U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

THE DISABLED:

THEIR HEALTH CARE AND HEALTH INSURANCE

August 1990

Office of the Assistant Secretary for Planning and Evaluation

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The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

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This paper was prepared by the Office of Disability, Aging and Long-Term Care Policy with the U.S. Department of Health and Human Services. For additional information about the study, you may visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP contact was Michele Adler.

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Michele Adler

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Prepared for
Office of the Assistant Secretary for Planning and Evaluation
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I. BACKGROUND

Persons with disabilities are of great policy concern. Many Federal programs--Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Veterans' Disability Pensions, Medicare and Medicaid--provide income support or pay for the medical care of persons with disabilities. Looking only at nonelderly persons with disabilities, $85 billion or about 7.7% of all Federal outlays were spent for programs targeted on disability during fiscal year 1989.

Access to health care is a major concern for all Americans. Access is often perceived simply as coverage by health insurance, but health status and health care utilization are also important components.

Persons with disabilities face unique problems in confronting the health care system and thereby obtaining access to care. For example, while disability is not the same as poor health, persons with disabilities are less likely to work and thus obtain employer-sponsored health insurance. Yet, they generally experience greater risks of poor health and have higher medical utilization and expenditures.

II. PURPOSE

This paper focuses on access to health care issues for persons with disabilities. Specifically, the health status, utilization and cost of services, and health insurance coverage of persons with and without disabilities are described and compared. Three age groups (children, working-age adults, and the elderly) are examined. Finally, information on usual source of care and health expenditures will be presented.

III. SOURCE OF DATA

The primary source of data was the Topical Module on Disability from the 1984 Survey of Income and Program Participation (SIPP). The SIPP, a nationally representative longitudinal survey of the civilian non-institutionalized population, collected data from nine interviews on income, program participation, employment, assets, health insurance, and a variety of other socio-demographic characteristics. The sample included approximately 20,000 households. Other sources include the National Health Interview Survey (NHIS) and the 1977 National Medical Care Expenditure Survey (NMCES). Much of the information in this paper was derived from the final reports of a contract awarded by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services (DHHS) to Mathematica Policy Research, Inc. and SysteMetrics/McGraw-Hill.

IV. DEFINITION OF DISABILITY

Definitions of disability differ so much that the number of disabled persons ranges widely. Disability may be defined: functionally, programmatically (receipt of benefits from disability programs, such as SSDI), or epidemiologically (the presence of a certain disease or impairment, such as mental illness or AIDS). The SIPP data were chosen as the primary source of data, because both functional and programmatic measures could be derived and all ages were included.

Functional disability, the most widely used measure, is the one primarily employed in this paper. Functional disability is a measure of how well an individual can perform certain activities suitable for his or her own age and can be defined as either difficulty with or the complete inability to perform these activities. These activities include: playing for children under age 6, attending school for children aged 6 to 17, working or keeping house for persons aged 18-64, and carrying out basic life activities necessary for living independently for persons aged 65 or over.

Using the broadest measure of functional disability, there were 39 million persons with disabilities--or 17% of the population--residing in the community according to the 1984 SIPP. This included 2 million children, 24 million working-age adults, and 15 million elderly.

Six mutually exclusive levels of functional disability are used for adults. Level I is the most severe and Level VI the least. The functions used to define disability are the activities of daily living (ADLs), instrumental activities of daily living (IADLs), sensory impairments, and three activities (lifting 10 lbs., walking three city blocks, and climbing a flight of stairs), which indicate how well overall physical body systems work.

Level I disability is the inability to perform basic life activities or ADLs without the help of another person. These ADLs are: getting around inside the house, walking, getting in and out of bed, or personal needs (eating, dressing or undressing, or personal hygiene). In 1984, approximately 2,870,000 non-institutionalized adults or 1.7% had a Level I disability.

Level II disability is the inability to perform IADLs without the help of another person. These IADLs measure the ability to live independently and include: getting around outside the house, doing light housework, and preparing meals. The number of adults with a Level II disability was 4,790,000 or 2.8% of the population.

Level III disability is either an inability to perform more than one of the following activities (seeing, hearing, lifting ten pounds, walking three city blocks, or climbing a flight of stairs) or has difficulty with two ADLs, yet reports no need for assistance from another person. Nearly seven and a half million (7,470,000) adults or 4.4% had a Level III disability.

Level IV disability includes persons with difficulty (but no inability) with two or more of the following activities (seeing, hearing, lifting ten pounds, walking three city blocks, or climbing a flight of stairs). Slightly over eight million (8,090,000) or 4.8% of adults had a Level IV disability.

Level V disability includes persons with difficulty (but no inability) with only one of the following activities (seeing, hearing, lifting 10 lbs., walking 3 city blocks, or climbing a flight of stairs). The number of adults with a Level V disability was 13,917,000 or 8.2%.

Level VI disability includes persons who have no limitations at all in functioning. The largest group was Level VI, persons with no disabilities: 132,524,000 or 78.1%.

Children's disability was defined in SIPP to include those (under age 18) who either had: a long-lasting physical condition which limited the ability to walk, run, or play or a long-lasting mental or emotional condition, which limited the ability to learn or perform regular schoolwork. There 2,326,000 children with disabilities, representing 3.7% of all children.

V. AGE AND DISABILITY

Most disabled persons are under age 65 and are in their working years. According to the 1984 SIPP, there were over 24 million persons (including 2 million children) with disabilities in the civilian non-institutionalized population compared to 15 million aged persons.

However, older people are more likely to have a disability and that disability is more likely to be severe. The risk of disability increases sharply with age. Thus, the prevalence of disability is highest for the elderly--58.8 per 100 are reported as disabled, lower for working-age adults--15.1 per 100, and lowest for children--3.7 per 100.

Nearly 8 million civilian non-institutionalized adults (7,66,000) have the most severe levels of disabilities (SIPP Levels I and II defined as needing help from another person in order to perform ADLs or IADLs). This figure includes 3,178,000 working-age adults (18-64) and 4,482,000 elderly persons. The prevalence rates for the most severe disabilities are much higher for the aged: 17.1 per 100 compared to 1.5 per 100 for non-aged persons.

VI. WORKING-AGE ADULTS

A. Causes of Disability

Disability can be attributed to one or more of many chronic medical conditions, that is those which have been present for at least 90 days. Many of these conditions are rare. Therefore, the disabled working-age population is made up of people in numerous smaller groups, (i.e. spinal cord injuries, the mentally retarded), each of which has different medical conditions and, thus, vastly different health care needs.

According to the 1983-86 NHIS, of the 62 specific health conditions or groups of health conditions, the five most common conditions responsible for any degree of work limitation are, in order: (1) mental retardation, (2) absence of leg(s), (3) lung or bronchial cancer, (4) blindness in both eyes, and (5) multiple sclerosis. The five leading causes of a complete inability to work are: (1) lung or bronchial cancer, (2) blindness in both eyes, (3) absence of leg(s), (4) mental retardation, and (5) cerebral palsy. (LaPlante)

B. Health Status and Utilization

Ill health is an uncommon occurrence among working-age people. Only 5.5% or one in twenty persons with no disabilities report themselves as having fair or poor health. However, half (49.5%) of working-age adults with disabilities rate their own health as fair or poor. Furthermore, three out of four persons with Levels I and II disabilities aged 18-64 rate their health status as fair or poor. (Table 1)

Perceived health status (excellent, very good, good, fair, or poor) is subjective, but nevertheless over the years been shown to be associated with high medical utilization and cost and to be a good predictor of major health events (i.e. entering an institution or death).

The number of days spent in bed is also higher for disabled persons. During the last four months, persons with no disabilities spent an average of one day in bed compared to over a week (7.8 days) for persons with disabilities and nearly four weeks (25.6 days) for persons with Levels I and II disabilities.

Persons with disabilities are heavy users of medical care. The average number of doctor visits during the past year was 2.6 for persons with no disabilities, 7.6 for persons with Levels I through V disabilities, and 13.6 for persons with Levels I and II disabilities.

While almost 10% of persons without disabilities were hospitalized during the previous year, the figure was 21.8% for persons with Levels I through V disabilities, and 36.1% for those with Levels I and II disabilities. Time spent in the hospital was also higher for those with disabilities: persons with no disabilities spent an average of 0.6

days in the hospital compared to 3.2 days for those with disabilities, and 8.4 for those with Levels I and II disabilities.

C. Health Insurance Coverage of Working-Age Adults

There are no real differences in the proportion of persons without health insurance among the disabled and the nondisabled. However, sources of insurance vary greatly. The vast majority of persons under age 65, particularly those with no disabilities, have private insurance typically through their own or a spouse's employer. Disabled working-age adults are just as likely to be married as those with no disabilities, regardless of the severity of their disability: 57% of adults with Levels I and II disabilities are married and live with their spouse compared to 61% of persons with no disabilities. (Table 2)

Four out of five (80.2%) of those with no disabilities receive insurance only from private sources, while only 4% receive coverage from public plans, such as Medicare and Medicaid. The remaining 15.8% are uninsured. Health insurance coverage patterns change from almost all private to a mix of public and private, as the level of disability becomes more severe. Two-thirds (66.3%) of persons with Levels I through V disabilities receive health insurance from private sources, one in five (20.7%) have some type of public coverage, and 18.6% are uninsured. Slightly over half (55.5%) of persons with Levels I and II disabilities have private coverage and 44.1% have public coverage (almost evenly spilt between Medicare at 24.7% and Medicaid at 26.1%). Another 14.1% are uninsured.

Public coverage through Medicare and Medicaid is subject to strict eligibility criteria for nonelderly adults. Medicare is offered to persons who have received benefits from the Social Security Disability Insurance program (SSDI) after a 24-month waiting period has been satisfied. SSDI benefits are paid to non-elderly persons who meet the Social Security Administration's (SSA) strict disability criteria and who are insured workers with a certain number of SSA covered quarters. Dependent coverage is also provided to disabled widows/widowers over age 50 and to adults disabled in childhood one of whom's parents are either a retired, disabled, or deceased worker insured under SSA. About 3 million disabled persons under age 65 receive Medicare under these circumstances.

Medicaid eligibility depends on low-income and is automatically extended to persons who receive AFDC payments and in most instances, for those who receive disability payments from the Supplemental Security Income (SSI) program. The SSI disability criteria are identical to those used for SSDI. Over the years, Medicaid eligibility has been gradually extended to other low-income persons who do not necessarily receive either AFDC or SSI. In 1989, approximately 3.6 million persons were entitled to Medicaid on the basis of their disability.

VII. THE ELDERLY

A. Causes of Disability

Causes of disability change in later life. Prevalence rates for certain chronic conditions rise with age, particularly for those conditions which are not life-threatening, such as rheumatoid arthritis. However, conditions with onset in childhood, such as mental retardation, or those which first occur in early adulthood (multiple sclerosis) are overshadowed by those which develop during later life.

The five leading causes of limitation of activity for the aged are: (1) absence of leg or legs; (2) lung or bronchial cancer; (3) rheumatoid arthritis; (4) blindness in both eyes; and, (5) partial paralysis in extremity. Similarly, the five leading causes of need for help with ADLs in the non-institutionalized elderly population are: (1) absence of leg or legs; (2) blindness in both eyes; (3) lung or bronchial cancer; (4) partial paralysis in extremities; and, (5) other orthopedic impairments. (LaPlante)

B. Health Status and Utilization

Many elderly are in good health and are not high users of medical care, but this changes with the level of disability. The proportion of aged persons with self-perceived fair or poor health increases rapidly with the severity of disability. Whereas, only one in six (18.3%) of those with no disabilities are in fair or poor health, nearly two in three (65.1%) of those with disabilities, and over four in five (82.7%) of those with Levels I and II disabilities describe their health in this way. (Table 3)

Bed-disability days are also highest for those with the most severe disabilities. Elderly persons with no disabilities spent only an average of 1.1 days in bed during the last four months, compared to 10 days for those with disabilities, and 24.6 days for those with Levels I and II disabilities.

Utilization patterns for the elderly are similar to those for the non-elderly, with persons with no disabilities having the lowest utilization and those with Levels I and II disabilities the highest. Non-disabled elderly persons averaged 3.54 physician visits during the past year compared to 6.9 visits for disabled persons, and 9.7 visits for those with Levels I and II disabilities.

The proportion with a hospital stay during the past year was also lowest for the non-disabled (14%), next highest for all disabled (27%), and highest of all for those with Levels I and II disabilities (40.5%). The average number of days spent in the hospital ranged from 1 day for the non-disabled to 4.5 days for all disabled to 9.1 days for those with Levels I and II disabilities.

C. Health Insurance Coverage

The elderly are almost universally covered by Medicare, which is provided to retired workers who were covered by Social Security. Over 97% of aged persons are enrolled on Medicare, regardless of their disability. Many aged persons also have private insurance, either through their former employers or purchased privately to pay for care not covered by Medicare. This is often referred to as "Medigap" coverage. The proportion of the aged with Medicare and private insurance is higher for persons with no disabilities (77.9%) than for those with disabilities (64.7%) or those with Levels I and II disabilities (55%). This may be because elderly persons with the most severe disabilities are more likely to be covered by Medicaid, which typically picks up expenses not covered by Medicare. (Table 4)

Low-income elderly who receive benefits from SSI are also usually entitled to Medicaid, depending on State rules. SSI payments are made to low-income elderly and to the low-income blind or disabled under age 65. As for the non-elderly, Medicaid eligibility can also be extended through State "medically needy" programs. Medicaid coverage is lowest for persons with no disabilities (3.5%), and highest for those with Levels I and II disabilities (19.2%).

VIII. CHILDREN

A. Causes of Disability

Conditions which pose the greatest risks for childhood disability differ from those which occur in adults. The five leading causes of major activity limitation in children are: (1) mental retardation; (2) cerebral palsy; (3) speech impairments; (4) epilepsy; and, (5) other selected impairments (mostly spina bifida and cleft palate). Eighty-seven percent of children with mental retardation and 74% of children with cerebral palsy are limited in their major activities. (LaPlante)

B. Health Status and Utilization

Most children are very healthy. However, disabled children are much heavier users of medical care. Table 5 shows comparisons between children with no limitation in activity, those with some limitation, and those with a limitation in their major activity.

Nearly half (49.5%) of children with no limitations spent not a single day in bed for health reasons. However, only one in five (20.3% of those with a limitation and 18.4% with a major limitation) stayed out of bed during the past year. Disabled children are also much more likely to spend many days in bed. Only one in fourteen (6.9%) of children who were not limited stayed in bed at least a week compared to one in three (31.7%) of those with a limitation and two in three (65.3%) with a major limitation. Looking at children who spent at least a month in bed, only one in 200 (0.5%)

nonlimited children spent this much time in bed compared to one in twelve (7.7%) of those with limitations and one in three (32.6%) of those with a major limitation.

The average number of physician visits is much greater for children with a limitation (7.7 visits) and those with a major limitation (14.2 visits) than for those with no limitations (2.7 visits).

The greater the severity of the limitation, the more likely children are to be hospitalized and the higher the number of stays. Only one in ten (10.9%) of children with no limitations had at least two hospital stays during the past year compared to 38.8% of those with a limitation and 65.5% of those with a major limitation.

C. Health Insurance Coverage

Little difference exists between the proportion of disabled children who have no health insurance (16.6%) and nondisabled children (17.3%). Altogether, 10.4 million children with no disabilities and nearly 400 thousand disabled children are uninsured. (Table 6)

The proportion of children who have private health insurance coverage is not also very different for the disabled and the nondisabled (65% versus 71.2%, respectively).

However, children with disabilities are more likely to be on Medicaid than those with no disabilities: 23.1% of disabled children have Medicaid either by itself or in conjunction with private coverage compared to 12.6% of nondisabled children. Most children are enrolled on Medicaid, because their families receive AFDC. However, low-income children who receive SSI, because of their own disability by meeting SSA's disability criteria and income and asset restrictions, are usually also entitled to Medicaid. Children can be enrolled on Medicaid through State specific "medically needy" provisions. Like adults, Medicaid eligibility has been gradually extended to low-income persons who do not necessarily receive AFDC or SSI.

IX. USUAL SOURCE OF CARE AND EXPENDITURES

Another measure of access to care is the existence of a usual source of medical care and the setting in which care is received. According to the 1977 National Medical Care Expenditure Survey (NMCES), persons who have a limitation of activity are slightly less likely to have no usual source of care (9%) than those who are not limited (15.1%). The settings where usual care is received are also not much different for persons who are limited and those who have a limitation.

X. MEDICAL EXPENDITURES

The SIPP and NHIS data consistently indicate that disabled persons (of any age) have more medical utilization than those who have no disabilities or limitations. Table 7, derived from the 1977 NMCES, underscores these utilization patterns for many types of services and also includes information on expenditures. Not only are utilization rates higher for limited than for nonlimited persons, but the average (mean) expense per medical event is also higher for every type of service presented. The mean expense per hospital stay is 25% higher for limited than for unlimited persons, ambulatory physician visits are 10% higher, prescribed medicines are 10% higher, and the purchase or rental of medical equipment or supplies is 81% higher.

XI. SUMMARY

There are so many diverse causes of disability that it is difficult to think of persons with disabilities as one group. Yet, even so, some general patterns emerge. Regardless of age, the entire health care experience of persons with disabilities is different than for those with no disabilities. Furthermore, the more severe the disability, the more different health care becomes.

There are marked differences in health status, whether measured by bed-disability days or self-perceived health status, with persons with disabilities far more likely to be in fair or poor health and to spend more time in bed than those with no disabilities.

Similar patterns are seen for medical care utilization with disabled persons having more physician visits and more and longer hospital stays than those who are not disabled.

There are no real differences in health insurance coverage between the disabled and the nondisabled, but the source of coverage varies, particularly for the nonelderly. Whereas, most nonelderly persons with no disabilities receive health insurance from private (usually employer-based) sources, nonelderly persons with disabilities receive a mix of private and public coverage. The existence of a usual source of care does not vary much by disability.

Health care expenditures are expected to be higher for the disabled than for the nondisabled, because of their higher utilization rates. However, the mean expense per event for all types of services available are also higher for the disabled than for the nondisabled.

XII. SOURCES

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TABLE 1: HEALTH STATUS AND UTILIZATION BY LEVEL OF DISABILITY FOR AGES 18 TO 64

	Not Disabled (Level VI)	All Disabled (Levels I-V)	Needs Help of Another Person with ADL/IADL (Levels I & II)
Total Population (thousands)	121,676	21,680	3,178
Percent with Fair or Poor Health	5.5%	49.5%	75.4%
Average Number of Bed Days in Last 4 Months	1 day	7.8 days	25.6 days
Average Number of Physician Visits in Past Year	2.6 visits	7.6 visits	13.6 visits
Percent with Hospital Stay in Past Year	9.9%	21.5%	36.2%
Average Number of Hospital Days in Past Year	0.6 days	3.2 days	8.4 days
Average Number of Hospital Stays in Past Year	0.1 stays	0.4 stays	0.8 stays
SOURCE: Thornton and Doyle, October 1989.			

TABLE 2: HEALTH INSURANCE COVERAGE BY LEVEL OF DISABILITY FOR AGES 18 TO 64			
	Not Disabled (Level VI)	**All Disabled (Levels I-V)**	**Needs Help of Another Person with ADL/IADL (Levels I & II)**
Private Coverage	80.9%	66.3%	55.5%
• Private Only	80.2	60.7	41.7
• Private and Public	0.7	5.6	13.8
Public Coverage	4.0	20.7	44.1
• Public Only	3.3	15.1	30.4
• Medicare	***	9.4	24.7
• Medicaid	3.7	13.3	26.1
No Insurance	15.8	18.6	14.1
SOURCE: Thornton and Doyle, October 1989.			

TABLE 3: HEALTH STATUS AND UTILIZATION BY LEVEL OF DISABILITY FOR AGES 65+: 1984			
	Not Disabled (Level VI)	**All Disabled (Levels I-V)**	**Needs Help of Another Person with ADL/IADL (Levels I & II)**
Total Population (thousands)	10,848	15,466	4,482
Percent with Fair or Poor Health	18.3%	65.1%	82.7%
Average Number of Bed Days in Last 4 Months	1.1 days	10 days	24.6 days
Average Number of Physician Visits in Past Year	3.4 visits	6.9 visits	9.7 visits
Percent with Hospital Stay in Past Year	14.0%	27.0%	40.5%
Average Number of Hospital Days in Past Year	1 day	4.5 days	9.1 days
Average Number of Hospital Stays in Past Year	0.1 stays	0.5 stays	0.8 stays
SOURCE: Thornton and Doyle, October 1989.			

TABLE 4: HEALTH INSURANCE COVERAGE BY LEVEL OF DISABILITY FOR AGES 65+: 1984			
	Not Disabled (Level VI)	**All Disabled (Levels I-V)**	**Needs Help of Another Person with ADL/IADL (Levels I & II)**
Total Population (thousands)	10,848	15,466	4,482
Medicare Coverage	97.7%	97.7%	97.3%
• Medicare Only	16.7	21.8	24.3
• Medicare & Medicaid	2.6	9.3	15.1
• Medicare & Private	77.9	64.7	55.0
• Medicare, Medicaid & Private	0.5*	1.9	2.9
Medicaid Total	3.5	12.1	19.2
Private Only	1.6	0.7	0.6*
No Insurance	0.3*	0.7	0.9*
SOURCE: Thornton and Doyle, October 1989.			

TABLE 5: HEALTH STATUS AND UTILIZATION BY LEVEL OF DISABILITY FOR CHILDREN: 1981			
	Not Limited	**Limitation of Activity**	**Unable to Perform Major Activity**
Bed Days			
Percent with No Bed Days in Past Year	49.7%	20.3%	18.4%
Percent with More than a Week in Past Year	6.9	31.7	65.3
Percent with More than a Month in Past Year*	0.5	7.7	32.6
Physician Visits			
Average Number in Past Year	2.7 visits	7.7 visits	14.2 visits
Hospital Stays			
Percent with No Stays in Past Year	66.6	35.8	16.2
Percent with 1 Stay in Past Year	22.5	25.4	18.3
Percent with 2+ Stays in Past Year	10.9	38.8	65.5
SOURCE: Human Services Research Institute, December 1985.			

TABLE 6: Health Insurance Coverage by Level of Disability for Children: 1984		
	Not Disabled	**Disabled**
Private Coverage	71.2%	65.0%
• Private Only	70.2	60.4
• Private and Medicaid	1.1	4.6
Medicaid Only	11.5	18.5
No Insurance	17.3	16.6
SOURCE: Thornton and Doyle, October 1989.		

TABLE 7: UTILIZATION AND ANNUAL EXPENDITURES (IN 1977 DOLLARS) FOR PERSONS WITH LIMITATIONS OF ACTIVITY DUE TO CHRONIC HEALTH CONDITIONS: 1977			
	Mean Number of Events Per User	**Mean Expense**	**Mean Expense Per Event**
Hospital Admissions			
Not Limited	5.6 stays	$1,386	$247.50
Limited	9.7 stays	$2,998	$309.07
Ambulatory Physician Contacts			
Not Limited	4.8 visits	$120	$25.00
Limited	9.2 visits	$253	$27.50
Prescribed Medicines			
Not Limited	5.7 med.	$34	$5.96
Limited	16.6 med.	$109	$6.57
Purchase/Rental of Medical Equipment or Supplies			
Not Limited	1.4 p/r	$50	$35.71
Limited	1.7 p/r	$110	$64.71
Nonphysician Health Care Personnel Contacts			
Not Limited	4.2 visits	N/A	N/A
Limited	7.5 visits	N/A	N/A
SOURCE: Berk, Cafferata, Hagan, October 1984.			