FACT SHEET

MEDICAID AND LONG-TERM CARE FOR OLDER PEOPLE

Introduction

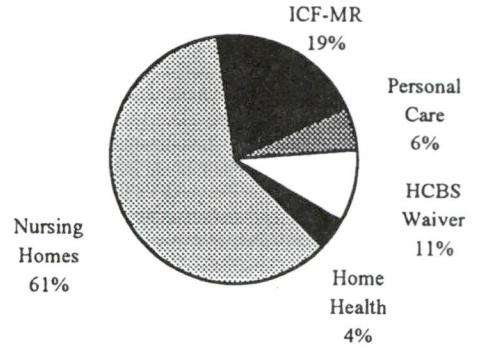
The Medicaid program was designed to provide coverage for health care and nursing home services to the poor. Today, one-third of all Medicaid spending pays for long-term care, making Medicaid our nation's largest source of payment for long-term care services. Medicaid funding is shared between federal and state governments and, consistent with federal law, each state has flexibility in designing and administering its Medicaid program.

Medicaid's role in providing coverage for long-term care is critically important to older people with disabilities, since Medicare -- the nearly universal source of acute health care coverage for people age 65 and older -- covers few long-term care services.

Services

Each state's Medicaid program *must* pay for nursing home care for eligible persons age 21 and older. Medicaid is also required to pay for home health services for individuals who would qualify for nursing facility coverage. Home health services include skilled nursing and, at state option, a number of therapies. State Medicaid programs have the *option* of covering other long-term care services that can include personal care (help with daily activities such as bathing and dressing and related household help), Intermediate Care Facilities for the Mentally Retarded (ICF/MR), and home and community-based services (HCBS) under a "waiver" of federal Medicaid rules. Using the Medicaid waiver option, states provide a range of home care services, which may include personal care, transportation, respite care, homemaker, chore, and other related services.

Figure 1
Medicaid Expenditures for LTC Services, 1996*
(Total Expenditures = $51.3 billion)



Source: HCFA-64 Medicaid Statistics Report, FY 1996.
* Percentages do not add to 100 percent due to rounding.

Eligibility

In general, individuals must meet strict income and asset rules to be eligible for Medicaid. In most states, aged or disabled adults who are eligible for Supplemental Security Income (SSI) are also eligible for Medicaid. In 1998, the federal SSI limits for individuals are $494 per month in countable income and no more than $2,000 in countable assets.

Special *income* eligibility rules pertain to persons who receive Medicaid long-term care services in a nursing home or through a waiver program. Individuals whose income is not adequate to cover their health and long-term care costs can usually qualify for these long-term care services, even if their income exceeds the SSI standard. To qualify, however, individuals must contribute nearly all their income to pay for their care.

In addition to meeting financial eligibility criteria, such individuals must meet the state's *functional* eligibility criteria to receive Medicaid-covered long-term care services. These criteria vary across the states, but generally include both health status and physical and cognitive functioning.

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Preventing Spousal Impoverishment

Special income eligibility rules pertain to nursing home residents whose spouses reside in the community. To prevent the high cost of long-term care from impoverishing the spouses of nursing home residents, Congress enacted special laws that *require* states to protect the income and assets of community-dwelling spouses. In 1998, each state must allow a spouse to retain $1,326 per month (this amount will increase to $1,357 in July 1998), and states *may* allow a spouse to protect as much as $2,019 per month. In addition, states must allow the spouse to retain the *greater* of $16,152 in assets or half the couple's joint assets up to $80,760. States are allowed to apply these rules to the spouses of individuals who receive home and community-based services under a "waiver," but not all states exercise this option.

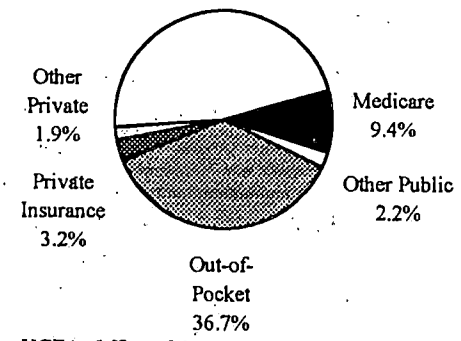
Medicaid Spending

In 1996, the Medicaid program spent $51.3 billion paying for long-term care. Of this amount, $40.8 billion (80 percent) paid for institutional care and $10.5 billion (20 percent) paid for home and community-based care. **Figure 1** illustrates Medicaid long-term care expenditures, by type of service.

These expenditures make Medicaid the single largest payer of long-term care services in the U.S., paying for nearly half (46.5 percent) of nursing home costs in 1995. **Figure 2** illustrates the sources of payment for *nursing home care* in the U.S.

Because the average cost of care in a nursing home was about $46,000 per year in 1995, most people who need extended nursing home care rely on Medicaid for at least a portion of the cost of their care. About one-third of people who enter a nursing home are eligible for Medicaid upon admission, while another third deplete their assets paying for care and then turn to Medicaid to pay for the portion of care that exceeds their income.

Figure 2
Sources of Nursing Home Payments, 1995



Source: HCFA, Office of the Actuary, 1996.
*Percentages do not add to 100 percent due to rounding.

Issues and Concerns

Although the majority of people who need long-term care prefer to remain at home, Medicaid spending for long-term care remains heavily weighted toward institutional care. States have been working to provide more services in home and community-based settings; however, progress has been slow. Medicaid provided nursing home services to 1.7 million persons in 1995, while home and community-based waiver programs served approximately 500,000 individuals.

Secondly, because Medicaid was designed as a program for the poor, its eligibility criteria are quite restrictive. Many individuals must deplete their life savings before they can qualify for Medicaid to cover the cost of the care they continue to need.

Finally, some policymakers are concerned that individuals attempt to "game the system" by sheltering or giving away their assets to qualify for Medicaid. Recent laws have attempted to eliminate this practice.

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FACT SHEET

LONG-TERM CARE INSURANCE AND THE NEW TAX LAW

Background

Few older persons have private insurance that covers the cost of *long-term care*. Many common long-term care needs (e.g., bathing, dressing, and household chores) do not require skilled help and, therefore, are not generally covered by private health insurance policies or Medicare. But, without private insurance or public program coverage, the high cost of long-term care is unaffordable for most Americans. In 1995, the average cost of a nursing home was about $46,000 per year.

As an alternative to public program coverage and direct payments for services, a market for private long-term care insurance has developed, and grown, in recent years. Its overall role is still limited, however; private long-term care insurance currently pays for less than 6 percent of all long-term care costs.

This fact sheet briefly describes the characteristics and costs of private long-term care insurance policies and the tax consequences resulting from recent legislative and regulatory changes.

Private Long-term Care Insurance Policies

As of 1995, 4.4 million long-term care insurance policies were sold in the U.S. Most policies sold today include coverage of services received in nursing homes and at home. Typically, policies reimburse the insured for long-term care expenses up to a fixed amount, such as $100 per day for nursing home care and $50 per day for home care. To receive benefits, however, the insured must meet the policy's disability criteria. For example, some policies require the individual to be severely cognitively impaired or to need help in performing two "activities of daily living" (such as bathing and dressing). Other policies will pay benefits based on the loosely defined term "medical necessity." The stringency of a policy's "benefit triggers" affects an individual's ability to collect benefits.

The Cost of Long-term Care Insurance

Private long-term care insurance is fundamentally different from many other types of insurance. While health and life insurance policy premiums generally increase with age, most long-term care insurance policies offer the purchaser a premium that will not increase as a result of individual circumstances, such as age or health condition. Insurance companies can, however, increase premiums for entire *classes* of individuals (e.g., all policyholders age 75 and older) based on their experience in paying benefits. Yet any premium increase can make the cost of coverage unaffordable for some consumers.

Other factors that affect the policy's premium include the duration of benefits (e.g., years of coverage), the length of any waiting period before benefits are paid, the stringency of benefit triggers, whether policyholders can retain a partial benefit if they let their policy lapse ("nonforfeiture benefit"), and whether the policy's benefits are adjusted for inflation ("inflation protection"). Inflation protection is an important policy feature because the cost of long-term care has risen rapidly in recent years. An individual who purchases long-term care insurance in his or her 60s may not need benefits for 20 or more years.

Table 1
Average Annual Premium, 1995

Age	Base Plan	With Lifetime 5% Compounded Inflation Protection	With Nonforfeiture Benefit	With Nonforfeiture *and* Lifetime 5% Compounded Inflation Protection
50	$378	$798	$540	$1,124
65	$1,010	$1,881	$1,395	$2,560
79	$4,148	$5,889	$5,676	$8,146

Source: Health Insurance Association of America, 1997.

Without inflation protection, the value of the insurance benefits can be eroded over time.

The cost of long-term care insurance varies dramatically according to the age of the consumer at the time that the policy is purchased, the amount of coverage, and other policy features. **Table 1** illustrates the average annual premium for a policy providing $100 per day for nursing home coverage and $50 per day for home care coverage.

New Tax Law: The Health Insurance Portability and Accountability Act

In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA). The legislation was designed partly to provide favorable tax treatment to "federally qualified" long-term care insurance policies. Policies sold before January 1, 1997, are generally considered to be tax-qualified. Policies sold after December 31, 1996, must meet new standards to be considered qualified. While these standards include a number of consumer protections, they also specify the criteria that a covered individual must meet before any benefits can be paid. In some instances, tax-qualified policies may require an individual to meet disability criteria that are more restrictive than many non-tax-qualified policies.

Individuals who are covered by tax-qualified policies are allowed to deduct their premiums, up to a maximum limit (provided the taxpayer itemizes deductions and has medical costs in excess of 7.5 percent of "adjusted gross income"). **Table 2** illustrates the limits imposed on the deductibility of premiums, which are based on the policyholder's age. HIPAA clarified that benefits received from federally qualified policies will not be considered taxable income to the policyholder.

Although HIPAA addressed the tax rules for qualified policies, the treatment of non-tax-qualified policies is still unclear. As a result, there is disagreement about the relative merits of tax-qualified and non-tax-qualified policies.

Table 2
Limits on the Deductibility of Long-term Care Insurance Premiums, 1997

Age	Maximum Deduction
40 years or under	$200
41-50	$375
51-60	$750
61-70	$2,000
71+	$2,500

Source: Internal Revenue Code Sec. 213(d)(10)(A).

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February 1998

ISSUE BRIEF

DETERMINING COMPARABLE LEVELS OF FUNCTIONAL DISABILITY

Introduction

Long-term care services are used by people who have a wide range of disabilities caused by physical, cognitive, and other mental impairments. In recent years, there has been a growing interest in developing and improving policies and programs to meet the long-term care needs of people with disabilities. A critical issue for policymakers is finding an equitable way to establish eligibility criteria for these programs and benefits.

A desirable social goal is to ensure that people with comparable long-term care needs have equitable access to publicly-supported benefits, regardless of the *type* of disability they have. Yet the diversity of conditions that create a need for long-term care has led to considerable disagreement about what criteria should be used to determine eligibility for long-term care services (Maslow and O'Keeffe, forthcoming). There is agreement that different measures must be used to assess the impairment of people with physical conditions, as opposed to cognitive and other mental conditions. For example, when assessing whether a person is eligible for long-term care benefits, a woman with severe arthritis is asked about her ability to perform physical tasks, such as dressing and climbing stairs. A man with Alzheimer's disease is assessed for his ability to perform cognitive functions, such as remembering where he lives or what medications he takes. There is, however, less agreement about which measures to use, and little research about the comparability of various measures.

Since the Katz index of Activities of Daily Living (ADL) was developed in 1963, it has gained increased acceptance as an accurate measure of physical functioning. National databases, state long-term care programs, insurers who offer private long-term care insurance policies, federal legislation, and a body of research literature routinely use limitations in the ADLs identified by Katz et al. (eating, bathing, dressing, toileting, transferring, and continence) as appropriate proxies for an individual's level of physical impairment. ADLs can also be proxies for an individual's level of cognitive impairment, depending on the wording of the assessment instrument. For example, assessing whether a person requires physical assistance to perform an ADL primarily measures physical impairment. But assessing whether a person needs prompting or cueing to initiate and complete an ADL primarily measures cognitive impairment.

Physical disability can *also* be measured with a scale of Instrumental Activities of Daily Living (IADLs), which was developed by Lawton and Brody in 1969. Their IADLs were designed to capture more complex life activities (Rodgers and Miller 1997), and include light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. IADLs are proxy measures that can also be used to identify individuals with cognitive impairments. While cognitive impairment may lead to limitations in the ability to perform all IADLs, those that are generally considered to be most closely related to cognitive impairment are limitations in a person's ability to manage medications,

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manage finances, or to use the telephone (Spector 1994).

New research by Spector and Fleishman (1998) attempted to develop a *single* scale of functional disability combining ADLs and IADLs. Using a total of 15 ADL and IADL measures, their research found that there is not necessarily a strict hierarchical relationship between IADLs and ADLs. For example, while ADL limitations *generally* capture the smallest percentage of persons with disabilities (indicating the most severe levels of disability), "using the telephone," an IADL, had the third lowest proportion of people with limitations. This finding indicates that an inability to use the telephone could constitute a more severe level of disability than many of the ADL measures. Spector and Fleishman also compared the mean hours of help received by persons with zero to 15 ADL/IADL limitations. Raw counts of five to seven limitations were associated with means of 30 to 36 hours of help per week. They conclude that "using a scale that includes both ADLs and IADLs may enable more precise assessment of the level of functional disability...than using ADLs alone."

Ultimately, the ability to perform both ADLs and IADLs diminishes as physical and cognitive functioning declines. Limitations in ADLs and IADLs are now commonly used to estimate the size of the population with disabilities. ADLs and some IADLs also are used to establish eligibility for public and private long-term care programs, services, and benefits, but there has been little understanding of how *comparable* the disabilities of persons with limitations in IADLs are to persons with limitations in ADLs. The need to find eligibility criteria of *comparable severity* to established ADL or cognitive impairment criteria was addressed during the debate over the long-term care program proposed in the 1994 Health Security Act (HSA). The eligibility criteria originally proposed by the HSA included:

- Individuals who required hands-on or standby assistance, supervision, or cueing to perform three or more ADLs over a period of at least 100 days;
- Individuals with severe cognitive or mental impairments who (for at least 100 days):
  - Attained a score on a standard mental status protocol (appropriate for the person's condition) that indicated severe cognitive or mental impairment, or both;
  - Required hands-on or standby assistance, supervision, or cueing to perform one or more ADL or such number of IADLs related to cognitive or mental impairment, or displayed symptoms of one or more serious behavioral problems that created a need for supervision to prevent harm to self or others;
- Individuals with severe or profound mental retardation; and
- Severely disabled children under age 6 who would otherwise be institutionalized.

During the Congressional debate on this legislation, the Senate Committee on Labor and Human Resources revised these eligibility criteria in two ways:

- Including disabled children under age 6 with severe disabilities or medical conditions that limit functioning "in a manner that is *comparable in severity*" to the other eligibility criteria of the HSA; and

- Allowing states to spend a percentage of their funds "to serve individuals with disabilities of *comparable severity* who fail to meet the eligibility criteria of any single category" (Committee on Labor and Human Resources 1994, emphasis added).

Measures of cognitive impairment included in the HSA were intended to be comparable to its ADL criteria (Jackson and Doty, 1995). Researchers at that time also determined that older persons with at least three out of four IADL limitations (where the four IADLs were medication management, money management, telephoning, and meal preparation) used approximately the same hours of care per week as did people with three or more ADL limitations (Doty, 1998). This standard was not applied to the HSA's eligibility criteria, however, because its implications for persons under age 65 were unclear. Although the HSA was not enacted, refining the eligibility criteria for programs that provide long-term care services and benefits remains an important policy issue.

A new focus on the comparability of different types of disabilities was created with the enactment of the Health Insurance Portability and Accountability Act (HIPAA) in 1996. This law contained several provisions that address long-term care, including standards that long-term care expenses and insurance policies must meet to qualify for favorable federal tax treatment. To take advantage of HIPAA's tax provisions, the definition of a "chronically ill" individual must be met.[1] Tax qualified long-term care insurance policies may only provide benefits to individuals who are chronically ill, and long-term care expenses may be deducted only by chronically ill individuals. The definitions contained in HIPAA are similar to the eligibility criteria used in the HSA (limitation in three out of five ADLs), but are somewhat more liberal in allowing access to benefits by persons who need help with two out of five or six ADLs. The HIPAA definition of a chronically ill individual also includes a "similar severity" standard.[2]

Purpose

The purpose of this paper is to demonstrate what level of disability would constitute a similar, or comparable, severity to the "two ADL" standard established by HIPAA. Such a standard could be used to trigger eligibility for HIPAA's benefits. Specifically, this research seeks to understand what level of ADL and IADL limitation results in long-term care service use that is comparable to the level of services used by individuals who are unable to perform two ADLs without substantial assistance from another person.

Methodology

AARP contracted with The MEDSTAT Group to analyze data from the community-dwelling sample of the 1994 National Long-Term Care Survey (NLTCS), a nationally representative survey of the Medicare population age 65 and over. The research attempted to determine what level of disability is comparable to being unable to perform (without substantial assistance from another individual) two ADLs out of six. These six ADLs -- bathing, dressing, toileting, transferring, eating, and incontinence management -- are used in both HIPAA and the original Katz index. Although HIPAA and the Katz index include "incontinence" as an ADL, for this analysis we selected the more restrictive

category of "incontinence management," because many persons who experience incontinence are able to manage it without assistance from another person.

The NLTCS was selected because it includes data elements that can be used to derive estimates of functional limitation in this population, including the six ADLs specified in HIPAA. Furthermore, the NLTCS included the components needed to operationalize the HIPAA criteria: receipt of hands-on and/or stand-by assistance in ADLs; inability to perform an IADL without human assistance[3]; and a measure of chronicity (90+ days duration) that can be applied to both ADLs and IADLs. Although this analysis conforms to the specific definitions contained in HIPAA, it has broader applicability, given the widespread use of ADL and IADL measures as reliable proxies for disability and the need for long-term care services.

The NLTCS includes data that are crucial to assessing the comparability of alternative functional criteria: hours of care that an individual receives from caregivers, both formal (paid) and informal (unpaid). A focus on hours of care provides an objective and quantifiable method for assessing the comparability of functional disability. It must be noted, however, that the NLTCS contains data only on the population age 65 and older. Thus, the findings of this analysis may not be entirely applicable to service use patterns among younger persons with disabilities.

Step One – Establish Hours of Care

The first step was to establish the total number of hours of care provided by informal and formal helpers to persons in the 1994 NLTCS with two ADL limitations. The hours of care associated with every combination of two ADL limitations were analyzed. Any estimates based on sample sizes below 30 were likely to be statistically unreliable and were excluded from the analysis. Table 1 illustrates the findings of this analysis. It is important to recognize that the *hours of care* received by people with specific ADL limitations pertain not only to help with those ADLs. For example, an individual who is limited in bathing and dressing does not necessarily receive, on average, 36 hours of assistance per week with only those activities. ADLs are simply proxy measures for a person's overall level of functional disability. An individual who is unable to bathe or dress independently is likely to also need help with IADLs and, in addition, may need assistance with both routine and special health care needs.

The analysis then focused on the two-ADL combination associated with the lowest number of hours of care. This combination was bathing and dressing, which was associated with 36 hours of care per week, on average. The rationale for selecting the two-ADL combination with the lowest hours of care is that an individual can meet HIPAA's definition of chronic illness with *any* two of six ADL limitations. One should not, therefore, need to meet a more rigorous standard in demonstrating a disability of "comparable severity." This method of analysis should also be relevant to other policy applications, since the eligibility requirements for long-term care services through Medicaid and other long-term care programs generally specify the *number* of ADL limitations an individual must have to gain program or benefit eligibility, without specifying *which* ADL limitations an individual must have.

Table 1
Hours of Care Per Week Associated with 2 out of 6 ADL Limitations*

Standard Criteria	Mean Number of Hours (Weighted)	Sample Size (Unweighted N)
Any 2 ADLs	39	255
Bathing & Dressing Only	36	71
Bathing & Toileting Only	41	78
Toileting & Transferring Only	39	36

* Mean hours of care have been rounded.
Source: The MEDSTAT Group, based on data from the 1994 National Long-Term Care Survey.

Step Two -- Identify Alternative Eligibility Criteria

The analysis exploring alternative criteria comparable to the two-ADL standard focused on two groups of persons with disabilities:

- Those with one chronic ADL limitation who also have one or more chronic IADL limitations; and
- Those with no chronic ADL limitation who have one or more chronic IADL limitations.

These groups were selected to capture all individuals with IADL limitations who would not be included under a two-ADL criterion. Combining data on individuals with zero or one ADL limitation provided adequate sample sizes for analysis. The analysis considered the eight IADLs that were included in Lawton and Brody's original IADL scale: light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.

The mean hours of care for combinations of *zero or one* ADL and *one through eight* IADLs were calculated, and examined for comparability to the bathing-dressing criteria (i.e., 36 hours per week of care, on average). Table 2 illustrates the results of this analysis: people with zero or one ADL limitation who have five, six, or seven IADL limitations are closest in hours of care used to persons who have ADL limitations in bathing and dressing.

Two ADL/IADL combinations were identified as potential alternative criteria:

- 0-1 ADL and 5(+) IADLs; and
- 0-1 ADL and 6(+) IADLs.

These two criteria were chosen for further analysis since their associated mean hours of care either approached or slightly exceeded the mean care hours associated with the bathing-dressing criteria (i.e., 36 hours). The 7(+) IADL standard was not analyzed further because individuals with this level of limitation would be captured among the population with 5(+) or 6(+) IADLs.

Step Three -- Perform Tests of Statistical Significance

Having identified two potential alternative criteria, the final step was to determine whether the estimates of the mean hours of care used per week by persons in the different ADL and IADL categories were indeed comparable. Thus, a t-test was applied to each alternative

Table 2
Hours of Care Per Week Used by Persons with 0 or 1 ADL Limitation (out of Six) by Number of IADL Limitations (out of Eight)*

Number of IADL Limitations	Mean Hours of Care Per Week (Weighted)	Sample Size (Unweighted N)
1	10	492
2	12	399
3	17	291
4	22	184
5	32	148
6	41	66
7**	32	50
8	73	25

* Mean hours of care have been rounded.
** The mean hours of care received by persons with 7 IADL limitations appear to be lower than the hours of care received by persons with 6 IADL limitations. This counterintuitive finding may be an artifact of relatively small sample sizes.
Source: The MEDSTAT Group, based on data from the 1994 National Long-Term Care Survey.

IADL criterion and the bathing-dressing criterion. This test measures the difference between means (on hours of care) for independent samples.[4] A *non-significant* t value indicates that the mean of the alternative IADL criterion is not statistically different from the mean of the bathing-dressing criterion. In other words, the level of disability, as measured by hours of services used, is *comparable* for the two criteria compared. Conversely, a *significant* t value (greater than 1.96) indicates that the two means are *statistically different*, and therefore not comparable.

Findings

As shown in Table 3, the analysis found that the total hours of care received by individuals with limitations in the ability to bathe and dress is not significantly different from the total hours of care received by individuals who have limitations in zero or one ADL (out of six) who also have limitations in five or six (out of eight) IADLs. As such, individuals who are unable to perform at least five (out of eight) IADLs, whether they have zero or one ADL limitation, can be considered to have a level of disability of "comparable severity" to individuals who are unable to perform two (out of six) ADLs.

Policy Implications and Conclusions

Many legislative proposals to provide long-term care services to persons with disabilities have crafted eligibility criteria based only on limitations in ADLs and limited measures of cognitive impairment. In part, policymakers have focused more attention on ADLs because they are commonly considered to capture more severe levels of disability than do IADLs. Policymakers also are concerned that basing program or benefit eligibility on a limited number of IADL limitations could allow too many individuals into long-term care programs and result in dramatically higher program costs. This concern is based on the higher prevalence of IADL disabilities among older persons. For example, according to the 1994 NLTCS, about 2.3 million older persons are disabled in ADLs, whereas some 4.4

Table 3

T-Tests for Differences in Mean Hours of Care Associated with 2 ADL Criteria and Alternative Eligibility Criteria*

	Limitation in Bathing & Dressing	Limitation in 0-1 ADL & 5 IADLs	Limitation in 0-1 ADL & 6 IADLs
Mean Hours of Care (Weighted)	36	32	41
Standard Error	5.84	2.72	3.90
t-value	----	1.25	-0.97

* Mean hours of care have been rounded.
Source: The MEDSTAT Group, based on data from the 1994 National Long-Term Care Survey.
Results are significant at the $p < .05$ level.

million are disabled in ADLs and/or IADLs.

The findings of this analysis indicate that older persons with significant limitations in five or six IADLs have levels of disability that are comparable to those experienced by people with two or more ADL limitations. By focusing on the hours of care used by people with varying levels of ADL and IADL limitations, this paper presents an objective, measurable standard for comparing the severity of functional disability. While this information should be helpful in developing regulations to implement HIPAA's long-term care provisions, it also could have broader applications. By quantifying the hours of service that are actually used by persons who have five or six IADL limitations and zero or one ADL limitation, this paper demonstrates the importance of including IADL measures in determining program and benefit eligibility. Further research to examine the degree of IADL limitation experienced by individuals with varying levels of ADL limitations would be useful. Additional work in this area could help determine how program and benefit eligibility would be affected by a broader inclusion of IADL criteria.

A substantial number of persons with disabilities are affected by the eligibility criteria used in long-term care programs, services, and benefits. According to estimates from the 1994 NLTCS, 3.0 percent of the Medicare population age 65 and older have severe cognitive impairments. An additional 3.1 percent are disabled in two or more ADLs, and another 1.0 percent meet the zero or one ADL and five or more IADL criteria. This 7.1 percent of the older population with significant disabilities constitutes some 2.2 million individuals. These individuals need access to public programs, private insurance benefits, and other sources of funding to help them pay for their long-term care needs. The responsiveness of public and private policies to the needs of persons with disabilities would be improved by greater attention to the role that IADLs play in functional disability.

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April 1998

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[1] A chronically ill individual is defined by HIPAA as *any individual who has been certified by a licensed health care practitioner as --*

(i) being unable to perform (without substantial assistance from another individual) at least 2 activities of daily living for a period of at least 90 days due to loss of functional capacity,
(ii) having a level of disability similar (as determined under regulations prescribed by the Secretary in consultation with the Secretary of Health and Human Services) to the level of disability described in clause (i), or
(iii) requiring substantial supervision to protect such individuals from threats to health and safety due to severe cognitive impairment.

Interim guidance on interpreting HIPAA, issued by the Treasury Department on May 27, 1997 (Notice 97-31), defined "substantial assistance" as hands-on and standby assistance, which were defined as:

'Hands-on assistance' means the physical assistance of another person without which the individual would be unable to perform the ADL.
'Standby assistance' means the presence of another person within arm's reach of the individual that is necessary to prevent, by physical intervention, injury to the individual while the individual is performing the ADL (such as being ready to catch the individual if the individual falls while getting into or out of the bathtub or shower as part of bathing, or being ready to remove food from the individual's throat if the individual chokes while eating).

[2] Codified in the Internal Revenue Code, Section 7702B(c)(A)(ii).

[3] The NLTCS measures an individual's ability to perform an IADL as follows: respondents are asked if they perform the activity by themselves. If they report that they do *not*, they are asked a follow-up question to find out if they *could* perform the activity if they had to. If they respond *no* to the first question but *yes* to the second question, they are not treated as disabled in the IADL. If they reply *no* to both questions *and* they say the reason they don't perform the activity is due to a disability or health problem, then they are treated as disabled in the IADL. If, however, the reason they do not perform the IADL is *not* due to a disability or health problem, they are not considered disabled in the IADL.

[4] Calculation of the t-test statistic involves the use of standard errors. However, because the 1994 NLTCS is based on a complex sampling frame (not simple random sampling), an adjustment for the design effect of sampling was necessary. Non-adjusted standard errors based on complex samples typically underestimate true variation. The tests reported herein were derived from adjusted standard errors calculated using the SUDAAN software package (Shah, Barnwell, Hunt, & LaVange, 1991).

Friday, March 27, 1998

Lex:

1) Rosemarie Fllart pager: 606-6045; home: 747-5991

2) Arlene Russell (713) 845-2481 I think this is her office number--not the call in number (she checks this number, though).

3) Julie Clay called (520) 523-1340

4) Cindy Lucia 942-6154; home:(713) 667-6671

5) Jerry Andrew: 461-3867, re her daughter Kacky: carcinoid syndrome

6) Paul Terini of RWJ called. (609) 243-5931.

7) Charlene: (415) 476-4030

Ashley
Rosemary / Sutton / Isabell 4/25-26

Expenses:

Printing $731.77
T. Young 398.00
D. Johnson 632.00
FedEx 30 plus x 12.00 = $340 ? (est.)
Gerber 470.08
Kane 496.37
Kupka 542.02
Nadash 302.42

3812.66

1MC032698				MANAGED CARE 305														
LATEST ACCT DATE	12/31/97			ILRU SPREAD SHEET														
LATEST ILRU DATE	03/26/98																	
DESCRIPTION	ACCT JUNE ACTUAL	ACCT JULY ACTUAL	ACCT AUG ACTUAL	ACCT SEPT ACTUAL	ACCT OCT ACTUAL	ACCT NOV ACTUAL	ACCT DEC ACTUAL	ACCT YTD PAID ACTUAL	UNPAID ACTUAL	ILRU JAN F/CAST	ILRU FEB F/CAST	ILRU MAR F/CAST	ILRU APR F/CAST	ILRU MAY F/CAST	YTD PAID + UNPAID + F/CAST	BUDGET	(OV)/UND F/CAST	UNEXPENDED
Salaries	0.00	4,245.16	1,684.92	2,341.41	3,674.01	3,668.95	4,063.71	19,678.16	0.00	5,030.83	5,030.83	5,030.83	5,030.83	5,030.83	44,832.31	59,972.00	15,139.69	40,293.84
Fringe Benefits	0.00	971.38	424.18	390.99	556.96	748.79	997.20	4,089.50	0.00	1,136.66	1,136.66	1,136.66	1,136.66	1,136.66	9,772.80	18,592.00	8,819.20	14,502.50
SALARY TOTAL	0.00	5,216.54	2,109.10	2,732.40	4,230.97	4,417.74	5,060.91	23,767.66	0.00	6,167.49	6,167.49	6,167.49	6,167.49	6,167.49	54,605.11	78,564.00	23,958.89	54,796.34
SUPPLIES	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	463.55					1,336.00	1,799.55	1,800.00	0.45	1,800.00
POSTAGE	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	29.75					3,570.00	3,599.75	3,600.00	0.25	3,600.00
TELEPHONE	0.00	0.00	82.95	179.09	290.69	170.57	440.46	1,163.76	650.35					585.00	2,399.11	2,400.00	0.89	1,236.24
CONSULTANTS	0.00	0.00	0.00	0.00	0.00	0.00	663.72	663.72	180.85			2,000.00			2,844.57	6,000.00	3,155.43	5,336.28
TRAVEL	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	3,584.22			20,099.00			23,683.22	35,900.00	12,216.78	35,900.00
MEETING EXPENS	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00			9,547.00			9,547.00	5,200.00	(4,347.00)	5,200.00
PRINTING	0.00	0.00	0.00	0.00	60.31	0.00	13.13	73.44	114.14					8,900.00	9,087.58	9,150.00	62.42	9,076.56
RENT	0.00	0.00	0.00	0.00	325.00	325.00	325.00	975.00	1,300.00	325.00	325.00	325.00	325.00	325.00	3,900.00	2,600.00	(1,300.00)	1,625.00
ACCOMMODATION	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	267.00						267.00	1,000.00	733.00	1,000.00
TOTAL DIR EXP	0.00	5,216.54	2,192.05	2,911.49	4,906.97	4,913.31	6,503.22	26,643.58	6,589.86	6,492.49	6,492.49	38,138.49	6,492.49	20,883.49	111,732.89	146,214.00	34,481.11	119,570.42
INDIR COST		782.48	328.81	436.72	736.05	737.00	975.48	3,996.54								21,926.00		17,929.46
TOTAL EXP	0.00	5,999.02	2,520.86	3,348.21	5,643.02	5,650.31	7,478.70	30,640.12								168,140.00		137,499.88

(OV)/UND F/CAST = BUDGET - (ACTUAL+UNPAID+F/CAST)
UNEXPENDED = BUDGET - PAID ONLY

ACCT CHANGED BUDGET FIGURES IN SEPT: TOTAL DIFF = $341
TOTAL DIR EXP DIFFERENCE = $302

SPREAD	57,127.78	(OV)/UND + O/S INV - $3	40,768.97
GL	7,440.68	ACCOUNTING SPREAD	119,268.42
DIFF	49,687.10	DIFF	(78,499.45)

Minnesota Governor's Council on Developmental Disabilities
Department of Administration

300 Centennial Office Building
658 Cedar Street
St. Paul, Minnesota 55155
(612) 296-4018 voice
(612) 296-9962 TDD
(612) 297-7200 fax

March 25, 1998

Charlene Harrington, Ph.D.
Department of Social and Behavioral Sciences
University of California, San Francisco
Room N631, Box 0612
San Francisco CA 94143-0612

Dear Ms. Harrington:

I am responding to your report, *A Review of Federal Statutes and Regulations for Personal Care and Home and Community Based Services: A Preliminary Report,* as part of my duties on the Blue Ribbon Panel on Personal Assistance Services. The following are the priorities I have assigned to the various options, with notes where further explanation is needed. Page numbers are referenced in parentheses.

HIGH PRIORITY RECOMMENDATIONS

I. Personal Care Services (PCS)

State Plan Requirements - Designating Personal Care Services/HCBS as a mandatory program (11)

Benefits - Allocating hours and types of services based on individuals needs and ability to benefit (15) These allocations should take into account that people with the **most severe disabilities** will often see the **most benefit** in **quality of life** when services are provided in the community.

Benefits - Regulation change regarding needs-based and domestic only services (16)

Screening - Individual/Family involvement in assessment and planning procedures (20)

Consumer Choice and Information - Regulations amended require states to facilitate choice among providers (21)

Authorization - Statutory change regarding physician authorization of services (22)

Providers - Spouse/Parent payment prohibition and evaluation of quality when reimbursement to relatives for care is in place (26)

Providers - Regulations amended to require states to give individuals the right to select, train and manage their own personal care attendants (27)

HIGH PRIORITY RECOMMENDATIONS, CONTINUED
I Personal Care Services

Quality Controls and Supervision - Regulations amended to require states to make recipients aware of the supervision option (28)

Quality Controls and Supervision - Requirement for plans for consumer training on management of providers of services (30)

Location of Services - Regulation change regarding provision of PCS in other locations (32)

Grievances and Appeals - Clarify applicant rights for services and fair hearing/appeals process (33)

Grievances and Appeals - Regulations give identical rights to recipients of personal care services as home health agency care recipients (33)

II Medicaid Home and Community Based Waiver Program (HCBS)

State Plan Requirements - Waiver Program - HCBS as a mandatory state plan option (37)

Comparability of Services Across Eligibility Groups - Removal of limits to total number of persons eligible for waiver programs (41)

Financial Eligibility and Spend-Down - Changes in SSI and medicaid statutes to increase asset levels for individuals in community settings who would otherwise be forced into institutional care (45)

Benefits - Lifting the limitation of services to only individuals who have been deinstitutionalized (49)

Benefits - Study of the Respite Care benefit (50)

Consumer Choice and Information - Amendment of HCBS regulations to require provider registries and other means of consumer information. (59) If the information collection is focused on customer satisfaction with the providers and the process of receiving services, this change has the possibility of generating the data needed to create a truly consumer-centered system of services and supports.

HIGH PRIORITY RECOMMENDATIONS, CONTINUED
II Medicaid Home and Community Based Waiver Programs

Consumer Choice and Information - Increased federal monitoring of the provision of information about available alternatives to institutional care (60). In conjunction with the resources outlined in the previous option, this strategy could be highly effective.

Case Management - Self-directed case management services (62)

Providers - Amendment of HCBS regulations to encourage or require states to give individuals the right to select, train and manage their own providers (65)

Providers - Change to HCBS regulations to allow for spouse/parental payment prohibition and evaluation of the effect of reimbursement on other options for care (66)

Quality Control and Supervision - Study of the variations in provider and client training requirements (69)

Consumer Oriented Care - Clarifications of regulations regarding the essential nature of individual client and family involvement in the planning process (70).

Consumer Oriented Care - Consumer evaluation of their HCBS services (70) - This recommendation should be the starting point for all the other studies, evaluations and task forces that HCFA may undertake.

Consumer Oriented Care - Nature and extent of consumer advisory committees and input (70)

Consumer Oriented Care - Change in HCFA regulations so that they may be provided in other locations (71)

Grievance and Appeals - Clarification in HCFA regulations that the rights of recipients of /applicants for HCBS are equivalent to those for other Medicaid services (73).

Financial Requirements - Giving states a financial incentive for reducing institutional costs (74)

III Home Health Agency Certification

Medicare Definitions of Health Agency Services - Statutory and regulatory changes regarding location of service provision (78)

Standards for Quality - Exemptions allowed for PCA's (83)

HIGH PRIORITY RECOMMENDATIONS, CONTINUED
III Home Health Agency Certification

Standards for Quality - Changes in supervision requirements for PCA's (83) This change should emphasize that the individual who is receiving the services or that individual's designated support person will pick up the supervisory duties.

MEDIUM PRIORITY RECOMMENDATIONS

I. Personal Care Services (PCS)

Financial Eligibility and Spendown - Relating eligibility provisions to care needs of the individual (12)

Benefits - Addressing state barriers in definitions of services (14)

Benefits - Short term respite care study (16)

Screening Procedures - Coordinated screening and assessment system in State Plan requirements (20)

Case management - Access to case management (24)

Providers - Evaluation of relationship between family member restrictions and placements in institutional care (26)

Consumer-Oriented Care - Identification study of consumer advisory committees/input and comparison between state policy and program management (30)

Payment Methods and Financial Requirements - HCFA study regarding timely payment for PCS (34)

Payment Methods and Financial Requirements - Statutory change regarding advanced payments based on demonstration project effectiveness (34)

II Medicaid Home and Community Based Waiver Program (HCBS)

Statewideness - Sunshine Clause on waiver of statewideness in HCBS waiver programs (38)

Comparability of Services Across Eligibility Groups - Statutory change/regulatory limit on waiver of comparability for different eligibility groups (40)

MEDIUM PRIORITY RECOMMENDATIONS
II Medicaid Home and Community Based Waiver Program (HCBS)

Financial Eligibility and Spend-Down - Statutory Change making special financial eligibility mandatory (42)

Financial Eligibility and Spend-Down - Special financial eligibility provision application to PCS, so it can be combined in the state plan option.

Benefits - Study of the effect on co-residence with caregiver on institutional placement (49)

Benefits - Study of needs and services for people who have mental illness.(51) This study should focus on the needs as defined by the individuals with MI and their families.

Need Criteria for Services - Study to determine desirability of expansion of HCBS program to people at risk of institutional levels of care. (55)

Case Management - Managed Care Case management (63)

III Home Health Agency Certification

Personal Care Service Providers - Survey of states regarding personal care services and licensing requirements (75)

Standards For Quality - Training differential between PCA's and home health aides clarified (81)

LOW PRIORITY RECOMMENDATIONS

I. Personal Care Services (PCS)

Financial Eligibility and Spendown - Sliding fee scale/buy in feasibility study (12)

Need Criteria For Services - Minimum Criteria expert panel (17)

Need Criteria For Services - Evaluation of targeting those at risk for institutional care and those with less disability (18)

Screening Procedures - Expert panel, evaluation and uniform instrument (19)

Case Management - Managed care and alternative models

Payment Methods and Financial Requirements - Study of relationship between disability rates and service availability (35)

Payment Methods and Financial Requirements - Study of effects of FFP incentives in personal care services on nursing home, assisted living, employment, and health care use.

II Medicaid Home and Community Based Waiver Program (HCBS)

Benefits - HCBS specification of minimum benefit sets (47)

Benefits - HCFA specification of services and distinctions across categories (48)

Benefits - Study on respiratory care benefit (50)

Benefits - study on the amount, duration and scope of benefits leading to an institutional bias (52).

Need Criteria for Services - External Panel for criteria and measures for institutional care (54)

Screening Procedures - External panel and evaluation regarding common core assessment process (56).

Screening Procedures - Research and Evaluations of assessment and care planning process (57)

Screening Procedures - Research on different types of assessment (58)

Screening Procedures - State Plan provisions for single entry point systems, including studies of prevalence rates(58).

Authorization Procedures - Actual state procedures for authorization of HCBS waivers (61)

Case Management - Independent case management study (62)

Provider - Study to examine social models of care and quality of life in different sizes and types of community facilities (64).

Quality Control and Supervision - HCFA study of quality of care and relationship to home health care agencies (67)

Quality Control and Supervision - Variation in the supervision of HCBS programs (68)

LOW PRIORITY RECOMMENDATIONS, CONTINUED
II Medicaid Home and Community Based Waiver Program (HCBS)

Quality Control and Supervision - National independent evaluation of state programs.

III Home Health Agency Certification

Medicaid Certification and Medicare Certification - Study of home health licensing requirements (77)

These priorities are based upon the level of customer orientation evident in the option. In addition, policy/legislative changes were favored over studies and expert panels. If you have questions about the criteria used to determine these priorities, please do not hesitate to contact me.

Our Council recently completed a series of focus groups with people with disabilities and their family members. I have enclosed a copy of *Minnesotan's Speak Out - 1997*, the publication that resulted from this process. The comments of the focus group participants provide ample anecdotes for many of the changes that the preliminary report proposes.

Thank you for the opportunity to review the report. The challenge you and your colleagues faced was substantial. Your efforts produced a highly comprehensive set of options.

Sincerely,

Colleen Wieck

Colleen Wieck, Ph.D.
Executive Director

cc: Lex Frieden

enclosure

MC

Hotel Rooms:	8,399.14
Banquets	9,500.24
Business Ofc.	47.00
	17,946.38
2 Ballups	1,000.00
Jan	1,000.00
	19,946.38
+ other expenses.	11,700.75
- 1000 for Jan on list	31,647.13

Pay to Janice for PTE Center Cost

PAS

Hotel Rooms	1,478.88
Banquets	1330.09
	2,808.97

Billed to Charlene

McCare Banquets

3/1	Sun.	4,435.	22	Lunch
3/1	Sun	187.	85	Breakfast
3/1	Sun	344.	27	Dinner
3/2	Mon	140.	89	Breakfast
3/2	Mon	4,392.	01	Lunch
		9,500.	24	

Business Off. Chg. 47.00
7.50 + 39.50
$9,547 24

PAS Banquet

2/28	Sat.	1,330.	09	Lunch

Costs for Managed Care Conf.

Batavia	909.41 ✓	pay bill
Steve Brown	603.00	pay $800 (for S + Lill)
travel only		
Chamberlin	408.55	
Galvin travel	426.00	
Galvin	1000.00	
Griss	297.00	
Kailes	456.58	
McDonald	460.71	
Silverstein	444.50	
Patti Smith air	323.00	(air – TIRR pd)
Thomas air	329.00	(air TIRR pd)
	5,657.75	

Anthony	400.00	
Beatty ?? or PAS	243.00	
Lill Brown/Steve	?	other
Carr + PCA	≃ 800.00	
Clay	400.00	
Duncan	400.00	
Enders	400.00	
Gray	≃ 800.00	
Griffin	400.00	
Janoff	400.00	
McGinley	400.00	
Mitchell	400.00	(air only)
	10,700.75	

MC

Premo	400.00
Schuler	400.00
Seekins	400.00
Todd	400.00
White	400.00
	12,700.75

+ 2 Backups 1,000.00

13,700.75

+

+ (Rooms) Hotel Bill: 21,125.07

34,825.82

Banquet Org. 10,877.33

$45,703.15

FINANCIAL REPORT

The Robert Wood Johnson Foundation
P.O. Box 2316
Princeton, NJ 08543-2316
Phone: (609) 452-8701 Fax: (609) 452-9564

FA: RSH PA: DM PO: RG

Project Director: Lex Frieden (713) 797 - 5283
Fiscal Officer: Virgil Dice (713) 942 - 6164

Grantee: The Institute for Rehabilitation and Research
Grant Number: 031313 for [SCH]
Budget Period: Mar-01-1997 to Feb-28-1998
Grant Period: Mar-01-1997 to Aug-31-1998

Budget for Year : 1

Item	Approved Budget Amount	Period 1 03/97 - 08/97	Period 2 09/97 - 02/98	Total	Variance	Percent (%)
PERSONNEL:						
Project Director - Lex Frieden	$5,490.00	$1,793.52	$0.00	$1,793.52	$3,696.48	67%
Research Associate - Pamela Dautel	$7,600.00	$2,529.86	$0.00	$2,529.86	$5,070.14	67%
Writer/Editor - Quentin Smith	$7,875.00	$2,412.00	$0.00	$2,412.00	$5,463.00	69%
Administrative Associate	$5,000.00	$0.00	$0.00	$0.00	$5,000.00	100%
Fringe Benefits (31%)	$8,049.00	$1,427.24	$0.00	$1,427.24	$6,621.76	82%
Personnel Subtotal	$34,014.00	$8,162.62	$0.00	$8,162.62	$25,851.38	
OTHER DIRECT COSTS:						
Supplies	$900.00	$482.65	$0.00	$482.65	$417.35	46%
Duplicating	$900.00	$0.00	$0.00	$0.00	$900.00	100%
Telephone	$1,200.00	$326.41	$0.00	$326.41	$873.59	73%
Postage	$900.00	$263.07	$0.00	$263.07	$636.93	71%
Service Agreements (s)	$600.00	$0.00	$0.00	$0.00	$600.00	100%
Communications/Marketing	$1,000.00	$0.00	$0.00	$0.00	$1,000.00	100%
Meeting Expenses	$3,000.00	$0.00	$0.00	$0.00	$3,000.00	100%
Travel	$12,540.00	$1,347.08	$0.00	$1,347.08	$11,192.92	89%
Consultant Travel	$15,960.00	$0.00	$0.00	$0.00	$15,960.00	100%
Attendant Travel	$9,120.00	$0.00	$0.00	$0.00	$9,120.00	100%
Other Direct Subtotal	$46,120.00	$2,419.21	$0.00	$2,419.21	$43,700.79	
Space Rental	$1,300.00	$304.00	$0.00	$304.00	$996.00	77%
Equipment	$1,000.00	$1,179.50	$0.00	$1,179.50	($179.50)	-18%
Consultant Fees	$8,700.00	$0.00	$0.00	$0.00	$8,700.00	100%
Indirect Costs	$7,329.00	$979.72	$0.00	$979.72	$6,349.28	87%
GRAND TOTAL	$98,463.00	$13,045.05	$0.00	$13,045.05	$85,417.95	87%

3/14-2

30 IL people paid for hotel, meals, & travel
28 - 2/28 Mtg of PCH devices - Tuesday PDT RWJ
20 - locals

$33M RRTC - Lew
20M RWJ

small groups - need 5 B/Os
brief group leaders & reporters & intended
result is clear.

① Handout packet - mail out prior to con.
② Group leaders & reporters
& meet w/ night before & day of

Possible Reporters:
Ellen White
Peg Kavellas
Jan Dalvan
5 Ellen Drabin
4 Tom Deskins
6. Mary Faithfull
7. Drew Batavia

Budget ?'s
Fac. Fees ?
Reporter's Fees ?
Fac. organizer fees ?

Interpreters ?
Phones ?

RRTC

Meals $8,000
Rooms 13,000
travel 12,000
33,000

RWJ

Rooms 2,000 - free room & board

Consultant Fees - 10 people

5 Leaders @ 200 1000
4 Reporters @ 500 2000
1 Leader Facilitator + Reporter 1000 =

3000
4000

Planning - basics & basics

ATTACHMENT 1.A

STATEMENT OF WORK

Administration of the RTC
Budget $9,777

2 others Lex Frieden will serve as Co-Director for the RTC. In this capacity, he will assist in administrative manners related to implementation of RTC goals and objectives. Administrative oversight will include managing and monitoring the subcontract budget, project management for ILRU research and training projects, and active participation at regularly scheduled meetings.

Adams Mark Hotel

tent. dates Feb 6-8

Feb 20-22

Feb 27- March 1

7/8

6997

rtc_mc\subcont\nidrrcon

ATTACHMENT 1.B

STATEMENT OF WORK

Training Project 1----Associated with Research Projects R5 and R6
Budget $41,541

Task 1. Conduct Focus Groups:

a) to assist in determining the criteria and measures that consumers identify as critical for the effective delivery of managed care programs for people with disabilities.

b) to obtain feedback about the format in which health plan decision making information is presented in written materials and computer prototypes.

Subcontractor will conduct a minimum of six focus groups in the third and fourth quarter of year 1, and six focus groups in the first and second quarter of year two. Each focus group will be composed of between 8-12 individuals with disabilities. A minimum of three focus groups should be conducted in each region of the United States (North, South, East, West). Of the three focus groups conducted in each region, the first set will consist of individuals with primarily cognitive disabilities, the second set will consist of individuals with primarily physical disabilities, and the third set will consist of individuals with mental disabilities. It is understood that some individuals with severe cognitive disabilities may not be able to adequately participate in the focus group sessions. The subcontractor will therefore include surrogates for these individuals in the focus groups. The subcontractor will limit participants to individuals aged 18 years and older.

All costs associated with the focus groups will be the responsibility of the subcontractor.

1.1 Identify Focus Group Participants

Subcontractor will contact national organizations that represent persons with disabilities, such as the National M.S. Society, United Cerebral Palsy, to obtain membership or mailing lists of potential focus group participants.

Subcontractor will recruit participants from these membership lists.

1.2 Coordinate and Conduct Focus Group Meetings

Subcontractor will make all necessary arrangements for and coordinate each of the focus group meetings. These activities include, but are not limited to: identifying meeting sites, arranging for and reimbursing participants for transportation, and providing participants with a $25 honorarium.

Subcontractor will arrange and pay for audio taping of each focus group session. Written summaries or transcribed copies of each focus group session will be provided to the contractor within fifteen (15) working days following each focus group session.

The Subcontractor will facilitate all focus group meetings.

1.3 Assist NRH-RC staff with the development of focus group questions.

The subcontractor will develop a draft of the focus group questions approximately forty-five (45) days prior to the first focus group. The contractor will provide feedback to the subcontractor within seven (7) working days. The subcontractor will revise focus group questions based on this feedback and will submit revised questions to the contractor for final approval.

2. Participate in conducting Delphi Survey of Consumers and Providers

2.1 Identify Delphi Survey participants

The subcontractor will obtain the names of providers and consumers to include in the Delphi survey. The subcontractor will seek the participation of both primary care and specialty providers who are experienced in delivering care in a managed care setting and who understand the needs of individuals with physical and mental disabilities. The subcontractor will also elicit names of potential Delphi survey participants from members of the advisory panel as well as from the literature, organizational directories, and key leaders in the disability community.

A minimum of 125 individuals will be included in the Delphi Survey, 75 of which will be consumers, and 50 of which will be providers.

The subcontractor will provide NRH-RC with a list containing the names, addresses, phone numbers, fax numbers (as available) of individuals to be surveyed. This list will be delivered to the contractor by December 1, 1997.

2. Assist NRH-RC staff in drafting Delphi questions

The subcontractor will develop a draft of the Delphi survey questions approximately fifteen (15) days prior to the first focus group. The contractor will provide feedback to the subcontractor within seven (7) working days. The subcontractor will revise focus group questions based on this feedback and will submit revised questions to the contractor for final approval.

The final set of questions will be delivered to NRH-RC by December 1, 1997.

ATTACHMENT 1.C

STATEMENT OF WORK
Training Project 2 – Information Service
Budget $27,933

This project is designed to assure that information on managed care is secured in a timely fashion and is made available to persons with disabilities, researchers, health care providers, policymakers, staff of regulatory agencies, and others. The traditional functions of securing, filing, retrieving, and disseminating information are fairly well established. However, with the development of World Wide Web and the Internet as tools for linking geographically dispersed audiences, new avenues of access to information have opened. The activities described in this project are designed to take advantage of time-tested information management methods as well as new technology in ways that facilitate access to the broadest possible range of individuals and organizations using the most cost-effective methods and tools. The Information Service has three interrelated components: (1) an Information Center library; (2) a Managed Care and Disability Web Site; and (3) dissemination through other media.

This project has six objectives.

1. *Establish an Information Center as a central resource for materials on managed care and disability.*

2. *Develop a corresponding Managed Care and Disability Web Site on the Internet, facilitating access to Internet resources as well as the resources collected at the Information Center.*

3. *Use current technology to create a variety of information vehicles for the dissemination of information and resources, tailored to the needs of target audiences.*

4. *Disseminate information on managed care and disability through other conventional media, including such vehicles as newsletters, newspapers, and radio.*

5. *Evaluate information-sharing strategies to assess consumer satisfaction and timeliness of information delivery.*

6. *Identify strategies for sustaining the most effective information-sharing vehicles beyond the period of grant funding.*

Managed Care and Disability Web Site

ILRU will take the lead on establishing the Managed Care and Disability Web Site that will focus on the effective use of the Internet and the World Wide Web in facilitating information exchange. The ILRU and NRH RC web site for the RTC on Managed Care and Disability will link the two institutions and allowing project staff to implement programs that will showcase their expertise.

The development and implementation of the web site must be in conjunction with NRH RC and preapproved before finalization. ILRU will perform the following functions:

a) designate a co-webmaster by August 1, 1997.
b) co-webmasters will create guidelines for production, assign responsibility and create a schedule for updates, and produce a map of a proposed layout by September 15, 1997.
c) ILRU will develop a logo, navigation buttons, and page template, which must be approved by Directors of IRLU and NRH RC by October 1, 1997.
d) ILRU and NRH RC co-webmasters will produce HTML pages of research and training projects, staff profiles, and web links by October 15, 1997.
e) ILRU will design a reading room and solicit contributions by November 1, 1997.
f) ILRU will create and manage a listserv or newsgroup by January 1, 1998.
g) ILRU will provide a search engine to search the web site by March 1, 1998.
h) ILRU will produce an online conference using "chat room" technology by May 1, 1998.

Dissemination through other media

In addition to the Information Center and Managed Care and Disability Web Site, we will also disseminate information through other avenues. Both NRH-RC and ILRU publish periodical newsletters, the NRH-RC *Research Update* and ILRU's *Insights*.

Accessibility

Assuring access to information is the primary goal of this project. Efforts will be made to provide resource materials in alternative formats when requested by consumers. People preparing materials for the Information Service will be informed that materials must be provided on diskette so that they can be reproduced in large print, braille, and other requested formats.

The web site will be accessible in both graphic and text interfaces to make it accessible to people who use voice synthesizers or other assistive technology. Project staff will use the recommendations for accessible HTML as outlined in the document from the Trace Research and Training Center, *Design of HTML Pages to Increase Their Accessibility to Users with Disabilities: Strategies for Today and Tomorrow* (http://trace.wisc.edu/TEXT/GUIDELNS/HTMLGIDE/ htmlgide.htm).

Dissemination/publication

The goal is extensive dissemination with a primary focus on the information needs of people with disabilities. The Managed Care and Disability Web Site will provide a variety of methods for dissemination of information, including a searchable database, interactive e-mail forms, topical information areas, and chat rooms. The Information Center will provide assistance to consumers in identifying and locating information and materials on managed care and disability.

Evaluation Plan

In order to determine the quality and usefulness of the Information Center and its dissemination vehicles, data on usage by different target groups will be gathered and summarized.

- Both the ILRU and NRH RC project staff will keep a reference log to record number of contacts, consumer affiliation, method of contact, type of request, and service or product provided. Individuals contacting the Information Service will be asked to provide their names and contact information; any names provided will be kept confidential. However, persons who refuse to provide this information will be given the same level of service as those who identify themselves.

- ILRU will provide monthly statistical reports from the Managed Care and Disability Web Site to track and profile the number of contacts for each topic area.

- ILRU will provide monthly E-mail evaluation reports of consumer evaluations of the web site service.

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ATTACHMENT 1.D

STATEMENT OF WORK

Training Project 4 – Conference
Budget $88,548

Develop philosophical principles for the provision and governance of managed care for individuals with disabilities and obtain substantive input into the Managed Care RTC research agenda.

ILRU will take the lead in planning the first conference, which will be held in Houston over a weekend during the final quarter of Year 1. ILRU will identify approximately 40 direct consumers and 40 representatives of consumer organizations from around the country. ILRU will provide stipends for direct consumers for those not affiliated with a national organization.

The conference will have two goals: to obtain consumer feedback on each component of the RTC research and training agenda, and to develop a set of philosophical principles. Conferees will participate in small working groups focused on achieving the conference goals.

1. Identify conference dates and hotel site (September 15)

2. Identify keynote speaker (in collaboration with NRH RC) for conference (October 15)

3. Identify conference participants (40 consumers who will receive stipends and 40 advocates) (February 1, 1998)

4. Finalize agenda, in collaboration with NRH RC. (March 15, 1998)

5. Arrange for alternative formats and other access needs (March 15, 1998)

6. Hold conference (April 15, 1998 - Approximately)

7. Publish conference proceedings (June 30, 1998)

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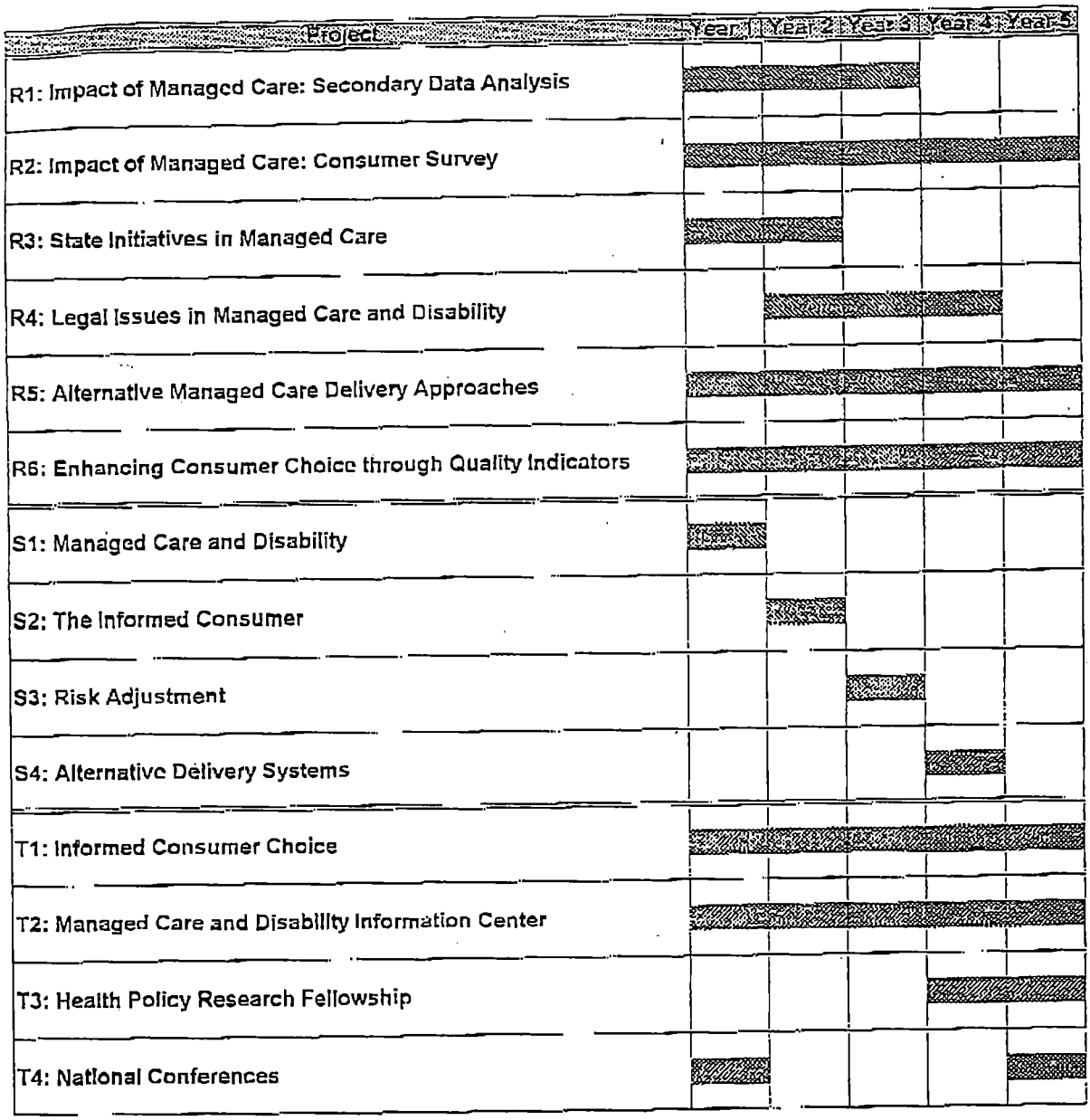
RTC Budget Template

Consolidated Summary of ILRU Budget Projection
YEAR 1

Personnel Name	FTE	R4	T1	T2	T4	Admin.	TOTAL
L.Frieden	20.0%		5,490	5,490	5,490	5,490	21,960
W. Wilkinson	5.0%			2,100			2,100
Q. Smith	15.0%		7,875	3,937			11,812
P. Dautel	45.0%		7,600	1,900	7,600		17,100
G. Shore	35.0%			2,000	4,000	1,000	7,000
Fringe Benefits (31%)			4,058	4,783	5,298	2,012	18,591
Non-Personnel							
Supplies			600	600	600		1,800
Mailing Costs							
Routine			300	300	3,000		3,600
Data Collection							
Other							
Duplicating							
Routine			300	300	2,400		3,000
Data Collection							
Data Entry							
Telephone			600	600	1,200		2,400
Advisors							
Consultants			3,000		3,000		6,000
Subcontract							
Travel							
Local							
Out-of-Town			2,400		33,500		35,900
Meeting Costs							
Space			600		4,000		4,600
Food							
Travel			600				600
Consultants					2,400		
Advertising							
Printing			750		2,400		3,150
Graphics			300	1,500	1,200		3,000
Data Acquisition							
Equipment							
Office Space Rental			910	780	910		2,600
Accommodation Costs			1,000				1,000
TOTAL DIRECT COSTS		0	36,383	24,290	76,998	8,502	146,214
INDIRECT COSTS (15% MTDC)		0	5,457	3,643	11,550	1,275	21,926
TOTAL PROJECT COSTS		0	41,840	27,933	88,548	9,777	168,140

Figure 7

RTC - MC & D
Cross-project Timeline



Attachment 2

RTC Budget Template

Consolidated Summary of ILRU Budget Projection
YEAR 1

Personnel		R4	T1	T2	T4	Admin.	TOTAL
Name	FTE						
L.Frieden	20.0%		5,490	5,490	5,490	5,490	21,960
W. Wilkinson	5.0%			2,100			2,100
Q. Smith	15.0%		7,875	3,937			11,812
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G. Shore	35.0%			2,000	4,000	1,000	7,000
Fringe Benefits (31%)			4,058	4,783	5,298	2,012	18,591
Non-Personnel							
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Mailing Costs							
Routine			300	300	3,000		3,600
Data Collection							
Other							
Duplicating							
Routine			300	300	2,400		3,000
Data Collection							
Data Entry							
Telephone			600	600	1,200		2,400
Advisors							
Consultants			3,000		3,000		6,000
Subcontract							
Travel							
Local							
Out-of-Town			2,400		33,500		35,900
Meeting Costs							
Space			600		4,000		4,600
Food							
Travel			600				600
Consultants					2,400		
Advertising							
Printing			750		2,400		3,150
Graphics			300	1,500	1,200		3,000
Data Acquisition							
Equipment							
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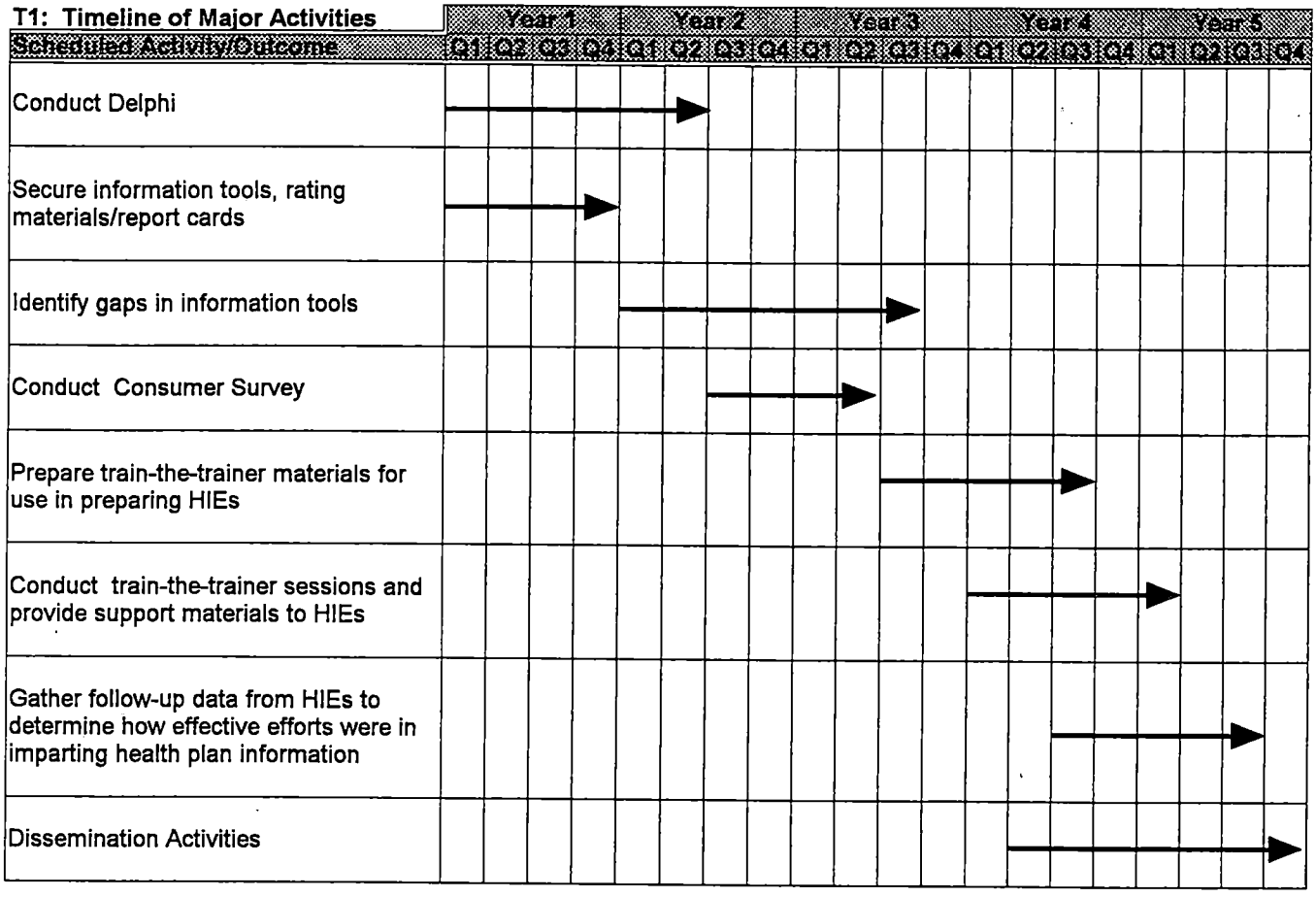
TOTAL DIRECT COSTS		0	36,383	24,290	76,998	8,502	146,214
INDIRECT COSTS (15% MTDC)		0	5,457	3,643	11,550	1,275	21,926
TOTAL PROJECT COSTS		0	41,840	27,933	88,548	9,777	168,140

TRAINING PROJECT 1: Informed Consumer Choice



TRAINING PROJECT 1: Informed Consumer Choice

Abstract

Choosing between competing health plans and between options within plans is not always a simple process. Information available to consumers is generally limited to marketing materials that may not disclose all the details concerning plan benefits. Many organizations such as the National Committee for Quality Assurance (NCQA), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and the Maryland Hospital Association have assumed a pivotal role in the development of quality indicators. These efforts, however, are designed to enhance the information available to employers in identifying plans to offer employees or as a means for hospitals to compare their performance relative to that of other organizations. Plan ratings available through lay publications such as *Consumer Reports, US News and World Reports, Consumer Checkbook, and Health Pages* have, perhaps, done the best job informing consumers on the types of probing questions they should ask of their providers and health plans, the type of detailed information required to determine if one option has advantages over another, and the "quality of care" rendered by competing plans. These sources may contain a wealth of information helpful to the consumer in drawing some general conclusions about options available to him or her. Nevertheless, if disabled consumers are to make "informed" choices then they must be able to ask the types of questions and secure the answers specific to their health care needs. This project is designed to assist in the development of resources to enhance the effectiveness of the consumers' decision-making process.

Types of Activity

The types of activities contained in this project include: (1) Identification of the types of information that people with disabilities require in making "informed" health care purchasing decisions, (2) obtaining consumer feedback on the types of formats which are most conducive to understanding informational materials, and (3) conducting activities to prepare consumers to use the materials effectively.

Personnel (Year 1)

Name	Role	Discipline	Percent Time
Q Smith, MS	Project Director	Health Care Admin./IL	10
L Frieden, MA	Content Specialist	Psychology/IL	5
P Dautel, MPH	Training Associate	Public Health	20
S Hanson	Consultant	Social Policy	

Target Audiences

Primary audiences include consumers, consumer groups, community service agencies, and health educators. Secondary audiences include policy makers and regulatory agency personnel, accreditating agencies, and health plans.

Description and Objectives

New sources of information to assist consumers in making health plan purchasing decisions are being introduced into the public sector at a steady pace. Most of these information sources were designed to appeal to the widest audiences, and it is unclear whether or not they address questions or issues that may be of particular concern to people with disabilities. The **objectives** of this project are:

1. *To conduct a Delphi survey to identify the health plan decision-making information needs of people with disabilities*
2. *To identify existing gaps in the information tools presently available to people with disabilities*
3. *To assess the utility of various information formats in assisting persons with disabilities in making the best choices among various health plan options*
4. *To disseminate the information obtained from Objective 2 and 3 to key organizations and individuals involved in the development of information tools for people with disabilities*
5. *To conduct "train-the-trainer" activities to prepare persons with disabilities to serve as health information extenders, assisting other individuals with disabilities in effectively securing and using information on health plans*

Background

Transformation of the health care system, as envisioned by DeJong and Sutton (1995), from a payer-driven-system to a consumer-driven system can only occur if the public recognizes and accepts a more active role in the health care process. In other words, health care users must change from being passive "patients" to becoming active "consumers." As health care "consumers," individuals must transcend the role of passive dependence in their health care interactions in which they "relinquish autonomy to professionals who exercise authority on the patient's behalf" and assume "an active role in assessing the relative cost and quality of alternative sources of care, and make informed choices in the use of health services. Consumers must also choose the health plan which will best meet their anticipated financial and health circumstances" (Hibbard and Weeks, 1988). *Thus, the markers of a more consumer-driven health care system are congruent with the sentinel values of the independent living movement such as self-direction, choice, individual autonomy, and control over one's life.*

How prepared is the public to assume ITS roles as consumers? Unfortunately, not very well. The availability of adequate, standardized, and readily available information is the linchpin to achieving a consumer-driven health care system. Indeed, at least one study has shown that, when given an opportunity to select among competing health plans, knowledge of various health plans' coverage was the most important determinants of Medicare beneficiaries' decision to disenroll or remain with their current health plan (Sofaer and Hurwicz, 1993). Yet, the scientific literature abounds with research that has shown that consumers lack basic knowledge or an understanding about their health insurance plan,

the benefits covered under the plan, and of the availability of health plan alternatives (Sofaer and Hurwicz, 1993; Newcomer et al., 1990; Friedlob and Hadley, 1985; Cafferata, 1984; Marquis, 1983; Newhouse et al., 1981; Lambert 1980). Moreover, of particular relevance to this study, research has shown that knowledge of coverage has a differential impact on the health plan enrollment decision depending on health status (Davidson et al., 1992). (The presence of a disability is not necessarily indicative of poor health status. This study does, however, suggest a possible interaction effect between the presence of a disability and consumer information.)

While persons with disabilities often have significantly greater knowledge about their health care needs than does the typical individual without a disability, it is unclear how well people with disabilities are prepared to make the best choice from competing health care options (e.g., health plans, providers). At present there is a great deal of attention focused on developing informational materials related to health care plans and services. However, the most prominent effort, HEDIS, was designed primarily for use by employers in making purchasing decisions, and does not address issues of specific importance to people with disabilities, which may differ from that of the general population. Similarly, many organized efforts to develop health plan decision-making tools from the consumer's perspective, such as those currently under development by the Foundation for Accountability and the Minnesota Health Data Institute, are geared toward the general population and do not focus on issues of importance to people with disabilities.

The most comprehensive decision-making tool currently under development is the Consumer Assessment of Health Plans (CAHPS) which is sponsored by AHCPR and conducted by a consortium of Harvard Medical School, RAND, and the Research Triangle Institute. Once completed, this five-year effort will assist consumers in identifying and selecting the best health care plan for their specific needs. A key advantage of the CAHPS project is that it was developed with extensive consumer input and that it will contain a supplement directed toward people with chronic and disabling conditions. The biggest drawback of CAHPS is that the types and quantity of information initially being considered for the disability supplement is significantly limited in scope.

Clearly, the attention being focused on service quality information for consumer decision-making is a positive step toward a consumer-directed health care system. Nevertheless, there are a number of questions about these initiatives and their value to consumers which remain to be answered. For instance, does the information being generated address the questions of greatest concern to consumers? Is it presented in language and formats that make it accessible to the people who need it? Does it address the information needs of persons with different types of disabilities and different levels and types of health risks?

This project will generate data on the extent to which available informational materials address the needs of persons with disabilities and identify information gaps which will require further development. The project team will also evaluate alternative formats available to disseminate this information to the public to ensure that the information is presented in the most accessible and user-friendly manner. Lastly, it will employ a concept involving training of health information extenders (HIEs) to promote better understanding of

health care options by persons with disabilities living in the community--including low income individuals and individuals from racial or ethnic minority groups.

Methods and Materials

Objective 1: Identification of the health plan decision-making information needs of people with disabilities

To obtain consensus on the domains which consumers require to address their information needs, the research team will conduct a three-stage Delphi study of approximately 100 consumers with disabilities. We will identify Delphi participants, including persons with different types of disabilities and from different parts of the country, from the membership of national organizations that represent persons with disabilities (e.g., United Cerebral Palsy, National MS Society) and from centers for independent living (CILs) with which ILRU has established contacts.

As the first stage of the Delphi we will survey consumers with disabilities on the types of information which they consider necessary to select between alternative health plans. The second and third stages of the Delphi will establish a ranking for each of the elements identified in Stage 1. In Stage 2, consumers will be asked to rate the criteria identified in stage one on a scale from 0-10, where "10" indicates the greatest importance and "0" indicates no importance. In Stage 3, participants will be provided with two lists of criteria weightings. The first list will contain the individual's own weighting for each criterion and the second list will contain the average weighting given to the criterion by all participants. We will give respondents the opportunity to either change or retain the weighting they initially assigned each criterion.

Objective 2: Identification of existing gaps in available information tools

Informational materials, such as HEDIS 3.0, CAHPS, and "report cards" designed by *Health Pages* and *Consumer Reports,* will be gathered and reviewed to ascertain the extent to which the information contained in these materials conforms to the criteria identified in objective 1. The research team will work with the members of the Advisory Committee to evaluate: (1) the thoroughness of various materials in providing information of interest to the individual; (2) the clarity and logic of the presentation (e.g., Does it lead you through a review of key issues in a logical fashion?); (3) issues or concerns about the information provided (or the way it is presented); and, most importantly, (4) key elements not covered within this material.

The project team will mail copies of this material to a subset of 25 individuals who participated in the Delphi survey. We will ask these individuals to provide substantive comments on the materials which they received. To assist consumers in this process we will include a set of open-ended questions (e.g., What questions do you have about your health plan which were not covered in the enclosed materials?) to which we will ask them to respond.

We will use the input from the Advisory Committee and the consumers who reviewed this material to identify gaps in the information sources currently available to people with disabilities.

Objective 3: Assessing the utility of various information formats

We will obtain feedback from consumers concerning their opinion of the manner in which the information in these materials, such as CAHPs, *Consumer Reports*, *Health Pages*, is formatted and presented to consumers. We will attempt to determine the style of presentation (e.g., report cards, written summaries, scaled scores, and rankings) that most accurately conveys the intended meaning of the information and that facilitates understanding of the material. We will also attempt to obtain consumer input about the usefulness of a prototype interactive, computer-based systems which has previously been developed specifically as a health plan decision-making tool.[1]

Questions pertaining to the effectiveness of the informational materials' formatting will be included as part of the consumer survey identified in Objective 2, above. Moreover, in conjunction with the R6 research team, we will obtain feedback about the format in which information is presented in both the written materials and the computer-based prototype from consumers participating in the quality indicator focus groups sessions. (As stated in the discussion of R6 these focus groups will be based at each of the demonstration sites.)

Objective 4: Dissemination of information to organizations developing consumer decision-making tools

Together, the information gleaned from Objectives 2 and 3 will enhance the ability of organizations and individuals, who are in the process of developing consumer-focused decision-making tools, to address issues of specific concern for people with disabilities. The research team will compile the information obtained from this study into a monograph that will be distributed to both public and private sector individuals and organizations, including the CAHPs Consortium, NCQA, and the Maryland Hospital Association, that are in the process of developing quality indicators. We will work with members of the Advisory Committee to identify other organizations.

Additionally, this monograph will be made available on the Internet to individuals accessing the RTC's Web site, which is described in further detail in R2.

Objective 5: Conduct "train-the-trainer" activities

The final component of this project involves training health information extenders (HIEs) to use informational materials to enhance the understanding of health plan selection

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[1] Stuart Hanson, an independent consultant, has developed a prototype computer program by which individuals with disabilities may obtain information on different health plans characteristics. This interactive system was designed to address issues of specific importance to people with disabilities.

Mr. Hanson will participate as a consultant, and will provide the research team with access to this prototype system for use in this project.

issues among people with disabilities in selected communities. In addition to increasing knowledge and understanding of key health care issues that should be considered in the selection process, this activity is designed to foster the development of community networks of people with disabilities who can provide peer support in assessing health plan options and sorting out health-related issues.

Research staff will mail each of the CILs operating in the U.S. a letter informing them of the opportunity to participate in this "train-the-trainer" program. Once three to five CILs have indicated willingness to participate, project staff will travel to each of the CILs and will work with designated staff to prepare them to use available materials to guide persons served by the CILs to be more informed consumers when selecting among health plan or provider options. The train-the-trainer sessions will focus on how to use materials, "prepping" persons to ask the "right" questions of plan and provider representatives, and understanding differences between marketing information that may be used in recruiting new customers.

Strategies on how to attract people from the community to attend informational sessions, including holding sessions in different parts of the community, will also be covered during preparation of the HIEs. Each of the HIEs will be expected to commit to convening at least four sessions involving members of the community who want to learn more about choosing health care plans and providers.

Accessibility

Consumer focus groups, which are common to project R6, will be conducted in a fully accessible site. Furthermore, we will make transportation available to participants, at no charge. HIEs will be cautioned about the need to hold sessions targeted to community members in locales that are fully accessible to people with disabilities.

Relevance to Minority Populations

Project activities will target low-income and minority populations. Specific attention will be given to identifying at least two sites for testing informational materials using HIEs who are from minority backgrounds. At least one HIE will be an African-American individual working in a CIL which also serves a significant African-American population, and at least one will be an Hispanic individual who is bilingual, and who works in a CIL serving a significant Hispanic population. In addition to testing the effectiveness of the materials in conveying relevant information to target audiences, the cultural relevancy of the materials will be tested using feedback from the HIEs and from persons in community groups convened by the HIEs.

Relevance to Regional and National Needs

This project addresses the national need for a better understanding of the effectiveness of health information resources in addressing issues relevant to people with disabilities. It will address regional needs through activities carried out in CILs in different parts of the country. Through the evaluation activities described below, the RTC will make

an effort to determine if there are regional or state-to-state variations in the information needs of persons with disabilities.

Relationship to RTC Research Efforts

One of the information "domains" which individuals with disabilities are anticipated to need are the quality indicator generated from R6. Research staff from R6 and T1 will collaborate to ensure the suitability of the information contained in these indicators and the formats in which they are presented. Furthermore, the monograph developed as part of this project will be made available on the Internet as part of project T2.

Dissemination

In addition to the dissemination activities detailed in Objective 4, we will disseminate the findings of this project in *ILRU Insights,* which is mailed to CILs as information flyers; consumer-focused journals, such as the *Disability Rag* and *Step One;* and to journals targeted to researchers and policy-makers, such as *Health Services Research* and *Inquiry*.

Evaluation Plan

The focus of this project is on evaluating the utility and relevancy of materials that are being made available (or will be made available) to assist persons in making decisions about health care choices.
In addition to the wealth of data that we will generate about consumer perceptions of the quality and utility of health plan/provider information available, the research team will also follow-up with the HIEs trained through this project to determine: (1) how many sessions they conducted with people in the community care plans and providers; (2) how many people attended each session and what were the characteristics of attendees (with respect to types of disabilities represented and participation by persons from racial/ethnic minority groups); (3) participant evaluation of the value and quality of the information sessions (strategies for developing and using evaluation instruments will be covered in the train-the-trainer sessions); and (4) comments and recommendations from session participants on what they would like to see included in health plan/provider informational materials available to people with disabilities. (We will provide a standardized form for collecting these data.) These data will be examined by project staff to assess the efficacy of the HIEs in promoting awareness of health plan/provider issues among people with disabilities in targeted communities.

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X-Sender: lfrieden@bcm.tmc.edu
Date: Thu, 18 Dec 1997 19:25:52 -0600
To: funchess@bcm.tmc.edu
From: Lex Frieden <lfrieden@bcm.tmc.edu>
Subject: T-1 work plan draft

>Date: Sat, 11 Oct 1997 14:44:06 -0700
>From: June Isaacson Kailes <jik@pacbell.net>
>Reply-To: jik@pacbell.net
>Organization: Disability Policy Consultant
>X-Mailer: Mozilla 3.01GoldC-PBWF (Win95; I)
>To: "Frieden, Lex" <lfrieden@bcm.tmc.edu>
>Subject: T-1 work plan draft
>
>as requested. Is this close?
>
>codes used throughout document
>1q1 = year 1, quarter 1
>obj = objective
>xxx = questions for Lex
>
>KAILES WORK PLAN:
>
>Target Audiences
>
>Primary - consumers, consumer groups, community service agencies, and
>health educators. Secondary - policy makers and regulatory agency
>personnel, accreditating agencies, and health plans.
>
>Objectives and work activities
>
>2. To identify existing gaps in the information tools presently
>available to people with disabilities
>
>- incorporate findings from research that conducts a Delphi survey to
>identify the health plan decision-making information needs of people
>with disabilities
>
>4. To disseminate the information obtained from Objective 2 and 3 to key
>organizations and individuals involved in the development of
>information tools for people with disabilities
>
>1q1- 3q4 Resources to be read, reviewed and drawn from will include:
>- all RTCMC website material
>- HEDIS 3.0- designed primarily for use by employers in making
>purchasing decisions
>- variety of health plan decision-making tools for consumers such as
>those currently under development by the:
>..Foundation for Accountability
>..Minnesota Health Data Institute
>- Consumer Assessment of Health Plans (CAHPS) which is sponsored by
>AHCPR and conducted by a consortium of Harvard Medical School, RAND, and
>the Research Triangle Institute.
>- "report cards" designed by Health Pages and Consumer Reports
>- existing pieces in the disability press
>- other materials recommended by RTC staff and the Advisory Committee
>
>
>-1q3-4q4 Write pieces targeted at the people with disabilities
>
>- pieces will:
>..be user-friendly
>..be in plan language
>..address issues of specific importance to people with disabilities
>..fill the current existing information gaps
>..will be continually updated throughout the project as new information
>is uncovered from reseach activities and new resources.

>
>- pieces with focus on:
>1q4 CHOOSING AND EVALUATING PLANS
>..managed care lingo / glossary of terms
>..how to evaluate health insurance plans
>..questions to ask
>..written materials to review
>..types of plans, comparability, report cards,
>..benefits covered under the plan,
>..availability of health plan alternatives
>
>2q3 HOW TO MANAGE IN MANAGED CARE
>..unwritten rules, provider incentives, dangers
>..strategies: appeals process, advocacy organizations
>..public policy and advocacy issues: what needs to be fixed
>
>3q1 AGING WELL: STRATEGIES FOR PLANNING FOR CHANGE
>..space, social and financial resources
>..technology
>..PAS
>
>
>2q3 - 4q3 Advisory Committee will review thoroughness, accuracy of
>materials developed.
>
>2q1-5q4 Disseminate information through presentations made at 2 - 5
>selected disability-related state, regional and national conferences per
>year.
>
>
>5. To conduct "train-the-trainer" (TOT) activities to prepare persons
>with disabilities to serve as health information extenders, assisting
>other individuals with disabilities in effectively securing and using
>information on health plans.
>
>3q1 - 4q2 Develop TOT Workshop content to include at least 3 hours worth
>of training activities
>..divided into five or six modules, each module 30 minutes to 1 hour in
>duration, modules should be self contained so trainers can choose
>between modules for workshop of less than 3 hours.
>
>Each module / activity will be organized using the following format:
>
> Activity: (name)
> Objectives:
> Estimated time: (an approximation of the time the exercise will take,
>actual time will vary depending on the makeup and size of the group.)
> Materials:
>
> Handouts:
>
>
>4q1-5q1 Conduct 4 TOT sessions at 4 - 6 disability-related state,
>regional and national conferences.
>
>xxx Change here rather than just travel to 3-5 ILC's, this material
>should be presented at disability-related
>
> Each of the TOT participants will be expected to commit to convening
>at least four sessions involving members of the community who want to
>learn more about choosing health care plans and providers.
>
>
>Evaluation
>
>2q1-5q4 All presentations will end with a participants completing an
>evaluation form focusing on participants self-accessing the change in

>their basic understanding of the workshop topics BEFORE and AFTER the
>training, as well as the most helpful and least helpful parts of
>workshops, what they will use, etc.
>
>4q1-5q1 HIEs (TOT) trained through will be asked to report:
> (1) how many sessions they conducted with people in the community and
>providers;
> (2) how many people attended each session and what were the
>characteristics of attendees (with respect to types of disabilities
>represented and participation by persons from racial/ethnic minority
>groups);
> (3) participant evaluation of the value and quality of the information
>sessions (strategies for developing and using evaluation instruments
>will be covered in the train-the-trainer sessions); and (4) comments and
>recommendations from session participants on what they would like to see
>included in health plan/provider informational materials available to
>people with disabilities. (We will provide a standardized form for
>collecting these data.)
>
> These data will be examined by project staff to assess the efficacy of
>the HIEs in promoting awareness of health plan/provider issues among
>people with disabilities in targeted communities.
>
>
>Budget:
>
>$ 15,000 Kailes subcontract
>billed at $ 4,750 / quarter =
>
>Project assistant
>$2,400 ($200/mo = 10 hrs)
>up to 5 hrs/mo from ILRU staff
>
>xxx Can I bill for 1q1 and complete that work over 1q2-4?
>
>
>$5,320 Travel:
>Presentations and meetings
>($115 hotel +$40 meals x 3 days) = $465 + $600 airfare = $1064 x 5 trips
>
>Costs:
>mailing, telephone, long distance, and supplies, copying, will be
>reimbursed from ILRU's budget with approved documentation.
>
>
>--
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