make it on his or her own. The VR system can make available some short-term post-employment services which may be necessary, such as an adjustment of a prosthesis, but the VR system is not designed to provide on-going support services for persons who need those services to continue working. Although less than 16.8 percent of VR clients in 1985 were SSI or SSDI recipients with permanent and total disabilities¹⁵¹, the VR program makes no effort to help them meet their health related needs once they are employed. With most group health insurance not providing coverage for on-going maintenance needs, it is increasingly recognized that many disabled persons cannot afford to work. Congress has recently taken an important step to reduce this work disincentive for disabled SSI recipients by permanently adding Section 1619 to the Social Security Act (see p. 77). But this option has not been extended to SSDI beneficiaries who, ironically, are in a much better position to be able to enter the labor force because of their education, skills and work experience, and their previous relationship with an employer before the onset of their disability. Instead of allowing the use of Social Security dollars to help people with disabilities to purchase the support services which they need to maintain employment, the Social Security system spent \$16 million in 1987 reimbursing the VR system for placing SSDI recipients in competitive employment, and \$20.5 billion in cash benefits to disabled workers because they could not work¹⁵². This is reminiscent of the paradox of costs highlighted by Frank Bowe when he wrote: "America is spending ten dollars on dependence among disabled people for every dollar it expends upon programs helping them become independent." The challenge of disability policy is to recognize that "it is far more expensive to continue handicapping America than it would be to begin rehabilitating America."¹⁵³

¹⁵⁰Rehabilitation Services Administration Information Memo #88-21, "1986 Expenditure Report", February 11, 1988.

¹⁵¹These unpublished figures are taken from the Case Service Report System, RSA-300 for FY 1985.

¹⁵²Social Security Administration, Social Security Bulletin, Annual Statistical Supplement, 1988, Table 4.A4, p. 124.

¹⁵³Frank Bowe, Rehabilitating America: Toward Independence for Disabled and Elderly People, Harper & Row, Publishers, New York, 1980, pp. 4 and xv.

¹⁴⁹Federal Register, Vol. 45, p. 86390, December 30, 1980.

Conclusion to Policy Options:

This chapter has examined various public policy options for changing the public and private insurance systems in order to improve access to health care for uninsured and underinsured persons. Unlike many studies which assess policy options in terms of their acceptability to the most powerful interests, this policy bulletin has evaluated strategies in terms of their effectiveness in promoting the goals of access, affordability, and adequacy for the special health care needs of persons with disabilities or chronic illness.

Private health insurance, which has only covered a majority of Americans since 1950, has been shaped by and can be changed through regulations or incentives embodied in public policy. The advantage of relying on regulations of insurers and employers is that the cost to government can be minimized. The danger of defining the minimum essential health care package in terms of what is affordable to marginal employers would tend to reverse the trend toward comprehensive health insurance upon which many nondisabled and disabled employees have come to rely on. The advantage of relying on a combination of incentives and regulations is that some of the resistance to the changes can be reduced. On the other hand, these public incentives to the private sector may fail to correct the acute care bias of traditional health insurance which denies access to health care for many persons with disabilities and continues the arbitrary separation of acute care and long term care.

Using existing public systems, like Medicare, as the basis for expanding access to health care has the advantage of a federally administered social insurance financing mechanism which taxes persons who are supposedly most able to pay and does not charge premiums on the basis of probability of risk. On the other hand, the Medicare benefit package still does not recognize on-going maintenance needs. Improving access to health care through modifications of the Medicaid system has the advantage of the most comprehensive benefit package for on-going maintenance needs. On the other hand, severe financing constraints at the state level have impeded expansion of eligible populations, limited the availability of many optional services, and restricted reimbursement levels far below market rates. The major limitations to expanding public programs at the present time are constraints imposed by the federal deficit, the growing number of persons without health insurance, and the fear of "dumping" from the private sector. These constraints can only be removed

by developing strategies which redirect existing financing streams to the health care system.

This policy bulletin has examined five choices for improving access to health care for persons with chronic conditions. Whether private health insurance, public incentives to the private sector, Medicare, Medicaid, or other federal programs are chosen as the best vehicle for ensuring access to health care for persons with disabilities or chronic illness is the major strategy question confronting the disability movement. The choice will not only affect which groups will favor or oppose particular strategies, but more importantly, may affect the future of accessibility, affordability, and adequacy of health care for all Americans. The final section will briefly consider the role of the disability movement in health insurance reform.

ROLE FOR DISABILITY MOVEMENT

People with disabilities and chronic illness are not the only groups poorly served by the private health insurance system. There are 37 million uninsured persons (of whom people with chronic conditions probably represent less than 10 percent) who cannot afford private health insurance. There are almost 30 million elderly persons who, although they have Medicare, lack coverage for Long Term Care needs should they develop functional limitations. And there is an even larger number of temporarily able-bodied persons (TABs for short) who will develop chronic conditions at some time in their lives for whom their private health insurance will be inadequate or unaffordable.

To give greater meaning to the concept of TABs, it would be useful to construct a life expectancy table for the entire U.S. population that represented the probability that a person at a given age would develop a functional disability or chronic illness at some time in their life¹⁵⁴. Many TABs would be much more concerned about the limitations of private and public health insurance if they knew the probability that they would: (1) develop one of the more prevalent disabilities or chronic illnesses (e.g. heart disease, cancer, cerebrovascular disease, diabetes, spinal cord injury, traumatic brain injury, blindness, mental illness, multiple sclerosis, Alzheimer's disease), (2) have a family member who is born with mental retardation or cerebral palsy, or who develops a disability or chronic illness in later life, (3) have to stop work or at least reduce it because of a chronic condition which lasts for more than one year, (4) pay out-of-pocket costs for health care that exceed \$2000 per year, (5) develop functional impairments which interfere with performing activities of daily living, (6) use a wheel chair, or (7) enter a nursing home. In addition, there is a growing number of Americans who are disenchanted with the rising costs of health care, the limitations in health insurance coverage, the inequities in health care financing, and the inefficiencies of claims management, overlapping policies, etc.

Clearly, health insurance reform is on the public agenda. Employers are rebelling against average health care cost increases of 18.6 percent in 1988 over last

year¹⁵⁵, health care providers are concerned about the burden of uncompensated care that exceeded \$9.5 billion dollars in 1985¹⁵⁶, the federal government is experimenting with different strategies for cost containment, and many health insurance companies are abandoning the market¹⁵⁷. While this report has not examined many of these factors, it is important for people with disabilities and chronic illness to recognize that the disability movement is not driving health insurance reform. One reason for this is that people with disabilities are probably less than ten percent of the uninsured population because of the availability of Medicare and Medicaid, and are also less than ten percent of Medicare beneficiaries¹⁵⁸. Nevertheless, the special vulnerability of people with disabilities to the limitations of private and public health insurance raises crucial issues that can affect the direction of health insurance reform in the U.S.

While most persons who are uninsured cannot afford a standard private health insurance plan, many persons with disabilities cannot afford the cost of the health related services which they need to function as equal members of society. Because they need more than they can afford, people with disabilities force society to recognize that it is unfair that eligibility for private health insurance is based on ability to pay. It is equally unfair to limit publicly subsidized health care to persons who are unable to work. To accommodate persons with disabilities, it may be necessary to create a system that is financed from each according to his income and provides to each according to his health care needs. Whether this can be accomplished within a health care financing system that is organized to make a profit remains to be seen. Faced with this challenge, the disability community must decide whether it views itself as a vanguard in the movement for equitable health care financing for everyone, or as a tiny minority whose needs cannot be expected to be dealt with through the generic health care financing system. This crucial choice by the disability community will affect which groups are regarded as its allies, and may ultimately influence the direction of health insurance reform in the U.S.

¹⁵⁴Sidney Katz, et.al. have developed an "Active Life Expectancy table for persons over 65 years old which uses life-table techniques to represent the expected remaining years of functional well-being, in terms of capacities to perform the activities of daily living (see Sidney Katz, et.al., "Active Life Expectancy", *New England Journal of Medicine*, Vol. 309, November 17, 1983, pp. 1218-1224).

¹⁵⁵Foster Higgins, *Health Care Benefits Survey, 1988*, Princeton, New Jersey, p. 11.

¹⁵⁶American Hospital Association, 1985 Annual Survey of Hospitals, provided by state in American Hospital Association, *Medicaid Options: State Opportunities and Strategies for Expanding Eligibility*, Chicago, Illinois, 1987, Table 13, p. 125.

¹⁵⁷*National Underwriter*.

¹⁵⁸*Access to Health Care*, Vol. I, Nos. 1-2, p. 11

Different disability groups have different priorities. For some groups the priority is ending actuarial discrimination where private insurers may be using inappropriate data to disqualify them from coverage. This may involve strengthening anti-discrimination laws to reduce the number of uninsured persons with disabilities. Among persons with disabilities, the number of under-insured is much greater than the number of uninsured. Some groups seek to examine actuarial data to interest private insurers in marketing a supplemental private policy¹⁵⁹. For many groups with higher health care needs, however, the priority is likely to be distributing health care costs in a more equitable way. This report has tried to assess the feasibility of different options for achieving greater access to adequate and affordable health care for persons with disabilities or chronic illness through such mechanisms as employer and insurer mandates, high risk pools, Medicaid buy-in plans, Medicare entitlements for persons with disabilities, and even National Health Insurance.

Unfortunately, the options for change often create dilemmas for the disability community. If people with disabilities support special health insurance programs for themselves, this may interfere with strategies to restructure health care financing for all persons. On the other hand, the most expedient solutions to the problem of the uninsured, may not provide adequate coverage for the special health care needs of persons with disabilities. Another dilemma for the disability community is whether to go after programs which replace the way private health insurance is provided or to try to supplement existing private coverage. A replacement strategy for the private health insurance system may generate substantial resistance from those with vested interests in the existing system while a supplemental strategy may create incentives for the private system to reduce the comprehensiveness of its coverage. It is important for the disability community to be concerned about whether changes made in access to health care for persons with disabilities will reinforce or compete with strategies to restructure health care financing for other groups.

The disability movement has a special contribution to make to health insurance reform. By exposing the limitations of private and public health insurance, the disability community can help influence the way different

interest groups assess the various options for health insurance reform. Because persons with disabilities or chronic illness are likely to have higher health care costs, they are very sensitive to the principles of affordability and the equity of health care financing. Because persons with disabilities or chronic illness are likely to need a range of health related services that extends beyond acute care, they are in a critical position to help broaden the definition of health care to include both preventive services and long term support. And because persons with disabilities recognize how barriers to health care create obstacles to employment and to meaningful participation in the community, the disability movement can effectively share the issue of health care as a right which all citizens should be entitled to. **Just as our society would not tolerate health insurance companies charging higher premiums to black Americans when the actuarial tables reveal their higher mortality or health problems, we must question the legitimacy of charging higher premiums to persons with disabilities or chronic illness.** Like black citizens, persons with disabilities should be viewed as members of the larger community. A "community" can be defined as the group with whom one shares risks. While actuarial tables may be appropriate for pricing life insurance which is not an entitlement, their use for determining access to health care poses a major obstacle to meaningful participation in society and may increasingly be viewed as one of the most important civil rights issues of the 1990s.

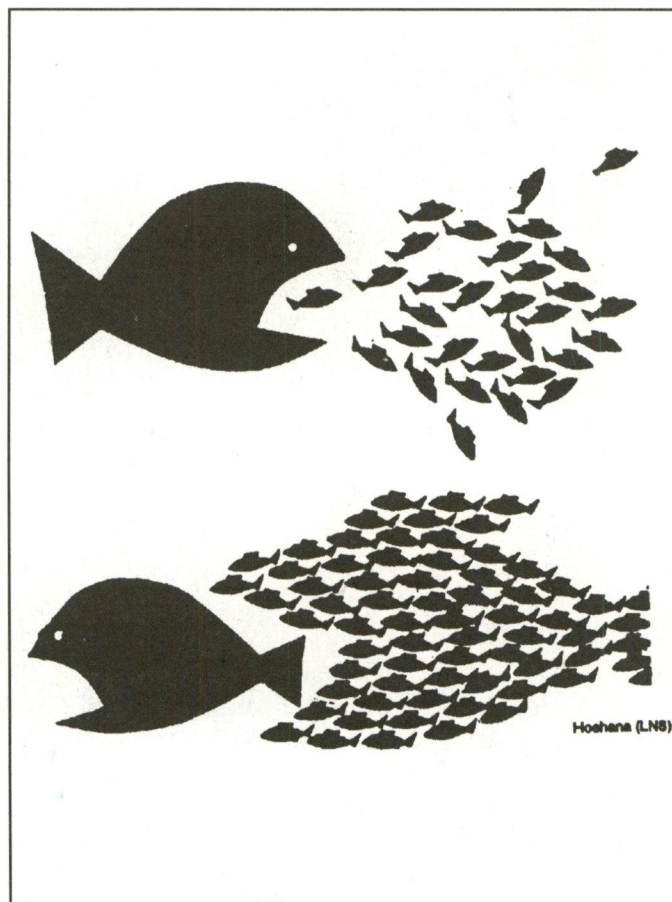
¹⁵⁹The American Diabetes Association is exploring the feasibility of the Colonial Life Insurance Company to test market a supplemental health insurance policy for persons with diabetes which covers preventive health care such as nutritional and dietary services and special equipment such as therapeutic shoes and artificial limbs that are often not covered in standard health insurance plans.

Postscript:

Thank you for weighing through two fairly complex policy bulletins on various aspects of disability policy which are highly relevant to health insurance reform. **Disability policy provides a unique perspective on the values of our society and the logic governing the institutions which determine access to health care.**

To improve the accuracy and relevance of the information which has been presented, you are strongly encouraged to share your perceptions of the problem and potential solutions, raise new questions, send favorite cartoons on access to health care, and identify suggestions for future topics. This information will be incorporated into future publications, presented at various conferences, and used in technical assistance at the state and federal levels to improve access to health care. With the network of over 5000 organizations and individuals with whom the World Institute on Disability has shared these policy bulletins around the country, there is a great opportunity to address the special health care needs of persons with disabilities and chronic illness in the current efforts for health insurance reform. Future policy bulletins will be planned when appropriate funding can be found.

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