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ABSTRACT

The problems of access, adequacy, and affordability of health insurance for persons with severe chronic conditions are analyzed. Part 1 defines the target population by considering conceptual and methodological issues, and examines statistics from various national surveys. Part 2 examines the distribution of health insurance throughout the population by age, family income, employment, and health status, and then compares the health insurance status of persons with and without disabilities. Attention is focused on the working-age disabled population, divided into those who are employed, those receiving public health insurance, and those neither employed nor recipients of public health insurance. Part 3 explores the limitations of acute care-oriented health insurance for meeting such special needs as rehabilitation, maintenance therapies, personal assistance services, durable medical equipment, assistive devices, disposable medical supplies, and drugs. Part 4 identifies barriers to adequate and affordable health insurance, including medical underwriting, the cost of health care services in relation to the income of persons with disabilities, and the limitations imposed on health insurance plans because of pre-existing conditions. Part 5 examines national survey data on health care costs and utilization patterns for persons with disabilities, critiques the limitations of the data, and identifies areas for further research. (JDD)

ACCESS TO HEALTH CARE

by Bob Griss

Vol. 1, No. 1 & 2 World Institute on Disability September 1988

MEASURING THE HEALTH INSURANCE NEEDS OF PERSONS WITH DISABILITIES AND PERSONS WITH CHRONIC ILLNESS

Statement of Purpose:

This first issue of Access to Health Care begins a series of health policy bulletins analyzing the health care needs of persons with disabilities or chronic illness. The World Institute on Disability (WID) received a one year grant from the National Institute on Disability and Rehabilitation Research (NIDRR) to develop and publish a series of policy bulletins on the financing of health care for persons with severe chronic conditions. The topics which will be examined in Access to Health Care include: (1) "Measuring the Health Insurance Needs of Persons with Disabilities or Chronic Illness", (2) "Evolution and Limitations of Private and Public Health Insurance for Meeting the Needs of Persons with Disabilities or Chronic Illness", and (3) "Federal and State Policy Options for More Equitable Health Care Financing that Better Accommodates the Needs of Persons with Disabilities or Chronic Illness".

In the future, Access to Health Care will seek funding to examine "Lessons from Other Countries: International Comparison of the Financing of Health-related Services for Persons with Disabilities or Chronic Illness" as well as other topics which readers may recommend.

The purpose of this policy bulletin is to focus attention on a wide range of information which is relevant to assessing the adequacy of the health care system for persons with disabilities or chronic illness. By examining the health insurance needs of persons with severe chronic conditions, Access to Health Care will inform federal and state policy makers, health care providers, insurers, and disability advocates about the limitations of the private and public insurance systems for responding to the needs of this vulnerable group. It will also analyze the forces which have shaped the health care system, evaluate public policy

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Acknowledgments: This policy bulletin has been supported by an Innovation Grant from the National Institute on Disability and Rehabilitation Research. The views expressed in this policy bulletin, however, are solely the responsibility of the author and the World Institute on Disability. WID also acknowledges the Research Office of the National Rehabilitation Hospital for its in-kind support and technical assistance, the Epilepsy Foundation of America which prepared mailing labels, and the Paralyzed Veterans of America which provided graphics production.

options for change, and consider how changes designed for other groups, such as the elderly, uninsured workers, and low income persons, will affect access to health care for persons with disabilities or chronic illness. But beyond this, the policy bulletin is addressed to the disability community to help it decide whether to view itself as a vanguard in the movement for equitable health care financing for everyone, or as a tiny but deserving minority whose needs cannot be expected to be dealt with through the generic health care financing system.

To meet these objectives, Access to Health Care will analyze and interpret existing data on health care needs, present new findings, highlight recent reports, and identify issues which require further exploration. This information has been assembled as a technical resource to be used by policy makers, planners, and advocates at the state and federal levels who are concerned how public policy affects access to health care for persons with disabilities or chronic illness. It is hoped that this information will be useful to remove the gaps in our health care financing system for both persons who are uninsured or under-insured.

To get this information directly into the hands of persons who are involved in the formulation of public policy on access to health care, WID has developed an extensive mailing list of organizations around the country to whom Access to Health Care is being sent. At the state level, these organizations include Developmental Disability Councils, Protection and Advocacy agencies, Governor's Committees for Persons with Disabilities, Vocational Rehabilitation agencies, Commissioners of Insurance, Medicaid agencies, Department of Education Programs for Children with Special Needs (formerly Crippled Children's Services), Offices on Aging, Independent Living Centers, and National Information Centers for Handicapped Children and Youth. At the national level, this policy bulletin is being sent to Congressional representatives and staff responsible for setting health policy, appropriate federal agencies, national voluntary health organizations and consumer groups, health care providers, insurers, advocacy groups, and health policy researchers.

The diversity of this intended audience creates a challenge to decide what information to cover and in what depth. Unfortunately, some of this information is highly technical and requires extensive qualification in order to interpret appropriately. At the risk of providing more detailed information than some readers may want to know, it was decided to include whatever information we believe is essential to the process of reevaluating public policy, planning, and researching changes in access to health care. WID hopes that this policy bulletin will assist in the planning process, stimulate discussion, promote further inquiry, and contribute to shaping the public policy debate on health insurance reform.

Political Context:

This examination of the problems of financing health care for persons with disabilities or chronic illness occurs in the midst of continuing escalation of health care costs throughout the U.S. health care

Access to Health Care is published by the World Institute on Disability, a non-profit research and information center focusing on public policy and program issues from the perspective of persons with disabilities. Founded by persons in the Independent Living movement, WID is committed to the elimination of handicappism through the promotion of independence, equity of opportunity, and full participation of people with disabilities.

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system. In response to rising health care costs, the two major payors, the federal government and employers, have developed cost containment strategies to limit their costs. While the effectiveness of these strategies to control health care costs is questionable, they have reduced access to health care for specific groups. As a result, critical attention has recently focused on the failure of the private and public health insurance systems to respond to the needs of various populations.

There is widespread concern about the growing number of uninsured persons in the U.S., now totaling 37 million persons, who lack any form of private or public health insurance at least part of the year. One consequence of this large and growing uninsured population is the financial burden of uncompensated care on public and non-profit health care providers. Another consequence is that many uninsured persons do not receive the appropriate preventive care or primary care which they need to avoid developing serious health conditions. Moreover, in the absence of access to appropriate primary care, uninsured persons rely inappropriately on expensive treatment at public hospitals. There is also concern about the high rate of infant mortality in the U.S., now ranking 17th among the world's nations, due to a high rate of teenage pregnancies, lack of prenatal care for uninsured pregnant women, and limited access to health care for low income families. Inadequate prenatal care contributes to low birth weight infants who account for half of all children needing extensive medical care.

In 1986, Congress responded to the problem of the uninsured by attempting to protect workers who lost their health insurance when they were displaced from jobs which provided health insurance. Congress passed what may be regarded as the first federal insurance mandate guaranteeing the continuation of insurance plans under certain conditions. Employersproviding group insurance are obligated to extend group rates to unemployed workers at group rates for eighteen months if the unemployed workercan pay both the employer's and the employee's share of the group insurance premium. However, it is now recognized that two-thirds of the uninsured are workers or dependents of workers whose employers are not contributing to their health insurance coverage. Responding to this new perception of the uninsured population, Congress is considering whether it would be appropriate for the federal government to require employers to provide a minimum health insurance plan for all employees and their families.

There is also growing support for extending Medicaid eligibility to low income families up to 100 percent of the federal poverty level who could not afford private health insurance. This strategy is increasingly viewed as an essential component of welfare reform in order to reduce the disincentives for persons on the public assistance program Aid to Families with Dependent Children (AFDC), who currently face the loss of eligibility for Medicaid if they transition into low wage jobs which do not provide health insurance. In 1987, Congress modified the Supplemental Security Income (SSI) program under section 1619(b) to enable disabled SSI recipients to retain Medicaid coverage when they return to work until their earned income exceeds the value of the cash benefits and health care services which they would have been eligible for by not working. A similar work incentive is being considered for Social Security Disability Insurance (SSDI) beneficiaries who face the loss of Medicare coverage two years after returning to work.

The high cost of health care has also promoted interest in catastrophic health insurance to protect high health care users from out-of-pocket costs which exceed a certain dollar amount or percentage of their income. Recognizing that some elderly persons face catastrophic costs for repeated hospital stays in spite of their Medicare coverage, Congress recently passed a Catastrophic Insurance bill to expand Medicare coverage for hospitalization, physician services, and out-patient drugs.

The demand for long term care services is growing rapidly as the population ages, as women, the traditional providers of informal support in the family, enter the labor force, and as technological advances increase the survivability of persons who would previously have died. In the absence of private long term care insurance, states are trying to respond to the widespread demand for long term support services by developing community based alternatives to nursing home care to enable persons to continue living at home in spite of functional limitations. Recognizing that elderly persons over 85 years old represent the fastest growing age group in the population, there is increasing interest in expanding Medicare benefits to cover long term care needs as well as exploring the potential for stimulating private long term care insurance.

In addition to issues about eligibility and benefits in public and private health insurance there are fundamental questions about reimbursement policy in the financing of health care. Do capitated payments increase efficiency in health care delivery or increase competition in the recruitment of healthy consumers? How is quality of care affected by prospective payments when health care providers are limited to a predetermined maximum level of reimbursement? Is the federal government prepared to finance the health care of all persons who private insurance wishes to avoid? Answers to these questions bear directly on the access to health care for persons with severe chronic conditions.

Faced with a myriad of health care financing problems, Congress is considering different approaches to fill the existing gaps in the private and public health insurance systems for different populations. These solutions range from responding to the basic health care needs of the 37 million uninsured persons under age 65, to reducing the burden for acute care needs on the under-insured population, to extending coverage to Medicare beneficiaries for long term care needs.

With considerable momentum for health insurance reform, it is critical that the health care needs of persons with disabilities or chronic illness be well understood. It is also important to consider how changes in health care financing which are designed for other groups, such as the elderly, uninsured workers, or low income persons, will affect access to health care for persons with disabilities or chronic illness. Finally, it is important to consider what persons with disabilities or chronic illness can contribute to the growing debate on health insurance reform.

Importance of a Disability and Chronic Illness Perspective:

The experience of persons with disabilities or chronic illness with the limitations of health insurance coverage provides a useful framework for considering health insurance reforms for all persons. Because their access to health care is highly dependent on health care financing issues, persons with disabilities or chronic illness are very aware of the limitations of the current health insurance system. Many persons with disabilities or chronic illness are very knowledgeable about the types and amounts of health care which they need to maintain their health which most "temporarily able-bodied" persons cannot begin to imagine until they are affected by a traumatic accident, birth defect, environmental hazard, or the natural aging process. Since it has been estimated that the number of under-insured persons in the U.S. is at least as high as the number who are uninsured, persons with disabilities or chronic illness can help us all understand how inadequate is most health insurance for such health related services as rehabilitation, in-home services, and durable medical equipment.

Secondly, the vulnerability of persons with disabilities or chronic illness to health care financing issues also confronts us with the societal choice between health care as a right versus a privilege and the moral issue of equity in how health care costs are distributed throughout the population. If cost-containment strategies are based on "experience-rating", what mechanisms will exist for sharing costs among high users and low users? There is already a considerable public subsidy for employer-sponsored health insurance but with no federal standards for a minimum health insurance package and no federal controls on health care costs mediated through the private insurance system. One consequence of this publicly-subsidized employer-sponsored health insurance system is that persons may lose their health insurance when they lose their jobs. Another consequence is that persons who are not in employer groups have less opportunity to share risks with a relatively healthier population and therefore have to pay higher health care costs. Ironically, it is those who are not in employer groups who generally have lower incomes from which they are expected to pay a disproportionate amount of their income for health related needs.

Thirdly, the response to the health care needs of persons with disabilities or chronic illness will greatly affect how they can participate in society.

Access to health care can affect their ability to work, as well as the willingness of an employer to hire them. In the absence of adequate and affordable private health insurance, many persons with disabilities may not be motivated to jeopardize potential eligibility for Medicare or Medicaid coverage by taking the risk of earning an income after the onset of a disability.

Fourthly, health care financing issues determine not only what services a person has access to but also whether they can receive those services while living at home. Many health insurance policies will only reimburse for services which are provided in medical institutions thus denying services to persons who need those same services while living in their own homes. In addition, access to appropriate health care services can reduce the health care costs and utilization of persons with disabilities or chronic illness. In the absence of adequate primary care, rehabilitation care, and on-going maintenance services, many persons with disabilities or chronic illness are more vulnerable to medical complications which contribute to costly and unnecessary rehospitalizations.

Fifthly, it is important to consider how the needs of persons with disabilities or chronic illness will be accommodated by system changes designed for other groups. Besides questions of equity, there are questions about efficiency and effectiveness in deciding whether to create or expand separate public programs for different populations or whether to create a unified system for health care financing. If separate programs like high risk pools are created for persons with disabilities or chronic illness, what will be the incentive for private health insurance to expand the scope of benefits to accommodate the needs of persons with disabilities or chronic illness. If a unified system is created, will the system be flexible enough to deal with comprehensive needs in a cost-effective way? In short, the solution to the health care needs of persons with disabilities or chronic illness does affect the feasibility of solutions to other groups whether uninsured, under-insured, or fully insured.

An inquiry into the health insurance experience of persons with disabilities or chronic illness can also serve another important purpose besides illuminating the broader issues concerning the adequacy of health insurance for all persons. Critical analysis is needed to help the disability community to assess its options and decide which priorities it is prepared to advance for health insurance reform. Among the strategic options which the disability community can support are changes in the generic system of health care financing for everyone or support for the creation of separate categorical programs for persons with severe chronic conditions. Whether the disability community 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 may affect which groups are regarded as its allies, and may ultimately influence the direction of health insurance reform in the U.S.

Over the next few years there are many opportunities to focus national attention on disability priorities for access to health care. Through the Rehabilitation Act Amendments of 1986, Congress authorized the National Institute on Disability and Rehabilitation Research (NIDRR) to issue a Report to Congress by February 1990 on the health insurance needs of persons with disabilities. In addition, the recently passed Medicare Catastrophic Coverage Act called for the creation of a U.S. Bi-Partisan Commission on Comprehensive Health Care. Within six months, this Commission is expected to examine shortcomings in the current health care delivery and financing mechanisms and develop recommendations for financing comprehensive long-term care services and comprehensive health care services for elderly and disabled persons. Within twelve months, the Commission is expected to develop recommendations for financing comprehensive health care services for all individuals in the U.S. Meanwhile, recent reports and recommendations have come from the Task Force on Technology Dependent Children[1], The Presidential Commission on AIDS[2], and the General Accounting Office report on high risk pools[3]. It is essential that the disability community become familiar with these reports and consider to what extent these reports represent the priorities of the disability community for health insurance reform.

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[1] Task Force on Technology-Dependent Children, Fostering Home and Community-Based Care for Technology-Dependent Children, Department of Health and Social Services, Washington, D.C., April 7, 1988, Vols. 1 and 2.

EXECUTIVE SUMMARY

Persons with disabilities or chronic illness face unique obstacles in getting their health-related needs met through private or public health insurance. First, there are problems of access due to the medical underwriting practices of private insurers and the eligibility policies of public programs. Second, there are problems of adequacy because health insurance does not generally cover on-going maintenance needs. Third, there are affordability problems because many persons with disabilities or chronic illness are not employed full time and cannot afford to pay in premiums the cost of the health related services which they need. This policy bulletin will analyze the problems of access, adequacy, and affordability of health insurance for persons with severe chronic conditions.

Part One defines the target population by considering conceptual and methodological issues, and then examines statistics from various national surveys including the National Health Interview Survey and the recently released Survey of Income and Program Participation.

Part Two examines the distribution of health insurance throughout the population by age, family income, employment, and health status before comparing the health insurance status of persons with and without disabilities. Attention is focused on the working-age disabled population divided into those who are employed, those receiving public health insurance, and those neither employed nor recipients of public health insurance.

Part Three explores the limitations of acute-care oriented health insurance for meeting the special needs of persons with disabilities and persons with chronic illness. Special health care needs include: rehabilitation, maintenance therapies, personal assistance services, durable medical equipment and assistive devices, disposable medical supplies, and drugs.

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[2] Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, Washington, D.C., June 1988.

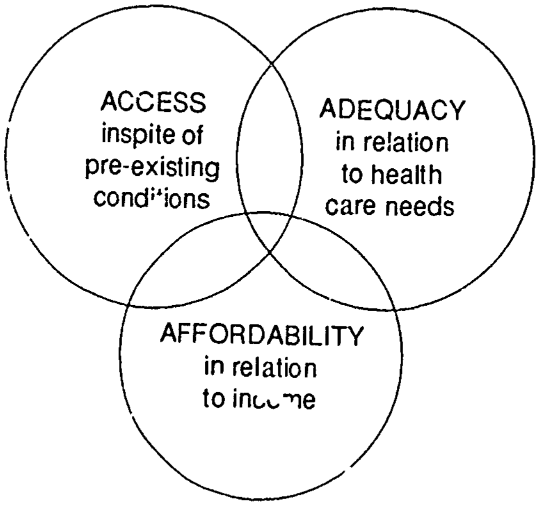
[3] U.S. General Accounting Office, Health Insurance: Risk Pools for the Medically Uninsurable, GAO/HRD-88-66BR, Washington, D.C., April 1988.

Part Four identifies specific barriers to adequate and affordable health insurance for persons with disabilities and chronic illness. The major barriers include medical underwriting, the cost of health care services in relation to the income of persons with disabilities, and the limitations imposed on health insurance plans because of pre-existing conditions.

Part Five examines national survey data on health care costs and utilization patterns for persons with disabilities, critiques the limitations of this data, and identifies areas for further research.

This policy bulletin lays the groundwork for an examination of the evolution of private and public health insurance in the U.S., and an analysis of the options which exist at the federal and state levels for improving health care coverage for persons with severe chronic needs.

Three overlapping problems limiting health insurance availability to persons with severe chronic conditions.



PART ONE:

DEFINING THE TARGET POPULATION

Before it is possible to measure the health insurance needs of persons with disabilities and persons with chronic illness, it is necessary to be able to identify the number of persons with these severe chronic conditions. This first section will consider both conceptual issues and methodological issues in defining the population with severe chronic health care needs. In the second section, statistics will be examined from various national surveys on the number of persons with disabilities.

Conceptualizing Disability and Chronic Disease:

The target population consists of persons with disabilities and persons with severe chronic disease[4]. It is useful to use both terms for describing persons with severe chronic conditions, because specific chronic conditions can have a wide variety of disabling effects. To avoid overlooking persons with severe chronic conditions which create special health care needs but which do not produce disabling effects, the target population should consist of both persons with disabilities and persons with chronic disease.

Table 1 presents an overview of three types of disability risks associated with different impairments and chronic conditions monitored by the National Health Interview Survey. For each chronic condition, Table 1 reports the percentage of persons who have any functional limitation due to that chronic condition,the percentage of persons who are limited in major activity, and the percentage of persons who need assistance from another person for personal care (see Table 1).

These statistics reveal that a significant percentage of persons with certain chronic conditions do not experience disabling effects as a result of theirchronic condition. For example, 72.1 percent of persons with diabetes, 71.0 percent of persons with epilepsy, 82.7 percent of persons with breast cancer, 70.2 percent of persons with emphysema, 65.0 percent of persons with ischematic heart disease, 91.1 percent of persons with hypertension, and 94.9 percent of persons with enteritis and colitis report no limitation in major activity due to their chronic conditions. While many of these chronic conditions create special health care needs and may interfere with a person obtaining private health insurance, these persons are not counted in the statistics on persons with disabilities.

The concept of *disability* in the World Health Organization classification scheme refers to the consequences of a bodily impairment which limits the functional performance or activity of an individual[5]. An *impairment* is any loss or abnormality of psychological, physiological, or anatomical structure or function within the body. This may occur as a result of a disease, injury or sudden trauma, aging, or a congenital anomaly. *Handicap* refers to the social or economic disadvantages which are experienced by the individual as a result of a perceived or actual condition. Since many persons with chronic disease are also handicapped by health insurance practices even when their chronic conditions do not cause disability, it is important to broaden the focus to include all persons who experience any social or economic disadvantage resulting from a chronic disease or impairment.

Conceptually, the target population is all persons who have difficulty getting access to adequate and affordable health care because of the severity of their chronic condition. The severity of the chronic condition could be measured by degree of functional limitations, indicators of health care utilization, or measures of health care costs.

Functional indicators, such as limitation in major activity, are readily available in national surveys which will be described below. One rationale for utilizing limitation in major activity for estimating the severity of chronic conditions in the working-age

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[4] The term "disability" also has a political meaning which encompasses both groups. All persons who are handicapped by discrimination on the basis of disability, chronic disease, or even perceived disability status such as disfigurement, a history of an illness or impairment, or a precondition which can lead to an illness or impairment, are covered by civil rights legislation protecting persons with disabilities.

[5] World Health Organization, International Classification of Impairments, Disabilities, and Handicap, Geneva, 1980.

TABLE 1: DISABILITY RISKS OF SELECTED IMPAIRMENTS AND CHRONIC CONDITIONS, BY GENDER: UNITED STATES CIVILIAN NONINSTITUTIONALIZED POPULATION, 1983-1986 (FOUR-YEAR AVERAGE)

	Both Genders			
		Percent		
Chronic Condition	*Persons (1,000s)*	*Limited In Any Activity*	*Limited In Major Activity*	*Needing Personal Care*
All selected chronic conditions	393899	11.7	8.5	2.6
Skin and musculoskeletal				
Rheumatoid arthritis	1223	51.0	39.4	14.9
Osteoarthritis/other arthropathies	29245	19.6	13.8	5.3
Intervertebral disk disorders	3987	48.7	38.2	5.3
Osteomyelitis/bone disorders	2998	21.0	15.7	5.9
Bursitis	4539	6.2	4.5	*0.7
Psoriasis and dermatitis	11329	1.9	1.3	*0.1
Skin cancer	1459	*2.3	*1.7	*0.9
Other selected skin and musculoskeletal	27747	2.1	1.6	0.4
Impairments				
Absence of arm(s)/hand(s)	84	43.1	*39.0	*4.1
Absence of leg(s)	289	63.3	73.1	39.0
Absence of fingers, toes, feet	1811	7.0	4.5	*1.3
Other absence, NEC	1031	20.8	13.3	*4.4
Complete paralysis of extremities	617	52.7	45.5	26.1
Cerebral palsy	274	69.7	62.2	22.8
Partial paralysis of extremities	578	59.6	47.2	27.5
Paralysis of other sites	247	47.8	43.7	*14.1
Curvature of back or spine	4689	14.7	10.6	1.4
Other impairment of back	9898	27.7	19.4	2.8
Impairment of upper extremities	3106	27.9	17.0	2.9
Impairment of lower extremities	10893	26.5	15.6	4.8
Other orthopedic impairment	316	58.7	46.2	*14.3
Speech impairment	2469	18.3	17.4	*2.3
Blind in both eyes	396	64.5	58.8	38.1
Cataracts	5173	10.6	6.4	4.4
Glaucoma	1707	14.9	8.4	5.1
Other visual impairment/retinal disorders	8596	14.0	10.0	5.4
Deaf in both ears	1700	16.4	11.3	*3.2
Other hearing impairment	19254	4.6	2.7	0.9
Other selected impairments	1371	13.6	10.3	*2.5
Digestive				
Ulcers	4469	9.7	7.0	*1.0
Abdominal hernia	4830	12.5	9.1	2.4
Enteritis and colitis	2392	7.2	5.1	*0.8
Cancer of digestive sites	228	45.3	40.3	15.9
Other selected digestive disorders	20556	3.6	2.9	0.8
Circulatory				
Rheumatic fever	1536	15.7	11.5	*1.9
Ischemic heart disease	6948	35.0	26.1	8.1
Heart rhythm disorders	7404	7.2	4.7	1.5
Other heart disease	4708	46.9	35.1	13.6
Hypertension	28689	12.4	8.9	2.2
Cerebrovascular disease	2599	38.2	33.3	22.9
Arteriosclerosis	3008	12.1	9.4	5.1
Phlebitis, varicose veins	7891	5.5	3.9	0.8
Other selected circulatory	11519	3.8	2.7	1.2
Respiratory				
Chronic bronchitis	11196	3.6	2.5	0.6
Asthma	8869	20.6	12.6	1.3
Hay fever	20431	1.5	1.1	*0.0
Sinusitis	31969	0.4	0.3	0.1
Emphysema	2074	43.6	29.8	9.6
Lung or bronchial cancer	200	74.8	63.5	34.5
Other selected respiratory	9097	5.5	4.1	1.2
Miscellaneous				
Diabetes	6096	35.4	27.9	9.4
Anemias	3409	4.6	3.4	*0.3
Kidney disorders	3559	9.6	7.8	2.4
Female genital disorders	6379	3.7	2.4	*0.2
Mental retardation	1202	84.1	80.0	19.9
Epilepsy	1162	41.0	29.0	6.3
Multiple sclerosis	171	70.6	63.3	40.7
Migraine headache	7934	2.9	2.2	*0.3
Cancer of female breast	443	27.4	17.3	*4.6
Cancer of genitourinary sites	302	41.8	34.7	*8.5
Other selected miscellaneous	15602	4.0	2.9	1.0

* Figure has low statistical reliability or precision (relative standard error exceeds 30 percent)

Sources: National Health Interview Surveys, 1983-1986; analyzed from public use tapes by Mitchell P. La Plante, Director, Disability Statistics Program, University of California, San Francisco, for paper on "Disability Risks of Chronic Illness and Impairment" at Society for Disability Studies, Washington, D.C. June 17, 1988.

population, is that chronic conditions which interfere with full time employment create a major obstacle to group insurance, the primary form of private health insurance in the U.S. through which health risks are shared. Another reason for using functional indicators of chronic conditions is that they often represent needs for which persons may require health related services.

Measures of health care utilization in the previous year could provide another basis for gauging the severity of a chronic condition. Some of this information is available for persons with activity limitation due to chronic conditions in various national surveys. In the absence of this information for specific individuals, insurers rely on actuarial statistics in determining "insurability" based on various predictors of health care risk. This process of medical underwriting will be examined in a subsequent policy bulletin.

The severity of a chronic condition can also be measured by the total costs of an individual's health related services. The definition of what constitutes health related services will obviously affect the amount of the health care costs. It makes a difference if health care is arbitrarily limited to acute care needs or also includes rehabilitation and on-going maintenance needs for persons with severe chronic conditions. The sources of payment for various health related services are important determinants of affordability. Out-of-pocket expenses for health-related services which exceed a fixed amount (e.g. $2,000) per year or exceed an accepted level of a family's income (e.g. 10-15 percent) can also be used as indicators of catastrophic health care costs from which severity of a chronic condition can be inferred.

Summary:

The target population includes all persons who have difficulty getting access to adequate and affordable health care because of the severity of their chronic condition. The severity of the chronic condition could be measured by degree of functional limitations, various indicators of health care utilization, or measures of health care costs.

Methodological Issues in Measuring Disability and Chronic Disease:

Empirically, it is difficult to estimate the number of people with severe chronic conditions. The most common method for estimating the prevalence of chronic conditions in the civilian noninstitutionalized population is with national household survey data. These data provide two types of measures of chronic conditions. There are data on degree of functional limitation related to any chronic condition and data on the number of persons who identify themselves as having specific chronic conditions. Data on functional limitations attributable to any chronic condition is easier to gather and to interpret than data on specific chronic conditions. People can readily report whether they have any physical or mental impairments which interfere with various activities or create specific needs. On the other hand, data on the prevalence of specific chronic conditions require some standardized measures of severity in order to be meaningful. This would require clinical diagnosis or accurate measures of health care utilization and costs. In addition, it is difficult to ask every respondent to consider every possible chronic condition.

Self-reported data on health conditions may be distorted by limited knowledge of respondents about their current health status. Thus persons without access to health care may report that they do not have a chronic condition even though they may have signs and symptoms which would be identified by a clinical assessment. Or respondents may prefer to avoid identifying health conditions which are stigmatizing. For example, chronic conditions like mental illness are greatly underestimated by the National Health Interview Survey. On the other hand, there are no reporting requirements of clinical diagnoses by medical personnel for most chronic conditions[6].

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[6] An exception is the Surveillance Epidemiology and End Results (SEER) program of the National Cancer Institute which contracts with eleven population-based registries geographically represented throughout the United States to report data on all patients diagnosed with cancer and to provide current follow-up information on all previously diagnosed patients. In addition, some states have established other registries with mandatory reporting requirements for hospitals or doctors treating certain conditions (e.g. head injury, spinal cord injury.)

Another problem with the prevalence data on specific chronic conditions provided by the Health Interview Survey is that different segments of the national sample are asked about different health conditions. While this procedure allows for accurate projections of specific health conditions to the national population, it is not possible to provide an unduplicated count of the number of people who have chronic conditions. Due to the presence of multiple chronic conditions among persons who are provided with different "checklists" of chronic conditions, the total number of chronic conditions reported in Table 1 is 393,899,000 chronic conditions even though the national population was only around 236 million persons in 1986.

Gathering accurate data on health care costs and utilization patterns for specific chronic conditions is also difficult. One of the reasons for this difficulty is the fact that the most severe chronic conditions have the lowest prevalence rates within the general population, and therefore are difficult to identify through national surveys based on randomly selected samples[7] For example, for a low prevalence condition like cerebral palsy which affects only 1.1 persons per 1,000, a random sample would have to contain at least 27,273 persons in order to identify 30 persons with cerebral palsy.

Another difficulty in accurately measuring health care utilization and costs from self-reported data is that most people, insulated by third party reimbursement, do not know the costs of the health services which they use. Research comparing household surveys with data verified from employers and insurers has shown significant discrepancies with consumer knowledge of health insurance coverage, benefits, and premiums[8].

Summary:

To accommodate the lack of data on chronic illness, it has been expedient to limit our attention to persons with disabilities even though this excludes people with chronic illness without disabling conditions. Using different measures of disability as a surrogate for severity of the chronic condition, it has been possible to examine health insurance status and health care costs and utilization patterns for a segment of the population with chronic conditions.

The decision to ignore persons with chronic illness without disabling conditions, however, does not imply that they are less vulnerable in the way health care is financed. Nor is it intended to legitimate the bias implicit in much disability policy, such as embodied in the Social Security system, that persons who are capable of earning an income are assumed to be able to afford all of the support services which they need to live. If the goal of public policy is to reduce handicaps related to severe chronic conditions, it is necessary to assist all persons with social or economic disadvantages due to either a health problem or functional limitation of long lasting duration.

Estimating the Population with Disabilities:

Estimates of the disabled population from national surveys vary widely based on different definitions of disability, the wording of survey questions, and the sampling approach to the national population. To illustrate the influence of these factors, consider the magnitude of the discrepancy between two federal government surveys conducted only two years apart both attempting to measure the same statistic of work disability. In a review of sources of data on work disability, McNeil points out that the Social Security Administration Survey on Disability and Work estimated there were 21.9 million persons aged 18-64 with a work disability in 1978, while the Census Bureau in 1980 estimated there were only 12.3 million persons aged 16-64 with a work disability[9]. This example demonstrates some of the dangers of combining statistics from different surveys.

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[7] The number of persons with specific conditions may be too small to generate a reliable estimate of from a random sample of the national population. The standard error is likely to be too high for describing persons with specific conditions if there are not at least 30 persons in the total sample from that group (assuming 50% difference, 90% power and 95% confidence level, one tail test).

[8] Daniel C. Walden, Constance M. Horgan, and Gail Lee Cafferata,"Consumer Knowledge of Health Insurance Coverage", in Health Survey Research Methods, National Center for Health Services Research, September 1984, DHHS Publication No.(PHS) 84-3346, pp. 219-231.

[9] U.S. Bureau of the Census, Current Population Reports, Series P-23, No. 127, Labor Force Status and Other Characteristics of Persons with a Work Disability: 1982, U.S. Government Printing Office, Washington, D.C., 1983, pp. 45-46.

An overview of national estimates of the disabled population from different national surveys is provided in Table 2. The indicators of disability include degree of activity limitation, presence of a work disability, limitations in specific functional activities, need for personal assistance, residence in an institution, and the number of persons who receive income payments from either SSI or SSDI, the two major disability programs administered by the Social Security Administration. The estimates are listed sequentially by age group to facilitate comparisons among various surveys. In the course of this analysis the National Health Interview Survey (HIS) and the Survey of Income and Program Participation (SIPP) will be primarily used to examine characteristics of the disabled population in terms of age, income level, employment, and health insurance status.

National Health Interview Survey:

The National Health Interview Survey (HIS) provides an important source of information on degree of activity limitation for all age groups in the noninstitutionalized population[10]. The population with severe chronic conditions is dichotomized into those limited in major activity and those limited, but not in major activity. The concept of major activity has different meanings for different age groups. For working-age persons 18-64 years old, work is presumed to be the major activity. For persons over 65 years old, the major activity is considered to be self-care, and for children 5-17 years old, the major activity is going to school. For children under 5, the major activity is participation in play.

Major activity limitation in the HIS can also be sub-divided into persons unable to carry on the major activity and persons who are limited in the amount or kind of major activity. Although this distinction appears to provide an important measure of severity of a chronic condition, it may actually reflect differences in the nature of the environment in which an individual functions. Some environments would enable a person with specific impairments to engage in a major activity like work, while others in a different environment with the same degree of functional limitation are unable to carry on their major activity. To minimize confounding the disabling effects of the environment with the severity of an impairment, we will use limitation in major activity as the best available measure of the severity of a disabling condition.

According to Table 2 (Section I) data from the Health Interview Survey (1986) indicate that there are approximately 33.0 million persons with any activity limitation in the non-institutionalized population including 22.3 million persons with limitation in major activity (see Table 2). Among those with major activity limitation are 13.7 million working-age persons, 6.3 million persons over 65, and 2.3 million children 0-17 years old.

To put these statistics in perspective and to indicate the extent to which current disability programs address the health care needs of persons with disabilities, it is interesting to consider to what extent persons with major activity limitation are covered by the two major disability programs administered by the Social Security Administration. Table 2 (Section IX) identifies the number of persons who receive either SSDI or SSI because of their disability. Among the 13.7 million working-age persons with major activity limitation there are only 4.4 million who receive SSI or SSDI. In fact, the number of noninstitutionalized working-age persons who receive SSI or SSDI is actually smaller than 4.4 million because the administrative records of the Social Security Administration include SSI and SSDI recipients living in the community as well as those who are institutionalized. It is significant that *less than one-third of working-age persons with major activity limitation and less than ten percent of children with major activity limitation receive either the publicly-subsidized health coverage of Medicare or Medicaid*[11]. For persons with disabili,

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[10] The National Health Interview Survey is conducted annually by the National Center for Health Statistics and is based on a large random sample of 40,000 households including approximately 110,000 persons.

[11] It is not possible to identify all SSI recipients over 65 who are disabled. Persons 65 and over who become eligible for SSI on the basis of low income are identified by the Social Security Administration as "aged" SSI recipients, while SSI recipients who were classified as "disabled" before age 65 retain the "disabled" category when they reach age 65.

Table 2: Estimates of U.S. Population with Disabilities by Age Group, Based on Various National Surveys Using Different Indicators of Disability

(in thousands)

	Children (0-17)	Working-Age (18-64)	Elderly (65+)	Total (All Ages)
I. Degree of Activity Limitation (HIS, 1986) (a)				
A. Any activity limitation	3,168	19,107	10,698	32,972
B. Major activity limitation	2,292	13,730	6,258	22,281
1. Unable to carry on major activity	251	6,086	2,933	9,270
2. Limited in amount or kind of major activity	2,042	7,644	3,325	13,011
C. Limited, but not in major activity	876	5,377	4,440	10,692
II. Work Disability (SIPP, 1984) (b)	-----	17,949	-----	
A. Full time employed with work disability	-----	5,633	-----	
B. Part-time employed with work disability	-----	1,978	-----	
C. Not employed with work disability		10,338		
III. Work Disability (SSA Survey of Disability and Work, 1978) (c)	-----	21,900	-----	
IV. Work Disability (Census, 1980) (c) Ages 16-64	-----	12,300	-----	
Work Disability (Current Population Survey, March Supplement, 1982) (c) Ages 16-64	-----	13,110	-----	
V. Limitations in Specific Functional Activities (SIPP, 1984) (d)				
A. Any Limitation	n/a	21,839 *	15,465	37,304
B. Severe Limitation	n/a	5,997 *	7,539	13,53
VI. Need for Assistance from Another Person (SIPP, 1984) (e)				
A. With personal care	n/a	842	1,459	2,301
B. With housework, meal preparation, getting around, or personal care	n/a	2,747	4,450	7,197
VII. Need for Personal Assistance (HIS, 1983-85) (f)				
A. With activities of daily living (ADL)	148 **	866	1,507	2,521
B. With instrumental activities of daily living (IADL)	n/a	3,059	4,369	7,428

Table 2: Estimates of U.S. Population with Disabilities by Age Group, Based on Various National Surveys Using Different Indicators of Disability

(in thousands)

	Children (0-17)	Working -Age (18-64)	Elderly (65+)	Total (All Ages)
VIII. Institutionalized Population (1986 Inventory of Long TermCare Places) (g)				
A. Nursing homes (SNF, ICF)	-----	133 ****	1,248	1,381
B. Residential facilities	-----	46 ****	126	172
C. Mental retardation facilities	39 *****	180 *****	18	237
D. Psychiatric Facilities (h)	25	118	34	177
E. Total in institutions		541 ****	1,426	1,967
IX. SSDI Beneficiaries and SSI Recipients (SSA Administrative Records, 10 Percent Sample, December 1986) (i)				
A. Disabled workers	-----	2,719	-----	2,719
B. Disabled adult children	-----	550	-----	550
C. Disabled widows or widowers	-----	107	-----	107
Subtotal of SSDI beneficiaries	-----	3,378	-----	-----
D. SSI recipients eligible on the basis of disability or blindness	238	1,978	540 ***	2,756
Minus dual enrollees (SSDI and SSI)	-----	1,078	-----	
E. Unduplicated total	238	4,276	540 ***	

Footnotes:

*	Age range is 15-64
**	Age range is 5-17
***	There may be additional SSI recipients over 65 with a disability. Persons over 65 who become eligible for SSI on the basis of low income are identified as "aged" recipients whether or not they develop a disability. Persons who were SSI recipients before age 65 based on disability or blindness continue to be identified as "disabled or blind" SSI recipients after age 65. The total number of SSI recipients over 65 was 2,016,000 persons in September 1986.
****	Under 65 years
*****	Children are under 22 years; working-age are 22-64 years.

ties, these public health programs are linked to receiving the federal income support programs. SSI or SSDIrather than to having a certain level of health care needs.

Summary:

There are 22.3 million persons with limitation in major activity. This includes persons who are unable to carry on their major activity and persons who are limited in the amount or kind of major activity. In the absence of reliable measures on health care utilization or costs, this is the best available measure of severity of a disabling condition.

Survey of Income and Program Participation:

The Survey of Income and Program Participation (SIPP) provides measures of work disability, limitations in specific functional activities, and the need for personal assistance for persons 15 years and older[12].

For persons with work disabilities or the need for personal assistance, SIPP also collects informa-

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[12] The Survey of Income and Program Participation is a national survey with extensive questions on disability status in the third wave supplement to the 1984 panel. Conducted by the Bureau of the Census, the 1984 SIPP panel was based on interviews with a random sample of approximately 20,000 households including approximately 46,000 persons.

References for Table 2:

(a) National Center for Health Statistics. Current Estimates from the National Health Interview Survey, United States, 1986, Vital and Health Statistics, Series 10, No. 164, October 1987, Table 68, p. 111.

(b) Survey of Income and Program Participation, 1984 Panel, Wave 3. Data analyzed by Bureau of Economic Research, Rutgers University, 1988.

(c) U.S. Bureau of the Census, Current Population Reports, Series P-23, No. 127, Labor Force Status and Other Characteristics of Persons with a Work Disability: U.S. Government Printing Office, Washington, DC, 1983, p. 45.

(d) U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, Disability, Functional Limitation and Health Insurance Coverage: 1984/85: Data from the Survey of Income and Program Participation, U.S. Government Printing Office, Washington, DC, 1986, Table C, p. 4

(e) SIPP data on working-age population provided by Bureau of Economic Research, Rutgers University; data on elderly population from Disability,Functional Limitation, and Health Insurance Coverage: 1984/85, op. cit., Table 4, p. 28.

(f) LaPlante, Mitchell P. (1988). Data on Disability from the National Health Insurance Survey, 1983-85, An InfoUse Report, Washington, DC, U.S.National Institute for Disability and Rehabilitation Research, Table 4, p. 51.

(g) National Center for Health Statistics, "The 1986 Inventory of Long Term Care Places: An Overview of Facilities for the Mentally Retarded." AdvancedData from Vital Health Statistics, No. 143, DHHS Pub. No. (PHS) 87-1250, September 30, 1987; and "Nursing and Related Care Home as Reported from the 1986 Inventory of Long Term Care Places." Advanced Data from Vital and Health Statistics, No. 147, DHHS Pub. No. (PHS) 88-1250, January 22,1988.

(h) National Institute for Mental Health, Series CN #11, Specialty Mental Health Organizations, United States, 1983-84 DHHS Publication No. (ADM) 86-1490,1986.

(i) Committee on Ways and Means, U.S. House of Representatives, Background Material and Data on Programs Within the Jurisdiction of the Committee on Ways and Means, 1988 Edition, March 24, 1988; Table 15, pp. 28-31 for SSDI; Table 16, p. 534 for dual enrollees;Social Security Administration, Annual Statistical Supplement: 1987, Social Security Bulletin, Table 185, p. 270 provides the number of OASDI beneficiaries also receiving SSI by reason for SSI eligibility and type of OASDI benefit for December 1986.

tion on the health conditions mainly responsible for the functional limitations.

According to Table 2 (Section II), SIPP data from 1984 reveal a higher number of working-age persons with a work disability (17.9 million persons) than HIS identifies as having a major activity limitation (13.7 million persons). Among the 17.9 million working-age persons with a work disability are 5.6 million persons who are employed full time, 2.0 million persons who are employed part-time, and 10.3 million persons who are not working at all[13]. This probably indicates that a sizeable number of persons who are able to work without limitation, inspite of their chronic conditions, do not report any limitation in major activity. Interestingly, the SIPP data also reveal that at least 178,977 working-age persons report needing assistance with housework because of a chronic health condition even though they do not report any work limitation.

SIPP also provides a measure of functional limitations in performing specific activities such as seeing, hearing, speech, lifting or carrying, walking, using stairs, getting around outside the house, getting around inside the house, and getting into and out of bed (see Table 2, Section V). Persons were considered to have a "functional limitation" if they had difficulty performing one or more of the above activities and were considered to have a "severe limitation" if they were unable to perform one or more of the above activities without assistance. Among all persons 15 years of age and over there were 37.3 million persons who had some functional limitations including 13.5 million persons with severe limitations.

Interestingly, it appears that SIPP identifies 13.5 million persons with severe limitations while the Health Interview Survey identifies only 9.3 million persons who are unable to carry on their major activity. For the 6.0 million persons aged 15-64 which SIPP identified as having severe functional limitations, the number is practically identical to the 6.1 million working-age persons 18-64 identified by HIS as being unable to carry on their major activity. However, for elderly persons the number with severe functional limitations is more than two and half times larger than the number of elderly persons who cannot carry on their major activity. This indicates that many elderly persons with severe functional limitations report being able to care for themselves which is regarded by the Health Interview Survey as their major activity, while many working-age persons with severe functional limitations report being unable to work which is regarded as their major activity. Although more working-age persons had some functional limitations than elderly persons (reflecting the much larger number of working-age persons in the population than elderly persons (see Table 4), there were actually more elderly persons with severe limitations than working-age persons. This indicates that the incidence of severe impairments greatly increase with age.

In analyzing SIPP data for working-age persons, the category of persons with a work disability was based on persons with a health condition which prevented work or limited the amount or kind of work they could do. It was assumed that the limitation in work activity was related to the presence of the health condition. However, it is possible that the lack of work was not related to the health condition. This might account for the larger number of working-age persons which SIPP identified with a work disability than was identified by HIS as having a major activity limitation. In fact, the SIPP survey asked working-age respondents whether they were able to work full time, part-time, regularly, or occasionally, in addition to whether they actually worked during a certain period prior to the SIPP interview. From these data, it appears that only 75 percent of those who said they were able to work full time were actually working full time, and only 52 percent of those who said they were able to work part-time were actually working part-time in the month prior to the SIPP interview[14].

Whether this indicates that working-age persons with an impairment were unable to work because

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[13] The measure of employment status for a person with a work disability is based on the respondent's report of work activity within a four month period prior to the SIPP interview.

[14] U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, Disability, Functional Limitation, and Health Insurance Coverage: 1984/85, U.S. Government Printing Office, Washington, D.C. 1986, Table 3, p. 26.

of their impairments or because of job discrimination or an unwillingness of employers to modify the workplace to accommodate their impairments cannot be ascertained from these data. It is also possible that some portion of the 17.9 million persons identified as having a work disability may have been unemployed for other reasons unrelated to their disability.

Within the SIPP survey there are clues to some of the conditions surrounding a person's disability that may suggest different ways to improve access to health care coverage. Table 3 presents selected characteristics of persons aged 18-64 with a work disability by the health conditions responsible for the work disability (see Table 3). For example, among all persons aged 18-64 with a work disability, 87.7 percent were disabled during their working-age while only 12.3 percent were disabled at birth or in childhood. In fact, as many as 63.1 percent of all working-age persons with a work disability were employed at the onset of their disability. For 28.3 percent of them, their disability was the result of an injury with 45.6 percent of the injuries occurring on the job, 9.4 percent of the injuries occurring during military service, 10.6 percent of the injuries occurring in the home, and 34.4 percent of the injuries occurring somewhere else. From these statistics one would expect that over half of the injuries occurring to working-age persons with a work disability would be covered by workers compensation programs and veterans compensation programs, and a certain percentage of the other accidents would be covered by casualty insurance for automotive bodily injury and miscellaneous bodily injury. Nevertheless, as many as 71.6 percent of the disabilities are not the result of an injury and would therefore rely on health insurance to pay for health care coverage.

Not surprisingly, both HIS and SIPP provide very similar estimates of the need for personal assistance in the noninstitutionalized population. According to Table 2 (Section VI and VII), assistance with personal care is needed by between 842,000-866,000 working-age persons and between 1,459,000-1,507,000 persons over 65. The number of persons needing assistance with housework, meal preparation, getting around, or personal care is between 2,747,000-3,059,000 working-age persons and between 4,450,000-4,369,000 persons over 65.

Summary:

SIPP data provide a basis for corroborating the disability estimates from the HIS and examining the relationship between employment status and health insurance status among working-age persons with a work disability. There are approximately 17.9 million working-age persons with a work disability including 5.6 million persons who are employed full time, 2.0 million persons who are employed part-time, and 10.3 million persons who are not working at all. Besides data on work disability, the SIPP survey also provides measures of limitations in specific functional activities, and the need for personal assistance for persons 15 years and older.

Institutionalized Population:

The disability statistics presented above represent noninstitutionalized civilian persons in the U.S. based on a household survey which excludes approximately 2 million persons who live in institutional settings such as nursing homes, hospitals, or special care facilities (see Table 2, Section VIII). An estimate of the institutionalized population should also include some nonmedical residential settings in which personal care is provided that the Bureau of the Census may not capture in its household surveys.

Age Distribution of Disabled Population:

The disability statistics provided in Table 2 were presented by age group for a specific purpose. Not only does the prevalence of disability vary with age, but access to health insurance varies by age group. Using major activity limitation as the most expedient indicator of the target population, Table 4 highlights the age distribution of noninstitutionalized persons with limitation in major activity (see Table 4).

Although it is commonly known that disability increases with age, Table 4 reveals that working-age persons account for over 60 percent of persons with major activity limitation while elderly persons account for less than 30 percent and children account for less than 10 percent.

The significance of this observation is often ignored or discountedbecause different criteria are

Table 3: Selected Characteristics of Persons Aged 18 - 64 with a Work Disability by the Health Condition Responsible for the Disability, SIPP (1984)

(percent)

Health Condition	Age of Onset		Employment Status at Time of Disability		Cause of Disability		Occurence of Injury*			
	Under 18	18-64	Employed	Not Employed	Injury	Non-Injury	Job	Military	Home	Other
Arthritis or rheumatism	1 97	98 03	64 96	35.04	18 66	81 34	47.20	8 35	12.97	31 48
Back or spine	4.37	95 63	80 74	19 26	64.64	35 36	55 22	5 70	9 14	29 94
Blindness	26 94	73 06	63 98	36 02	18 09	81 91	14 81	0 00	18 48	66 71
Cancer	3 23	96 77	63 41	36 59	1 85	98 15	18 33	81 67	0 00	0 00
Deafness	59 95	40 05	59 06	40 94	16 55	83.45	6 79	42 29	9 36	41 56
Diabetes	8 29	91.71	63 01	36 99	1 59	98 41	52.40	0 00	0 00	47 60
Heart trouble	5 56	94 44	78 77	21 23	2 37	97 63	15 77	23 43	7 49	53 32
Hernia	6 30	93 70	65 70	3. 30	30 35	69 65	67 73	0 00	12 44	19 83
Hypertension	6 27	93 73	56 46	43 54	4 94	95 06	38 80	30 02	31 18	0 00
Kidney	9 44	90 56	68 24	31 76	3 52	14 80	9 94	0 00	37 04	53 02
Respiratory	18 92	8. 08	76 43	23 57	2 47	97 53	33 04	0 0	10 87	56 08
Mental illness	10 20	89 80	55 32	44.68	12 25	61 31	45 93	18 07	3 41	32 59
Mental retardation	88.52	11 .8	17 32	82 68	6 17	93 83	25 93	0 00	16 33	57 73
Missing appendages	15 97	8. 03	69 03	30 97	73 67	26 33	30 13	13 94	0 00	55 93
Nervous or emotional	16 62	83 38	63 74	36 26	12 10	87 90	19 46	31 04	19 36	30 15
Paralysis	30 32	69 68	64 35	35 65	40 92	59 08	19 06	17 74	4 45	58 75
Senility	18 49	81 51	66 23	33 77	14 33	85 67	100 00	0 00	0 00	0 00
Stiff appendage	10 08	89 92	78 11	21 89	71 29	28.71	40 12	13 72	11 44	34 71
Stomach	5 83	94 17	69 65	30 35	2 54	97 46	0 00	0 00	0 00	100 00
Stroke	2 50	97 50	1 66	28 34	4.85	95 15	49 25	0 00	0 00	50 75
Thyroid	0 00	100 00	63 17	36 83	0 00	100 00	0 00	0 00	0 00	0 00
Tumor, cyst, etc	4 15	95 85	70 73	29 27	7.70	92 30	14 23	85 77	0 00	0 00
Other	16 15	83 85	69 34	30 66	33 70	66 30	37 21	12.04	13 40	37 36
Total	12 30	87 70	63 10	36 90	28 30	71 60	45 60	9 40	10 60	34 40

Footnote * The number of persons with a work disability due to an injury is 5 1 million, the total number of all working age personswith a disability is 17 9 million

Source. Data analyzed by Bureau of Economic Research, Rutgers University, from SIPP (1984) data.

Table 4: Age Distribution of Persons with Major Activity Limitations, 1986
(in thousands)

Age Group	Persons with Limitations in Major Activity	Percentage of Persons with Major Activity Limitations by Age Group	Percentage of all Persons in Each Age Group with Major Activity Limitations	Total Number of Persons in Non-institutionalized U.S. Population
under 18	2,292	10.3%	3.6%	63,132
18 - 64	13,730	61.6%	9.4%	145,678
65+	6,258	28.1%	22.7%	27,538
All ages	22,281	100.0%	9.4%	236,348

Source: National Center for Health Statistics, Current Estimates from the National Health Interview Survey, United States. 1986, Series 10, No. 164, October 1987, Table 68, p. 111

used to measure disability among working-age and elderly persons. As was described above, elderly persons are judged to be disabled if they have difficulty performing self-care activities while working-age persons are judged to be disabled if their chronic conditions interfere with employment. It is true that the use of different criteria for measuring disability make it difficult to compare the size of both groups in relation to a certain level of functional limitations. However, a measure of work disability for the working-age group is the most relevant determinant of their access to health care and a measure of self-care activities is the most relevant indicator of the long term care needs of persons over 65 years old who are no longer in the labor force and who already have access to acute care through Medicare. While there are fewer working-age persons with need for personal assistance than elderly persons with the same level of disability (as we see in Table 2, Section VI and VII), there are many more working age persons with chronic impairments which interfere with full time employment than elderly persons with self-care needs. Although the prevalence rate of disability is greater among the elderly than among working - age persons, there are many more working-age persons than elderly persons accounting for the larger number of working-age persons with major activity limitation. The significance of this observation is that health insurance reforms which are targeted to the elderly or to children will not improve access to health care for the majority of persons with major activity limitation. As will become apparent from the tables below, the working age population of disabled persons is at least as vulnerable to health care financing problems as are elderly persons or children with disabilities.

The age distribution of the prevalence of disability also has other implications which affect health insurance reform. With 22.7 percent of elderly persons with major activity limitation compared to 9.4 percent of working-age persons, and 3.6 percent of children, it has been easier to mobilize political support for assisting the elderly than for recognizing the needs of the disabled population under 65 years. The problem of recognizing the needs of the disabled population under 65 is further complicated by the fact that they are a small percentage of the much larger population of persons under 65 who lack access to health care because of poverty. To justify singling out for special treatment persons with disabilities requires a complicated disability determination process to distinquish persons with disabilities from other persons who lack needed health related services because they are poor. It also raises the important class question of whether disabled persons should be entitled to public support when they are not poor while so many poor persons currently lack access to public support.

Summary:

Working-age persons account for over 60 percent of persons with major activity limitation, while elderly persons account for less than 30 percent, and children account for less than 10 percent.

Nevertheless, 22.7 percent of elderly persons are limited in major activity, compared to 9.4 percent of working-age persons, and only 3.6 percent of children.

Conclusion:

This section has reviewed various estimates of thepopulation with severe chronic conditions in order to define the population whose health insurance needs will be measured. Although it is recognized that both persons with diseases and impairments may have difficulty getting their health care needs met through a health insurance system which is oriented to acute care needs, national surveys have tended to collect information on persons with disabilities. Unfortunately, this excludes many persons with chronic diseases which do not produce disabling effects even though they require expensive health care services to treat. Nevertheless, in order to make use of the existing national survey data, it has been necessary to focus on persons with disabilities.

For the purposes of measuring health insurance needs, the most relevant definition of disabilities is based on limitation in major activity. This has the advantage of providing a measure which permits comparisons across age-groups. Moreover, a focus on persons with a limitation in major activity also has the advantage of excluding persons with less severe disabilities while including persons who are either unable to carry on their age-appropriate major activity or persons who are limited in the amount or kind of their major activity due to a chronic condition. Because the difference between being unable to carry on one's major activity and being limited in the amount or kind of major activity may have more to do with the nature of one's environment than with the severity of one's impairment, it is important that the definition of disability include both groups. Since access to private health insurance in the U.S. is closely linked to employment for persons 18-64, the definition of a work disability should also include both persons with a chronic condition who are unable to work and those who are limited in the amount or kind of work they can do.

PART TWO:

ACCESS TO HEALTH INSURANCE

In the United States, private health insurance is the primary mechanism for financing health care. This section will examine the health insurance status of persons with and without disabilities. The National Health Interview Survey (HIS) will be utilized to provide an estimate of the number of persons who report being covered by private health insurance, some form of public health care coverage, or no health insurance at all. Then the Survey of Income and Program Participation (SIPP) will be utilized to examine the relationship between employment status and health insurance status for working-age persons with a work disability. The experience of persons with disabilities confronting specific barriers to access to health insurance will be examined in Part Four.

Unfortunately, this analysis of health insurance status does not distinguish between different types of private health insurance such as commercial, or non-profit insurers, self-insured employers, or HMO coverage, group or individual plans, and coverage for an individual or a family. Although the HIS survey does collect information about the name of the private insurance plans and the type of coverage, these data have not been analyzed and therefore could not be incorporated into this examination of access issues. The SIPP survey also provides data on whether a private insurance plan was a group plan or an individual plan, and whether the respondent was covered by health insurance in his or her own name or in somebody else's name. While this information has important implications for identifying avenues and barriers to access, it too was not examined in the preparation of this report.

Distribution of Health Insurance in the U.S. Population:

The type of health insurance which people have access to varies largely by age, family income, and employment status. Private insurance is generally associated with employment and higher income levels, and public insurance is generally associated with being over 65 years old, being poor, or being disabled. While public insurance picks up many persons who lack private insurance, there are many gaps in public coverageas evidenced by the large number of uninsured persons.

Table 5 presents the percentage of persons with different health insurance statuses by age group, family income for persons under 65, and employment status for persons 18-64 (see Table 5).With Medicare providing health insurance to 95.6 percent of persons over 65, uninsurance is largely a problem of the under 65 population. Among those under 65, 14.6 percent are uninsured compared to less than 1 percent of persons over 65 years old. For this reason, the data on family income in Table 5 pertains to the under 65 population and the data on employment status relates to the so-called working-age population, persons 18-64 years old.

Private insurance varies directly with family income among persons under 65 years old. Only 30.1 percent of persons with family incomes less than $5,000 per year are covered by private insurance compared to 95.8 percent of persons with family incomes over $50,000 per year. With most private insurance financed through employer groups, the low rate of private insurance among persons with family incomes under $10,000 reflects an unwillingness of employers to contribute to the health insurance of low wage workers.

The significance of employment for providing private health insurance is revealed by the fact that 85.3 percent of persons who are currently employed have private insurance compared to 47.0 percent of those who are unemployed but looking for work. Perhaps more surprising is that 65.2 percent of the working-age population out of the labor force have some private insurance, as do 73.8 percent of persons over 65. Many working-age persons who are out of the labor force are likely to be covered by the private insurance of a spouse, and many persons over 65 are likely to have private insurance as a Medicare supplement.

Public health coverage provides some substitution for the lack of private insurance among persons with the lowest income levels, although a large percent of the poor are not eligible for Medicaid. While Medicaid covers 35.9 percent of persons with family

Table 5: Percent of U.S Noninstitutionalized Population by Selected Health Insurance Status, (HIS, 1984)

Types of Health Insurance

Age	No. of Cases* (thousands)	Private Insurance (%)	Medicaid (%)	Medicare (%)	Military-VA (%)	Uninsured (%)	Total** (%)
(0-17)	62,129	72.5	10.7	0.0	2.8	14.0	100.0
(18-64)	141,590	78.6	4.0	1.2	10.3	14.8	108.9
65+	26,156	73.8	6.4	95.6	5.1	0.9	181.8
Family income: Under Age 65							
Less than 5,000	12,186	30.1	35.9	2.9	1.8	31.1	101.8
5,000 - 9,999	20,423	36.7	23.2	3.0	2.2	36.6	101.7
10,000 - 19,999	50,557	72.4	4.1	1.5	3.4	20.3	101.7
20,000 - 34,999	63,842	89.6	1.1	0.6	3.7	7.1	102.1
35,000 - 49,999	31,112	94.2	0.4	0.3	4.1	3.6	102.6
50,000+	16,932	95.8	0.3	0.2	2.3	3.2	101.8
Employment status: Ages 18 64							
Currently employed	100,909	85.3	0.9	0.2	2.8	12.5	101.7
Unemployed	7,226	47.0	11.8	0.6	2.5	38.3	100.2
Not in labor force	33,455	65.2	11.7	6.4	5.3	16.8	105.4

Footnotes:

* The number of cases estimated for each population category of age, family income, and employment status is arbitrarily based on Table 2, (pp. 20-21) which represents the number of persons with and without private health insurance coverage. These population estimates vary slightly in the various tables from which the actual percentages for selected health insurances statuses were drawn due to complex estimating procedures in the multistage probability sample for the Health Interview Survey. These procedures are used to improve the reliability of the estimates by making the sample more closely representative of the civilian noninstitutionalized population by age, sex, income, and residence.

** Percentages sum to more than 100% due to duplicated counts when an individual has more than one type of health insurance.

Source:

National Center for Health Statistics, Health Care Coverage by Sociodemographic and Health Characteristics, U.S., 1984, Data from the National Health Survey, Vital and Health Statistics, Series 10, No. 162, November 1987, DHHS Publication No. (PHS) 87-1590, Tables 1, 2, 5, 7, 9, 11, 15, 17.

incomes under $5,000, as many as 31.1 percent of persons with incomes under $5,000 remain uninsured without public or private health coverage. For persons with incomes between $5,000-$9,999, the percentage covered by Medicaid drops to 23.2 percent, accounting for the slightly higher percentage of uninsured. Many states do not provide Medicaid coverage to persons with incomes below the federal poverty level[15].

While Medicaid covers 4.0 percent of working-age persons, Medicare covers only 1.2 percent of working-age persons. Among those receiving Medicare are only 3 percent or less of low income persons under age 65 and less than one percent of persons with incomes above $20,000. The other major public health care program, the military-VA program, serves a higher percentage of persons under age 65 with incomes over $20,000 than both Medicaid and Medicare combined. The military-VA program provides some health related services to veterans on the basis of financial need and other services are entitlements on the basis of active military service or service-connected disabilities. While these distinctions can be made from data within the VA system, they cannot be made from the HIS and SIPP surveys on which this section is based.

In contrast to the strong link between private insurance and employment, public insurance is virtually unavailable to persons who are currently employed, except for those in the military. Medicaid is primarily available to low income working-age persons if they are unemployed parents who are eligible for Aid to Families with Dependent Children (AFDC), or if they are out of the labor force due to a severe disability and eligible for Supplemental Security Income (SSI) program because of low income and limited assets. Medicare is available to working-age persons who are beneficiaries of Social Security Disability Insurance (SSDI) as disabled workers or adult dependents of workers who are disabled, retired, or deceased. SSDI beneficiaries can retain Medicare for up to two years after returning to the labor force which accounts for the small percentage of employed and unemployed persons with Medicare. Military-VA coverage serves a slightly smaller percentage of working-age persons who are not in the labor force than Medicare but less than half as many persons as Medicaid.

The uninsured consist primarily of unemployed persons, low income persons who are employed, and their children. Among working-age persons who are unemployed, 38.3 percent are uninsured as are 16.8 percent of those out of the labor force. Families with income under $20,000 are also disproportionately uninsured. The percentage of uninsured persons under age 65 varies from 31.1 percent for persons with family incomes under $5,000, to 36.6% for persons with family incomes $5,000 - $9,999, and 20.3 percent for persons with family incomes $10,000-$19,999.

Summary:

This overview of the health insurance status of the U.S. population indicates that access to health care is a major problem for persons with low incomes and persons who are unemployed. Children and working-age persons are also much more likely to be uninsured than elderly persons who have the benefit of Medicare coverage.

Health Status and Health Insurance:

One measure of the effectiveness of the health insurance system is the extent to which it finances the health care of persons who need it. The HIS survey provides data on various indicators of self-reported health status including respondent-assessed health status, annual bed days, annual physician contacts, annual hospital episodes, and annual hospital days. Table 6 represents the health insurance status for persons under 65 years by different indicators of health status (see Table 6).

Three patterns quickly emerge from Table 6. One is that private insurance covers a higher percentage of persons in better health than persons in poorer health. Two is that public health insurance covers a higher percentage of persons in poorer health than persons in better health. Interestingly, this pattern occurs in each of the three main public health insurance programs. Three is that persons in poorer health are more likely to be uninsured than persons in better health. The only exception to this pattern appears to be the higher percentage of uninsured persons with no

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[15] The federal poverty level for a family of four in 1984 was $10,609; in 1987, the poverty level was $11,611.

Table 6: Type of Health Insurance for Persons Under 65 Years, by Selected Health Status Indicators, HIS (1984)

(percent)

	Type of Health Insurance				
Respondent-assessed Health Status	Private Insurance	Medicare	Medicaid	Military-VA	Uninsured
Excellent	81.6	0.2	4.0	2.9	12.0
Very good	80.2	0.3	4.7	3.0	13.0
Good	70.5	1.0	8.0	3.0	18.9
Fair	61.0	5.4	13.2	5.2	20.8
Poor	48.5	22.6	20.5	7.6	19.0
Annual bed days*					
None	75.6	0.8	5.6	3.0	16.3
1 - 7 days	80.5	0.6	5.3	3.0	12.0
8 - 30 days	74.1	2.6	8.8	4.0	13.4
Over 30 days	62.4	11.9	15.5	6.6	15.4
Annual hospital days					
None	76.9	0.9	5.7	3.0	14.9
1 - 6 days	77.5	2.4	8.8	4.6	10.2
7 - 15 days	74.0	6.0	9.9	6.2	10.8
Over 15 days	66.4	13.3	13.7	8.6	11.6

Footnote: * Annual bed days refers to the number of days a person stayed in bed more than half a day because of illness or injury.

Source: National Center for Health Statistics, Health Care Coverage by Sociodemographic and Health Characteristics, U.S., 1984, Data from The National Health Survey, Vital and Health Statistics, Series 10, No. 162, November 1987, Tables 3, 6, 9, 13, 17.

annual bed days and no annual hospital days This exception may reflect the fact that most uninsured persons are in good health and that some persons are uninsured because they choose not to purchase health insurance expecting that their health will not require medical care. The real significance of Table 6 is that persons who most need health care are least likely to have access to private health insurance. This may be due to lower employment rates and lower incomes of persons with poorer health or selection criteria of insurers to minimize their coverage of persons who are likely to be high health care users. If the public insurance system could substitute perfectly for the decline in private health insurance, then access to health care could be maintained. However, data indicate that the rates of uninsurance actually increase as health status deteriorates. A limitation of relying on the market to ensure access to health care is that persons with poor health cannot afford the health insurance premiums and that private insurers will want to exclude them in any case.

Summary:

Private insurance is more likely to cover people who are in better health than people in poorer health. Public insurance covers a disproportionate number of people in poorer health.

The substitution of public for private insurance is not perfect, however, accounting for the fact that the percentage of uninsured increases with poorer health status.

Comparison of Health Insurance Status for Persons with Limitation in Major Activity and Persons without Any Limitation:

The health insurance status of persons with disabilities differs significantly from the health insurance status of the nondisabled population. This difference is represented in Tables 7a/7b (see Tables 7a/7b) Private insurance is utilized by approximately 63 percent of persons with limitation in major activity compared to almost 80 percent for persons without limitation. The difference between persons with and without major activity limitation is greatest for working-age persons and least for children. The lower percentage of private insurance among working-age persons with major limitation reflects a combination of low family incomes, lower rates of employment, and access barriers based on medical underwriting criteria. The discrepancy appears lower between children with and without limitations, however, because many children without limitation are uninsured when they come from low income families.

Although persons with disabilities are less likely to have private insurance than non-disabled persons, they are more likely to receive public insurance. The largest programs of public insurance for persons with disabilities are Medicare, Medicaid, and the military health care programs CHAMPUS and CHAMPVA[16] which will be referred to as military/VA. Table 7a provides a comparison of the number of persons with major activity limitation receiving each type of public insurance by age group. Over 95 percent of disabled persons over 65 receive Medicare compared to only 14.8 percent of disabled working-age persons, and virtually no disabled children. Medicaid is the primary public insurance program for disabled children covering as many as 22.7 percent compared to 14.1 percent of disabled working-age persons and 12.3 percent of disabled elderly persons. The Veterans Administration health insurance program covers approximately 8.1 percent of disabled adults, 7.7 percent of disabled elderly persons, and less than one half of one percent of disabled children.

A comparison between Tables 7a/7b reveals that a higher percentage of persons with major activity limitation are covered by the public health insurance programs than persons without limitations. For example, among persons with major activity limitation, Medicaid covers 22.7 percent of children, 14.1 percent of working-age persons, and 12.3 percent of persons over 65 years. By contrast, for those without limitation Medicaid covers only 10.2 percent of children, 2.8 percent of working-age persons, and 3.7 percent of elderly persons. Similarly, Medicare covers 14.8 percent of working-age persons with a major activity limitation compared to only 0.2 percent of

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[16] CHAMPUS is the abbreviation for Civilian Health and Medical Program of the Uniformed Services and CHAMPVA is the abbreviation for Civilian Health and Medical Program of the Veterans Administration.

Table 7a: Profile of Health Insurance Status of Persons with Limitation of Major Activity due to Chronic Condition by Age Group, (HIS 1984)

(in millions and percentages)

	All Ages		Under 18		18-64		Over 65		Under 65	
	Million	%	Million	%	Million	%	Million	%	Million	%
Private Insurance	14.0	63.1	1.4	63.6	8.4	62.2	4.2	64.6	9.8	62.0
Public Insurance										
Medicaid	3.2	14.4	0.5	22.7	1.9	14.1	0.8	12.3	2.4	15.2
Medicare	8.2	36.9	0.0	0.0	2.0	14.8	6.2	95.4	2.0	12.7
Military-VA	1.7	7.6	0.009	0.4	1.1	8.1	0.5	7.7	1.2	7.6
Uninsured	2.4	10.8	0.3	13.6	2.1	15.6	.07	1.1	2.4	15.2
Total No. of persons with Limitations of major activity	22.2	100.0	2.2	100.0	13.5	100.0	6.5	100.0	15.8	100.0

Table 7b: Profile of Health Insurance Status for All Persons Without Limitation of Major Activity due to Chronic Condition by Age Group

(in millions and percentages)

	All Ages		Under 18		18-64		Over 65		Under 65	
	Million	%	Million	%	Million	%	Million	%	Million	%
Private Insurance	154.5	78.3	43.0	73.4	99.2	80.9	12.4	77.0	142.2	78.5
Public Insurance										
Medicaid	10.0	5.1	6.0	10.2	3.4	2.8	0.6	3.7	9.4	5.2
Medicare	15.6	7.9	0.0	0.0	0.3	0.2	15.3	95.0	0.3	0.2
Military-VA	5.7	2.9	1.6	2.7	3.4	2.8	0.6	3.7	5.0	2.8
Uninsured	26.5	13.4	8.3	14.2	18.1	14.8	0.1	0.6	26.3	14.5
Total	197.3	100.0	58.6	100.0	122.6	100.0	16.1	100.0	181.2	100.0

Footnote: Persons with more than one type of insurance are counted more than once

Source for Tables 7a and 7b Derived from National Center for Health Statistics, Health Care Coverage by Sociodemographic and Health Characteristics, United States, 1984. Data from the National Health Survey, Vital and Health Statistics, Series 10, No 162, November 1987, DHHS Publication No. (PHS) 87 - 1590; Table 4, 6, 9, 13, 18 working-age persons without major activity limitation.

The percent of persons who are uninsured is remarkably similar between persons with limitation in major activity and persons without limitations. Among children with limitation in major activity, 13.6 percent are uninsured compared to 14.2 percent among children without limitations. Among working-age persons, 15.6 percent with major activity limitation are uninsured compared to 14.8 percent without limitations. These statistics are slightly misleading, however, because one-third of all uninsured working-age persons are 18-24 years old. When persons between ages 25-44 are compared, the percent uninsured is actually 19.0 percent for persons with major activity limitation compared to 13.6 percent for persons without any limitations. Likewise, among the population 45-64, the percent of uninsured drops to 12.8 percent for those with major activity limitation compared to 8.5 percent for those without any limitations[17]. These statistics suggest that a greater percentage of working-age persons with limitation in major activity face barriers to access than do persons without limitations.

While the percent uninsured among working-age persons with limitation in major activity may be higher than the percent uninsured among persons without limitations, it is important to recognize that the actual number of so-called standard risk persons without health insurance is much greater than the number of uninsured persons with pre-existing conditions. Tables 7a/7b indicate that the number of uninsured persons in 1984 was 2.4 million persons with limitation in major activity and 26.5 million persons without limitation. Of the total 29.8 million uninsured persons in 1984, people with limitation in major activity represent approximately 8 percent. This is one of the reasons that persons with disabilities are not driving the health insurance reform debate. Nevertheless, a large proportion of persons with disabilities experience the limitations of private and public health insurance which make them a logical leader to close the gaps of under-insurance.

Summary:

Approximately 63 percent of persons with limitation in major activity have some form of private insurance compared to almost 80 percent of persons without limitation.

Persons with limitation in major activity are more likely to receive some form of public insurance than persons without limitations. For example, 22.7 percent of children with limitation in major activity receive Medicaid compared to 10.2 percent of children without limitation.

Without the greater availability of public insurance for persons with disabilities, the percent uninsured among persons with disabilities would be much higher than the percent uninsured among the non-disabled population.

While the percent uninsured among working-age persons with limitation in major activity is higher than the percent uninsured among persons without limitation, persons with limitation in major activity represent only 8 percent of the total uninsured population.

Employment and Health Insurance:

With most private health insurance linked to employment in the U.S., SIPP data provide a unique opporunity to examine the relationship between health insurance status and employment for working-age persons with a work disability. Of the 17.9 million persons with a work disability, 7.6 million are employed full time or part-time, 4.7 million are not employed and not receiving SSI or SSDI, and 5.7 million are neither employed nor receiving SSI or SSDI. These categories provide a useful framework for analyzing the health insurance status of persons aged 18-64 with a work disability.

As can be seen in Table 8, private insurance ranges from 82.6 percent of persons with a work disability who are employed full time, to 65.0 percent who are employed part-time, to 39.5 percent who are not working at all. The 82.6 percent with private insurance is slightly less than the 85.3 percent of persons with private health insurance who are currently em-

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[17] National Center for Health Statistics, "Health Care Coverage by Sociodemographic and Health Characteristics, United States, 1984", Data From the National Health Survey, Vital and Health Statistics, Series 10, No. 162, November 1987, Table 17, p. 43-

Table 8:

Type of Health Insurance by Employment Status for Working Age Persons with a Work Disability, 1984
(in millions of persons and percentages)

	Employment Status													
	Employed						Not Employed							
Health Insurance Status	Full Time		Part Time		Subtotal		Receiving SSI or SSDI		Not Receiving SSI or SSDI		Subtotal		Totals	
	Million	(%)	Million	(%)	Million	(%)	Million	(%)	Million	(%)	Million	(%)	Million	(%)
Private Only	4.65	82.6%	1.30	65.0%	5.95	78.0%	1.18	25.2%	2.90	51.3%	4.08	39.5%	10.03	55.9%
Private and Medicare	0.05	0.9%	0.03	1.5%	0.08	1.0%	0.79	16.8%	0.11	1.9%	0.90	8.7%	0.98	5.5%
Private and Medicaid	0.06	1.1%	0.02	1.0%	0.08	1.0%	0.16	3.4%	0.07	1.2%	0.23	2.2%	0.31	1.7%
Medicare Only	0.01	0.2%	0.03	1.5%	0.04	0.5%	0.69	14.7%	0.02	0.4%	0.71	6.9%	0.75	4.2%
Medicaid Only	0.25	4.4%	0.16	8.0%	0.41	5.4%	1.01	21.5%	1.00	17.7%	2.01	19.4%	2.42	13.5%
Medicaid and Medicare	0.04	0.7%	0.01	0.5%	0.05	0.7%	0.43	9.2%	0.02	0.4%	0.45	4.4%	0.50	2.8%
Other	0.10	1.8%	0.03	1.5%	0.13	1.7%	0.03	0.6%	0.14	2.5%	0.17	1.6%	0.30	1.7%
No Insurance	0.67	11.9%	0.42	21.0%	1.09	14.3%	0.60	12.8%	1.52	26.9%	2.12	20.5%	3.21	17.9%
Adjusted Totals *	5.63	100.0%	2.00	100.0%	7.63	100.0%	4.69	100.0%	5.65	100.0%	10.34	100.0%	17.95	100.0%

Footnote:

* All percentages are based on adjusted totals rather than on the actual sum of the health insurance statuses represented in this table. In this preliminary analysis of the SIPP data, the adjusted totals, based on the single estimate of employment status, are likely to be more reliable than the actual sum of the multiple health insurance statuses. Although the health insurance categories were selected to be mutually exclusive, there may be some duplication accounting for this small discrepancy. For this reason, percentages total slightly more than 100 percent because the adjusted totals range from 1.8% to 4.2% less than the sum of the health insurance statuses.

Source: Calculated from SIPP (1984) data analyzed on special request by the Bureau of Economic Research, Rutgers University, 1988.

ployed as reported in Table 5. This may indicate that persons with a work disability who are employed full time may not have much more trouble getting health insurance than persons without a disability.

Unfortunately, the HIS data reported in Table 5 did not break-out part-time employment or self-employment for the percentage of persons with private insurance. It is well known that part-time employees are less likely to be eligible for private insurance than full time employees in employer sponsored group health insurance plans. This would suggest that the percent of employees with private insurance should be higher for full time employees than for part-time employees. As a result, the 82.6 percent of private insurance for full time employees with a work disability may actually indicate greater barriers to access than would be experienced by full time employees without a work disability. Moreover, since self-employed persons would likely have to purchase an individual policy subject to strict medical underwriting criteria, it is likely that a full time employee with a work disability would have a harder time obtaining private insurance as a self-employed person. While the Health Insurance Association of American (HIAA) reports that the number of insured persons with individual policies under age 65 has dropped to 4.6 percent in 1986[18], it has not been possible to identify the number of persons with disabilities who have individual policies.

Another factor which might disguise differential treatment of employees with a work disability is the fact that many persons with a work disability who do not have access to private health insurance may not

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[18] Health Insurance Association of America, 1988 Update: Source Book of Health Insurance Data, Washington, D.C., Table 1.4, p. 6.

be working at all for fear of jeopardizing eligibility for public health insurance. For the most part, Medicaid and Medicare have not been available to persons with disabilities who are working full time or part-time if they earn more than $300 per month. This measure of "substantial gainful activity", which is used by the Social Security Administration as part of its legal definition of disability, is little more than half of minimum wage and is certainly not a reasonable indicator of a person's capacity to be self-sufficient at all much less afford all of the costs associated with a disability. This can present a major disincentive to work when private health insurance does not cover many of the health related services needed by a person with a chronic condition.

As noted above, public insurance is primarily available to persons with a work disability who are not employed. Medicaid coverage is reported by 26.0 percent of persons not employed compared to only 6.2 percent of persons working full time and 9.5 percent of persons working part-time. Likewise, Medicare is reported by 20.0 percent of persons who are not employed compared to 1.8 percent of persons working full time and 3.5 percent of persons working part-time.

Uninsured persons with a work disability appear to range from a low of 11.9 percent among those employed full time to a high of 21.0 percent among those employed part-time. Interestingly, the percent uninsured is slightly higher among those employed part-time than among those not working (20.5%). For those not working, an important difference exists between persons receiving SSI or SSDI and persons not receiving SSI or SSDI. Almost half of the 3.2 million uninsured persons with a work disability between 18 64 are neither working nor receiving SSI or SSDI. It would be interesting to see how many of these 1.5 million persons reported in the SIPP survey that they have the capacity to work full time even though they were currently unemployed. This information would provide a basis for an estimate of the extent to which lack of health insurance may be discouraging employment. In any case, developing a strategy to provide health insurance to this group remains one of the major challenges for health insurance reform.

Among the 5.7 million persons with a work disability who are neither employed nor receiving SSI or SSDI, as many as 51.3 percent appear to receive some form of private insurance. It remains to be seen whether they are covered by a continuation of the group plans which they may have had when they were employed, or by the insurance of a spouse, or by an individual plan. Answers to these questions can be learned from further analysis of the SIPP data.

Another question concerning the category of persons neither employed nor receiving SSI or SSDI is why as many as 17.7 percent report receiving Medicaid when this group is supposed to exclude persons who receive SSI. Although this estimate is somewhat suspect, it is conceivable that a certain percentage of these persons became eligible for Medicaid through a medically needy program. Thirty - five states have a medically needy program which extends Medicaid to persons with incomes above the poverty level if their medical expenses drop their income below the poverty level.

While only 12.8 percent of those receiving SSI or SSDI are uninsured, the fact that any of these recipients of the two major disability programs administered by the Social Security Administration are uninsured deserves some attention. In practically all states, SSI recipients are automatically eligible for Medicaid immediately. In a few states, the so-called 209(b) states, there are some additional state requirements, but the vast majority of SSI recipients even in the 209(b) states receive Medicaid. For the federally administered Medicare program, however, persons who are determined to be too disabled to work are required to wait for two years after qualifying for SSDI payments before they become eligible for Medicare. This can impose a substantial burden on persons who have become recently disabled, especially when they face expensive initial rehabilitation costs associated with their disability. Some of these SSDI recipients are able to continue receiving private health insurance coverage, but many are uninsured at some time during their two year waiting period for Medicare.

SSA has recently reported from SIPP (1984) data that 6 percent of all disabled worker beneficiaries of SSDI are uninsured[19]. With 2.4 million disabled

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[19] Social Security Administration, Social Security Bulletin: Annual Statistical Supplement, 1987, December, 1987, p.92, Table 18.

worker beneficiaries, the total number of uninsured would be approximately 143,280 persons. If the number of new beneficiaries who are on their two year waiting period is approximately 449,748 persons [twice the number of disabled worker new beneficiaries reported by SSA between July 1980 and June 1981 in the General Accounting Office report Social Security Disability: Demographic and Economic Characteristics of New Beneficiaries, January 1988], then the number of uninsured disabled workers could be as high as *one-third.* Further analysis could reveal how many SSDI beneficiaries appear not to be uninsured because they have had to spend down to poverty in order to qualify for Medicaid coverage during their two year waiting period for Medicare.

This section has focused on the health insurance status and employment status of persons aged 18-64 with a work disability. Persons were classified as having a work disability if they reported a chronic condition which either made them unable to work or which limited the amount or kind of work they could do. The determination of employment status was based on whether a person was employed during a certain period prior to the SIPP interview. This classification gives a primacy to the labor force attachment of persons with work disabilities because both private and public health insurance are highly dependent on employment status.

This approach has been criticized, however, for obscuring the severity of limitation by failing to distinguish between people with a chronic condition who are unable to work and those with a chronic condition who are unemployed for other reasons[20]. Surprisingly, the Bureau of the Census estimates from the SIPP survey that only 8 million persons aged 16-64 reported that they were "prevented from working" because of a chronic condition[21], rather than the 10.3 million persons identified in Table 8. It was decided touse the higher estimate of 10.3 million persons in this report, however, because 2.3 million working-age persons with a work disability were not employed during the criterion period even though they reported that they were "able to work". LaPlante believes that this response may indicate a lower level of severity and that persons who report being "able to work" are likely to be unemployed for reasons other than their impairment. The interpretation used in this report is that the impairment might be an obstacle to employment because of job discrimination or an unwillingness of an employer to modify the workplace to accommodate a person's impairment regardless of a person's perception of his or her ability to work. It is therefore reasonable to group together working-age persons with a work disability who are not employed whether or not they indicate that their chronic condition prevented them from working. Further research should explore whether disabled persons who report that they are not prevented from working because of a work disability have different disabling conditions, levels of severity, age of onset for the disability, and work histories than persons who report that they are prevented from working because of a work disability.

Summary:

Among working-age persons with a work disability, the most vulnerable group is persons who are not employed and not receiving SSI or SSDI. About half of the uninsured persons with a work disability are in this category.

SSDI beneficiaries are also highly vulnerable during the two year waiting period for Medicare. It is estimated that as many as one-third of new SSDI beneficiaries are uninsured at some time during the required two year waiting period for Medicare.

Part-time employees are another group with a high percent of uninsured persons. In fact, part-time employees are slightly more likely to be uninsured than persons who are not employed.

Full time employees with a work disability have the lowest percent uninsured among persons with a work disability. However, it is not clear to what extent they are more likely to be uninsured than full

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[20] Mitchell P. LaPlante, "Disability and Health Insurance in the United States," Unpublished paper prepared for the National Invitational Working Group Meeting on public and private health insurance policies and practices affecting persons with disabilities, sponsored by the National Institute on Disability and Rehabilitation Research, Washington, D.C., June 14-15, 1988. Revised August 15, 1988, pp. 10-11.

[21] U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, Disability, Functional Limitation, and Health Insurance Coverage: 1984/85, U.S. Government Printing Office, shington, D.C., 1986, p. 26.

time employees without a work disability. Moreover, it is not known how many full time employees have been excluded from employer-sponsored group insurance plans on the basis of medical condition.

Conclusion:

Part Two has reviewed national survey data on access to private health insurance, public health insurance, and uninsurance for persons with limitation in major activity and persons without limitation. Private health insurance is more available to persons who are employed, have higher family incomes, and have better health status and no limitations. Public insurance is more available to persons who are unemployed, have incomes below poverty, and have poorer health and limitation in major activity. Nevertheless, the substitution of public for private health insurance is far from perfect, as rates of uninsurance remain high for persons with incomes below poverty and for persons with limitation in major activity, and appear to increase for persons with poorer health.

The problem seems to stem from the failure of many employers to provide private health insurance to their employees and their dependents, and the failure of public insurance to cover persons who do not have access to private health insurance whether they are employed, unemployed, or not in the labor force.

PART THREE:

ADEQUACY OF HEALTH INSURANCE FOR PERSONS WITH DISABILITIES AND PERSONS WITH CHRONIC ILLNESS

The types of health insurance which people with limitation in major activity have access to was examined inPart Two. This section will focus on the adequacy of health insurance to meet the special needs of persons with disabilities and persons with chronic illness. Adequacy refers to the extent to which a health insurance policy meets an individual's health related needs. Among the special needs which will be described are rehabilitation, maintenance therapies, personal assistance services, durable medical equipment, disposable medical supplies and drugs.

Unlike health insurance status, it is difficult to generalize about the adequacy of health insurance plans for several reasons. First, health insurance plans differ widely in scope and depth of coverage, price, enrollment requirements, etc. Most comparisons of health insurance plans concentrate on basic acute care hospital and medical services such as inpatient hospital services, inpatient physician services, and physician office visits. These surveys have revealed important differences in the range of covered services and cost sharing requirements between group plans and individual plans, self-insured employers and group plans, and group plans for different size firms[22].

Some surveys have focused on the adequacy of coverage for specific services in different health insurance plans. The most notable example is the survey of the American Psychiatric Association which examined the availability and depth of coverage for mental health benefits in various insurance plans. Among the insurance plans systematically surveyed were employer-sponsored benefit plans, Federal Employees Health Benefits Program, HMOs, Medicare, Medicaid, State Employee Insurance Plans,County Employee Insurance Plans, Municipal Employuee Insurance Plans and state mandates for psychiatric insurance coverage[23].

A few studies have begun to look at the range of services which are likely to be needed by persons with disabilities or persons with chronic illness. Fox and Yoshpe's study of sixty employer health insurance plans looked at benefits for occupational therapy, physical therapy, speech therapy, outpatient mental health treatment, home care services as well as laboratory and X-ray services, prescription drugs, and medical supplies and equipment[24].

Besides cataloguing the covered benefits, Fox and Yosphe described the copayment requirements, various limits on the level of reimbursement, the number of visits, types of service providers eligible for reimbursement, lifetime maximum benefits and annual out-of-pocket limits. On the basis of a telephone survey with the employee benefit administrators in sixty relatively prosperous firms randomly selected from the Dunn and Bradstreet U.S. Business Directory and the Business Insurance Directory, Fox and Yosphe describe a trend toward expanded comprehensive benefits and greater flexibility through individual benefits management which could provide greater protection against expenses for high cost chronic conditions. This optimistic assessment downplayed the fact that many of these benefits would only be provided if they afforded a lower cost alternative to hospitalization and would not be available on a maintenance basis. The study also did not measure trends toward more restrictive eligibility criteria for private health insurance coverage. Fox and Yosphe did recognize, however, that the recent trend toward increased use of cost-sharing requirements will substantially

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[22] U.S. Department of Labor, Bureau of Labor Statistics, Employee Benefits in Medium and Large Firms, Washington, D.C., June 1987; Wyatt Company, Group Benefits Survey: A Survey of Group Benefit Plans Covering Salaried Employees of U.S. Employers, Washington, D.C., 1984; Health Insurance Association of America, A Profile of Group Medical Expense Insurance in the United States, Washington, D.C., 1980; Chollet, Deborah J. Employer-Provided Health Benefits: Coverage, Provisions and Policy Issues, Washington, D.C., Employee Benefit Re- rch Institute, 1984.

[23] American Psychiatric Association,The Coverage Catalog:Coverage for Mental and Nervous Disorders:A Compendium of Public and Private Sector Health Insurance Plans and An Annotated Bibliography on the Financing of Psychiatric Care, American Psychiatric Press, Washington, DC, 1986.

[24] Harriette B. Fox and Ruth Yoshpe, "Private Health Insurance Coverage of Chronically Ill Children", Fox Health Policy Consultants, Washington, D.C., March 1986.

raise the out-of-pocket expenses of families with persons with disabilities.

There are many problems in gauging the adequacy of health insurance coverage for persons with severe chronic needs. Firstly, many of the services which are needed by persons with severe chronic conditions are not explicitly described in insurance plans. Moreover, the Department of Labor which monitors various characteristics of employer group policies does not monitor "rehabilitation" even when it is provided as a covered service.

Secondly, even if a service is listed in a health insurance policy as a "covered service" there are many conditions which will determine whether the service is actually reimbursed. There are often dollar limits on the amount of certain services which will be reimbursed during a year as well as life-time maximums and annual maximums for all services. In addition, an insurer will typically have policies which restrict the providers who are eligible to be reimbursed. These criteria may include licensing or certification standards, or the type of setting in which a service is provided. The insurance company will also have policies which determine the conditions under which a policy holder is eligible to receive a specific service. For example, an insurance company may limit reimbursement for home care to persons who have been recently discharged from a hospital or would require hospitalization if the home care was not provided. While this limitation is likely to be specified in the insurance policy, there are other limitations which may not be apparent from the policy. For example, insurers may limit reimbursement to services which are "medically necessary", and it is the insurance company which determines the definition of "medical necessity".

It is difficult to determine the adequacy of health insurance without examining the actual experience of the policyholder in getting covered for certain services. National survey data is available on the health care costs and utilization patterns by sources of payment for a representative sample of the noninstitutionalized population, but the number of persons with severe chronic conditions is too small in these national samples to examine the adequacy of health insurance for specific chronic conditions. Moreover, these national surveys have not collected sufficient information about many of the health related services which people with disabilities or chronic illness need because they tended to be guided by what is generally covered by private health insurance. As a result, it has not been possible to use national survey data to identify the number of persons who need specific types of services or the amount or cost of delivering those services. In addition, private insurers claim that they cannot break-out the claims experience for selected services for persons with specific chronic conditions.

While this type of information might be useful to develop actuarial estimates about the cost of building these services into a health insurance policy, the aim here is to highlight the absence of current financing mechanisms for certain services which are essential to the health care of many persons with severe chronic conditions. The purpose of this section is to highlight a need, not to emphasize that all of these services should necessarily be covered through existing health insurance plans.

In the absence of adequate financing for these health related services, many persons with severe chronic conditions are forced to pay a disproportionate amount of their income for essential health related services, or to sustain a diminished quality of life when they cannot afford to pay for certain essential services. Sometimes the lack of affordable health care for persons with a very thin margin of health leads to unnecessary medical complications resulting in costly rehospitalizations.

Interdependence of Acute Care, Rehabilitation, and On-going Maintenance Needs:

For persons with severe chronic conditions, there are at least three interdependent stages in the health care process: acute care, rehabilitation, and on-going maintenance. The goal of acute care is to stabilize the health condition of a person affected by a disease, injury, or a congenital disorder. Stabilization may involve primary care, trauma care, and diagnostic services for early detection of health problems. The goal of rehabilitation is to improve an individual's functional capacity which has been limited by an illness or impairment. On-going maintenance services are provided to enable a person to maintain a maximum level of independence and self-sufficiency and to prevent an exacerbation of the chronic condition.

With improvements in acute care and advances in medical technology there are more persons who survive acute conditions. These persons contribute to the growing demand for rehabilitation and on-going maintenance services. The recent emphasis on cost-containment among governmental and employer payors of health insurance has limited reimbursement in hospitals thus acceleratating the demand for outpatient, clinic-based, and in home services for rehabilitation and on-going maintenance. But at the same time there is strong resistance among both private and public insurers to include rehabilitation and on-going maintenance services as mandated benefits for comprehensive health insurance.

The source of this resistance among private insurers is directly related to the structure of the health insurance marketplace. Private insurers argue that health insurance should protect people against short-term, uncertain risks for acute care rather than provide a financing mechanism for long term, predictable risks. Once a chronic condition develops, the rehabilitation and on-going maintenance needs become both predictable and long term, generating costs beyond what private insurers may be able to collect from policyholders in a limited employer group. With premiums based on the claims experience of each group separately, insurers are concerned that they cannot raise their premiums in a competitive situation without driving lower risk groups to insurers with lower premiums. To ensure the viability of financing acute care through employer groups, insurers want to limit their liability for chronic conditions. In a competitive marketplace, private insurers also have an incentive to resist providing long term benefits in order to discourage the enrollment of persons with severe chronic conditions who are viewed as high cost users (see Part Five for examination of health care costs and utilization). Insurers also claim that on-going maintenance services which they call "custodial care", are not "medically necessary". While the debate swirls around the definition of "medical necessity", the real issue is who will pay for the range of health-related services which are needed by persons with disabilities and persons with severe chronic illness.

Broadening Definition of Health Care to Reduce Its Acute Care Bias:

Private health insurance has largely evolved to finance the provision of primary care for acute conditions. The acute care bias in the U.S. health care financing system was shaped by the interests of hospitals and physicians who originally developed health insurance during the Great Depression to ensure payment for the services which they provided. This acute care bias has been reinforced by the major payors of health insurance, both employers and the government, to limit their immediate costs. But the development of effective primary care and the advance of medical technology has increased the survivability of many persons who would previously have died and ensured that increasing numbers of persons live long enough to develop various chronic conditions. Even the medical technology which was previously available only in a hospital setting can now be delivered in a clinic office or in a person's home. These medical advances have made it possible to overcome or at least reduce the disabling effects of many chronic conditions, but it also raises the questions: who will pay for these health related services, who will be allowed to provide them, and should there be any limits on the services which a person should be entitled to receive? These are difficult questions for a society to confront, but they are inescapable whether the health care system is operated on a market basis, or through a national health insurance system, or a national health service. [WID will seek funding to examine health care coverage for persons with chronic conditions in different countries.]

Moving beyond acute care needs to include rehabilitation and on-going maintenance needs is one of the major priorities of persons with disabilities or chronic illness and remains one of the greatest challenges to health care financing policy. To the extent that the mechanism of health insurance can be used to address these rehabilitation and long term support needs, it is necessary to broaden the definition of health care. One measure of the need for on-going maintenance services can be found in the National Health Interview Survey, 1979 - 1980 Home Care Supplement. According to this survey, there are approximately 3.5 million persons who need personal assistance or special equipment to perform basic physical activities of daily living (ADL). Activities of daily living include walking, eating, going outside, bathing, dressing, using the toilet, and getting out of bed. Table 9 provides prevalence of limitations in activities of daily living due to chronic health problems by age and type of limitation (see Table 9).

According to Table 9, there are 2.5 million persons who cannot walk without assistance, 314,00 persons who cannot eat without assistance, 2.2 million persons who cannot go outside without assistance, 1.4 million who cannot bathe unassisted, 1.1 million who cannot dress without assistance, 914,000 who cannot use the toilet without assistance, and 786,000 who cannot get out of bed without assistance. For each type of basic ADL, Table 9 provides an estimate of the number of persons who require special equipment, need personal assistance, or need both special equipment and personal assistance due to their chronic health conditions. In the sections which follow, various needs will be described which are essential to maintain the health of persons with disabilities and chronic illness but are often not adequately covered by health insurance.

Rehabilitation

Under hospital care, most health insurance plans will cover rehabilitation in an acute care hospital. As long as a person needs to be hospitalized, his or her health insurance is likely to pay for certain rehabilitation services including physical therapy (PT), occupational therapy (OT), and speech-language and hearing therapy. Some private insurance plans will also provide rehabilitation in a specialized rehabilitation facility. The greatest problem, however, is that many insurance plans will not provide post-acute rehabilitation after a person is discharged from an acute care hospital or a rehabilitation facility and returns home to live.

Resistance by insurers to paying for rehabilitation in a clinic or in home is based on their perception that this is an extension of the definition of health care. To the extent that the goal of rehabilitation is to increase functional capacity rather than to reduce illness or to increase survivability, it can be argued that rehabilitation is not "medically necessary" and therefore should not be paid for through health insurance. The issue here is not whether rehabilitation can improve functional capacity or whether improved functional capacity contributes to greater independence and quality of life, but how rehabilitation should be paid for.

One of the major problems which insurers have with reimbursing rehabilitation is how to distinguish it from on-going maintenance services. For persons with chronic conditions which cannot be cured, it is difficult to determine when enough rehabilitation services have been provided and when the financial obligation of the insurer should cease. While insurers are generally willing to rely on physicians to determine what is appropriate medical treatment for acute care conditions, insurers appear less willing to rely on the professional judgment of rehabilitation professionals for chronic conditions. Some of the skepticism of insurers is based on the financial incentives which rehabilitation professionals have to provide as many services as they will be reimbursed for. While this financial incentive is similar for physicians, the environment in which some independent rehabilitation professionals operate may lack well-accepted standards of appropriate practice, well-established outcome measures to demonstrate that rehabilitation has occurred, or well-established administrative mechanisms for utilization review. Meanwhile, rehabilitation professionals contend that quality of care suffers when reimbursement decisions of insurers determine which rehabilitation services a consumer can receive.

While some insurers are willing to reimburse for rehabilitation services which are provided to persons with acute care problems, they have been less willing to reimburse for rehabilitation when a person's acute care need has ended. This creates a problem because most rehabilitation is provided after a person's acute care needs have been stabilized. Persons recovering from a stroke or traumatic brain injury may have to relearn basic skills in walking, talking, or acting in socially appropriate ways after the onset of a disability. Persons with spinal cord injury may have to relearn how to feed and wash themselves and how to get around both inside and outside of their homes. The rehabilitation process involves learning new and old behaviors, learning how to use technical aids like wheelchairs and braces, and modifying the environ-

Table 9: Prevalence of Limitations in Activities of Daily Living (ADL) Due to Chronic Health Problems by Age and Type of Limitation, United States Civilian Noninstitutionalized Population, 1979-1980 (Two-Year Average)

Type of ADL and Nature of Limitation	All Ages	Age Group 6-17	18-44	45-64	65-74	75-84	85+
	Number of persons in thousands						
Walking:							
Completely unable	311	*16	61	55	66	58	54
Special equipment only	1168	23	126	281	267	308	162
Receives help only	276	*7	40	71	59	59	39
Equipment and help	680	*16	42	170	163	181	110
Unknown nature	68	*4	*16	*16	*11	*15	*6
Total	2503	66	285	593	566	621	371
Eating:							
Completely unable	22	*1	*6	*2	*6	*1	*5
Special equipment only	*8	*0	*2	*5	*1	*1	*0.0
Receives help only	251	20	39	54	37	58	43
Equipment and help	30	*1	*5	*7	*9	*5	*2
Unknown nature	*3	*1	*0	*0	*2	*0	*0
Total	314	23	52	68	55	65	50
Going Outside:							
Completely unable	275	*7	22	36	59	80	71
Special equipment only	534	*11	74	123	123	129	75
Receives help only	520	*18	52	118	109	126	96
Equipment and help	852	23	62	187	205	231	145
Unknown nature	41	*0	*8	*5	*10	*12	*5
Total	2222	59	218	469	506	578	392
Bathing:							
Completely unable	65	*5	*13	*8	*10	*13	*15
Special equipment only	85	*1	*14	25	*16	22	7
Receives help only	1050	55	105	219	206	272	192
Equipment and help	209	*4	22	59	44	47	33
Unknown nature	20	*1	*2	*3	*3	*10	*1
Total	1429	66	156	314	279	364	248
Dressing:							
Completely unable	57	*3	*12	*6	*14	*8	*14
Special equipment only	*11	*0	*0	*5	*2	*3	*1
Receives help only	946	59	128	243	176	209	130
Equipment and help	56	*2	*7	*18	*15	*8	*5
Unknown nature	*11	*1	*2	*2	*2	*3	*1
Total	1081	65	149	274	209	231	151
Using the Toilet:							
Completely unable	133	*8	22	*17	24	25	36
Special equipment only	240	*5	30	60	55	54	36
Receives help only	260	25	35	60	47	53	40
Equipment and help	268	*6	30	60	60	79	34
Unknown nature	*13	*0	*2	*1	*1	*7	*2
Total	914	44	119	198	187	218	148
Getting Out of Bed:							
Completely unable	62	*3	*11	*10	*12	*11	*16
Special equipment only	71	*1	*10	20	*15	*15	*11
Receives help only	463	21	73	127	80	103	60
Equipment and help	177	*4	20	52	39	44	*18
Unknown nature	*13	*0	*1	*6	*3	*3	*0
Total	786	29	115	215	149	176	105

Source: National Health Interview Survey, 1979-1980 Home Care Supplement; unpublished tabulations from public use tapes by Mitchell P. LaPlante, Director, Disability Statistics Program, University of California, San Francisco, for paper on "Personal Care Assistance and Age: Data from National Surveys" presented at the 10th Annual Pew Health Policy Fellows Conference, Napa, California, May 27, 1988.

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ment to accommodate one's impairments. Insurers are also willing to reimburse for rehabilitation as long as a "patient"[25] is continuing to make progress. The problem is how to determine when the recovery process has stopped. Since rehabilitation services may be reimbursed only as long as the functional capacity of the person continues to improve, the decision that the recovery process has stopped will determine the termination of reimbursement for rehabilitation services. Medicare uses a 30 day period for recertifying an outpatient plan of care and a 60 day recertification period for home care services. If a person is not making progress during that period, Medicare reimbursement will be terminated. For certain disability groups like traumatic brain injury, however, it may take a longer period of time to demonstrate improvement in functional capacity. For other disabilities like rheumatoid arthritis or multiple sclerosis, it may be difficult to demonstrate improvement in functional capacity where the prognosis is for degeneration. For these groups, it would be more appropriate to measure progress in terms of preventing or postponing expected deterioration rather than improving functional capacity.

Another issue related to how progress is to be measured bears on what is considered an appropriate form of rehabilitation for a person with a chronic condition. For example, for a person who cannot speak because of cerebral palsy, no amount of speech therapy may be effective in improving his or her capacity to speak. But a speech therapist can also assist in providing that person with an augmentative communication device. Equipped with an electronic key board which activates a voice synthesizer, the communication skills of a person with the most severe speech impairment can be greatly improved.

Recognizing the potential costs associated with rehabilitation, many insurers prefer to provide rehabilitation on an extra-contractual basis. This enables the insurer to determine the extent to which rehabilitation services will be reimbursed beyond what may be specified in the contract. Rather than specifying in the insurance contract the level of services which will be paid for, an extra-contractual arrangement holds the policy holder hostage to the insurer's calculation of whether it is cheaper for the insurer to provide more rehabilitation now to reduce subsequent health care costs in the future. Providing rehabilitation on an extra-contractual basis also avoids attracting the enrollment of persons with severe chronic conditions who are generally regarded as high health care users.

Unlike workers' compensation or no fault auto insurance, where the scope and level of rehabilitation benefits are specified in the contract, health insurance does not generally specify the level of benefits for rehabilitation. On the other hand, some health insurers specify a level of benefits which may not be adequate in a particular case. For example, health maintenance organizations (HMO's) which comply with the Federal HMO Act of 1973 are required to offer up to two months of inpatient rehabilitation. The willingness of insurers to cover rehabilitation appears to be related to whether they decide in a particular case that rehabilitation will reduce subsequent health care costs which the insurer is contractually responsible for.

Maintenance Therapies:

Some persons with severe chronic conditions need Physical Therapy (PT), Occupational Therapy (OT), or Speech-Language or Hearing Therapy on a maintenance basis in order to maintain their capacities for independence and self-sufficiency. Although these services are often listed as "covered services" in health insurance plans, they may actually be available under very restrictive conditions. These conditions might include that the therapies are available only if "medically necessary" or only if the person is expected to increase his or her functional capacity. Rarely will a health insurance plan provide therapies on a maintenance basis, such as for one or two hours a week, in

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[25] The term "patient" is deliberately used because health care financing in the U.S. continues to revolve around the physician as gatekeeper. This is objectionable to health care consumers for three reasons. First, it reinforces a dependent role for the health care user with chronic health care needs, who, unlike the person with a short-term acute care problem, is often very knowledgeable about his or her chronic condition. Moreover, for a person with long term limitations, it is more important that he or she feels in control as much as possible. Secondly, it legitimates the physician as the expert in rehabilitation though rehabilitation involves functional adaptation to the environment. Thirdly, it disguises the fact that the professional judgement of physicians has become significantly constrained by reimbursement considerations in the health care marketplace.

order to prevent the deterioration of existing capacities.

While HMO's and other insurers increasingly recognize the cost-effectiveness of "wellness" campaigns, this concept has not been extended to persons with disabilities or persons with chronic illness. Some insurers will require lower premiums or reimburse policy holders for participation in physical fitness clinics if certain functional outcomes are achieved. Persons with disabilities, however, are usually denied reimbursement for maintenance therapies which can improve their functional capacity or prevent deterioration. It would be useful to be able to demonstrate that maintenance therapies can reduce the health care utilization of persons with disabilities or chronic illness in order to weaken the resistance of insurers to this expanded concept of health care.

Personal Assistance Services:

Many persons with disabilities or chronic illness need the assistance of another person to live in their own home. Personal assistance may be needed with housework, meal preparation, getting around in the home, or personal care. Personal care refers to assistance with activities of daily living (ADL's) such as bathing, dressing, feeding, toileting, and transferring. Most of this assistance is provided by spouses, adult children, other relatives, neighbors, or friends without payment. In the absence of informal supports who can provide personal assistance, some persons with disabilities are forced to enter nursing homes. While relying on family members is often the preferred solution for persons on a short term basis, the consequences of exclusive dependence on informal supports for chronic conditions over the long term can be very disruptive to the family. Being expected to provide extensive personal assistance on a continuous basis can generate tensions and interfere with family members working outside the home. Dependence of disabled adults on their parents or on their children can also disrupt normal family relationships under certain conditions and undermine the independence of the person with a disability. For all these reasons, having access to paid personal assistance services can be very important for the independence of persons with disabilities as well as for sustaining the viability of informal supports.

Unlike many of the other health related needs described in this section, national survey data can provide an estimate of the need for different forms of personal assistance for persons with specific health conditions[26]. According to data from the Survey of Income and Program Participation, 15.3 percent of working-age persons with a work disability need some form of personal assistance services to meet their daily needs (see Table 10)[27].

The row percentages indicate the percentage of persons with each health condition reporting a need for personal assistance services, while the column percentages indicate the size of each health condition group among those with personal assistance needs. Comparing the different forms of personal assistance in Table 10, 12.1 percent of working-age persons with a work disability need assistance with housework, 8.1 percent need assistance with meals. 6.1 percent need assistance getting around in their homes, and 4.7 percent need assistance with personal care. Unfortunately, the SIPP survey did not collect information about the number of hours of personal assistance services needed or received.

Based on extensive research on the need for personal care among working-age persons in Massachusetts and other states, DeJong estimates that the number of working-age persons (who are non-cognitively impaired) needing two or more hours of personal care each day is approximately 150 per million persons in the total population[28].

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[26] An expanded analysis of the demand for personal assistance services based on the SIPP data is contained in "Towards an Understanding of the Demand for Personal Assistance." This recent pamphlet produced by a joint research effort of Rutgers University-Bureau of Economic Research and the World Institute on Disability is available from the World Institute on Disability.

[27] This data was based on persons with a work disability because it was erroneously assumed that only working-age persons with a work disability would need personal assistance services for chronic conditions. Subsequent examination of the SIPP data revealed, however, that at least 178,987 persons reported needing personal assistance services because of a chronic condition even though they did not report a work disability.

[28] Personal communication.

Table 10: Type of Personal Assistance Needed by Working-Age Persons with a Work Disability by Health Condition Responsible for Work Disability (SIPP, 1984)

Health Condition Mainly Responsible for Work Limitation	Total Group	column pct	Getting Around	row pct	column pct	Housework	row pct	column pct	Meals	row pct	column pct	Personal Care	row pct	column pct	Number of persons needing assistance by health condition	row pct	column pct
Arthritis or rheumatism	1,800,000	10.03	107,135	5.95	9.71	255,307	14.18	11.77	140,449	7.80	9.71	103,532	5.75	12.30	305,307	16.96	11.11
Back or spine problems	3,880,000	21.61	166,377	4.29	15.08	423,142	10.91	19.50	204,074	5.26	14.11	100,289	2.58	11.92	487,340	12.56	17.74
Blindness or vision problems	480,675	2.68	69,585	14.48	6.31	54,549	11.35	2.51	40,663	8.46	2.81	11,928	2.48	1.42	91,425	19.02	3.33
Cancer	327,454	1.82	49,064	14.98	4.45	97,049	29.64	4.47	60,881	21.04	4.76	47,615	14.54	5.66	110,791	33.83	4.03
Deafness	295,144	1.64	0	0.00	0.00	0	0.00	0.00	0	0.00	0.00	0	0.00	0.00	0	0.00	0.00
Diabetes	614,478	3.42	29,580	4.81	2.68	59,776	9.73	2.76	49,969	8.13	3.45	25,749	4.19	3.06	76,736	12.49	2.79
Heart trouble	2,274,000	12.67	87,048	3.83	7.89	230,674	10.14	10.63	113,706	5.00	7.86	59,765	2.63	7.10	277,611	12.21	10.11
Hernia	161,174	0.90	0	0.00	0.00	2,085	1.29	0.10	2,085	1.29	0.14	3,966	2.46	0.47	6,052	3.75	0.22
High blood pressure	665,564	3.71	19,421	2.92	1.76	129	11.44	3.51	15,335	2.30	1.06	3,521	0.53	0.42	84,049	12.63	3.06
Kidney stones or problems	222,604	1.26	31,873	14.32	2.89	4,166	15.36	1.58	23,605	10.60	1.63	15,760	7.08	1.87	38,292	17.20	1.39
Lung or respiratory problems	1,202,000	6.70	45,086	3.75	4.09	119,863	9.97	5.52	60,474	5.03	4.18	7,554	0.63	0.90	137,893	11.47	5.02
Mental illness	408,528	2.28	24,810	6.07	2.25	32,832	8.04	1.51	51,318	12.56	3.55	20,539	5.03	2.44	71,156	17.42	2.59
Mental retardation	519,326	2.89	41,277	7.95	3.74	115,088	22.16	5.30	167,282	32.21	11.56	97,864	18.84	11.63	199,814	38.48	7.27
Missing appendages	156,567	0.87	17,504	11.18	1.59	22,637	14.46	1.04	22,637	14.46	1.56	14,179	9.06	1.68	39,207	25.04	1.43
Nervous or emotional problems	560,653	3.12	20,869	3.72	1.89	46,980	8.38	2.17	42,968	7.66	2.97	16,875	3.01	2.01	55,966	9.98	2.04
Paralysis (any type)	254,829	1,42	78,567	30.83	7.12	76,176	29.89	3.51	61,433	24.11	4.25	49,948	19.60	5.93	101,509	39.83	3.70
Senility	31,568	0.18	13,703	43.41	1.24	13,703	43.41	0.63	23,343	73.95	1.61	12,983	41.13	1.54	23,343	73.95	0.85
Stiffness of appendage	926,054	5.16	33,221	3.59	3.01	70,322	7.59	3.24	39,743	14.49	2.75	31,893	3.44	3.79	96,581	10.43	3.52
Stomach trouble	274,283	1.53	10,722	3.91	0.97	17,290	6.30	0.80	17,290	6.30	1.20	0	0.00	0.00	21,051	7.67	0.77
Stroke	383,431	2.14	86,133	22.46	7.81	133,919	34.93	6.17	95,209	24.83	6.58	90,639	23.64	10.77	151,187	39.43	5.50
Thryoid trouble	36,482	0.20		0.00	0.00	4,361	11.95	0.20	4,361	11.95	0.30	0	0.00	0.00	4,361	11.95	0.16
Tumor, cyst, or growth	104,459	0.58	26,261	25.14	2.38	39,194	37.52	1.81	36,212	34.67	2.50	25,519	24.43	3.03	47,243	45.23	1.72
Other	2,372,000	13.21	145,173	6.12	13.16	244,286	10.30	11.26	165,439	6.97	11.44	101,497	4.28	12.06	320,247	13.50	11.66
Total	17,951,273	100%	1,103,359	6.1%	100%	2,169,548	12.1%	100%	1,446,476	8.1%	100%	841,615	4.7%	100%	2,747,161	15.3%	100%

Source: Data generated by Bureau of Economic Research, Rutgers University from SIPP (1984).

This estimate is based on the need for the more narrowly defined ADL personal care services instead of the range of personal assistance services represented in Table 10. Assuming a reimbursement rate of five dollars per hour, the annual cost for personal care alone would range from about $3650 for two hours per day to $14,600 for eight hours per day when the service is paid for. Since personal assistance services are rarely covered by private health insurance on a maintenance basis in one's own home, the cost for personal assistance services can become unaffordable for many working-age persons with disabilities who would be required to pay for personal assistance services entirely out-of-pocket.

National survey data from both SIPP and HIS estimate that personal assistance services are needed by as many as 9.9 percent of all persons 65-74 years old and 28.1 percent of all persons 75 years and over. While it is certainly cost-effective for these persons to live in their own homes rather than in medical institutions in order to receive assistance with their activities of daily living, neither private health insurance nor Medicare provide personal assistance services in one's home on a maintenance basis.

Both private health insurance and Medicare will generally pay for home health care to provide skilled nursing care in the home for a short-term recuperative period for an acute health problem if the alternative is a more expensive hospitalization. However health insurance will not pay for personal assistance services to increase a person's functional capacity to live at home. Medicaid is the only health related payment system which in certain states has been used to finance personal assistance on a maintenance basis outside of a medical institution.

Greater attention is needed on how access to paid personal care can increase independence and improve one's long-term health prospects. Personal assistance services are an important aid to the user in carrying out health maintenance activities and in detecting health problems at an early stage. Personal assistance can also be a cost-effective service for many persons with disabilities or chronic illness viewed as an alternative to medically managed institutional care. To ensure that personal assistance services are consumer-directed, it is important that the financing of personal assistance services be channeled through the person with a disability to increase accountability of the individual provider to the consumer and to strengthen the consumer's independence[29].

Durable Medical Equipment and Assistive Devices:

Persons with severe chronic conditions often depend on various assistive devices to live normal lives and prevent medical problems. These products consist of mobility aids, seating and positioning aids, prosthetics (e.g. artificial limbs), orthotics (e.g. braces), sensory and communication devices, and various forms of environmental modification in the home, school, workplace, or vehicle. Needed because of a chronic medical condition, these assistive devices can greatly contribute to a person's independence, functional capacity, and maintenance of health. The problem is that health insurance will only pay for assistive devices under certain conditions.

While durable medical equipment is often included as a covered benefit in major medical insurance plans, insurers generally resist paying for assistive devices which are not considered medically necessary. The determination of what is medically necessary and what is needed to improve functional capacity is often an arbitrary decision based on historical precedence. When the Medicare program was established in 1966, wheel chairs were considered to be medically necessary for persons who would otherwise be confined to a bed or chair. Augmentative communication devices, however, were not widely used at the time, and it has been difficult to get them covered as medically necessary, even for persons who do not have the capacity to speak without them. Recognizing that health insurance will often cover prostheses as a replacement for a body part, there is growing interest in viewing communication devices as communication prostheses in order to make them eligible for reimbursement through health insurance.

To determine whether an assistive device is "medically" necessary or a "convenience item" which will be denied for reimbursement, insurers generally rely on "certificates of medical necessity" submitted by appropriate physicians to document the severity of a person's disability and to prescribe the use of a specific form of durable medical equipment as medically necessary. Even when durable medical equipment is determined to be medically necessary, a problem sometimes arises in determining whether the insurer will pay for one type of durable medical equipment which greatly enhances functional capacity when a cheaper one can also meet medical needs. With incentives to contain costs, insurers find themselves weighing the difference between a power wheel chair which cost $5,000 and a manual wheel chair which cost $500.

In addition to the insurer's requirements for documenting "medical necessity", another problem with durable medical equipment coverage is unrealistic reimbursement limits imposed by the insurer for specific types of equipment. With reimbursement guidelines geared to the average costs for different types of durable medical equipment needed mostly by persons with acute care needs, Medicare will often pay less for durable medical equipment than the market price. This is especially a problem for persons with severe chronic disabilities who often need customized durable medical equipment because they will need to depend on it for many activities on an on-going basis. While Medicare determines maximum allowable charges for specific types of durable medical equipment for which it pays 80 percent, private insurers will generally pay a certain percentage of the market price, such as 80 percent, for durable medical equipment.

Another problem with coverage for durable medical equipment may occur if the insurer does not pay costs associated with the use of durable medical equipment such as repair, maintenance, replacement, and delivery. With most durable medical equipment used by persons with acute care problems on a temporary basis, the reimbursement policies of insurers often involve rental arrangements rather than the outright purchase of durable medical equipment. While rental arrangements usually include the cost of repair, maintenance, and replacement, these are likely to be

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[29] World Institute on Disability has produced several reports on the role of personal assistance for independent living. Among WID's reports are: Attending to America: Personal Assistance for Independent Living: Report of the National Survey of Attendant Services Programs in the United States, Berkeley, California, April 1987; and "The Personal Assistance For Independent Living Act of 1988: A Model Bill and Commentary," February 1988.

additional costs which are not included in the purchase price of durable medical equipment.

Many health insurance policies do not specify durable medical equipment coverage but will cover medically necessary expenses associated with home health care. This benefit is defined as a time-limited convalescent period following discharge from a hospital or nursing home. By narrowly defining the home care benefit, insurers can exclude coverage for health-related services and products needed on a maintenance basis in one's home for a chronic health condition.

A survey of policyholders with disabilities would be needed to measure the frequency of each of these adequacy problems with different types of durable medical equipment and assistive devices for persons with different types of health insurance coverage. The Health Interview Survey (HIS) collected some data on the utilization of mobility aids in 1977. In addition, the National Institute for Disability and Rehabilitation Research is planning to add some questions to the 1990 HIS Supplement on utilization of various forms of durable medical equipment and general sources of payment. However, this data will not identify costs or sources of payment for specific types of durable medical equipment, nor will it collect information on out-of-pocket expenses for durable medical equipment. To some extent, this type of data will be available for certain kinds of assistive devices in the soon to be released National Medical Expenditure Survey (1987).

Because of the limitations in insurance coverage, many persons with disabilities must pay out-of-pocket for all or a significant portion of the durable medical equipment and assistive devices necessitated by their severe chronic condition. While insurers have been willing to pay for standardized types of durable medical equipment needed by persons with acute care needs, it has been more difficult to get coverage for the customized types of durable medical equipment often needed by persons with severe chronic conditions. There has also been resistance to broadening the definition of durable medical equipment to include products such as environmental control and safety equipment, architectural modifications such as ramps, elevator lifts, and home modifications, sensory and communication aids, vehicle transportation aids, and assistive devices for recreational, educational, and vocational purposes.

Disposable Medical Supplies

The care of a disabling impairment or the treatment of a chronic disease often requires the routine use of disposable medical supplies. These include colostomy supplies, diabetic testing supplies, catheters, dressings, supplies for incontinence, etc. Even though the use of disposable medical supplies are necessitated by a health condition and have an important role in prevention of health risks, the expenses for disposable medical supplies are often not covered by insurance plans. Used on a daily basis, disposable medical supplies can generate substantial costs ranging from several hundred to several thousand dollars that many persons with severe chronic conditions have to pay out-of-pocket.

Surveys are needed on the average out-of-pocket costs associated with disposable medical supplies for persons with different types of health insurance by level of severity and for specific chronic conditions.

Drugs, Biologicals, and Medical Foods:

Many of the advances in survivability of persons with severe chronic conditions have occurred because of the development of new drugs, biologicals, and medical foods. Many persons with severe chronic conditions require drugs on a daily basis to maintain their bodily functioning, reduce disabling effects, and prevent medical complications. Drugs can control epileptic seizures, prevent infections, enable a person with diabetes to metabolize food, reduce pain, relax muscles, lower blood pressure, and avoid depression, etc. As with durable medical equipment and disposable medical supplies, there is great variation in whether insurers will pay for drugs, biologicals, and medical foods.

While insurers will pay for the cost of drugs administered in a medical setting like a hospital or nursing home, some insurers will not cover those same drugs on an outpatient basis. Until the recently passed Medicare Catastrophic Coverage Act of 1988, Medicare, like many private insurers, would not pay for drugs on an outpatient basis.

Insurers will generally refuse to pay for drugs which have not been officially approved for a specific health condition by the Food and Drug Administration (FDA). This can create a real problem for persons with rare disorders who may need experimental treatments. Some drugs which are used in other countries lack FDA approval for treating specific conditions because private drug companies do not have a sufficient financial incentive to invest in the complex and costly FDA approval process when the anticipated market is relatively small. Moreover, many insurers will not pay for drugs which are not listed as standard medical treatment for specific chronic conditions in various texts including the U.S. Pharmacopoeia Dispensing Information, the American Medical Association Drug Evaluations, and the American Hospital Formulary Services Drug Information. The National Organization for Rare Disorders (NORD) monitors problems associated with getting treatment for rare disorders[30]. Some insurers have been known to exclude coverage for specific drugs, like AZT, in order to discourage the enrollment of persons who might develop AIDS.

In addition, many insurers will only pay for drugs which are medically prescribed, thus eliminating many over-the-counter (OTC) drugs which persons with severe chronic conditions may depend on. Among the OTC drugs which may not be covered by some insurers are such basic items as insulin for diabetics, pain medications, muscle relaxants, vitamins and other medical foods.

Even for drugs that an insurer will cover, there are significant variations in the size of the deductible for this specific benefit, the percentage of reimbursement for drug expenses, and annual limits for drugs within the insurance policy. For example, Medicare will require a $589 deductible for outpatient drugs and will reimburse at only 50 percent of drug costs in 1990.

The percentage of reimbursement for outpatient drugs by Medicare will rise to 80 percent by 1993.

A survey is needed to measure the extent to which drugs are adequately covered by different types of health insurance for persons with severe chronic conditions. Many persons with severe chronic conditions face continuously high drug expenses, some exceeding several thousand dollars each year, which they cannot get private insurance to pay for because they are subjected to pre-existing condition exclusions.

Need for Further Research:

It would be useful for national disability and chronic disease organizations to sponsor or conduct research on the adequacy of health insurance for covering various health related needs of their constituencies. Ideally, the research design would stratify samples on the basis of age group and level of severity for specific chronic conditions. This research, which could be standardized across groups, should measure the types and levels of health related services needed, the costs for providing the service, current sources of payment, and the consequences of either receiving or not receiving the service. Without this information, it is difficult to move the health insurance debate beyond the priority of providing health insurance to the uninsured. Unless the health related needs of persons with severe chronic conditions are better recognized, the type of health insurance which is eventually designed for the uninsured may not cover many of the health related needs of persons with disabilities or chronic illness. Moreover, if the problems of the under-insured are not raised at this time, a strategic opportunity may be missed for appealing to a broad range of groups who would have an interest in modifying health care financing policy.

Part Three has focused on the adequacy of health insurance to meet certain special needs of persons with disabilities and persons with chronic illness. Another approach to the study of adequacy of health insurance would be to use existing national survey data to examine general indicators of health care utilization for persons with disabilities who have dif-

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[30] NORD publishes the "Orphan Disease Update" to call attention to the problems associated with treating rare disorders and maintains a Rare Disease Database on standard and investigational treatments for various chronic disorders. NORD can be ied at P.O. Box 8923, New Fairfield, Connecticut 06812.

ferent types of health insurance. By controlling for such factors as age, degree of activity limitation, nature of health status, and perhaps even specific chronic conditions, it would be possible to compare the adequacy of different types of health insurance in providing access to specific health services like short-stay hospital visits or physician visits. Depending on which characteristics of the health insurance plans are retrievable from a national survey like the Health Interview Survey, it might be possible to compare health care utilization for uninsured persons and persons in group plans of different sizes, HMOs, individual plans, etc. at different deductible levels. While focusing on health care utilization might identify persons with disabilities who are most vulnerable to not getting their health care needs met, it would not indicate whether the cause of the low health care utilization was an adequacy problem reflecting coverage restrictions, low reimbursement level for providers, or high deductibles, or was the result of health care delivery problems such as lack of transportation to the health care provider or limited number of health care providers in the area. As an example of a recent study of access to health care, the Robert Wood Johnson Foundation sponsored a telephone survey of a stratified sample of the national population in order to measure the consequences of having or not having health insurance. The survey found that among respondents with a serious or chronic medical illness, working-age adults were 3.5 times as likely as the elderly to have needed supportive medical care, medications, or supplies, without getting them, and 3.4 times as likely to have major financial problems due to their illness[31]. Although there are problems with the definition of persons with "serious or chronic medical illness" and with the small sample size and the use of a telephone survey, this type of study provides an important measure of the adequacy of health insurance.

Conclusion:

Part Three has discussed some of the limitations of health insurance for responding to various health related needs necessitated by severe chronic conditions. The needs which have been highlighted include rehabilitation, maintenance therapies, personal assistance services, durable medical equipment, disposable medical supplies, and drugs. These services are either not provided in an insurance plan, or when covered may actually be available in limited amounts under very restrictive conditions.

Additional research is required to measure the adequacy of health insurance plans in terms of coverage limits and reimbursement policies which affect the range of services which persons with disabilities or chronic illness need. Besides the health related services described above, it is important to also include such services as psychological counseling which persons may need to cope with severe chronic conditions. It is also important to measure the extent to which out-of-pocket expenses necessitated by severe chronic conditions constitute an economic handicap which could be reduced through alternative financing mechanisms. Moreover, it is important to estimate to what extent limited access to appropriate health related services for persons with severe chronic conditions contributes to preventable medical complications, disruptive social burdens, and expanded public disability costs which might not otherwise be needed if access to affordable health care was available to all persons with severe chronic conditions, regardless of their capacity to work.

Finally, it would also be useful to compare the health care utilization patterns of persons with disabilities with different types of health insurance status in order to measure the adequacy of different types of health insurance and to identify other barriers to health care delivery.

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[31] Rodney A. Hayward, et.al., "Inequities In Health Services Among Insured Americans: Do Working-Age Adults Have Less Access To Medical Care Than The Elderly?", New England of Medicine, Vol. 318, No. 23, p. 1510.

PART FOUR:

BARRIERS TO ADEQUATE AND AFFORDABLE HEALTH INSURANCE FOR PERSONS WITH DISABILITIES AND PERSONS WITH CHRONIC ILLNESS:

There are three distinct but overlapping barriers which prevent persons with severe chronic conditions from meeting their health care needs through adequate and affordable health insurance. Part Two described the various types of health insurance that persons with disabilities have access to. Part Three explored certain types of rehabilitation and health related maintenance services which people with severe chronic conditions often need but which health insurance, which is predominantly oriented to acute care, generally does not cover. Part Four will explore in greater depth some of the barriers to access, affordability, and adequacy which confront persons with disabilities and persons with chronic illness when they seek health insurance.

Barriers to Access:

Barriers to access exist when persons with disabilities or chronic illness cannot purchase private health insurance on the same terms as so-called standard risk persons because of the presence of preexisting conditions. Insurers have the option of rejecting a person for insurance, rating up the premium, or limiting the coverage which an individual can purchase based on the insurer's perception of anticipated costs. Insurers can establish their own medical underwriting criteria to reflect their assessment of the probability of risk and the costs associated with that risk. In this market system, health care is a commodity and health insurance is a product rather than an entitlement to essential services which citizens have a right to on the basis of need.

Insurance companies are free to determine their own medical underwriting criteria for assessing risk. Table 11 presents the risk classification by commercial health insurers reported in a recent survey of the Office of Technology Assessment. (See Table 11) This risk classification scheme represents the basis on which a representative sample of commercial health insurers require a higher premium, exclusion waiver, or denial of individual coverage. Without reviewing the actuarial statistics on which these underwriting criteria are presumably based, it is difficult to evaluate their reasonableness. However, data from the National Health Interview Survey (1983-1986) presented in Table 1 indicates the wide variance in disabling effects and in the need for personal care associated

**Table 11: Risk Classification by Commercial Health Insurers:
Common Conditions Requiring a Higher Premium, Exclusion Waiver, or Denial**

Higher Premium	Exclusion Waiver	Denial
Allergies	Cataracts	AIDS
Asthma	Gallstones	Ulcerative colitis
Back strain	Fibroid tumor (uterus)	Cirrhosis of liver
Hypertension (controlled)	Hernia (hiatal / inguinal)	Diabetes mellitus
Arthritis	Migraine headaches	Leukemia
Gout	Pelvic inflammatory disease	Schizophrenia
Obesity	Spine / back disorders	Emphysema
Psychoneurosis (mild)	Hemorrhoids	Stroke
Kidney stones	Knee impairment	Obesity (severe)
Emphysema (mild-moderate)	Asthma	Angina (severe)
Alcoholism / drug abuse	Allergies	Coronary artery disease
Heart murmur	Varicose veins	Epilepsy
Peptic Ulcer	Sinusitis, chronic or severe	Lupus
Colitis	Fractures	Alcohol / drug abuse

Source: Office of Technological Assessment. AIDS and Health Insurance: An OTA Survey, February 1988, p. 12, also included in U.S. Congress, Office of Technology Assessment. Medical Testing and Health Insurance, OTA-H-384 (Washington, DC. U.S. Government Printing Office, August 1988) p. 60.

with various impairments and chronic conditions. For example, there is no limitation in major activity for 71 percent of people with epilepsy, 72.1 percent of people with diabetes, 70.2 percent of people with emphysema, 91.1 percent of people with hypertension, 65.0 percent of people with ischemic heart disease, and 82.7 percent of people with breast cancer (see Table 1). It remains to be seen whether the medical underwriting criteria used by private insurers are sensitive to the variations in severity among persons with specific chronic conditions or whether the underwriting criteria are used to discriminate against persons in certain diagnostic categories on the grounds that it is difficult to predict which persons within a diagnostic category will become high health care users. Anecdotes abound about persons who were denied private health insurance coverage because of pre-existing conditions even though they claim that their health status was excellent and their health care utilization was standard.

People with disabilities or chronic illness are vulnerable to medical underwriting criteria whenever their health insurance plan changes. This may occur when a person changes jobs, seeks a new insurance policy because the insurer has changed the benefit package or price of the previous insurance policy, or when a family insurance policy is altered because of age, divorce, or the death of an insured spouse. A person with a preexisting condition may also become vulnerable if an employer changes group coverage from one insurance company to another. The Department of Health and Human Services estimates that there are as many as 7 million "insured uninsurable" persons who would not be able to purchase a new health insurance policy because of pre-existing conditions if they lost their present insurance[32].

The discretion which insurers can use in assessing risk is ultimately dependent on public policy. Until states outlawed the practice, many insurance companies refused to automatically cover newborn infants as dependents under group or family health insurance plans until the insurer could determine that the infant was healthy and thus constituted a good insurable (i.e. profitable) risk. A few states have also prohibited insurers from using pre-existing condition clauses when taking over an existing group which has been insured by another insurance carrier.

Insurers can erect different barriers to access for persons in large groups vs. small groups, and persons seeking individual health insurance policies. In larger groups, health insurers do not generally consider the health status of individuals, choosing instead to distribute the costs for individuals among all members of a large natural group[33]. Nevertheless, insurers may require new employees to be medically underwritten even when joining a large existing group. Private insurers resort to medically underwriting individuals to limit their financial risk when they cannot readily distribute the individual cost within a large group.

Competition among insurers based on experience rating also creates a financial incentive for private insurers to avoid covering persons who may need a high level of health services. Various strategies utilized by private insurers to discourage the enrollment of so-called high risk individuals and the implications of these practices for governmental costs will be analyzed in a subsequent policy bulletin.

The health insurance industry estimates that only one percent of the U.S. population under 65 year old is "uninsurable". One percent of the under 65 population represents around 2.1 million persons. This is approximately two-thirds of the 3.2 million uninsured working-age persons with a work disability estimated from SIPP survey (see Table 8). If there is any merit to the health insurance industry estimate, then many of the uninsured persons with disabilities would not technically be "uninsurable".

The health insurance industry's definition of "uninsurable" ignores two critical facts. One is that the determination of "uninsurability" has more to do with the size of the group with which one shares risk

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[32] Department of Health and Human Services, Insuring Catastrophic Illness for the General Population: Technical Report, Office of Health Policy and Office of the Assistant Secretary for Planning and Evaluation, Washington, D.C., 1987, p. i.

[33] From an insurer's point of view, a group is considered "natural" if it was created for purposes other than to purchase health insurance and therefore is more likely to represent a cross-section of the risks in the general population.

than with the health status of the individual. The second is that as long as insurers can choose their own medical underwriting criteria, they can greatly expand the size of the so-called "uninsurable" population when it is in their interest to do so.

Although the experience with health insurance of persons with disabilities has not been well studied, some insights into access barriers can be gleened from existing surveys. For example, a Louis Harris survey of disabled Americans for the International Center for the Disabled (ICD) found that 13 percent of persons with disabilities aged 16 and over reported that they have been refused health insurance, or had it cancelled, because of their disability[34].

The National Health Interview Survey provides an estimate of the number of all uninsured persons under age 65 by the main reason reported for not having health care coverage (see Table 12).

Table 12: Estmate of all uninsured persons under 65 by main reason reported for not having health care coverage, (HIS, 1984.)

Too expensive	17.9 million	(63%)
Job layoff, job loss	4.2 million	(15%)
Healthy haven't needed it	1.8 million	(6.2%)
Don't believe in insurance	0.5 million	(1.7%)
Can't obtain because of poor health	0.3 million	(1.0%)
Other reasons	3.3 million	(11.8%)
Unknown	1.3 million	
All main reasons	29.6 million	(100%)

Source: National Center for Health Statistics, "Health Care Coverage by Sociodemographic and Health Characterisucs, United States, 1984", Data From the National Health Survey, Vital and Health Statistics, Series 10, No. 162, Table C, p. 11.

From Table 12, it appears that economic factors accounted for at least 78 percent of the reasons that persons were uninsured, while inability to obtain health insurance because of poor health accounted for only 1 percent of the total uninsured. Since the number of those who reported not being able to obtain health insurance because of poor health was only around 300,000 persons, it appears that many uninsured persons with disabilities attributed their lack of health insurance to economic factors. This interpretation is supported by the SIPP survey which asked working-age persons without health insurance to identify the reason for lack of health insurance coverage. Responses for working-age persons with a work disability who do not nave any health insurance are presented below (see Table 13).

Table 13: Working-age persons with a work disability who do not have any health insurance by the reason reported for the lack of coverage (SIPP, 1984)

Reasons for lack of coverage:

Too costly	73.0%
Veterans or military coverage	8.8%
Poor health	8.5%
Not working	6.6%
Healthy	1.8%
Distrust of system	1.1%
Other	0.3%
	100.0%

Source: 1984 SIPP data generated on special request by Rutgers University-Bureau of Economic Research, 1988.

Interestingly, almost three-quarters of this uninsured group of persons with a work disability reported that they lacked health insurance because it was "too costly". Unfortunately, from this response it cannot be determined whether they were denied private insurance because of their pre-existing condition, offered insurance at a higher rate than they could afford, or were offered insurance with pre-existing

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[34] Louis Harris and Associates, Inc. The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream, New York, March 1986, pp. 86-87.

Table 14: Working-age persons with a work disability by self-reported health status and by health condition (SIPP, 1984)

Health Condition Mainly Responsible for Work Limitation	Self-reported Health Status																
	Total	column pct	Excellent	row pct	column pct	Very good	row pct	column pct	Good	row pct	column pct	Fair	row pct	column pct	Poor	row pct	column pct
Arthritis or rheumatism	1,799,570	10.03	20,742	1.15	2 18	160,153	8.90	8 35	443,350	24 64	9.20	721,560	40.10	12 38	453,765	25.22	10.26
Back or spine problems	3,880,419	21.63	211,902	5.46	22.31	559,504	14.42	29.18	1,192,000	30.72	24.73	1,132,000	29.17	19.42	785,013	20.23	17.75
Blindness or vision problems	480,673	2.68	73,144	15.22	7.70	51,165	10.64	2.67	130,847	27.22	2 71	135,273	28.14	2.32	90,244	18.77	2.04
Cancer	327,452	1.83	4,923	1.50	0.52	8,034	2.45	0.42	49,291	15.05	1.02	98,714	30.15	1.69	166,490	50.84	3.77
Deafness	295,141	1.65	48,301	16.37	5.08	79,216	26.84	4.13	123,872	41.97	2.57	38,918	13.19	0.67	4,834	1.64	0.11
Diabetes	605,230	3.37	1,027	0.17	0.11	32,827	5.42	1.71	75,661	12.50	1.57	260,587	43.06	4.47	235,128	38.85	5.32
Heart trouble	2,271,992	12.66	35,816	1.58	3.77	102,741	4.52	5.36	467,742	20.59	9.70	795,811	35.03	13.65	869,882	38.29	19.67
Hernia	161,172	0 90	8622	5 35	0.91	36,714	22.78	1.91	31,682	19.66	0.66	35,917	22.28	0.62	48,237	29.93	1.09
High blood pressure	665,562	3.71	18,883	2.84	1.99	37,562	5.64	1.96	154,940	23.28	3.21	301,696	45.33	5.17	152,481	22.91	3.45
Kidney stones or problems	222,603	1.24	4,177	1.88	0.44	0	0.00	0.00	64,008	28.75	1.33	81,438	36.58	1 40	72,980	32.78	1.65
Lung or respiratory problems	1,202,101	6.70	56,408	4.69	5.94	122,269	10.17	6.38	282,304	23.49	5.86	379,725	31.59	6.51	361,395	30.06	8.17
Mental illness	408,526	2.28	15,389	3.77	1.62	45,252	11.08	2.36	119,572	29.2	2.48	147,512	36.11	2.53	80,801	19.78	1.83
Mental retardation	519,325	2.89	100,297	19.31	10.56	67,530	13.00	3.52	195,454	37.64	4.05	108,244	20.84	1.86	47,800	9.20	1.08
Missing appendages	156,565	0.87	27,507	17.57	2.90	32,793	20.95	1.71	46,979	30.01	0.97	35,724	22.82	0.61	13,562	8.66	0.31
Nervous or emotional problems	560,652	3.13	22,272	3.97	2.34	41,164	7.34	2.15	132,604	23.65	2.75	223,425	39.85	3.83	141,187	25.18	3.19
Paralysis (any type)	254,827	1.42	29,564	11.60	3.11	24,980	9.80	1.30	86,719	34.03	1.80	68,817	27.01	1.18	44,747	17.56	1.01
Senility	31,568	0.18	0	0.00	0.00	0	0.00	0.00	9,881	31.30	0.20	3,803	12.05	0.07	17,884	56.65	0.40
Stiffness of appendage	926,052	5.16	66,027	7.13	6.95	148335	16.02	7.74	356,341	38.48	7.39	232,779	25.14	3.99	122,570	13.24	2.77
Stomach trouble	274,280	1.53	4,808	1.75	0.51	6,697	2.44	0.35	29,910	10.90	0.62	174,772	63.72	3.00	58,093	21.18	1.31
Stroke	383,428	2.14	4,908	1.28	0.52	19,214	5.01	1.00	65,091	16.98	1.35	122,691	32.00	2.10	171,524	44.73	3.88
Thryoid trouble	36,481	0.20	4,162	11.41	0.44	0	0.00	0.00	17,496	47.96	0.36	4,575	12.54	0.08	10,248	28.09	0.23
Tumor, cyst, or growth	104,457	0.58	5,055	4.84	0.53	18316	17.53	0.96	14,329	13.72	0.30	8,830	8.45	0.15	57,927	55.46	1.31
Other	2,372,335	13.22	186,038	7.84	19.58	323,173	13.62	16.85	730,365	30.79	15.15	717,628	30.25	12.31	415,131	17.50	9.39
Total	17,940,411	100%	949,972	5.3%	100%	1,917,639	10.7%	100%	4,820,438	26.9%	100%	5,830,439	32.5%	100%	4,421,923	24.6%	100%

Source: Data generated by Bureau of Economic Research, Rutgers University, from SIPP (1984) data.

condition exclusions which would ensure that the insurance would not cover the health related services which they were most likely to need.

It is likely that a sizeable percentage of the 8.5 percent of respondents who reported that they lacked insurance because of "poor health" were actually rejected by private insurers for reasons of poor health. The SIPP survey permits an examination of self-reported health status of working-age persons with a work disability by the health condition mainly responsible for the work limitation (see Table 14).

From Table 14, it appears that 24.6 percent of working-age persons with a work disability report that their health status is "poor" and another 32.5 percent report that their health status is "fair". The health conditions which appear to be most associated with poor health status are cancer and other tumors, senility, diabetes, and heart trouble followed by stomach trouble and high blood pressure. Among the 16 percent of the working-age disabled population who reported "excellent" or "very good" health status are persons with mental retardation, missing appendages, deafness, blindness, paralysis, and thyroid trouble.

It is also possible that a portion of the 6.6 percent of respondents in Table 13 who reported that they lacked insurance because they were not working may have lost group coverage when they lost their jobs and may not have been able to purchase individual coverage because of underwriting criteria of private insurers or the high premiums.

More surprising, was the 1.8 percent of the uninsured who reported that they lacked insurance because they are "healthy". Almost half of these persons (table not shown) identified chronic conditions like back or spine problems, arthritis or rheumatism, or stiffness of appendages which are high prevalence conditions which often interfere with certain kinds of work but may not require active medical care.

This analysis of the SIPP data is not necessarily inconsistent with the one percent estimate of so-called "uninsurable" persons claimed by the health insurance industry. It is important to note however, that the one percent estimate does not include the sizeable number of persons with disabilities covered by public insurance (see Table 7a). Moreover, the one percent estimate covers less than two-thirds of the uninsured

Table 15: Percentage of Families (Head less than 65) with Expenses exceeding Various Out - of Pocket Thresholds from NMCES (1977)

Expenses Thresholds	Total Population	Any Limitation	Major Limitation	No Limitation
$2200	4.2%	7.0%	9.6%	3.6%
5%/$11,000*	2.6	4.7	6.6	2.2
25%/$11,000*	1.5	3.0	3.7	1.2
$4400	1.5	2.5	3.6	1.3
$6600	0.9	1.5	—	0.7
5%/$11,000*	0.7	1.3	—	0.6
25%/$11,000*	0.4	0.9	—	0.3
Income				
5%	11.0	17.6	21.4	9.7
15%	4.0	7.7	9.2	3.9
25%	2.9	4.7	5.1	2.5

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*This expense threshold represents a fixed amount (e.g. $2200 or $6600) plus 5% or 25% of income over $11,000.

Source: Department of Health and Human Services, Insuring Catastrophic Illness for the General population: Technical Report, Office of health Policy and office of the Assistant Secretary for plannimng and Evaluation, Washington, D.C., 1987, p. 3.9

population ages 16-64 with a work disability. Furthermore, the one percent estimate does not include a significant proportion of the population with disabilities or chronic illness who face the twin barriers of health insurance affordability and adequacy.

Summary:

Persons with severe chronic conditions are vulnerable to medical underwriting criteria whenever their health insurance plan changes.Insurers may reject an application, charge a higher premium, or exclude coverage for pre-existing conditions.

Most working-age persons with a work disability who are uninsured report that health insurance is too expensive for them rather than that it is not available.

More research is needed on the problems that people with pre-existing conditions have in applying for health insurance and in renewing their health insurance plans.

Barriers to Affordability:

The problem of affordability refers to the cost that persons must pay for health related services in relation to their income. At issue is not the total charges for health care, some of which may be paid by third party reimbursement, but the costs to the health care user. The actual burden of out-of-pocket costs will depend on the cost of the health care, the level of income, and the adequacy of a health insurance plan. If the total out-of-pocket expenses exceed a certain percentage of a person's income, it can be assumed that the health care costs constitute a "catastrophic" expense.

The Department of Health and Human Services analyzed the best available data on health care costs and sources of payment from the 1977 National Medical Care Expenditure Survey (NMCES) to project out-of-pocket costs for different populations. Table 15 presents the percentage of families (with head of household less than 65 years of age) with health care expenses exceeding various out-of-pocket thresholds (see Table 15).

The Department of Health and Human Services used three different types of thresholds: fixed amounts (e.g. $2,200, $4,400, $6,600); fixed percentages of family income (e.g. 5%, 15%, 25%), and a combination of fixed amounts plus percentages of income above a certain level (e.g. $2,200 plus 5% of income above $11,000). Based on these thresholds, it was found that families with individuals having activity limitation experienced almost twice a higher incidence of catastrophic out-of-pocket expenses, regardless of the threshold level[34].

According to Table 15, 9.6 percent of families with a family member with a limitation in major activity had out-of-pocket expenses of at least $2,200 in 1977, and 21.4 percent had out-of-pocket expenses exceeding five percent of their family income. As will be explained in the Part Five on health care costs and utilization patterns, these figures underestimate families' exposure to catastrophic out-of-pocket expenses because they provide little information on non-hospital, non-physician costs, and they exclude the costs of persons who are institutionalized.

This section will describe three components of out-of-pocket expenses for health care which are highly significant for persons with severe chronic conditions and then consider the income level of persons with work disabilities.

Out-of-pocket expenses for health related services:

There are three types of out-of-pocket expenses facing persons with severe chronic conditions. One is the cost of health insurance including the premium, deductible, and copayments. The second type of cost is the out-of-pocket expenses for services which exceed the limits of a health insurance policy for "covered services". There might also be a difference between a fixed dollar amount which an insurance plan will pay and the amount that the health care provider will charge for a specific service. Some insurance plans reimburse at the "usual and customary rate" while others provide a fixed dollar amount which is frequently undisclosed at the time that the insurance plan is purchased. The third type of cost is the sum of the out-of-pocket expenses for health-related services which are not covered at all by the health insurance policy. While low users of health care services may be affected only by the cost of health insurance, persons with severe chronic conditions who are high health care users may be affected by all three types of health care costs.

The cost of health insurance generally includes a premium, deductible, and copayments. For a health insurance plan to take effect a *premium* must be paid to the insurer. In addition to the premium, there is the cost of the *deductible* which the consumer must pay to the health care provider before the insurer will pay anything. Finally, there is the cost of *co-payments*, which consumers may be required to pay, ensuring that the consumer shares a percentage of the cost, generally around 20 percent, of what the insurer is expected to pay. Interestingly, coverage limits and co-payments are more likely to be imposed on ancillary health care services such as mental health counseling, visiting nurses services, or speech therapy which persons with disabilities may need than on major health care services which all health care users may use. Insurers prefer to impose co-payments on consumers in order to discourage utilization of so-called "unnecessary" services as indicated by the fact that the consumer would prefer to forego the service rather than pay the co-payment. While many standard risk persons can avoid the costs of deductibles and co-payments for services which they do not need, persons with chronic conditions who must rely on certain health related services will often have to pay the combined cost of the premium, deductible, and co-payments. The amount of the co-payments may be limited by a catastrophic protection provision in many insurance policies.

The extent to which persons with severe chronic conditions are protected by catastrophic protection provisions is important to examine. In 1977, the percent of the privately insured population under 65 with no out-of-pocket limit on hospital and medical expenses was found to be 64.5 percent for persons in poor health status and 54.2 percent for persons in fair health status. By 1984, it was estimated that the percentage without limits on out-of-pocket expenses for catastrophic illness was reduced to 48.2 percent for persons with poor health and 40.6 percent for persons with fair health. Although self-reported health status is not equivalent to severity of a disability, approximately 57.1 percent of working-age persons with a work disability identified their health status as poor or fair according to the SIPP survey (See Table 14).

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[34] Department of Health and Human Services, Insuring Catastrophic Illness for The General Population: Technical Report, Office of Health Policy and Office of the Assistant Secretary for Planning & Evaluation, Washington, D.C., 1987, Chapter 3.

Using the National Medical care Expenditure Survey (NMCES) of 1977, Farley calculated that among the privately insured population under 65 years old that 31.2 percent of persons with poor health status and 22.9 percent of persons with fair health status had at least a one percent chance of out-of-pocket expenses greater than 10 percent of family income. This calculation was made to estimate the number of persons who are potentially underinsured whether or not they had high medical expenses in a particular year. Among the 21.4 million persons with poor or fair health status, there are 2.4 million (11.2 percent) who are uninsured all year, 2.5 million (11.9 percent) who are uninsured part of the year, and 2.6 million (12.2 percent) who are underinsured inspite of their private health coverage[35]. These estimates based on the 1977 NMCES data have been adjusted to reflect assumptions about the expansion of catastrophic protections in group major medical plans as of 1984 but do not include the out-of-pocket expenses for health related services which private insurance tends not to cover.

The cost of health related services which exceed the limit of a health insurance plan is important to consider for persons with severe chronic conditions. Even if they have the protection of a stop-loss for catastrophic expenses, the stop-loss only protects against out-of-pocket expenses for "covered services". The stop-loss will not extend to out-of-pocket expenses for health care services which may be excluded through a compulsory rider for treatment of health conditions which existed prior to the beginning of the health insurance policy. In the absence of an exclusion of treatment for specific conditions, it has been reported that some insurers will challenge the reimbursement of claims on the grounds that a rider would have been required had the person disclosed a pre-existing chronic condition at the time of application. This can put people with a pre-existing condition into a frustrating dilemma . On the one hand, if they choose to disclose a pre-existing condition they can expect a rejection of the health insurance policy or an exclusionary rider on the health care services which are most likely to be needed. On the other hand, if they fail to disclose the presence of a pre-existing condition at the time of application,the insurance company can invalidate the entire health insurance policy at the time of reimbursement.

The third type of out-of-pocket expense includes the health related costs of services which are not "covered" in a health insurance policy. As described in Part Three, health insurance generally does not cover such health related services as personal assistance services, on-going maintenance services, certain types of durable medical equipment, disposable medical supplies, etc.

Research is needed to identify the average annual costs associated with each of these health care costs for persons with specific chronic conditions at different levels of severity.

Summary:

The burden of out-of-pocket expenses for health care constitutes one of the primary barriers to health care access. Persons with activity limitations are more than twice as likely to experience "catastrophic" expenses for health care as persons without limitations.

While low users of health care services may be affected only by the cost of health insurance, persons with severe chronic conditions who are high health care users are likely to be affected by high deductibles and high copayments, out-of-pocket expenses for "covered services" which exceed the limits of the health insurance plan, and out-of-pocket expenses for health-related services which are not covered by a health insurance plan.

More research is needed on the adequacy of health insurance coverage for persons with severe chronic conditions in order to measure the out-of-pocket expenses associated with the full range of their health related needs. Without this information, it will be difficult to steer health insurance reform beyond providing a minimal type of health insurance to the relatively small percentage of the disabled population who are totally uninsured.

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[35] Pamela Farley, "Who Are the Underinsured?", paper presented at the 1984 meetings of the American Public Health Association; derived from Table 7, p. 39; revised version in Milbank Memorial Fund Quarterly/Health and Society, 63(3):476-503, Summer 1985

Table 16: Distribution of personal income for working-age persons 18 - 64 with and without work limitations, who have any private insurance compared to those who are totally uninsured, SIPP (1984)

(percent)

Total Monthly Personal Income	Total Population	Not Work Limited			Work Limited		
		Not Work Limited	Not Work Limited & Any Private Insurance	Not Work Limited & Uninsured	Work Limited	Work Limited & Any Private Insurance	Work Limited & Uninsured
$400 or less	31.1%	29.2%	24.1%	49.3%	44.3%	35.7%	61.2%
$401 - $800	16.4%	15.5%	13.5%	24.4%	22.1%	16.3%	23.0%
$801 - $1,600	26.9%	27.9%	30.3%	19.4%	19.9%	26.6%	11.7%
$1,601 -$2,400	14.3%	15.3%	17.4%	4.5%	7.8%	12.0%	2.5%
More than $2,400	11.4%	12.2%	14.4%	2.4%	5.8%	9.3%	1.5%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Source: SIPP (1984) data analyzed by the Bureau of Economic Research, Rutgers University, 1988.

Health User's Capacity to Pay:

The affordability of health care costs must be judged in relation to the health user's capacity to pay. While a private insurer will assess the "reasonableness" of a health insurance premium in relation to anticipated health care costs, the affordability of health insurance must be judged by the health care user in relation to his or her discretionary income. The Survey of Income and Program Participation provides some data on the personal incomes of working-age persons with and without a work disability (see Table 16).

Table 16 shows that persons with a work disability have significantly lower personal incomes than persons without a work disability. Moreover, Table 16 indicates that uninsured persons with a work disability have an even lower level of personal income than persons with a work disability who have private insurance.

If it is assumed that many persons with limitation in major activity have higher health care utilization and higher health care costs than persons without limitations (see Part Five), then clearly an affordability problem will exist for persons with low incomes. For low income workers whose employers do not contribute to their health insurance premiums, it is not realistic for them to spend at least $175 a month on health care coverage for their families which might represent around one-third of the gross monthly salary of a minimum wage worker. [Bureau of Labor Statistics data indicate that in 1985 the average monthly premium cost for family coverage was $178 for self-insured coverage, $175 for commercial coverage, and $165 for Blue Cross-Blue Shield plans.] These statistics suggest that low income workers with a severe chronic condition will not be able to afford private health insurance even if it is available to them, as well as absorb the additional out of pocket expenses for health related services often needed by persons with disabilities or chronic illness. The affordability problem for the health care consumer is shaped by the problem of adequacy of health insurance benefits.

Summary:

Persons with a work disability are likely to have lower incomes and higher health care costs than persons without a work disability. This creates a substantial affordability problem which is especially great for the large percentage of disabled persons with low incomes.

The affordability problem is even greater for uninsured persons with a work disability of whom more than sixty percent have incomes under $400 per month.

Barriers to Adequacy:

The adequacy of health insurance depends on the nature of health related needs and the criteria for eligibility. Rather than view all persons with severe chronic conditions as a homogenous group, this section will briefly consider how barriers to adequacy vary with different age groups.

Children are highly vulnerable to inadequate health insurance in three ways. A large percent of children with severe chronic conditions are infants needing short-term intensive medical care in a specialized hospital setting in order to survive. This medical care can create a catastrophic financial crisis for almost any family regardless of their health insurance status. Appropriate medical care to these infants can often eliminate or greatly reduce the long term effects of the disability or the chronic illness. A second group consists of children who are uninsured even though their parents have health insurance. Surprisingly, 29 percent of uninsured children live in families headed by someone with employer-based health insurance which does not provide dependent coverage[37]. The third group consists of children whose health insurance coverage is not sufficient to meet their long term support needs. Many of these children are technologically dependent or have unstable medical conditions which require various home care services on a maintenance basis. Several reports have focused on the technologically dependent children who are cared for in institutions because the funding sources will not pay for their care in their family homes[38]. In addition to health care services, many children with severe chronic conditions may have special developmental needs as a result of their chronic conditions.

At the other end of the age spectrum, elderly persons with severe chronic conditions face two major problems in meeting their health related needs. One stems from the failure of Medicare to provide protection from out-of-pocket expenses associated with acute care needs. The recently passed Catastrophic Insurance bill to expand Medicare coverage for hospitalization, physician services and out-patient drugs should prevent many elderly persons from having to impoverish themselves or do without needed health services when faced with frequent acute care needs. The second problem which continues to grow reflects the failure of financing mechanisms to provide for long term support services which an increasing number of elderly persons need to remain in their own homes. In the absence of adequate private or public financing for community based long term support services, elderly persons, who are living longer and developing more chronic impairments, face the growing prospect of costly and depersonalized nursing home care. This institutionalized option for long term care quickly depletes their lifetime savings causing them to spend down to poverty, expands Medicaid costs for institutional services, and isolates elderly persons from their family and friends and from the resources, like housing, which they have had access to.

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[37] Deborah Chollet, "Uninsured in the United States: The Nonelderly Population without Health Insurance", Employee Benefit Research Institute, March 4, 1987, p. 2.

[38] Foundation 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.

Working-age persons with severe chronic conditions face the twin problems of underinsurance and uninsurance. A large percentage of working-age persons with severe chronic conditions are underinsured because of the limitations of their private or public insurance in meeting their on-going maintenance needs as described in Part Three. Working-age persons with a work disability are most likely to be uninsured when they are working part-time, are on the two year waiting period for Medicare, or are neither employed nor on SSI or SSDI as seen in Part Two. Moreover, by limiting eligibility for publicly subsidized health care to persons who cannot [illegible], rather than to persons who do not have access to adequate or affordable private health insurance, public policy has created a major disincentive to work for working-age persons with a severe disability.

Summary:

Persons with severe chronic conditions face different barriers to adequacy depending on their health related needs. The adequacy of health insurance depends on the stability of the medical condition, the nature of the impairments, and the types of support services and products which are needed by persons with severe chronic conditions to maintain their health. Specific barriers to adequacy vary by age group because of the way health insurance is distributed.

Conclusion:

The primary barriers to adequate and affordable health care coverage for persons with severe chronic conditions stem from the acute care orientation of health insurance and from the lack of financing mechanisms to distribute costs in an equitable way between higher users and lower users. As a result, health insurance usually does not cover on-going maintenance services, except as a lower cost alternative to hospitalization, and many persons with pre-existing conditions face either rejection, higher premiums, or pre-existing condition exclusions from private insurers.

The private and public health insurance programs in the U.S. provide different types of coverage depending on age, income, employment status, and the conditions surrounding the onset of a severe chronic condition. This contrasts with many other industrialized countries in which access to health care is provided as an entitlement of citizenship based on health care needs. The evolution of the private and public health insurance programs in the U.S. will be examined in the next policy bulletin.

PART FIVE:

MEASURING HEALTH CARE UTILIZATION AND COSTS FOR PERSONS WITH DISABILITIES AND PERSONS WITH CHRONIC ILLNESS:

Lack of access to private health insurance largely reflects the systemic problems of low labor force participation and reduced ability to pay for premiums. For persons with disabilities and persons with chronic illness, however, there is the additional problem of various selection practices of private insurers who have a financial incentive to avoid covering high users of health care. This section will review national survey data on health care utilization and costs in order to consider whether private insurers have reason to avoid covering persons with disabilities. The limitations of this data will then be analyzed and suggestions for further research proposed.

Sources of Data:

Estimating the health care utilization and costs for persons with disabilities or chronic illness is very difficult. First, most health care users do not know the cost of the services which they consume. This occurs because they do not pay those charges directly as they have been insulated by a complex system of third party payors. Secondly, when consumers are asked to report their health care costs or utilization patterns there is a lot of missing information and inaccurate reporting. It is very time-consuming and costly, however, to verify the self-reported health care costs or utilization patterns which respondents provide on various surveys because of the fragmentation of the health care system. This tends to limit the size of the sample in most surveys which does not permit reliable estimates of costs or utilization patterns for persons with specific chronic conditions. This is particularly problematic for measuring the health care costs and utilization patterns of persons with severe disabilities because the most disabling conditions are the ones lowest in prevalence (see Table 1). Thirdly, while almost two-thirds of persons with limitation in major activity have some private health insurance coverage, private insurers treat the claims experience of specific categories of persons as proprietary information and have not been willing to report it even in an aggregated form that disguises the identity of specific insurers. For all these reasons, data on the health care costs and utilization patterns of persons with disabilities have been difficult to measure.

Nevertheless, there are four national surveys which provide different types of data on various indicators of health care utilization and costs. The National Health Interview Survey provides self-reported data on selected health services but does not collect data on health care costs. The primary sources of data on health care costs, utilization, and sources of payment come from three national surveys of representative samples of the noninstitutionalized U.S. population. These include the National Medical Care Expenditure Survey (NMCES,1977), National Medical Care Utilization Expenditure Survey (NMCUES,1980), and the National Medical Expenditure Survey (NMES,1987) which is currently in preparation for analysis.

Though eleven years old, NMCES provides the most statistically reliable estimates of health care cost and utilization patterns to date with a sample of approximately 14,000 households which includes 40,000 persons. In addition to the realatively large sample size, the information reported by respondents was subjected to verification through a companion survey of insurers and employers which greatly increased the accuracy of the household survey and reduced missing information. Although the data from this 1977 survey can be weighted to reflect recent changes in health care costs and in the age distribution of the noninstitutionalized population, the primary limitation of continuing to rely on the NMCES survey is that it does not reflect recent changes in insurance policies,such as increased deductibles and copayments and expanded use of pre-existing condition clauses, or reflect recent advances in medical technology since 1977. By contrast, NMCUES (1980) used a relatively small sample (approximately one-third the size of the NMCES sample) and relied exclusively on self-reported data which was not verified by a survey of employers and insurers. As a result, the NMCUES data though more recent are less reliable than NMCES data for estimating the health care costs and utilization patterns because of greater missing data and inaccuracies reported by respondents.

Table 17: Health Care Utilization by Degree of Activity Limitation and Age Group in the United States, (HIS, 1979)

	All Persons	No Limitation of Activity	Limited, but Not in Major Activity	Limited in Kind or Amount of Major Activity	Unable to Carry On Major Activity
No. of discharges from short-stay hospitals per 100 persons, per year					
All ages	13.9	9.8	20.8	34 3	64.1
Under 17	6.5	5.5	21.2	34 3	92.7
Ages 17-44	14.1	12.1	21.2	35.1	68 5
Ages 45-64	16.6	9.2	18.7	[illegible]	65.8
Age 65 and older	27.0	14 8	23.0	31.8	61.1
Average number of days spent in short-stay hospitals for persons discharged					
All ages	7.8	5.5	8 2	10.2	13.6
Under 17	5.6	4.8	5.7	10.4	10.9
Ages 17-44	6.2	4.8	8.2	10 2	16.0
Ages 45-64	9.4	6 6	8.1	10.0	13.6
Age 65 and older	10.8	8.6	9.7	10.3	13.0
No. of physician visits per person, per year					
All years	4.7	3.9	6.5	9.8	11.9
Under 17 years	4.1	3.9	5.2	13.0	15.1
Ages 17-44	4.5	4.0	7.1	10.0	16.0
Ages 45-64	5.2	3.7	6.6	10.5	12.7
Age 65 and older	6.3	4.3	6.3	8.4	10.1

Source: National Center for Health Statistics, "Health Characteristics of Persons with Chronic Activity Limitation: United States, 1979," Data from the National Health Survey, Vital and Health Statistics, Series 10, No. 137; December 1981, DHHS Publication No. (PHS) 82-1565; Tables 2, 7, 8.

The new survey, NMES (1987), used a sample of 14,000 households among the noninstitutionalized population which oversampled certain groups including persons with functional limitations. In addition, the NMES survey included 13,000 persons in nursing and personal care homes and facilities for the mentally retarded. Moreover, the NMES survey provided a more extensive probe of the range of health care and support services which respondents need to live in the community including home health services, special equipment or aids, medical supplies needed for self-care, therapies, and various forms of personal assistance. Although still limited in the numbers of persons with specific chronic conditions, the NMES survey will be better able to provide some data for comparing the health care costs and utilization patterns of persons with and without functional limitations associated with selected chronic conditions.

Health Care Utilization:

The measurement of health care utilization is usually presented as a comparison of the average number of health care services utilized by persons with and without disabilities. Table 17 presents 1979 HIS data on health care utilization by degree of activity limitation for each age group (see Table 17).

Hospital utilization can be measured by the number of discharges from short-stay hospitals per 100 persons per year and the average length of stay in short-stay hospitals for persons who are discharged. Table 17 indicates that the average number of discharges from short-stay hospitals is 13.9 per 100 persons per year for persons of all ages. This includes 6.5 discharges for children under 17 years, 14.1 discharges for persons 17-44 years old, 16.6 discharges for persons 44-64 years old and 27.0 discharges for persons 65 years and over. While the number of discharges rises with age, degree of activity limitation has an even more powerful effect on the number of hospital discharges. Among all ages, the number of charges rises from 9.8 for persons with no limitation in activity to 20.8 for persons limited, but not in major activity, to 34.3 for persons limited in the amount or kind of major activity to 64.1 for persons unable to carry on their major activity. While the rise in the number of short-stay hospital discharges is most pronounced among children under 17 years, the similarity in health care utilization patterns within each level of activity limitation suggests that the degree of disability may be a more important predictor of health care utilization than is age.

The pronounced effect of disability can also be seen in Table 17 for average lengths of stay in short-term hospitals. Persons unable to perform their major activity have an average length of stay of 13.6 days compared to 5.5 days for persons without activity limitations. Although average length of stay increases with age for the total population, within disability groups it remains fairly constant. In a similar fashion, the average number of physician visits per person per year increases from 3.9 visits for persons without limitation to 11.9 visits for persons unable to carry on their major activity.

The extent to which persons with activity limitations utilize more acute health care services than persons without limitation can also be measured in the NMCES and MNCUES surveys. Table 18 compares the means of different measures of hospital care, physician care, and prescribed medications for persons with and without activity limitations by age group constructed from the NMCES and NMCUES data (see Table 18).

In every case, the means for health care utilization of persons with activity limitation are greater than the means for persons without activity limitation. Variations in the means for different indicators of hospital care are most revealing. Persons with any activity limitation are about 2.1 - 2.5 times more likely to be admitted to a hospital than persons without limitations. For working-age persons with severe disabilities (i.e. unable to work) the mean jumps to 9.4 times for the average number of hospital days among those who have been hospitalized during the year. Meanwhile, working-age persons with partial disabilities (i.e. limited in the amount or kind of work they can do) have an average number of hospital days that is 3.1 times the average for persons without limitations. The size of the difference seems to vary with the nature of the health care indicator, the severity of the activity limitation, and the age of the group. National Health Interview Survey data also indicate that persons with disabilities under 65 years of age are more likely to have multiple hospital admissions during the year than persons without disabilities[39]. Whether these costly rehospitalizations could be prevented by better primary care delivery cannot be determined from this survey.

Table 19 provides additional confirmation from the NMCES data that working-age persons with disabilities are more likely to utilize hospitals, ambulatory physician contacts, non-physician health care personnel contacts, prescribed medicines, and medical equipment and supplies than persons without limitations. But instead of presenting only an average level of service utilization by disability group, Table 19 also highlights the percentage of persons who are likely to use selected health services (see Table 19).

It is important to measure how many persons with disabilities are expected to utilize various health care services in order to recognize that only a small percentage are likely to be very high users. For example, 30.1 percent of persons who are unable to

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[39] National Center for Health Statistics, Hospitalization of Persons under 65 Years of Age, United States, 1980-81, Vital and Health Statistics, Data From the National Health Survey, Series 10, No. 152, (DHSS Publication No. (PHS) 85-1580), September 1985, Tables 19-20.

Table 18

Use of Selected Health Services by Age Group With and Without Activity Limitations Due to Chronic Health Conditions from NMCES (1977) and NMCUES (1980)

Hospital Care	Age Group	Mean for Persons With Limitations	Mean for Persons Without Limitations	Ratio of Persons with Limitations to Persons without Limitations	Survey	Reference
No. of hospital visits for persons with one or more hospital episodes	18-64	4.1 ***	1.9	2.2	NMCUES	Dean, Table 3
	18-64	3.5 **	1.9	1.8	NMCUES	Dean, Table 3
Average no. of hospital days for persons with one or more hospital episodes	18-64	6.6 ***	0.7	9.4	NMCUES	Dean, Table 3
	18-64	2.2 **	0.7	3.1	NMCUES	Dean, Table 3
Hospital admissions per 1000	0-21	269.0 *	123.5	2.2	NMCUES	Newacheck, Table 3
Hospital days per 1000	0-21	1,739.1 *	441.9	3.9	NMCUES	Newacheck, Table 3
Percent with at least one hospital admission	0-64	23.8 *	9.6	2.5	NMCES	Berk, Table 6
	65+	28.0 *	13.5	2.1	NMCES	Berk, Table 6
Physician Care						
No. of physician visits	18-64	11.5 ***	4.7	2.4	NMCUES	Dean, Table 4
"	1 64	7.6 **	4.7	1.6	NMCUES	Dean, Table 4
"	0-21	5.1 *	2.8	1.8	NMCUES	Newacheck, Table 3
"	0-64	9.4 *	[illegible].7	2.0	NMCES	Berk, Table 6
"	65+	8.9 *	6.3	1.4	NMCES	Berk, Table 6
Prescribed Medications						
No. of prescribed medicines	18-64	21.5 ***	5.9	3.6	NMCUES	Dean, Table 5
"	18-64	11.8 **	5.9	2.0	NMCUES	Dean, Table 5
"	0-21	4.0 *	2.0	2.0	NMCUES	Newacheck, Table 3
"	0-64	15.3 *	5.2	2.9	NMCES	Berk, Table 6
"	65+	18.3 *	10.8	1.7	NMCES	Berk, Table 6

Footnotes:

*** Severely disabled persons who are unable to work

** Partially disabled persons who are limited in the amount or kind of work they can do

* Persons with any functional limitations due to ch[illegible] conditions

Sources:

Dean, David and Yates, Steven, "Medical Care Costs for Disabled Persons," unpublished paper, Bureau of Economic Research, Rutgers University, August 16, 1984.

Newacheck, Paul W., and McManus, Margaret A., "Financing Health Care for Disabled Children," Pediatrics, Vol. 81, No. 3 March 1988, Table 3, p. 388.

Berk, Mark L., Cafferata, Gail L. and Hagan, Michael, "Persons with Limitations of Activity: Health Insurance, Expenditures and Use of Services, Data Preview 19, National Center for Health Services Research, October 1984, Table 6, p. 9.

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carryon their major activity had at least one hospital admission during the year compared to 11.8 percent for persons without activity limitations. What this means is that on the average as many as 70 percent of working-age persons, who are unable to carry on their major activity because of a chronic condition, are not expected to enter a hospital in the course of a year. Whether they are more likely to enter a hospital in a subsequent year cannot be ascertained from this survey. From the insurers' point of view, it may be preferable to exclude the entire group, especially if it is not possible to predict which persons with severe chronic conditions will be high health care users. However, from the point of view of a consumer with severe chronic conditions, being denied access to health insurance because a minority of persons with disabilities may be high health care users can be viewed as a violation of civil liberties.

Sources of Misleading Data:

Data on the health care costs and utilization patterns for persons with disabilities can be highly misleading. First, by averaging high users and low

Table 19:Annual Health Care Utilization by Degree of Activity Limitation for Selected Health Services for Persons between 19 - 64 Years (1977)

	Not Limited	Not Limited in Major Activity but Otherwise Limited	Limited in Amount or Kind of Major Activity	Unable to Carry On Major Activity
Hospital admissions				
with at least one event	11.8%	19.3%	24.6%	30.1%
with three or more events	0.4%	1.2%	2.0%	3.9%
Ambulatory physician contacts				
with at least one event	74.4%	89.8%	89.4%	86.2%
mean events per person	4.9 visits	8.0 visits	9.0 visits	11.1 visits
Non-physician health care personnel contacts				
% with at least one event	24.5%	36.6%	33.9%	29.8%
mean events per person	4.5 visits	5.3 visits	7.9 visits	8.9 visits
Prescribed medicines				
with at least one event	60.5%	80.0%	83.7%	85.0%
mean events per person	6.1 drugs	12.4 drugs	15.7 drugs	20.4 drugs
Medical equipment and supplies				
% with at least one event	5.7%	10.7%	14.2%	13.8%
mean events per person	1.3	1.4	1.6	1.5

* Data from National Medical Care Expenditure Survey (1977) analyzed on special request the Center for Health Services Research.

users, a statistical profile is created that exaggerates the health care utilization of many persons with disabilities. Various rehospitalization studies of persons with spinal cord injury and other high risk populations have found that a small percent of persons with disabilities account for a major proportion of health care expenditures. For example, Young and Northrup found in the second and third years following spinal cord injuries that 20 percent of their sample accounted for about 80 percent of the care[40].

Furthermore, studies which present health care cost averages for all persons by degree of activity limitation without distinguishing between those who utilize a service and those who do not will underestimate the costs for those who actually use the service and exaggerate the costs of those who do not. This is evident in Table 20

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[40] Young, J. and Northrup, N. "Re-Hospitalization in Years Two and Three Following Spinal Cord Injury", Model Systems' Spinal Cord Injury Digest, 1980, Winter: 21-26.

Table 20: Annual Health Care Expenses by Degree of Activity Limitation for Selected Health Services for Persons between 19-64 Years (1977)*

Health Services	Not limited	Not limited in major activities but otherwise limited	Limited in amount or kind of major activity	Unable to carry on major activity
Inpatient hospital	$154.00	$519.00	$622.00	$936.00
Ambulatory physician contacts	$98.00	$187.00	$215.00	$269.00
Non-physician ambulatory care	$17.00	$27.00	$37.00	$58.00
Prescribed medicine	$22.00	$62.00	$87.00	$112.00
Medical equipment and supplies	$3.00	$9.00	$12.00	$18.00

Source: Data from National Medical Care Expenditures Survey (1977), analyzed on special request by the National Center for Health Services Research.

which provides annual health care expenses for selected health services by degree of activity limitation for working-age persons from the NMCES data. (see Table 20). As seen in Table 20, the average costs for inpatient hospitalization are more than six times greater for persons unable to carry on their major activity than for persons without limitation. In addition, the average costs for ambulatory physician contacts are almost three times greater, the non-physician ambulatory care contacts are almost three and one-half times greater, the prescription drugs are five times greater, and the medical equipment and supply costs are six times greater for persons unable to carry on their major activity compared to persons without limitation.

A second way that the health care cost and utilization data can be misleading is that they typically ignore many of the health related services which are not generally covered by traditional health insurance policies. As a result, the total costs for health related services and the out-of-pocket expenses which a person with disabilities must pay are not reflected in the national survey.

A third way that health care cost and utilization data are misleading is that they cannot differentiate between "preventable" complications which would not occur under conditions of appropriate health care and health related services which are likely to be necessary for specific chronic conditions. These data are not available not just because it calls for a hypothetical judgement, but because the health care costs and utilization patterns are based on an *aggregation* of different chronic conditions in order to generate a sufficiently large sample to minimize standard error estimates. By grouping together persons with different chronic conditions on the basis of level of disability, one loses important differences in health status (as was seen in Table 14) which are likely to affect health care utilization. Moreover, studies which identify persons with severe chronic conditions on the basis of higher than average lengths of stay in a hospital or higher than average charges per stay, (such as based on data from the National Hospital Discharge Survey), are often limited to the charges in the hospital and may not permit one to determine how many cases are readmissions or how many diagnoses are chronic or acute conditions.

Need for Further Research:

Measuring the insurance claims experience of persons with specific chronic conditions could provide an important source of data on health care costs and utilization. The problem is that in experience-rated group coverage, the insurer has no incentive to track the claims history of specific individuals. The premium which the insurer charges the employer is calculated on the basis of the total experience of the group with the cost of individuals shared within the whole group. Although a diagnostic code is attached to each medical claim, the diagnostic code refers to the immediate condition for which treatment is given, rather than identifying an underlying chronic condition. For small group and individual coverage, on the other hand, insurers have a powerful incentive to identify all pre-existing conditions and to monitor the costs associated with each insured person. To examine the claims experience of persons with specific chronic conditions in large group plans would probably require additional information from employers about the specific chronic conditions of individuals within the large group and a financial incentive for insurers to retrieve the claims experience for selected individuals.

One way that the private claims experience of persons with disabilities or chronic illness could be measured is through the cooperation of self-insured employers. Since most state governments are not only large equal opportunity employers but also self-insured employers, they are in a good position to be able to require the insurance carriers with which they contract for administrative services to break-out the claims experience of state employees and their dependents who have disabilities or chronic illness. This information can begin to fill an important information gap in the level and types of services which are utilized by persons with specific chronic conditions.

Another source of data which has not been sufficiently tapped is the Health Care Financing Administration data on Medicare and Medicaid utilization. Studies are beginning to link the Social Security Administration data on disability status for persons on SSDI with the Health Care Financing Administrtation data on Medicare to examine the health care use of Medicare's disabled enrollees by diagnostic groups using the ICD codes from the International Classification of Diseases[41].

A crucial study that the author has proposed to the Social Security Administration is to look at the adequacy of private health insurance for a sample of new disabled workers who become SSDI beneficiaries but are required to wait for two years before becoming eligible for Medicare. This study would not only reveal how many disabled workers are uninsured during some portion of the twenty-nine month period since the onset of their disability, but would also provide very important new information about the adequacy of existing private insurance for covering rehabilition needs which is difficult to measure in other ways. In addition, this type of study could probe into the employer's concerns about the future health care costs associated with the health care needs of the disabled employee and the anticipated costs of a workplace modification that would enable the disabled employee to continue employment. Remembering from Table 3 that 63.1 percent of working-age persons with a work disability were employed at the onset of their disability, this information may be crucial to the employer's willingness to accommodate the disabled employee during a transition back to the workplace after the onset of a severe disability.

Another type of study could look at the health care utilization of SSI disabled recipients. An exploratory study by Wisconsin's Department of Health and Social Services was able to link the diagnostic code information in the Vocational Rehabilitation system with Medicaid costs for specific health related services through the use of social security numbers of one hundred and four SSI disabled recipients who had been referred to the Vocational Rehabilitation system[42].

Although the size of the diagnostic groups was too small to generalize to other persons with the same chronic condition and degree of severity, this methodology was able to generate a suggestive profile of health care utilization and costs by diagnostic group and by status in the Vocational Rehabilitation system.

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[41] James Lubitz and Penelope Pine, "Health Care Use by Medicare's Disabled Enrollees", Health Care Financing Review, Vol. 7, No. 4, Summer 1986, pp. 19-31; Barry Bye, Gerald Riley, and James Lubitz, "Medicare Utilization by Disabled-Worker Beneficiaries: A Longitudinal Analysis", Social Security Bulletin, Vol. 50, No. 12, December 1987, pp. 13-28.

[42] Bob Griss, "Report on Health Care Coverage for Working-age Persons with Physical Disabilities: A Key to Reducing Disincentives to Work", Office for Persons with Physical Disabilities, Madison Wisconsin December 1985, pp. 31-35.

Data on the health care utilization of SSI and SSDI recipients, however, is likely to represent the experience of persons with the most severe disabilities. While this information may be useful to dispel some of the myths that most persons with disabilities have high health care needs, it is important to remember that *less than one-third of working-age persons limited in major activity and less than ten percent of children with major activity limitation receive either Medicaid or Medicare* (see Table 2).

A third source of data which is beginning to be tapped are purposive surveys of a representative sample of persons with specific chronic conditions. The Health Care Financing Project at Albert Einstein College of Medicine has targeted the health care needs of a national sample of children with severe mental retardation, autism, hemophilia, cystic fibrosis, spina bifida, and ventilator dependency randomly selected through special education programs in a representative sample of school districts[43]. The Paralyzed Veterans of America is currently financing a national survey of the economic consequences of spinal cord injury. To determine the precise incidence and prevalence of spinal cord injury within the U.S., researchers are using a probability sampling design of 120 geographical areas within which neighborhoods and housing units will be randomly selected to identify approximately 1,600 persons with spinal cord injury. An institutional sample will also be selected using probability techniques from a comprehensive list of nursing homes and long term care facilities in which persons with spinal cord injury reside[44]. These surveys are collecting health care utilization and cost data from a large number of persons with specific chronic conditions which will provide a much more meaningful profile of their health care needs, costs, sources of payment, and the variety of direct and indirect economic and social consequences to the individual with a disability, to the family, and to society.

A fourth source of data on health care costs is available from health care providers. Hospitals can provide the average costs of care for persons by diagnostic category. For example, the National Association of Children's Hospitals and Related Institutions (NACHRI) keeps track of the hospital costs for children with specific diagnoses treated at various Children's Hospitals. At a recent Senate Finance Committee hearing on catastrophic health care, a NACHRI representative reported that the care of a child for one hospitalization of acute leukemia with complications cost about $16,170 in 1986 and the care of a child for one episode of cystic fibrosis was about $10,450.

In a study sponsored by the National Association of Rehabilitation Facilities (NARF) regarding a prospective payment system for inpatient medical rehabilitation services, a comparison was made of the rehabilitation costs and average lengths of stay in hospitals or rehabilitation units for specific chronic conditions. Using the Health Care Financing Administration (HCFA) diagnostic categories, the average charge in 1983 for a spinal cord injury was $20,768, while the average charge for a stroke was $14,401, and the average charge for a brain injury was $21,140[45]. The Rand Corporation has also produced a cost study of rehabilitative care distinguishing between first time hospitalization and return hospitalizations[46]

While these health care costs represent the average charges for specific health care services provided by hospital providers to persons with specific conditions, these charges do not represent the total range of costs which the person with a severe chronic condition might be expected to pay. In its overview of the financial implications of experiencing a traumatic brain injury, the National Head Injury Foundation estimates that the average costs for acute medical care for 60-90 days is $150,000, the acute rehabilitation costs for 90-120 days is $60,365, and extended rehabilitation costs for an average of 15 months is

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[43] See Arnold Birenbaum and Dorothy Guyot, Reality and Policy in the Health Care of Developmentally Disabled Children and Young Adults, American Association on Mental Retardation, forthcoming monograph.

[44] Tom E. Stripling, "The Economic Consequences of Spinal Cord Injury", Research Brief No. 3, Paralyzed Veterans of America, Washington, D.C., April 1988.

[45] National Association of Rehabilitation Facilities, A Study Regarding A Prospective Payment System for Medical Inpatient Rehabilitation Services: Final Report, December 1985, p. 47

[46] Rand Corporation, Susan Hosek, et.al., Charges and Outcomes for Rehabilitative Care: Implications for the Prospective Payment System, November 1986

$195,000.[47] These costs do not include the costs of a residential program that might be needed for the remainder of a person's life which could cost between $60,000-$125,000 per year.

Summary:

Part Five has reviewed some of the available national survey data on health care utilization and costs for persons with disabilities. There are numbers which show that health care utilization and costs range anywhere from nine to two times greater for persons with the most severe limitations than for persons without limitation. The size of the difference seems to vary with the nature of the health care indicator, the severity of the activity limitation, and the age of the group. While the data on average levels of service utilization is usually presented by level of disability, this has the effect of greatly exaggerating the health care needs of the majority of persons with disabilities and underestimating the health care needs of a minority of high health care users. National survey data can also be misleading by ignoring the non-acute health related services (such as describe in Part Three) which health insurance has traditionally not covered. In addition, average health care utilization figures provde no basis for estimating the impact of "preventable" medical complications which could be eliminated by appropriate health care delivery.

Instead of relying on average levels of service utilization by level of limitation, greater attention should be given to the large percentage of persons with severe chronic conditions whose acute health care needs are largely comparable to the health care needs of so-called standard risk persons. Some of this information will become available in the soon to be released National Medical Expenditure Survey (1987). However, there are inherent limitations in relying on data from a representative sample of the U.S. population in measuring the health care needs of low prevalence groups such as persons with disabilities or chronic illness. In order to get beyond generalizations about the high utilization of acute health care by persons with disabilities, it is necessary to begin examining variations in utilization and costs among a sufficiently large number of persons with specific chronic conditions. What is needed are studies of health care costs and utilization patterns for persons with specific chronic conditions based on different age groups and ages of onset.

Among some of the important data sources that could be used for this purpose are the claims experience of private insurers, the Health Care Financing Administration data on SSDI and recipients, new purposive surveys of a representative sample of persons with specific chronic conditions, and data from health care providers.

CONCLUSION

This policy bulletin has focused on measuring the health insurance needs of persons with severe chronic conditions. The objective was to examine the health insurance status of persons with disabilities and to consider the adequacy of health insurance to meet the range of health related needs of persons with severe chronic conditions. An emphasis was placed on the methodology of examining the health insurance status and health care needs of persons with severe chronic conditions in order to assist federal and state policy makers, service providers, and consumer advocates to interprete current data and plan additional research to more adequately document the nature of the problem and to design appropriate solutions.

Most people with disabilities have some form of health insurance. Of the 37 million persons who are uninsured in the United States, the percentage who are disabled probably does not exceed 3-4 million persons. Many of these persons are working-age persons who are neither employed nor on SSI or SSDI, persons who are working part-time, self-employed, or working for small employers, and disabled workers receiving SSDI during the required two year waiting period for Medicare. In addition, children (with and without disabilities) are often uninsured when their parents are employed in low wage jobs which do not provide employee health insurance or family coverage.

While uninsurance is a major problem for a small percentage of persons with disabilities, a large

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[47] National Head Injury Foundation Insurance Committee, Traumatic Head Injury: A Review of Gaps and Problems in Insurance Coverages, Framingham, Mass., February 1988, p. 3

percentage of persons with severe chronic conditions face the problem of under-insurance. For persons with disabilities or chronic illness, the problem of under-insurance reflects the fact that health insurance was historically developed in the U.S. to finance acute medical care but has not been extended to outpatient rehabilitation, or on-going maintenance services which are necessitated by severe chronic conditions. This failure to cover chronic conditions imposes a severe burden on many persons with disabilities and chronic illness who do not have access to affordable and adequate services for their health related needs.

The problem of under-insurance is greatly expanding due to two major factors. One is the growing need for long term support services as the population ages with greater susceptibility to chronic conditions, and as medical and other technological advances have increased the survivability of persons who would have previously died. The other significant contributor to the problem of under-insurance is the recent emphasis on cost containment among the major payors of health insurance. The pressures for cost containment among the payors of health care have created new incentives for insurers and health care providers to minimize cost-shifting between high users and low users and have reduced the capacity of health care providers to provide uncompensated care to persons who cannot pay. The emphasis on cost containment by health care payors has also increased cost-shifting to the health care user who now faces higher premiums, deductibles, and co-payments. While these changes in health care financing affect all persons, those with severe chronic conditions are most vulnerable because of their greater health care utilization and their long term support needs. Instead of health care financing policy discriminating *in favor* of persons with special health care needs, public policy allows the health care marketplace to discriminate *against* persons with disabilities or chronic illness. Meanwhile, less than one-third of working-age persons limited in major activity and less than ten percent of children with major activity limitation receive either Medicaid or Medicare.

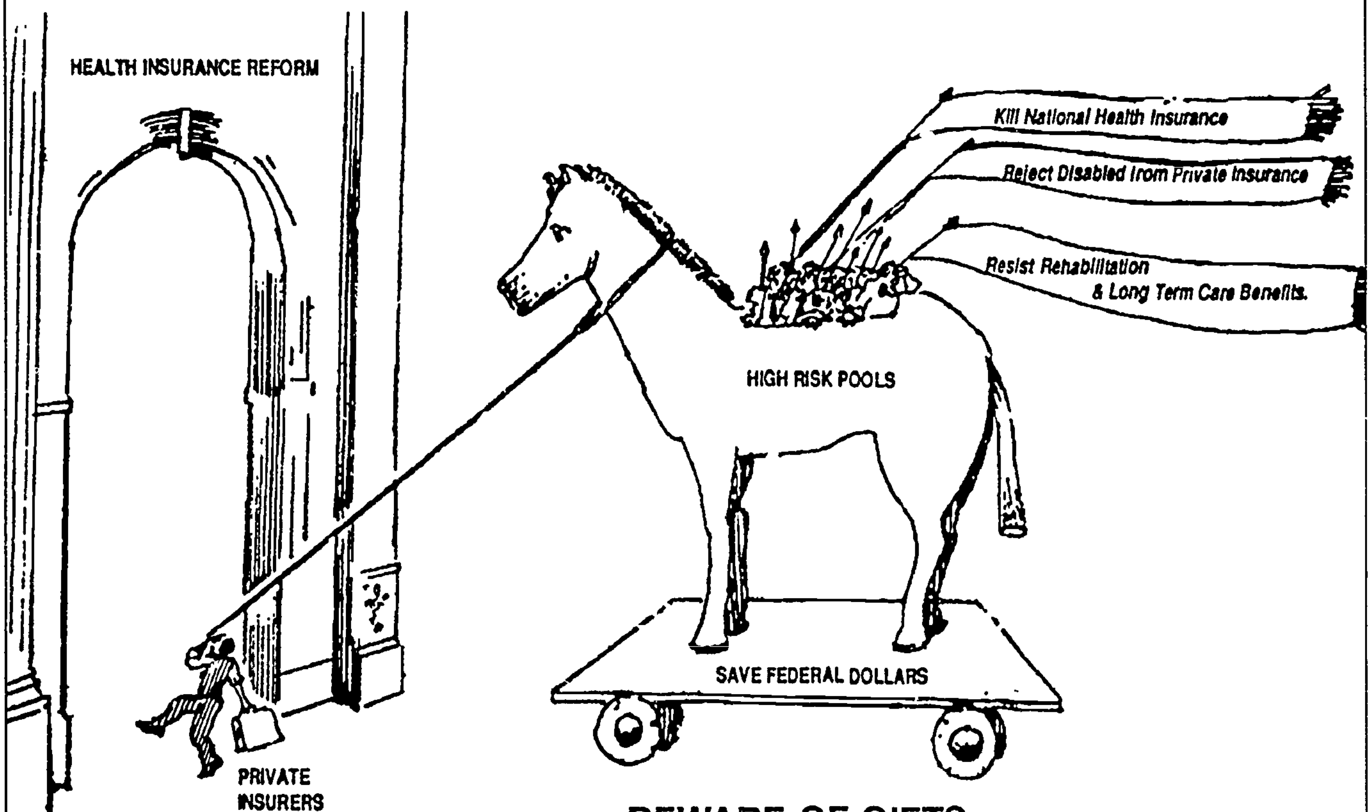
The efficiency, effectiveness, and equity of current health care financing policies are called into question by the failure to control medical costs in the highly fragmented health care system coupled with the increasing number of persons who are uninsured and the growing number of persons who are under-insured. Various legislative and regulatory proposals are being considered at the federal and state levels to modify reimbursement incentives, expand access to appropriate health care, and distribute costs in a more equitable way. Whether people with disabilities and chronic illness will benefit or suffer from these health care financing reforms will depend on our effectiveness in clarifying the special health care needs of persons with severe chronic conditions, and in showing how it is in society's interest to change the way health care is defined and financed in the U.S.

People with disabilities or chronic illness have a unique perspective to contribute to the health care financing debate.In some ways they are in a better position to identify the limitations in current health care financing policy and to generate support to establish precedents for entitlement to health care that other groups can build on. But what is regarded as an appropriate solution to the health care financing crisis depends on how the problem is defined. Some persons with severe chronic conditions view the major problem as one of "actuarial discrimination". If only private insurers could be made to look at true actuarial statistics in the medical underwriting process which take account of recent technological or treatment breakthroughs, then private insurers should be willing and able to sell affordable health insurance to many persons with severe chronic conditions. For others concerned about the range of health-related services which many persons with severe chronic conditions may need, the primary problem is not ending actuarial discrimination but creating a social insurance mechanism which can more equitably distribute the higher costs for appropriately serving the health related needs of all persons including those with severe chronic conditions.

The evolution of health insurance in the U.S. has created certain distinctions between acute care and long term care and between medical necessity and functional necessity. These distinctions serve to limit the liability of insurers and to protect the viability of employment-linked health insurance. One consequence of these distinctions, however, is to limit the pooling of risk among the broadest population for financing many health related services which are needed by persons with severe chronic conditions. As a society, we have to decide whether health insurance or some other financing mechanism is appropriate to ensure that all persons, including persons with severe chronic conditions, have access to affordable and adequate health related services which affect their functional capacity and the quality of their lives as well as their acute medical needs.

While this policy bulletin has focused on the health care needs of persons with disabilities or chronic illness, the next policy bulletin will analyze the historical evolution of the private and public health insurance system in the U.S. and explore its consequences for society. This will lead to an examination of the limitations of both private and public insurance for meeting the health care needs of persons with severe chronic conditions. Against this backdrop, various policy options will be examined at the federal and state levels for bolstering the private system, modifying the current public system, or creating a new public system. These alternatives will be compared in terms of current feasibility and in terms of providing stepping stones toward larger systemic changes. There will always be a creative tension between what incremental changes are perceived as possible within existing constraints and what changes are ultimately necessary in order to ensure access to adequate and affordable health care for all persons who need it.

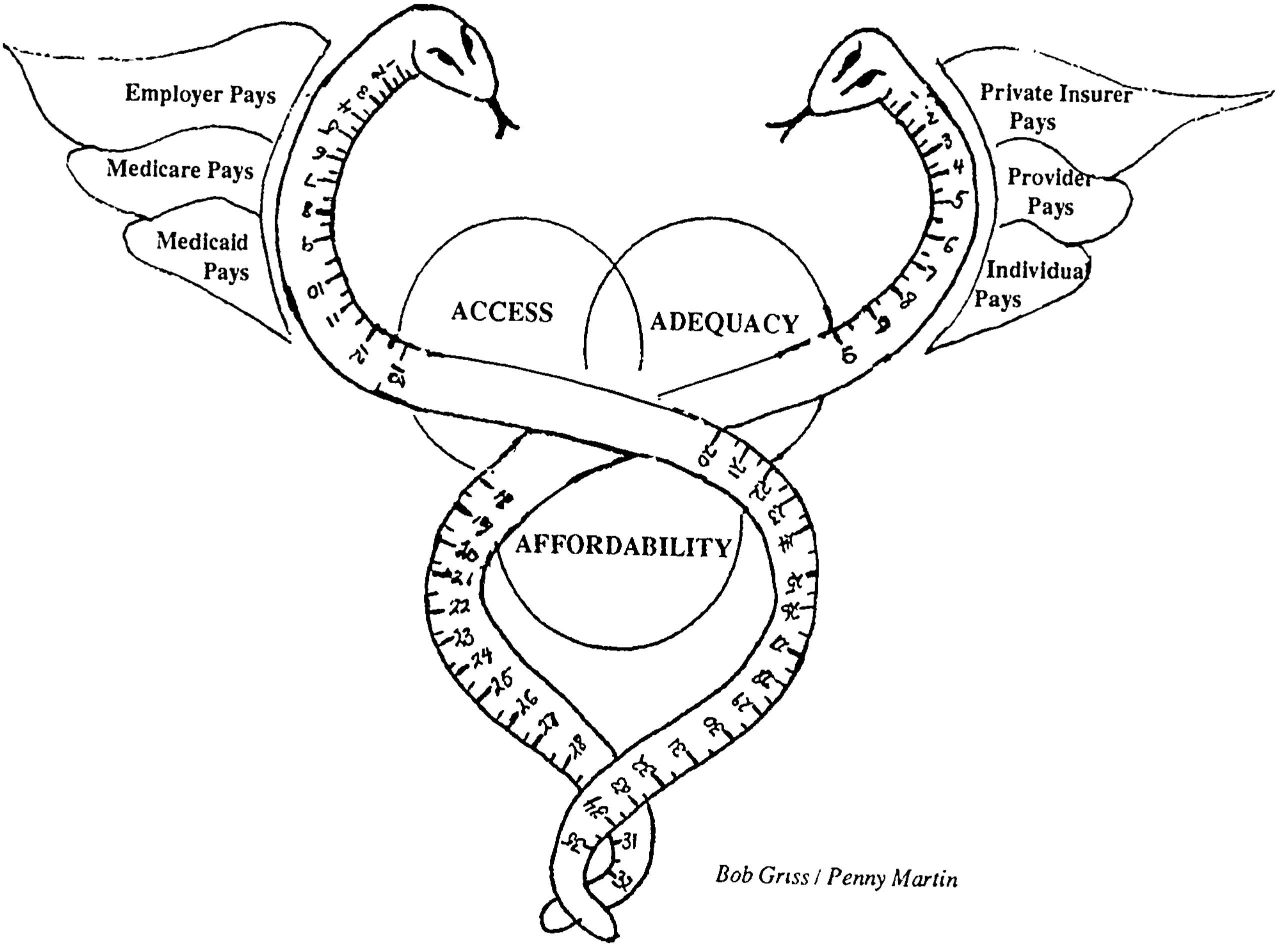
As a preview of the issues to be examined in the next policy bulletin, we will conclude this report with a political cartoon characterizing the policy dilemmas represented by the current momentum for high risk pools.



BEWARE OF GIFTS

"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 service) for everyone who needs it and distribute costs among all citizens on an ability to pay basis."

"Measuring Health Insurance Needs of Persons with Disabilities or Chronic Illness"



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